Risk factors and the impact of HIV among women living with HIV and their families in Yogyakarta and Belu district, Indonesia

by

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Dissertation Submitted to Flinders University for the degree of Doctor of Philosophy in Public Health

College of Medicine and Public Health

18 May, 2022

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EXECUTIVE SUMMARY

Introduction: Women living with HIV (WLHIV) account for more than half of all people living with HIV (PLHIV) globally (53%). In Indonesia, women aged 15 years and older represent 38% of the total number of PLHIV. HIV infection adds a significant burden on women, often leading to severe detrimental impact, not only on themselves, but also on their families. Despite the manifold increase of HIV infections in Indonesia in general, and among women in particular, little evidence exists about HIV-risk factors among WLHIV and impact on themselves and their families. The aims of this study were four-fold, to: (i) understand and compare HIV-risk factors among WLHIV and the impact of HIV on themselves and their families in Yogyakarta and Belu, Indonesia, (ii) understand and compare HIV-risk factors and the impact of HIV on WLHIV and MLHIV in Yogyakarta and Belu, (iii) understand and compare the perspectives and experiences of women/men living with HIV and healthcare providers about the determinants of access to HIV care services in Yogyakarta and Belu, and (iv) explore and compare the current and future perspectives of policy makers in Yogyakarta and Belu about policies and programs to address HIV and its impact on WLHIV and their families.

Methods: This thesis employed a qualitative design and one-on-one in-depth interviews with four groups of participants: (i) WLHIV (n=52), (ii) men living with HIV (n=40), (iii) healthcare providers (n=20), and (iv) policy makers (n=9) in both study settings. Participants were recruited using a combination of purposive and snowball sampling techniques. Data were analysed using a framework approach with five steps of qualitative data analysis. This analysis was guided by the logical model for behavioural and environmental determinants diagnosis, the conceptual framework for socio-economic impact of HIV on households and HIV stigma framework, and the access to healthcare framework. The consolidated criteria for reporting qualitative research (COREQ) with a 32-item checklist was also employed to represent best-practice in qualitative research as well as to support a transparent and comprehensive reporting of this qualitative study. Ethics approvals were obtained from Flinders University, South Australia (No. 8286) and Duta Wacana Christian University, Indonesia (No. 1005/C.16/FK/2019).

Results: The identified risk factors which facilitated HIV transmission among women and men living with HIV included: (i) poor knowledge of HIV and condoms, (ii) behavioural factors, (iii) socio-environmental factors, (iv) financial factors, (v) intimate partner violence, and (vi) religious and cultural factors. The study also identified several impacts of HIV on women and men living with HIV and their families: (i) stigma and discrimination, (ii) the psychological impact, (iii) family disputes and separation, and (iv) the physical impact. It also identified determinants of access to HIV care services among women and men living with HIV, including availability, approachability, affordability, appropriateness, acceptability of the services, and the ability of women and men living with HIV to reach the services, perceive need for the services, pay, engage in and seek the services. The study also reported HIV policies and programs that were in place in Yogyakarta and Belu, based on the perspectives of policy makers.

Conclusions: This thesis reports several risk factors for HIV transmission among women and men living with HIV and outlines a range of factors, including cultural norms, values, practices and religious beliefs that influenced sexual relations, practices and behaviours of women and men living with HIV as novel findings or the independent contributions of this study to knowledge of risk factors for HIV transmission. It also reports on several negative impacts HIV has on women and men living with HIV and their families, and outlines social perceptions, norms, values, cultural practices, religious beliefs and moral judgements about HIV, PLHIV, illicit drugs, sex, and spousal relationships that drive stigma and discrimination as novel findings of this study, which contribute to the understanding of HIV impact on PLHIV and their families. It also reports determinants of HIV care access among PLHIV, and presents traditional treatments of HIV using traditional medicines through traditional healers, and the social influence of families, friends and neighbours in supporting traditional treatments as novel findings which are also key contributions of this study to the knowledge about barriers to HIV care access among PLHIV. The thesis suggests the need for HIV policies in Yogyakarta and Belu, which continue to address both HIV-risk factors and impacts on PLHIV and their families, support and expand the provision and coverage of antiretroviral therapy and HIV interventions or programs and activities. Future large-scale studies to explore socio-cultural and religious aspects that contribute to HIV transmission, HIV impact on women in Indonesia, and hinder their access to HIV care services are recommended.

Key words: HIV-risk factors, HIV impact, facilitators and barriers to access to HIV care services, women living with HIV, men living with HIV, healthcare providers, policy makers, qualitative study, Yogyakarta, Belu, Indonesia

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AIDS : Acquired Immune Deficiency Syndrome

ART : Antiretroviral therapy

CD4 : Cluster of differentiation 4

CHCs : Community health centers

FSWs : Female sex workers

HIV : Human Immunodeficiency Virus

IDU : Injecting drug use

IPV : Intimate partner violence

LMICs : Low- and middle-income countries

MLHIV : Men living with HIV

NGOs : Non-governmental organisations

PLHIV : People living with HIV

PLWHA : People living with HIV/AIDS

STIs : Sexually transmitted infections

TB : Tuberculosis

UNAIDS : The Joint United Nations Programme on HIV/AIDS

VCT : Voluntary counselling and testing

WLHIV : Women living with HIV

DECLARATION

I certify that this thesis:

1. does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma in any university
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Nelsensius Klau Fauk

18 May, 2022

PUBLICATIONS

Thesis related published articles:

1. **Fauk NK**, Ward PR, Hawke K, Mwanri L. Cultural and religious determinants of HIV transmission: a qualitative study with people living with HIV in Belu and Yogyakarta, Indonesia. *PLoS ONE.* 2021; 16(11): e0257906

2. **Fauk NK**, Hawke K, Mwanri L, Ward PR. Stigma and Discrimination towards People Living with HIV in the Context of Families, Communities, and Healthcare Settings: A Qualitative Study in Indonesia. *International Journal of Environmental Research and Public Health.* 2021;18(5424):1-17.
3. **Fauk NK**, Ward PR, Hawke K, Mwanr L. HIV Stigma and Discrimination: Perspectives and Personal Experiences of Healthcare Providers in Yogyakarta and Belu, Indonesia. *Frontiers in Medicine.* 2021;8:625.

Accepted articles:

4. **Fauk NK**, Mwanri L, Hawke K, Mohammadi L, Ward PR. Psychological and social impact of HIV on women living with HIV and their families in low- and middle-income countries in Asia: A systematic review. *International Journal of Environmental Research and Public Health*. 2022 (in press).

5. **Fauk NK**, Mwanri L, Hawke K, Ward PR. Traditional Human Immunodeficiency Virus treatment and family and social influence as barriers to accessing HIV care services in Belu, Indonesia. *PLos ONE.*

Submitted manuscripts:

6. **Fauk NK**, Ward PR, Hawke K, Mwanr L. HIV-stigma and women's self-response: a case study of women living with HIV in Yogyakarta, Indonesia.

Non-thesis related publications during the PhD candidature

1. **Fauk NK**, Merry MS, Siri TA, Mwanri L, Ward PR. Structural, Personal and Socioenvironmental Determinants of HIV Transmission among Transgender Women in Indonesia. *International Journal of Environmental Research and Public Health*. 2021; 18(11):5814.

2. **Fauk NK**, Ziersch A, Gesesew H, Ward P, Green E, Oudih E, Tahir R, Mwanri L. Migrants and Service Providers' Perspectives of Barriers to Accessing Mental Health Services in South Australia: A Case of African Migrants with a Refugee Background in South Australia. *International Journal of Environmental Research and Public Health*. 2021; 18(17):8906.

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ACKNOWLEDGEMENTS

First and foremost, I would like to express my deepest gratitude to my supervisors: Associate Professor Lillian Mwanri, Professor Paul Ward and Dr Karen Hawke for their endless support, encouragement, mentoring and supervision throughout the period of my PhD candidature. I am also extremely thankful for their commitment and dedication to reading and reviewing the thesis, journal articles and providing feedback for improvement. The completion of this PhD project and the successful publication of journal articles would not have been possible without their excellent ideas, comments, suggestions and supervision. I would also like to extend my deepest appreciation to the College of Medicine and Public Health, Flinders University for the Australian Government Research Training Program Scholarship (AGRTPS). I am deeply indebted to each individual participant who was involved in this study and who shared their valuable information, stories, perspectives and experiences related to the topic being researched.

I am also extremely grateful to my lovely wife, Fredrika and son, Albert Klau Fauk for the love, support, understanding and sacrifice they have provided, especially during the past three and a half years in making it possible to reach the finishing line of this PhD journey. We have come a long way and passed through ups and downs together. Many thanks also go to my families back home in Indonesia who continuously support and encourage me in many different ways. Last but not least, I would like to thank Mrs. Cynthia Mchawala for editing my thesis.

CHAPTER ONE

INTRODUCTION

1.1 Background

1.1.1 Global HIV/AIDS Pandemic

Human Immunodeficiency Virus (HIV) and its subsequent sequel, Acquired Immune Deficiency Syndrome (AIDS), have been a global health issue for nearly four decades. The current report from the UNAIDS estimates that there have been 79.3 million people globally who have become infected with the virus since the beginning of the epidemic, of which 36.6 million have died (1). The same report also estimates 37.7 million people were living with HIV (PLHIV) worldwide in 2020, of which the vast majority resided in sub-Saharan Africa (SSA): 54% in eastern and southern Africa and 16.5% in western and central Africa (1, 2).

Although AIDS-related deaths and new HIV infections continue to be reported every year, the global trend shows a decline (1, 2). The latest report shows that AIDS-related deaths have declined markedly from a peak of 1.7 million in 2004 to 680,000 in 2020, having declined by 47% globally since 2010 (1, 2). The same report estimates that the number of annual new HIV infections has also gradually declined from a peak of 2.9 million in 1997 to 1.5 million in 2020, having declined by 31% since to 2010 (1, 2). The introduction and expansion of the coverage of antiretroviral therapy (ART) within and across countries have been reported as the main contributors to the reduction in both HIV infections and AIDS-related deaths (1, 2).

The UNAIDS report also shows a rapid global decline in the annual number of new HIV infections in girls and women, accounting for 27%, which is higher than that for boys and men, with 18% since 2010 (1, 2). However, the report estimates that over half of global HIV infections are diagnosed in females aged 15 and over (53%) (1). This seems to be supported by the high number of girls and women living with HIV (WLHIV) in SSA where they account for 63% of the total infection in the regions (1, 2). The report also estimates that around 5000 women aged 15-24 are reported to be infected with HIV every week, with sexual intercourse as the mode of transmission (1). Intimate partner violence (IPV), including physical and sexual violence, is also reported as a contributing factor to the transmission amongst women in this age group, and those who have experienced such violence are estimated to be 1.5 times more likely to acquire HIV than women who have not (3).

1.1.2 HIV/AIDS in Asia and the Pacific

Following the global trend, HIV infections and AIDS-related deaths have been reported to have declined by 12% and 29% respectively in Asia and the Pacific region since 2010 (1, 2). The decline is reported to be higher in women and girls than in men and boys, with 18% and 9% respectively (2). Despite the decline, the region has the second highest number of PLHIV globally, with an estimated 5.8 million PLHIV (1). India, Indonesia, Thailand, Vietnam and Myanmar are the top five countries in the region with the highest percentage of HIV infection, accounting for 40.4%, 12.1%, 8.5%, 4.8% and 4.2% respectively (1, 2).

The current report shows there were an estimated 240,000 people who became newly infected and 130,000 AIDS-related deaths in the region in 2020 (1, 2). Across the region WLHIV aged 15 years and older represent 30% of the total number of PLHIV: 11.5% reside in Thailand 13.7% in Indonesia and 54.9% in India, (2). In this region, risky sexual behaviours, such as unprotected sex with husbands or with partners who have had unprotected sex with multiple female partners, and with male sex clients, have been reported as the main supporting factors for HIV transmission in women (2, 4). Women who engage in sex work, or female sex workers

(FSWs) are estimated to be 29 times more likely to be living with HIV compared to other women of reproductive age in the region (4).

1.1.3 The HIV/AIDS Epidemic in Indonesia

The first HIV case in Indonesia, which was diagnosed in an overseas tourist who died of AIDS in Bali, was officially reported by the Indonesian Ministry of Health in 1987 (5). However, prior to that report, suspected symptoms of HIV which were indicated through low level of lymphocytes and other clinical symptoms, had been diagnosed in two transgender women in 1983 and three patients in Jakarta in 1984 (5, 6). Then, HIV symptoms were again diagnosed in six other patients in Bali and a woman suspected to have died from AIDS in Jakarta in 1985 and 1986 (5, 6). However, with the intention of avoiding worry and panic among Indonesians, the Indonesian Ministry of Health denied those detected HIV cases and did not report them to the public (5).

After the official report of the first HIV case in Bali, new HIV infections continued to be reported in many other parts of the country. The infections were reported in more than half of the Indonesian provinces in the first half of the 2000s and in all provinces in 2010, except North Kalimantan which had its first HIV case reported in 2015 (7). The top five provinces with the most reported HIV cases in Indonesia are Jakarta, East Java, West Java, Central Java and Papua (7).

Although the global trend, including in Asia and the Pacific, shows a decline in new HIV infections and AIDS-related deaths, HIV infections in Indonesia continue to increase every year. The cumulative number of HIV cases increased significantly from 55,848 cases in 2010 to 191,073 cases in 2015 and 427,201 cases in 2021 (3, 7). Similarly, the cumulative AIDS cases (PLHIV who have reached the AIDS stage) increased markedly during the same period, from

33,491 cases in 2010 to 83,241 in 2015 and 131,417 in 2021 and there has been 61,192 AIDS-related deaths in the country (7). The mode of HIV transmission across the country is mainly through sexual contact (78.3%), and this is evident by the prevalence among sexually active age groups: 70.7% of all infections were among people aged 25 to 49, and 15.7% among people aged 20 to 24 (7). Such an increase in the number of HIV infections and AIDS cases in Indonesia seems to be supported by low coverage of ART and a low number PLHIV accessing the therapy. The 2021 national AIDS report shows that of the total number of PLHIV in the country, only 63% (269,289) ever started ART (7). Of the ones who have started ART, 26.9% (72,391) have failed to follow up or have stopped the therapy, 18.3% (49,391) have died, and 53.7% (144,623) are currently on ART (7). The same report also shows that of the 53.7% of PLHIV who are currently on ART, only 32.7% (47,363) had undertaken a viral load test and 28.9% (41,754) had their viral load suppressed (7).

Women aged 15 years and older represent 38% of the total number of PLHIV in Indonesia (3, 7). Of these women, married women are one of the most groups susceptible to HIV infection, and may suffer the most from the impact of the HIV epidemic. The national AIDS report shows that more than a thousand married women reached the AIDS level each year over the course of the last ten years (7). This has placed them in the second leading position of the number of people living with AIDS, at 14.3% of the total AIDS cases in the country, following unskilled workers, who account for 16.2% (7).

In Belu district, since the first HIV cases were diagnosed in five FSWs in 2004, HIV has been reported to continue to spread into many other groups including farmers, motorbike taxi drivers, bus drivers, police officers, soldiers, civil servants, teachers, students, and married women (8). Married women (WLHIV) in the district have the highest HIV prevalence compared to other vulnerable groups, comprising 39.8% of the total number of 1,200 HIV cases in 2021 (8). In Yogyakarta municipality, HIV infections were reported for the first time in 1993. Yogyakarta municipality is reported to have the highest number of HIV cases, accounting for 1,335 cases in 2021, compared to four other districts in the Special Region of Yogyakarta province (9). Of the total number of HIV cases, WLHIV account for 29.9%, and of these, approximately one quarter have become AIDS sufferers (9, 10).

Globally, studies involving WLHIV have reported risky sexual behaviours - unprotected sex (sex without condoms) with HIV positive partners or husbands, and with multiple partners - as strong supporting factors for HIV transmission among them (11-14). The sexual behaviours of the women's partners or husbands, such as engagement in unprotected sex with other women or multiple casual female partners, including FSWs, have also been reported as supporting factors for HIV transmission among WLHIV (15-17). Low health literacy about HIV and condoms for the prevention of sexually transmitted infections (STIs), is one of the supporting factors for women's engagement in unprotected sex and is associated with HIV transmission among them (17-20). Other supporting factors for women's engagement in unprotected sex with their husbands or partners are IPV, women's low economic status, economic dependency on husbands, the lower status of women in marriage and husband-dominated sexual decision-making (15, 17). These factors have been reported as putting women at a lower bargaining position with their sex partners or spouses, including in negotiating protected sex, and supporting their engagement in unprotected sex, which facilitates HIV transmission among them (15, 17).

HIV diagnosis in women is reported to have a detrimental impact on themselves. Studies have shown that following the diagnosis, WLHIV experience a range of negative psychological consequences, such as stress, depression, anxiety, worry and paranoia (21, 22). They also experience manifold negative social impacts, including stigma and discrimination by others within families, communities, healthcare facilities and workplaces, all manifesting in various discriminatory and stigmatising attitudes and behaviours (21, 23, 24). Such attitudes and behaviours have often been reported to be supported by a lack of knowledge about how HIV is transmitted and prevented, and the fear of HIV transmission through physical, social and healthcare-related contacts (25, 26). Other studies have also reported that WLHIV experience economic or financial difficulties following the diagnosis due to their poor physical health or strength to work, leading to the reduced or loss of income, or an unwillingness to apply for jobs to prevent the disclosure of their HIV status and its unacceptability in workplaces (27, 28).

HIV diagnosis in women also imposes a negative impact on their family members. Some studies have reported that it negatively affects their children's psychological state, social life and education (29-31). It also causes child-mother separation, negatively affects the child-parent relationship, and leads to broken relationships or spousal divorce due to the refusal by partners or spouses or other family members to accept the women's HIV status (30, 32). Some studies have reported that it also attributes to stigma by association or courtesy stigma towards the women's children, manifested by rejection and social exclusion of the children by their friends or teachers within communities or schools (30, 31, 33). Other adverse effects of HIV on their families include reduced family incomes due to the loss of jobs, food insecurity, experiences of hunger, increased family health expenditure leading to financial hardship and poverty within families (28, 31, 32). Such impacts have often been reported as exacerbating the psychological and physical health conditions of WLHIV and their family members due to the difficulty in fulfilling basic necessities including food and health care (34-36).

Despite the manifold increase in reported HIV infections in Indonesia in general and among women in particular (7, 8, 10), evidence about HIV-risk factors among WLHIV and the impact of HIV on themselves and their families is still limited. Within the Indonesian context, of a small number of studies which have involved WLHIV, only three have focused on exploring their views about factors that may have facilitated HIV transmission amongst them (37-39). These studies have mainly reported behavioural factors (e.g., unprotected sex, having HIV-positive partners, multiple sex partners, premarital sex, engagement in sex work, injecting drug use (IDU)), multiple/forced marriages and sexual abuse which can result in unprotected sex, as risk factors for HIV transmission among WLHIV (37-39). It is, therefore, important to explore the views of WLHIV about these broader factors, including knowledge, behavioural, environmental, economic, socio-cultural and religious factors which may have contributed to HIV transmission among them.

Similarly, there are only five studies exploring the lived experiences of how HIV impacts WLHIV in Indonesia (40-44). These studies have mainly reported stigma and discrimination by family members, in-laws, friends and neighbours (40, 41), as well as self-stigma and poor quality of social life (41-43) as the negative impact WLHIV experience. These women also face psychological challenges, such as the fear of courtesy stigma against their children, and concern for the health condition and future of their HIV-positive children due to their poor financial condition, (40, 41, 44). In addition, feeling shocked, upset, and angry due to being infected by husbands, as well as the loss of sexual pleasure which led to depression, anger, disappointment towards husband, and avoidance of sex, are also experienced by the women (40, 41, 44). It is, therefore, imperative to form a comprehensive understanding of the women's lived experience about the various ways HIV impacts on them and their families, as well as their access to HIV care services. The full review of the literature about HIV-risk factors and the impact it has amongst WLHIV and the study gaps are presented in Chapter 2.

In order to develop a better understanding of HIV-risk factors, the impact of HIV, and facilitators and barriers to the access of HIV care services for WLHIV, the views and experiences of men living with HIV (MLHIV) in both study settings were also explored. Their views and experiences also help to differentiate between HIV-risk factors, the impact of HIV, the facilitators of and barriers to access to HIV care services that are specific to or only experienced by women due to their gender status from those that are experienced by both women and men. The views and perspectives of health service providers in both study settings were also explored to enable a comprehensive understanding of HIV care services in both settings, including facilitators of and barriers to the access of PLHIV to the services. Given the fact that WLHIV experience difficulties in accessing HIV care services, especially in more rural settings in developing countries (33, 45-47), it was expected that WLHIV in Belu and Yogyakarta may also have similar experiences. The perspectives of policy makers from the local government and non-governmental organisations (NGOs) in both study settings were also explored in order to understand HIV-related policies and programs currently in place as well as what needs to be done to halt HIV transmission, and to address the impacts of HIV facing WLHIV and their families.

1.2 Research Questions

The main research questions that explore these topics among WLHIV aged 18 years and above in Yogyakarta and Belu, Indonesia are:

1. What are the HIV-risk factors and impact on WLHIV and their families?
2. What are the available HIV care services, and the factors that determine access to the services by WLHIV?
3. What are the HIV policies and programs in place, and what is the future direction for addressing HIV and its impact on WLHIV and their families, and improving the women's access to HIV services in these settings?

1.3 Research Objectives

The objectives of this study are:

1. To understand and compare HIV-risk factors among WLHIV and the impact of HIV on themselves and their families in Yogyakarta and Belu, Indonesia.
2. To understand and compare HIV-risk factors and the impact of HIV on WLHIV and MLHIV in Yogyakarta and Belu.
3. To understand and compare the perspectives and experiences of women/men living with HIV and healthcare providers about the determinants of access to HIV care services in Yogyakarta and Belu.
4. To explore and compare the current and future perspectives of policy makers in Yogyakarta and Belu about policies and programs to address HIV and its impact on WLHIV and their families.

1.4 Thesis structure

The thesis consists of ten chapters. Chapter one is the introduction which comprises the background of the study, research questions, research objectives, and thesis structure.

Chapter two provides a review of the literature which consists of seven sections. Section one is an overview of the chapter. Sections two and three present the views and experiences of women and men living with HIV in developing countries about HIV-risk factors and the impact of HIV on themselves and their families. Sections four and five present the views and perspectives of women and men living with HIV and healthcare providers respectively about facilitators of and barriers to access to HIV care services. Section six offers a summary of the literature, and section seven presents gaps in the literature. Chapter three details the theoretical framework which comprises an overview of the chapter, a logical model for a diagnosis of behavioural and environmental factors, a conceptual framework for socio-economic impact of HIV on households, an HIV stigma framework and a framework for access to healthcare.

Chapters five to eight present the findings of the study. Chapters five and six present HIV-risk factors, the impact of HIV, the facilitators of and barriers to access to HIV care services among women and men living with HIV respectively. Some parts of chapters five and six present information about cultural and religious factors that contribute to HIV transmission, and HIV stigma and discrimination within family, community and healthcare settings. These parts have been published in PLOS ONE (48) (Appendix 1) and the International Journal of Environmental Research and Public Health (49) (Appendix 2). Chapter seven contains the healthcare providers' perspectives about HIV care services, and facilitators of and barriers to access to the services among PLHIV in both study settings. Some parts of this chapter provide the perspectives and the personal experiences of healthcare providers about HIV stigma and discrimination against PLHIV. These perspectives and personal experiences have been published in Frontiers in Medicine (50) (Appendix 3). Chapter eight presents the perspectives of policy makers regarding HIV policies and programs in the study settings. This includes challenges to the implementation of HIV programs and future responses to halt HIV transmission and address the impact of HIV on PLHIV and their families. Chapter nine is a discussion of the findings, which contains several sections. These include an overview of the chapter, the role of cultural and religious factors in HIV transmission, stigma and discrimination towards PLHIV, the traditional treatment of HIV and the social influence on the use of traditional treatment, HIV policies and programs in the study settings, and a critical reflection on the strengths and potential limitations of the study. Chapter ten presents the conclusions and implications of the study for policies and future studies.

CHAPTER TWO

REVIEW OF THE LITERATURE

2.1 Overview

This chapter consists of several sections. Section one presents a systematic review of HIV-risk factors and its impact on WLHIV and their families. Some parts of section one about the impact of HIV on WLHIV and their families have been submitted to International Journal of Environmental Research and Public Health (51). Section two presents a literature review of HIV-risk factors and its impact on MLHIV and their families. Section three presents a literature review on the views and experiences of PLHIV on facilitators of and barriers to their access to HIV care services. Section four presents a literature review on the perspectives of healthcare providers about facilitators of and barriers to access of PLHIV to HIV care services.

2.2 HIV-risk factors and its impact on WLHIV and their families

2.2.1 Systematic literature search, selection of the studies and data analysis

The systematic search of literature

The systematic literature search started with an initial search of relevant key terms guided by PICO (Population, Intervention, Comparison and Outcomes), a framework that has been used to inform evidence-based practice (52). The main search was then drafted and refined in Medline, using both MeSH terms and keywords as described in the inclusion criteria section below. The search was then translated into multiple databases, including Medline, PsycINFO, CINAL, Emcare, Scopus and ProQuest. The search was limited to the English language. Articles published between Jan 1, 1990 and Dec 31, 2019 inclusive were selected in order to capture evidence on the impact of HIV on women which seemed to emerge in 1990s (Appendix 4).

The literature search was conducted using the following key words (full key words or search strategy for all databases can be found in Appendix 4):

1. HIV*, "Human immunodeficiency virus", AIDS
2. Female*, girl*, women, woman, wives, wife, mothers
3. Predictor*, "risk factor*", determinant*, "sexual behaviour", "multiple sex partner*", extramarital*, "sell* sex*", "transactional sex", prostitut*, "sex work", condom*, "unsafe sex", "unprotected sex", knowledge, "social influenc*", "peer influenc*", "social norm*", cultur*, sociocultural*, socioeconomic*, "social environmental*", socioenvironment*, stigma, discriminat*, "psychological impact", "social impact", education, "school attendance", "withdraw* from school", stress or distress, depression, "psychosocial impact", employment, "loss of job", income, "nutrition security", "food insecurity", health, "physical health", wellbeing, "healthcare accessibility*", absenteeism, religio*, consequence*)
4. Family*, families
5. Developing, "less developed", "low resource*", disadvantaged, "resource limited", poor, "low* or middle income*" countr*, region*, nation?, area*

These key words were used in combination using the Boolean operator system including AND and OR. The use of Boolean helped to broaden or narrow down the search to obtain the desired outcomes. The key words in each concept were linked with OR and concepts one to five were linked with AND. The references of the relevant literature obtained through this search were also scrutinised, and articles with the full text were considered during the review. A search of grey literature and reports through Google was also conducted. The content of the relevant literature retrieved through this search was thematically analysed and grouped into several overarching themes as presented below (see Section 2.2.2 and 2.2.3).

Selection of the studies and methodological quality assessment

Articles retrieved from these databases were assessed based on the inclusion criteria:

(i) Studies with full text available

(ii) Studies written in English

(iii) Studies conducted in low- and middle countries because of similarities in known factors such as health care systems, socioeconomic and environment structures, which are different to those of developed countries

(iv) Studies involving WLHIV (married and non-married)

(v) Studies aiming at identifying HIV factors among WLHIV

(vi) Studies aiming at identifying the impact of HIV on WLHIV and their families.

A total of 3,371 articles were retrieved from the databases and eight from other sources. These were collated and imported into Endnote software. After removing 1,040 duplicates, 2,339 titles and abstracts were screened by two assessors (the student and a supervisor), which led to the further removal of 2,217 articles not meeting the inclusion criteria. The assessment of the full texts of the remaining 122 articles led to a further removal of 84 articles not meeting the inclusion criteria, leaving only 38 articles for further assessment. The reference listing of the 38 articles provided two additional articles. The 40 articles fulfilling the inclusion criteria were assessed for methodological quality using critical appraisal tools (Appendix 5) developed by the Joanna Briggs Institute (JBI) for study design (53). This later assessment excluded one article, resulting in 39 articles in this review (Figure 1). The methodological quality assessment was performed by two assessors (the student and a supervisor), and any disagreement between them was resolved through discussion. The appraisal forms for qualitative and cohort studies comprised ten and nine questions respectively, and the appraisal forms for cross sectional and case report studies each contained eight questions. The questions were about the quality of the studies; each question received a value of Yes, No, Unclear, and Not Applicable.

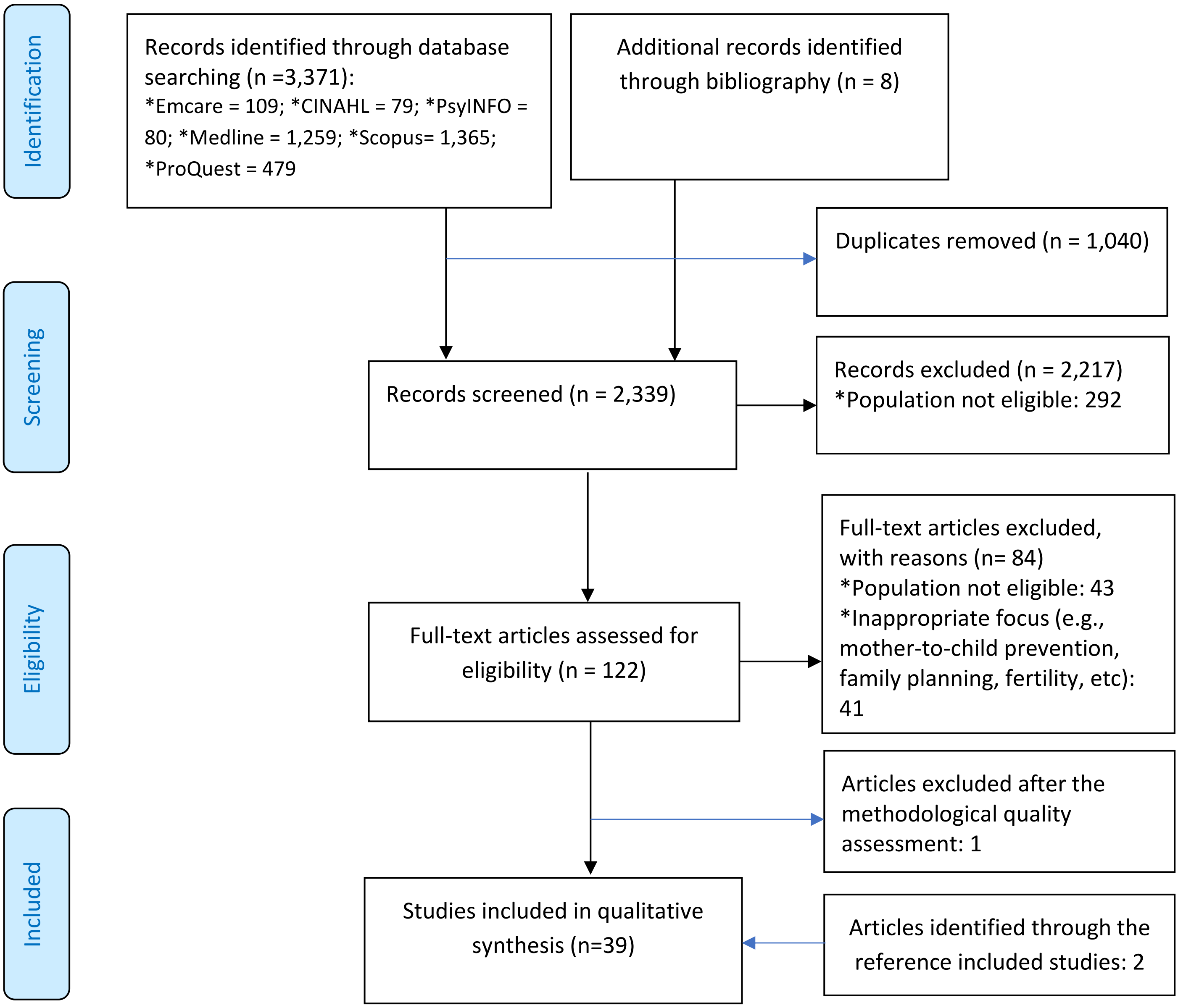

Figure 1: PRISMA Flow diagram of systematic literature search: records identified, removed, screened, and included in the review.

Data extraction and analysis

Guided by the Thomas and Harden framework (54), a thematic analysis of selected articles was systematically performed as follows: (i) conducting a line by line open coding, and extracting free codes from the findings of each article, (ii) developing descriptive themes where the free codes with similarity were organised or grouped together, (iii) reviewing the initial descriptive themes and thoroughly discussing (performed by the student and the supervisors) any discrepancies, and (iv) finalising the review of descriptive themes and sub-themes to decide the final analytical themes presented below (54).

2.2.2 HIV risk factors among WLHIV

2.2.2.1 Health literacy and behavioural risk factors

Poor health literacy about HIV, including how it is transmitted and the protective function of condoms to prevent infection is a socio-demographic factor associated with HIV transmission among women in low- and middle-income countries (LMICs) (17, 55, 56). A study in Vietnam has reported that a lack of knowledge and access to HIV information were factors associated with women's engagement in risky sexual behaviour including unprotected sex (56). Similarly, findings from an Asia Pacific study about HIV transmission between married women and their husbands has shown that a lack of knowledge and information about the protective function of condoms was a factor influencing unprotected sex which in turn facilitated HIV transmission (55). Other studies have elaborated further on this, citing girls' and women's limited knowledge of risky sexual behaviour has been associated with their engagement in unprotected sex with boyfriends or husbands who were injecting drug users and without realising the risk of HIV transmission (19, 20). A study with married WLHIV in Nepal has reported similar findings by showing that most women had poor health literacy about HIV infection and condom use and did not perceive themselves as being at risk of HIV infection prior to their HIV diagnosis (17).

Thus, unprotected sex has been reported as the main behavioural risk factor for HIV transmission among women (56-59). Studies with WLHIV in different settings have also reported HIV transmission among women to be the result of the low prevalence of condom use and unprotected sex with their regular partners or spouses who were living with HIV (12, 16, 18, 60-64). Similarly, previous studies have reported women's engagement in unprotected sex with multiple casual male partners, including those living with HIV and injecting drug users as a risk factor for HIV transmission among them (13, 14, 32, 61, 62, 65-68).

Women's engagement in risky sexual behaviours also occurs for a number of other reasons, including objection to using condoms by sex partners, and perceptions that condoms reduce sexual satisfaction (13, 56). For some married women, unawareness of their husbands' extramarital sexual behaviour, an explicit trust in their husbands, the unavailability of condoms at the moment of need, and alcohol consumption by their husbands have been reported as supporting reasons for their engagement in unprotected sex with their spouses (17, 18, 60). Husbands may also conceal their HIV status and sexual encounters with other women due to a fear of marital discord if their status is made known to their spouse, and may also resist using condoms to prevent the suspicion of their wives about why they want to start using them (17, 18, 60).

Extramarital sex, especially by males, is very common in LMICs, and is often with casual partners living with HIV (60), including FSWs (11, 16, 18, 56, 60), and male partners (11, 16).

Such high-risk sexual behaviours by men increases the likelihood of HIV transmission to women, especially their wives (11, 14, 60, 68). Male partner-to-female partner transmission has been reported in many studies, which overwhelmingly identify that the source of HIV infection for most women is via their regular partner or spouse (16, 32, 62, 69-71).

Injecting drug use is another high-risk behaviour for HIV transmission, and the association between IDU and HIV infection among women has been documented (32, 56). IDU has been reported to facilitate HIV transmission as it involves needle sharing among female drug users due to a lack of the availability of clean needles and syringes as well as a lack of knowledge regarding HIV transmission through the sharing of needles (56). Having a history of STIs is also a risk factor for HIV infection among women (16, 61).

2.2.2.2 Economic or financial factors

Economic and financial factors have been found to play a pivotal role in HIV transmission among women. A study in Nepal has reported that WLHIV in committed relationships and marriages often engage in unprotected sex with their partner, even when they know their partner is having unprotected sex outside the relationship, often with FSWs, because they are dependent on their husband or partner financially (17). Women’s financial dependency on husband due to the low economic status or financial hardship disempowers them, and makes it almost impossible to refuse sex or demand protected sex, due to the fear of not only losing financial support, but also being the victim of IPV (17, 72, 73). It has also been reported in some studies in India and Uganda that financial dependency on husbands or male partners is one of the factors associated with forced or coercive sex and physical violence such as being kicked, hit and punched by husbands or partners during sex (13, 14, 74).

Intimate partner violence, including physical, verbal and sexual abuse against women by male partners or husbands in the context of social and sexual relationships, is a serious risk factor associated with HIV transmission among women (14, 75). A study of married WLHIV in India has reported the increased prevalence of HIV infection among women who were physically and sexually abused by their partners or husbands (72). Similarly, another study by Dude (76) has reported that women who are sexually, physically and emotionally abused by their partners or husbands are more likely to test positive for HIV and other STIs. Physical and sexual IPV against women often leads to a fear of negotiating condom use and/or refusing the sexual demands of intimate partners. As a result, this forces women into unprotected and coercive sex, which puts them at high-risk for HIV infection (72, 74, 77, 78).

A lack of financial autonomy has also been reported as a reason some married WLHIV engage in sex work (13, 68). Studies across different countries have found that financial hardship was often the driver for women's engagement in sex work practice (11, 13, 17, 32, 56, 68). Sex work practice is a major HIV-risk factor among women as it often occurs unprotected or without condoms due to the rejection of male sex clients (13, 56).

2.2.2.3 Cultural factors

Cultural norms and values in some societies have an influential role in shaping the sexual relationships and behaviours between couples, including married women and men. For example, in some cultures in Cambodia a wife's fidelity to her husband is considered extremely important, and she is expected to sexually obey her husband and also accept his promiscuity (18). Similarly, among some cultures in Uganda it is acceptable for men to have more than one wife or multiple sex partners, while women are expected to remain faithful to their husbands (68). Infidelity by women may result in sanctions, including beating, divorce, being chased from their home and cut off financially, but the same does not occur if men are unfaithful (68). Studies in Zimbabwe and India have found that some traditional norms promote a hegemonic masculinity over women, where men or husbands are deemed to be entitled to sex, to have a stronger desire for sex and a justified dominance over women, while women or wives are expected to have the desire to please and submit to their husband (75, 79). As these values and norms encourage male-dominated sexual decision-making, they are also associated with a lack of condom use by husbands and husbands' engagement in sexual activities with multiple sex partners, including FSWs, who may be HIV-positive (18, 68, 75). These cultural practices, norms and values are recognised as being supporting factors for HIV transmission to women (18, 68, 75).

2.2.3 The impact of HIV on WLHIV and their families

2.2.3.1 Psychological impact

Psychological challenges, including stress, anxiety, depression, sadness and embarrassment are common negative impacts faced by WLHIV following their HIV diagnosis (21, 22, 80). The stressors for such psychological challenges on women include the advanced stages of their HIV infection, weak physical condition, and the fear of a breach of confidentiality about their HIV status which may cause shame for their family (21, 80, 81). Other stressors for these psychological challenges are the women's fear of HIV transmission to their unborn babies, concerns about their children's future, especially in the event of an untimely death, and a lack of resources needed to support their children and family without the additional strain of an HIV diagnosis (27, 32, 81-83). Similarly, a lack of social support from others, the experience of social rejection and social isolation, the perceived stigma (80, 84, 85) and poor economic conditions (81, 86) are also reported as determinants of depression, fear and worry among WLHIV.

Additional factors such as low level of education attainments, being the primary caretaker for children, the cessation of a relationship with a partner, a partner's death, being single, family misfortune, a high viral load or treatment failure, and a low cluster of differentiation 4 (CD4) cell count (81, 84, 85), all are the predictors of poor psychological functioning of WLHIV. A diagnosis of HIV in women is also reported to have a negative psychological impact on their children, such as them feeling hurt, sad and worried about HIV status and poor health condition of their mother (30, 31).

2.2.3.2 Stigma and discrimination

Stigma and discrimination are common negative impacts that are faced by most PLHIV. There are several forms of stigma: 'self-stigma', which is a negative self-image felt by PLHIV; 'anticipated stigma', which is an individual's belief of PLHIV that they will be discriminated against or judged negatively when their HIV diagnosis is disclosed; and 'external or enacted stigma', which is an actual event of discrimination experienced by PLHIV (25, 26).

WLHIV often experience anticipated stigma, especially following an HIV diagnosis, and believe that people, including family members, will react negatively to their HIV status (21-23, 80, 87). For example, WLHIV hold the belief that other people will spread the word about their HIV status, and family members will reject them after finding out (32, 80, 87-89). This belief is rooted in the experience of HIV-related discriminatory and stigmatising attitudes and behaviours towards PLHIV generally, and often lead to women isolating themselves in order to hide their HIV status from other people (32, 88, 89). WLHIV also perceive that they will receive less instrumental and emotional support from their communities once their HIV status is disclosed, and that this will also be extended to their children being stigmatised and isolated, which often leads to them avoiding participation in communal activities (85, 86). Exacerbating factors for this include being an older woman, having a limited education, and having a husband with multiple wives (24).

Most often, HIV-stigma and discrimination towards WLHIV are perpetrated by close family members, such as husbands and in-laws, parents and siblings, and include blame, verbal insults, avoidance and rejection (23, 80, 90). WLHIV are also accused by parents-in-law of transmitting HIV to their husbands and are sometimes expelled from their marital home (33, 47, 89, 90). A husband's occupation, a larger age gap between WLHIV and their husbands, the women's lower household economic status, financial dependency on their husbands and an inability to engage in income generating activities, are contributing factors associated with such discriminatory and stigmatising attitudes and behaviours (23). WLHIV also experience stigma and discrimination from their own biological families, including being asked to leave the home (27, 90), being excluded from the usual family activities including cooking, and having their personal items separated from those of other family members due to a fear of HIV transmission (23, 32, 47, 80, 88).

WLHIV also experience stigma and discrimination from their relatives, friends and neighbours (23, 24, 27, 31-33, 46, 47, 83, 88-90). Social isolation (e.g., refused entry or exclusion from social functions or being removed from public establishments) (47), the refusal of neighbours and relatives to share food and drink, having their personal possessions burned by friends and relatives, and eviction from rental properties due to the fear of contracting HIV through social contacts, are also some of the challenges that WLHIV face in their communities (24, 27, 32, 88, 89). WLHIV have also been known to experience physical assaults, negative labelling using discriminatory words such as “HIV carriers” or “she is (HIV) positive”, and harassment by others within communities where they live (33, 47, 90).

Similarly, within health care settings, WLHIV experience a range of discriminatory treatments or behaviours by healthcare providers due to the fear of contracting HIV. These manifest as criticism, blame, shouting at WLHIV, as well as throwing health records at their face, leaving them untreated, and preparing unnecessary referrals to new healthcare facilities or providers (24, 33, 46, 47, 80, 83). Other examples of healthcare-related discrimination against WLHIV after an HIV diagnosis include coercion to undergo HIV testing, abortion and sterilisation, and termination or loss of private health insurance (47). As a consequence, WLHIV often choose not to disclose their HIV status and remain untreated (33, 46), which is a major risk factor for the fast progression of the advanced stages of HIV infection. Stigma and discrimination against WLHIV also occur within workplace settings, manifested in the loss of prospects for promotion and unexplained changes in job descriptions due to employers worrying that customers may avoid using the services provided by WLHIV (27, 47).

HIV diagnosis in women is also reported to cause ‘courtesy stigma’ or ‘stigma by association’ towards their family members, such as husbands and children (30, 31, 33, 86, 88). For example, husbands’ relatives sterilise the food utensils of WLHIV and their families before anyone else uses them due to the fear of contracting HIV, which stems from a lack of HIV education and awareness (33). Children of WLHIV are also reported to experience community stigma and discrimination which are often manifested as being rejected, teased or mocked by their friends and significant others due to their mothers’ HIV-positive status. For example, children have been mocked with “your mother has HIV”, called “little HIVer” by other children at schools or within communities (30, 31) and separated from other students by their teachers

(82, 88). In some instances, the children of WLHIV are denied school admission or expelled from school because of pressure or complaints from the parents of other students, who fear HIV transmission to their children (47, 91).

2.2.3.3 The impact on education and social life of children

In addition to courtesy stigma, HIV diagnosis in women also negatively impacts on their children's education, with many children having poor attendance at school, and struggling with their performance due to the unavailability of essential provisions such as food and school fees (31). In some cases, children are reported to take on additional responsibilities after a mother's HIV diagnosis, including undertaking household tasks and taking care of their sick mother (32, 92). These additional responsibilities prevent children from socialising with friends, participating in extracurricular school or peer activities, and doing school homework (32, 92).

2.2.3.4 Family separation and child-parent conflict

Another impact HIV-affected families face, is the forced removal of children by the women's in-laws, due to the fear of mother-to-child HIV transmission, which leads to WLHIV feeling disappointed, sad and heartbroken (32, 33, 47). In some cases, WLHIV also report voluntarily sending their children to live with and be taken care of by their own siblings or the family of their brothers- or sisters-in-law when they are terminally ill or hospitalised (28). Their inability to raise their children due to their poor physical health and economic condition were the main reasons for such separations (28, 31). Spousal separation or abandonment by a husband or partner was another negative impact of HIV on the women's families (27, 31, 47), which rendered further difficulties for women in taking care of themselves and their children (27). A diagnosis of HIV in mothers also brought conflicts in parent-child relationships (92), and in some instances, children blamed their fathers when they perceived their fathers to be the source of their mothers' HIV infection (30).

2.2.3.5 Economic impact

A diagnosis of HIV in women is reported as having a negative influence on their economic condition at the individual level through several mechanisms. For example, a loss of jobs or potential work due to women's HIV-positive status (27, 47) and poor physical strength have been reported as preventing them from working which in turn affects their economic conditions (27, 28). HIV diagnosis also poorly influences women's intention to apply for jobs that require HIV testing (32), and leads to women losing financial support from their parents, siblings and spouse due to the unacceptance of their HIV-positive status by their husbands and other family members (47).

HIV diagnosis in women also economically impacts their entire family, often via a reduction in the family's income due to job loss or unemployment and women's inability to work (32). In some cases, clients or customers refuse using business services of the women's family after their HIV-positive status is known, which results in the downfall of the family business (33). Increased family expenditure for HIV care is another economic impact of HIV (27, 28), and these are reported to lead to the forced sale of household properties, such as land and houses to cover the expenses for healthcare and daily needs (28, 31). The sale of family properties is also reported to put additional economic strain on families which then leads to a vicious cycle of disadvantage, including food insecurity and poverty (28, 31).

2.3 HIV-risk factors and its impact on MLHIV and their families

2.3.1 HIV-risk factors among MLHIV

2.3.1.1 Health literacy about HIV and condoms

Poor general knowledge about the means of HIV transmission and prevention has been reported as a contributing factor in HIV transmission among men in LMICs (55, 56). For example, it is reported to lead to men being unaware of the possibility of contracting HIV through the unprotected sexual behaviours they engage in with multiple and high-risk partners, including FSWs (55, 56, 93). It also leads to men's wrongful belief or misperception that a healthy-looking female casual sex partner or FSW cannot have HIV, which seems to be a supporting factor for their unprotected sexual behaviour with such partners (94). Some studies have reported that men with poor health literacy about HIV and condom use for HIV prevention are more likely to engage in unprotected sexual behaviours, facilitating the spread of HIV among them (95, 96).

A lack of knowledge regarding the source of condoms, where to access condoms and how to use condoms correctly is also an influencing factor for low condom use practices in men's sexual encounters with their partners and the women from whom they purchase sex (94, 97). A study by Glenn and colleagues (97) has pointed out that a lack of knowledge about condoms and low condom use self-efficacy influence men's intention to access and use condoms in their sexual encounters. Men's poor health literacy about both HIV and condom use are reported to be influenced by several factors, including low education attainment and the limited dissemination of information about HIV and free condoms provided by governments and NGOs (56, 98). Another factor reported to contribute to such poor health literacy among men is the unavailability of HIV-related programs and activities which also promote and teach condom use (99-102).

2.3.1.2 Behavioural factors

Unprotected sexual practice and multiple sex partners

Unprotected sexual behaviour has been reported as a main contributor for HIV transmission among men (101, 103, 104). Men's engagement in such behaviour is supported by a range of factors. For example, in addition to poor health literacy about HIV, it is also supported by men's own negative attitudes and their partners' non-supporting attitudes towards condom use, a practice that facilitates HIV transmission among them and their sex partners (56, 96, 105). Men's negative attitudes towards condom use are reported to be influenced by their past negative experiences of condom use practices in previous sexual encounters, such as feeling uncomfortable during sex, and the reduced pleasure in sexual intercourse (56).

A lack of discussion about condom use between men and their female sex partners and men's intention to hide their HIV status from their sex partners are also reported as supporting factors for unprotected sexual practices among men (106-109). One reason for this lack of discussion and non-disclosure of their HIV status is the men's perception that proposing condom use may lead to their sex partner becoming suspicious about their sexual relations with other women, which could lead to the disruption of their spousal relationships (108, 109). Similarly, a fear of being rejected by their sex partners, a less perceived risk of contracting HIV and feeling it unnecessary to use condoms, are supporting reasons for both the absence of condom use discussion with their spouses or casual sex partners and the non-disclosure of their HIV status (106, 107). Several studies have also reported that men's beliefs about the effectiveness of ART to prevent HIV transmission and suppress the viral loads in their bodies are supporting factors for their prolonged engagement in unprotected sexual practices, which puts them at risk of co-infections and facilitates HIV transmission to their partners (106, 107, 110, 111). Being on ART, and having an undetected viral load without the correct knowledge of the possibility of contracting co-infections and transmitting HIV to their sex partners, seem to be the underlying reasons for such beliefs, and the perception of unnecessary condom use during men having sexual intercourse.

Engagement in sex with multiple concurrent and casual female partners is another behavioural factor that multiplies the risk of transmission of HIV among men, and has been reported as common sexual practice among men (93, 94, 98, 108, 109). Such practice has been associated with unprotected sex among men, which is a supporting factor for HIV transmission in them (56, 95, 104, 105, 107, 112-114).

IDU, substance abuse, and alcohol consumption

The engagement of men in IDU is another behavioural risk factor that facilitates HIV transmission among them (115, 116). Such a practice often involves needle sharing among male drug users, through which HIV can easily be transmitted (117-121). IDU is reported to also have an influence on other high-risk behaviours such as unprotected sex. For example, several studies have reported that male injecting drug users are less likely to use condoms in their sexual encounters, and have multiple concurrent or casual sex partners, which double the risk factor for HIV transmission among them (56, 122, 123). Similarly, non-injecting substance abuse and alcohol consumption prior to sex are associated with unprotected sex among men (93, 105, 109, 112, 123-125). Some authors have pointed out that men who are under the influence of drugs or alcohol before sex are more likely to engage in unprotected sex due to the sex being unplanned and unprepared with condoms, and the men’s unawareness of the negative consequences of their risky sexual behaviour (105, 109, 126). Besides, substance abuse and alcohol consumption are also associated with men having multiple concurrent sexual relations with non-spousal female partners or other women with whom they engage in unprotected sex (113, 126, 127).

A lack of knowledge about the possibility of HIV transmission through unsterile needles has been reported as an underlying reason for men's engagement in needle sharing during IDU practices (56, 115-117, 119). Having mental health problems or the experience of depression and emotional distress are also factors that predict behavioural problems among men, such as drug use, which in turn predict their engagement in unprotected sex practices, doubling the risk factors supporting HIV transmission among them (96, 97, 125).

2.3.1.3 Socio-environmental factors

Social factors, such as negative peer influences, norms and pressures that influence the risky behaviours of men have been reported as contributing to HIV transmission among them. A couple of studies have suggested that peer norms or pressures that encourage engagement in sex with casual female partners or FSWs and also discourage condom use, are some instances of the social factors that support HIV transmission among men (125, 128). Peer influences through sharing information about and linking each other to casual sex partners or FSWs are also social factors that support men's engagement in both sex with multiple concurrent or casual partners and unprotected sexual practices (100, 129, 130). Similarly, social influences among peers, through the introduction of illicit drugs and encouragement for engagement in drug use, as well as social networks facilitating the distribution of drugs among peers, are also social factors that contribute to the spread of HIV among men (56, 115, 117, 125, 131, 132).

The environments or surroundings where men live, work and interact have also been reported to be influential in the transmission of HIV among them. For example, environmental conditions where brothels are available and easily accessible, have been reported as facilitators of men’s engagement in unprotected sex with multiple casual partners, which puts them at risk for HIV acquisition (100, 101, 129, 130). Also, the environments where condoms are unavailable are another supporting factor in men’s engagement in unprotected sex (56, 128). Similarly, environments or communities where illicit drugs are available and easily accessible, and where clean needles are unavailable or difficult to access, are reported to increase drug use practices and syringe sharing among men, which facilitate HIV transmission among them (115, 131, 133).

2.3.1.4 Financial factors

Financial circumstances also exert a significant influence on men’s risky behaviours, which in turn facilitate HIV transmission among them. A few studies have reported that good financial conditions, or having money, are supporting factors in men purchasing sex from FSWs, and in their engagement in sex with multiple casual female partners (94, 95, 126). It is also reported that men’s extramarital sex and HIV risk behaviours, such as sex with multiple casual partners other than their wives, are influenced and shaped by their economic circumstances (134). Thus, relatively good financial conditions that enable the purchase of sexual services from women are a contributing factor for HIV transmission among men as studies have suggested that men who purchase sexual services from women are less likely to use condoms (56, 95, 114, 135). However, the findings of a study by Kongnyuy and colleagues (95) have reported similarities in the purchase of sexual services from women between rich and poor men. This indicates that men’s engagement in sex with multiple partners is not merely influenced by good financial conditions. Similarly, good financial conditions indicating a stable income are also reported to be an enabling factor in the purchase of illicit substances and engagement in IDU among men, a high-risk behaviour for HIV transmission (136).

2.3.2 The impact on MLHIV and their families

2.3.2.1 Psychological impact

A diagnosis of HIV in men can cause a range of psychological challenges for them, such as stress, anxiety and depression. Some studies have reported that MLHIV experience stress and anxiety due to the negative reactions they experience following their HIV-positive diagnosis or status. These are feelings of loss and failure as a man, an inability to retain control, hopelessness and worthlessness in connection with their HIV status (137-139). For some men or husbands in some societies, such negative reactions are reported to be influenced by concepts of masculine identity (137). These concepts are socially and culturally constructed and portray men as the ones with power and control, and the providers for families (137). Other stressors leading to such psychological challenges are men's concerns with their poor financial conditions, low income, unemployment, the costs for health treatment, and their dependency on support from others (140, 141). Such stressors or concerns seem to increase worry and stress among men in relation to how they are to cope with the situation of being HIV-positive as well as any possible negative challenges that may arise as the consequences of their HIV status.

Living alone and feelings of loneliness and shame are also factors that increase stress, anxiety, worry and depression among men following their HIV diagnosis (140, 142-144). Such factors reflect a lack of available supports that are required by men to cope with their various negative feelings and experiences that emerge due to their HIV-positive status (139). Several studies have suggested that feelings of loneliness and shame, low self-esteem, stress, anxiety and depression facing men following their HIV diagnosis are also influenced by anticipated and external stigma and discrimination towards them or other PLHIV (140, 143-147).

2.3.2.2 Stigma and discrimination

HIV stigma and discrimination are common negative social impacts experienced by men following their HIV diagnosis (145, 148-150). MLHIV are reported to experience self-stigma, reflected in their feeling not a good person, a negative self-image and the endorsement of negative public attitudes about PLHIV (145, 147, 149). They also experience anticipated stigma due to the belief that people around them will discriminate, isolate and avoid them, and no one will want to mingle with them if their HIV status is known to others (144, 151). Men’s own experiences and the experiences of other PLHIV regarding HIV stigma and discrimination are reinforcing factors for such anticipated stigma. Such experiences are reported to lead to the belief that they would receive the same negative treatment if their HIV status were to become known to other people around them within communities or healthcare facilities (150, 151). However, a study by Cloete and colleagues suggested that MLHIV who have undergone HIV treatment and disclosed their HIV status to healthcare providers experienced lower anticipated stigma (144). This seems plausible as the ones who have accessed healthcare services and consulted with healthcare professionals may be exposed to social supports which help them overcome the HIV stigma they face. MLHIV are also reported to face external stigma and discrimination by families, neighbours and healthcare professionals who know about their HIV status (146, 150, 151). These are reflected in acts of avoidance, rejection, refusal, distancing by friends and other community members, separation of clothes and eating utensils by parents and siblings, and delays of treatment and care by healthcare professionals due to the fear of contracting HIV (146, 150, 151).

HIV stigma is also reported to have a negative influence on the behaviour of MLHIV. For example, previous studies have shown that the fear of HIV stigma is a supporting factor for their engagement in unprotected sex with multiple partners, which thus increases their susceptibility to co-infections and further HIV transmission to their sex partners (144, 147). A possible explanation is that MLHIV are reluctant to propose condom use in order to avoid their sex partners questioning their HIV status and the possibility of HIV status disclosure which may lead to stigma and discrimination, such as being avoided or left and rejected by sex partners. Men's concerns about stigma and discrimination from healthcare providers, and the suspicion of families and neighbours about their HIV status, are also reported to adversely influence their access and adherence to HIV care services or ART (146, 150, 152). For some men, the decision not to access HIV care services is undertaken to avoid the negative public perceptions or judgements that would associate their HIV status with them misbehaving or being unfaithful in their relationships, which may also lead to the disruption of their relations with partners or spouses, and poor health status (146, 150, 152). These findings indicate men's concealment of their HIV status to overcome stigma could also lead to them missing family and social support. HIV stigma also leads to men being socially isolated due to the physical manifestations of the infection, being expelled from the place where they stay, and disengagement from work to avoid disclosure of their HIV status (142, 143, 145, 147, 150).

A diagnosis of HIV in men also causes stigma by association for their family members. It has been reported to negatively impact on a family's identity and interactions, such as causing shame to a family and damaging a family's reputation and social networks (153). For example, it leads to parents feeling ashamed of their son’s HIV status and avoiding any conversation related to their son’s health condition, and family members being avoided, excluded and discriminated against by relatives, neighbours and other people within communities where they live due to the HIV-positive status of a father, husband or son in the family (153, 154). Other examples of stigma by association are that the children of MLHIV are left or rejected by their friends due to the HIV-positive status of their father, and HIV-negative parents restrict their children from mingling with the children of MLHIV (154).

2.3.2.3 Economic impact

An HIV diagnosis in men is reported to have economic or financial consequences for them at the individual level through several mechanisms such as a decrease in income, a loss of jobs and an increase in health expenditure (145, 155). Similarly, at the familial level, a diagnosis of HIV in a male family member or husband leads to a decrease in or the complete loss of family income due to their decreased working hours or unemployment, and increased family expenditure for medical treatment and funerals (155-159). Poor physical health which may lead to the inability to work at all or to work for long hours, and the routine medical treatment, seem to be the underlying reasons for the loss of jobs, reduced or loss of family incomes and increased family expenses. Another mechanism through which HIV negatively impacts upon the economic or financial conditions of men at an individual and familial level is that MLHIV are less likely to be employed (145, 159). This seems to be an indication of the low acceptance of and stigma and discrimination towards PLHIV in workplace settings. Such economic or financial impacts are reported to be even worse within families that are dependent on a husband as the regular wage earner, as in some cases the decrease or loss of income may become permanent once the husband is unable to work for long periods of time or dies from AIDS (156, 158). Such economic hardships are also reported to have a further impact on other aspects of the family of MLHIV, such as family food insecurity, poor nutritional intakes among family members, especially the children, and the unaffordability of children’s school levies (155, 157). These have been reported to negatively affect children’s educational performances or lead to the withdrawal of children from school (155, 157). Other consequences of such impacts are the sale of a family’s assets as a strategy to cope with family needs, including basic necessities, health expenses and the children’s education fees, which put families in a vicious cycle of poverty (155, 156).

2.4 Facilitators of and barriers to the access to HIV care services: the views and experiences of PLHIV

2.4.1 Facilitators of access to HIV care services

Availability and approachability of the services and the ability to reach and perceive the need for the services

The availability of healthcare services for HIV treatment, such as ART, CD4, viral load, kidney and liver checks, and other tests to support HIV treatment, is reported as a facilitator for the access of PLHIV to the services (160, 161). Similarly, the availability of HIV-trained healthcare professionals (e.g., doctors and nurses) to deliver the services and provide support to PLHIV is a supporting factor in their access to the services (160, 162). The integration of HIV care services into the healthcare facilities providing other primary healthcare services is also reported as a factor that facilitates the linkage of PLHIV to HIV care (161). Thus, the integration of HIV care into other primary healthcare services, and other factors such as simple procedures to book and access the services and the availability of transportation to healthcare facilities, have been reported as facilitators for the access of PLHIV to the services (160, 162-164). These factors also help reduce the time spent by PLHIV for accessing the services. The ability of PLHIV in terms of physical capacity and mobility to reach healthcare facilities providing HIV care services is also a supporting factor for their access to the services (160). Similarly, the proximity to healthcare facilities providing the services is reported in some studies as an enabling factor for PLHIV to reach and access the services (160, 161).

The approachability of HIV care services, reflected in how well known the services are to PLHIV or people in healthcare need, is another supporting factor for the access of PLHIV to the services (160, 165). In addition, some studies have also reported that to generate access to the services, the approachability of the services should be supported by the ability of PLHIV to be aware of their health problems, disclose them to healthcare providers, and perceive their need for healthcare (160, 161, 165). The ability of PLHIV to perceive their need for HIV care is also a reflection of the level of their HIV-related health literacy (e.g., the recognition of HIV care services and how to access the services), which is a supporting factor for PLHIV's access to HIV care services (160, 166).

Affordability and appropriateness of the services and the ability to engage in the services

The affordability of HIV care services, which refers to both the low cost of the services and the capacity of PLHIV to spend resources for them, is a facilitator of their access to the services (160, 166). For example, these studies have reported that the free provision of HIV care services to PLHIV and the possession of health insurance that covers healthcare expenses, enable the access of PLHIV to the services (160, 166). This seems to be plausible as many PLHIV, especially in developing countries, come from families with low socio-economic status, and experience economic difficulties due to a lack of income, job loss, unemployment, and poor physical health condition.

The appropriateness of HIV care services, or the extent to which the services meet the health needs of PLHIV, also facilitates access to the services. Some studies have reported that the convenience of HIV care services and the contented experience of the services, support the access of PLHIV to them (160, 166). Similarly, the good quality of the service delivery and the friendly attitudes of healthcare professionals delivering the services to PLHIV, are also supporting factors for the access of PLHIV to HIV care services (160, 162, 164, 167, 168). Also, the ability of PLHIV to engage in HIV care, which is determined by their motivation to participate in the care and commit to its completion, is reported as a facilitator for their access to the services (160, 169). Some instances of their motivation to engage in HIV care are a strong desire to be healthy, to participate in social activities and to fulfil their social responsibilities as community members (160, 169). Similarly, trusting and relying on healthcare professionals are also enabling factors for the engagement of PLHIV in HIV care service (166).

Social relationships and supports

Long-term, respectful and supportive social relationships and interactions between PLHIV and healthcare professionals have been reported in several studies as facilitators for the access of PLHIV to HIV care services (160, 161, 163, 165, 169, 170). Through such constructive relationships, PLHIV receive constructive feedback, information and emotional support from healthcare professionals, and are linked to HIV care services (161, 163, 165, 168). Thus, such relationships and interactions lead to PLHIV feeling respected, encouraged, accepted and comfortable in continuing their access to HIV care services (160, 161, 169). It is plausible to allude that PLHIV experience negative psychological challenges which influence their response to the infection and access to HIV care services. Hence, receiving emotional and informational support from healthcare providers is considered as an important facilitator for their access to the services (165).

Furthermore, social support from families and friends is also a facilitator for PLHIV in accessing HIV care services. For example, financial support and emotional support from close family members and relatives through encouragement and reminders to access the services and adhere to ART, are reported by PLHIV as supporting factors for their access to HIV care services (161, 169, 171). Similarly, support from peers and colleagues within peer support groups and networks, such as providing information to each other about HIV treatment and accompanying each other to collect antiretroviral medicines, facilitates their access to HIV care services (160, 163-166, 168, 171). Emotional support from peers and colleagues through kind and caring attention and attentive listening, is also recognised as a facilitator in the access of PLHIV to the services (165, 166).

2.4.2 Barriers to access to HIV care services

The limited availability of services and the inability to reach and perceive the need for the services

The limited availability of HIV care services, which is reflected in the logistical constraints to accessing treatment, the inadequate numbers or healthcare facilities providing the services and the lack of medical equipment and antiretroviral medicines, has been reported as a significant barrier for PLHIV’s access to HIV care services (172, 173). The limited availability of the services is also reflected in the shortage of HIV-trained healthcare professionals in healthcare facilities to deliver HIV services to PLHIV, which is also another barrier to the access of PLHIV to the services (172, 174, 175). Some studies have reported that these shortages can lead to overburdened healthcare facilities providing HIV-related services, difficulties in appointment scheduling, PLHIV visiting multiple healthcare facilities to search for available services and a dissatisfaction with the quality of care (154, 172-174). Other consequences of these shortages include long queues or long waiting hours to get HIV care services, more time spent on travel to healthcare facilities, and the delivery of the services not in a timely manner (163, 169, 172, 174, 176). These consequences have been reported to influence the access of PLHIV the services (154, 172-174).

The inability of PLHIV to reach healthcare facilities providing HIV care services due to various reasons has also been reported to influence their access to the services (163, 169, 176). Time constraints due to demanding or inflexible work schedules, difficulties in requesting time off for medical appointments, and clashes between the treatment schedules and other activities such as caring for children or elderly family members and other household duties are some of the underlying reasons for the inability of PLHIV to reach and access HIV care services (163, 169, 176). The experience of income loss and the threat of losing their job because of taking time to visit an HIV clinic are also reasons that influence their ability to reach healthcare facilities and access the services (172). Poor transport infrastructures or the lack of public transportation and long distances of travel to HIV clinics providing the services are other factors that also limit the ability of PLHIV to reach HIV care services are (162, 163, 172).

The inability of PLHIV to perceive their need for HIV care is another barrier to their access to HIV care services. Several studies have reported that their inability to perceive their need for care is influenced by their poor HIV-related health literacy about HIV, HIV care services, and the consideration of nutrition as a superior alternative to ART; this has been acknowledged to further prevent their access to the services (166, 172, 175). A perceived healthy status or physical condition, an absence of symptoms and a mistrust of HIV test results are also factors that contribute to a low perceived need for care among PLHIV and hinder their access to the services (164, 166, 176, 177). Similarly, the perception of PLHIV about the adverse outcomes of ART, such as a loss of appetite, a weak physical health condition, and negative side effects of the treatment, leads to fear and doubt about the benefits of the treatment (164, 166, 168-170, 175, 176). Such perception has been reported to influence their perceived need for care and access to HIV care services (164, 166, 168-170, 175, 176).

The unaffordability and inappropriateness of the services and the inability to pay and engage in the services

The costs of medical treatment, such as the costs for standard blood, viral load and CD4 tests prior to the initiation of treatment, the treatment of opportunistic infections and administration, are also barriers to the access of HIV care services among PLHIV (162, 172, 175). Similarly, high transport costs due to long travel distances, especially from rural communities to healthcare facilities in urban areas, have often been identified as barriers to PLHIV in accessing the services (162, 163, 175, 176). These medical and transport-related costs seem to be worsened by the fact that many PLHIV in developing countries do not possess health insurance due to the unaffordability of insurance fees, and where public transport is poorly available (163). Besides, lack of income, unemployment, economic or financial hardship, food insecurity and poverty facing PLHIV following their diagnosis have also been reported as supporting reasons for their inability to afford costs associated with access to HIV care services (162, 169, 172, 177, 178). In several studies such situations have been identified as often leading PLHIV to making difficult choices daily, by prioritising basic necessities over health needs, or choosing to earn an income over visiting healthcare facilities, hence hindering their access to HIV care services (162, 169, 172, 177, 178).

The inadequacy of HIV care services in meeting the health needs of PLHIV, such as a lack of HIV care services adjusted to the needs of specific population groups (e.g., adolescents) and an unfriendly HIV service-delivery environment, have been reported as discouraging access to the services (164, 167, 174). The perceived stigma from family, community members and healthcare providers, which leads to the fear of being seen by others if accessing HIV care services and the non-disclosure of their HIV status, are also factors that demotivate PLHIV from engaging in HIV care services (154, 161, 163, 166, 172, 174, 176, 179). Similarly, enacted or experienced stigma from healthcare providers, which is reflected in their discriminatory and stigmatising attitudes and behaviours, such as rudeness, a delay of care and humiliation or abusive language towards PLHIV, is also a significant barrier to their engagement in the services (49, 154, 161, 164, 169, 174, 175, 180). Such stigma and discrimination by healthcare providers also lead to concern of PLHIV about privacy and confidentiality as regards their HIV status following their access to HIV care services, impacting their motivation to access the services and continue their HIV treatment (163, 168, 171, 175, 180). The experience of stigma from family and community members, which often leads to self-isolation, is also another factor that influences the motivation of PLHIV to engage in HIV care services (49, 169, 178, 181). This is to avoid the possibility of negative thinking, judgement from family members, and negative public attitudes and behaviour towards them (49, 169, 178, 181). Other factors such as having mental issues, engaging in substance abuse, concerns about spoiling their relationships and social identity, as well as losing sex clients if their HIV status is known to other people, are also reported as being barriers for PLHIV to initiate or continue their access to HIV care services and other social supports (163, 164, 168, 169, 180).

Mobility and internal migration which refers to moving voluntarily from one place to another within a country (182) for work or for economic purposes, or to search for employment in areas far from their places of origin are also factors that have been reported to influence the engagement of PLHIV in HIV care services (169, 172). These are plausible, as mobility and migration can disconnect PLHIV from the healthcare systems in their place of origin, and hamper their engagement in new healthcare systems in other places they might move into. For some WLHIV, a lack of support from their male partner is also a barrier to their engagement in HIV care services (176, 178). Similarly, for some WLHIV who are economically dependent on their husbands, the decision to access healthcare services is often made by the husband, a condition which hampers their engagement in HIV treatment (169, 176).

Poor PLHIV-healthcare providers' relationships and religious barriers

Poor social relationships between PLHIV and services providers, and poor patient-provider communication or one sided communication are also identified in some studies as factors that influence access to HIV care services among PLHIV (173, 175). Such poor social relationships and patient-provider communication are reflected in both a lack of support from healthcare professionals and the absence of open conversation between PLHIV and healthcare professionals (154, 169, 176, 180). These are reported to lead to PLHIV feeling unwelcome, ignored or unheard by healthcare providers, which influences their access to HIV care services delivered by healthcare providers (154, 169, 176, 180). Other factors that have been reported to influence the linkage or access to HIV care services among PLHIV are the strong religious and spiritual beliefs PLHIV have in a spiritual healing by God (161, 176). An underlying reason for such strong spiritual beliefs is that religious and spiritual healers are regarded as providing better explanations and treatments, hence they are trusted by community members (161). As a result, PLHIV often seek or choose spiritual healing from religious and spiritual healers over medical treatments or ART from healthcare providers (177).

2.5 Facilitators of and barriers to the access to HIV care services among PLHIV: perspectives of healthcare providers

2.5.1 The facilitators of access to HIV care services

Studies exploring the perspectives of healthcare providers on factors that support the access of PLHIV to HIV care services have reported on the availability of health services, such as HIV care, treatment, antiretroviral medicines, viral load and CD4 count tests in healthcare facilities as facilitating the access of PLHIV to the services (161, 183). The availability of HIV care services is also perceived by healthcare providers as facilitating the linkage of PLHIV to the services following their diagnosis, which increases their access to and retention of HIV treatment (161, 183). Similarly, non-HIV clinics or healthcare facilities that provide services for linking PLHIV to HIV care services or treatment are acknowledged by healthcare providers as an enabling for PLHIV in accessing the services (161). Service provision linking PLHIV to HIV care services is considered by healthcare providers as a very important facilitator of HIV care access due to the understanding that many PLHIV, especially those that are newly-diagnosed, have limited a knowledge about the availability of HIV care services and procedure to access the services (161, 183). In addition to the availability of services, healthcare providers in some studies have suggested that HIV care services that address the difficulties PLHIV have gone through and the specific needs or concerns of PLHIV from certain groups (e.g., children, women, transgender people), and also maintain the privacy of PLHIV, are facilitators for their access to the services (167, 180). It seems that such kinds of responses lead to the acceptance of the services and the feeling of being taken care of, which then encourage the access and retention of PLHIV in HIV treatment.

The understanding of PLHIV about HIV and the positive outcomes or benefits of HIV treatment, and their acceptance of their HIV status, are also raised by healthcare providers as facilitators to the access and retention of PLHIV in HIV care services and ART (183, 184). It is therefore acknowledged by some healthcare providers that a high-quality service such as counselling, can play an important role in the HIV care experience of PLHIV by helping to enhance their knowledge and understanding about both the infection and the treatment, and by preparing them to engage in and retain HIV care and treatment (184). Supportive social relationships between PLHIV and healthcare providers, support from family members and social networks with friends (e.g., ART support groups) who have been trained to help newly-diagnosed PLHIV, are acknowledged by healthcare providers as facilitators of both the access of PLHIV to HIV care services and their adherence to ART (161, 183).

2.5.2 Barriers to access to HIV care services

The limited availability of the services and the inability of PLHIV to reach, perceive and pay for the services

Similar to PLHIV, healthcare providers also acknowledge the limited availability of HIV care services reflected in the insufficient antiretroviral medicines, HIV care centres, and CD4 and viral load testing devices as barriers to the access of PLHIV to HIV care services (161, 183, 185). Such limitations are also reflected in the shortage of healthcare staff in HIV services, which is also a significant barrier to the access of PLHIV to the services (161, 183, 186). In addition, healthcare providers in some studies have also acknowledged that healthcare staff in HIV services are inadequately trained about HIV and HIV service delivery to PLHIV (167, 180). Such a lack of training is reported to influence their confidence in effectively delivering HIV care services to PLHIV, which is also considered as a factor that influences access to the services among PLHIV (167, 180, 186-188). The lack of training can lead to the failure of healthcare providers to respond to the specific needs and expectations of PLHIV, which is also a factor that demotivates PLHIV to seek and access HIV care services (167, 180, 187).

These aforementioned shortages (e.g., medication, HIV care centres or clinics, HIV trained healthcare staff) have been reported as leading to staff feeling overwhelmed with their responsibilities and overloaded with work, the inability of clinics to serve HIV patients efficiently, HIV clinics being overcrowded and long waiting hours at the clinics (154, 161, 176, 186). These shortages are also acknowledged to delay or hinder both the enrolment and access of PLHIV to HIV care services or ART, as in some cases, PLHIV who are in such situations are reported to return home or to work (154, 161, 176). Another consequence of these shortages is that PLHIV trying to access the services are not served, and are instead asked to come back another time, which is considered to create a feeling of rejection and to push PLHIV away from the services (161, 183, 186). Inconvenient clinic hours or limited opening hours are also reported by healthcare providers as barriers to the access of PLHIV to HIV care services due to these clashing with their working hours (154, 161, 186). Similarly, insufficient counselling and a lack of adequate counselling space are perceived by some healthcare providers as barriers to PLHIV accessing and engaging in HIV care services (184, 186).

In some studies, healthcare providers have also reported that the inability of PLHIV to afford the costs for opportunistic infection treatment and laboratory tests to support their HIV treatment are major barriers to their access to HIV care services (177, 186). Furthermore, long distances to healthcare facilities and high transportation costs are also identified by healthcare providers as deterrents to the access of PLHIV to HIV care services (161, 176, 177, 186). These are also indications of the inequitable distribution of healthcare facilities and services within communities and poor infrastructures, such as public transportation systems, which pose major barriers for many PLHIV to enter into HIV care. In addition to the direct cost-related barriers mentioned above, some healthcare providers have also reported indirect treatment costs, such as the loss of income and expenses for extra food, as factors that influence the ability of PLHIV to reach and access HIV care services (186).

Furthermore, healthcare providers in some studies have suggested that the inability of PLHIV to perceive their need for care is also a barrier to their access to HIV care services (161, 184, 186). This is reported to be influenced by their mistrust in their HIV test results and feeling healthy or having no HIV symptoms, which have led to their ignorance about treatment and decision not to attend HIV care services (161, 184, 186). A lack of understanding about the benefits of ART is also perceived by healthcare providers as a barrier for PLHIV in accessing HIV care services and starting ART (186). Similarly, misperceptions about the side effects of ART, including, in some cases, the perception that ART hastens the death of PLHIV, is also reported by healthcare providers as a barrier to the access and retention of PLHIV in HIV care services and ART (183, 184).

Social barriers to the access to HIV care services

Stigma and discrimination against PLHIV within families, communities, workplaces and healthcare facilities are recognised by healthcare providers as significant social barriers to the engagement of PLHIV in HIV care services (50, 154, 167, 185, 187). Some examples of such stigma and discrimination are rejection, gossiping, negative talk and cynical questions from healthcare staff about the HIV status or sexual behaviours of PLHIV (50, 154, 167, 185, 187). Other instances are the avoidance and refusal from community members and employers, and the separation of personal belongings of PLHIV from those of other family members (50, 154, 167, 185, 187). As a consequence of such stigma and discrimination, many PLHIV in some settings fear going to healthcare facilities, accessing HIV care services, disclosing their HIV status to anybody else, including healthcare providers, and being seen by other people at HIV clinics (161, 177, 180, 184-186). Similarly, some healthcare providers have acknowledged that stigma and discrimination against PLHIV within workplaces demotivate them from accessing HIV care services and lead to non-disclosure of their HIV status to avoid the possibility of being fired from their job (186).

Other factors such as food insecurity or worries about inadequate food are raised by healthcare providers as demotivating factors for PLHIV to access HIV care services and start ART (183, 184, 186). For example, healthcare providers in these studies have reported that in some settings many PLHIV postpone their access to HIV care services and the initiation of ART due to a lack of food and an inability to take medication on their empty stomachs (184, 186). Fear of the negative effects of taking medicines without food seems to be the possible underlying reason for the unwillingness of some PLHIV to access and initiate ART. Mental illnesses, substance abuse and alcohol consumption are also reported by healthcare providers as interfering factors for the access of PLHIV to HIV care services (185). It can be speculated that the influence of illicit drugs, alcohol, and mental health issues could lead to PLHIV missing out on schedules for accessing and taking the medications.

Mobility or moving from one place to another for work purposes is also recognised by healthcare providers as a barrier for PLHIV who are daily labourers, commercial sex workers, cross-border traders, farmers and long-distance truck drivers to access HIV care services (177). This seems plausible as they may not know or be unfamiliar with HIV healthcare systems and access procedures in new places they move into. Healthcare providers have also reported that in some settings, WLHIV are prevented from attending HIV clinics by their husbands in order to conceal the men’s HIV status and preserve their so-called masculine pride as strong persons and the main caretakers of the family (176). Such a situation is reported to create fear among women to make decisions contrary to their husband’s directive, or to go HIV clinics to access the services, as it may lead to domestic violence or marital dissolution (176, 186).

Religious barriers to the access to HIV care services

Religious beliefs, such as the belief that prayers by pastors in churches and the use of holy water given by pastors can heal HIV, are reported by healthcare providers to have a significant influence on access to HIV care services among PLHIV (161, 177). As reported by healthcare providers in some studies, such beliefs lead to PLHIV preferring such religious ‘cures’ over medical treatment or ART, thus hindering their access to HIV care services (177, 184). The use of such religious ‘cures’ (prayers and holy water ‘therapy’) by PLHIV in certain communities is reported to be influenced by several factors, including mistrust in the HIV test results, distrust in ART, knowledge that ART does not cure HIV, and rumours within communities that holy water can cure HIV (177). In addition, the influence of friends and relatives that encourage the use of such religious ‘cures’ is also acknowledged by healthcare providers as a barrier to the access of HIV care services among PLHIV (184). Similarly, the influence of religious leaders who encourage PLHIV to stop taking ART after praying for them, and to rely on healing through faith and prayer, is also reported by healthcare providers as a significant barrier to ART adherence among PLHIV (183, 186). Healthcare providers have also acknowledged that the influence of religious leaders in this matter seems significant, as in many communities in developing countries people still strongly hold their religious beliefs, and hence may tend to listen more to religious readers than healthcare professionals (183, 186).

2.6 Summary of the review of the literature

HIV risk factors among women and men living with HIV

The review of the literature reports a range of factors that support the transmission of HIV among women and men living with HIV. Poor health literacy about HIV, condom use and its protective function towards HIV transmission is a common risk factor for both women and men, as it leads to an unawareness of the possibility of contracting HIV through their risky behaviours. Behavioural factors, such as unprotected sex with partners or spouses who are HIV positive and with multiple casual partners, are also risk factors for HIV transmission among them. For women, the objection by sex partners, the perception that condoms reduce sexual satisfaction, an unawareness of their spouses' extramarital sexual behaviour, their trust in partners or spouses, depression, anxiety, the unavailability of condoms and alcohol abuse by husbands, are reported as supporting reasons for their engagement in unprotected sex. For men, their negative attitudes towards condom use, avoiding arousing the suspicions of their sex partner towards their extramarital sex, feeling it unnecessary to use condoms, their less perceived risk of contracting HIV, their concerns about sexual pleasure and beliefs in the effectiveness of ART in preventing HIV transmission, are the common underlying reasons for their engagement in unprotected sex prior to or following their HIV diagnosis. Engagement in IDU practices that often involve needle sharing among users is another high-risk behavioural factor that facilitates HIV transmission among both women and men.

The review of the literature has also shown that economic or financial factors play a role in HIV transmission among both women and men through different mechanisms. For women, poor economic or financial conditions are reported to lead to a dependency on support from their partners or spouses, thus disempowering their condom use negotiation ability and motivating their engagement in sex work practices in exchange for cash. For men, a relatively good financial condition reflected in them having a regular income which enables them to purchase the sexual services of FSWs and use illicit drugs, supports their supports their engagement in unprotected sex and needle sharing practices.

IPV against women in the form of physical, verbal and sexual abuse is another risk factor associated with HIV transmission among women as it leads to the fear of negotiating condom use or refusing the demands of their husbands for unprotected sex. Some studies provide evidence of cultural factors that promote hegemonic masculinity and emphasise women's fidelity to their husbands, which leads to male-dominated sexual decision-making and unprotected sex as factors that support HIV transmission among women.

Social factors, such as the influence of peers and negative peer norms or pressures that encourage men's engagement in sexual practices with multiple casual partners, unprotected sex and IDU, are also facilitators for HIV transmission among men. Similarly, environmental conditions where brothels, transactional sex practices and illicit drugs are available and accessible, and where condoms are hard to find, are also factors that support men's involvement in unprotected sex with multiple casual partners and IDU, facilitating HIV transmission among them.

HIV impact on women and men living with HIV and their families

The review of the literature shows that for various reasons an HIV diagnosis causes a range of psychological challenges to women and men, such as depression, worry, anxiety, sadness and embarrassment. For women, their concerns about poor physical health, lack of confidentiality of their HIV status, causing shame to their family, social rejection, children's health, growth and future, and the possibility of transmitting HIV to their unborn babies, are the common reasons behind such psychological challenges. For men, feelings of loss and failure as a man, an inability to retain control, hopelessness and worthlessness, their poor financial condition, unemployment, concerns about costs for health treatment and being dependent on support from others, are supporting reasons for the negative psychological challenges facing them. Some evidence shows that children of WLHIV also experience psychological challenges, such as feeling upset, hurt, sad and worried due to the HIV status of their mothers.

Social impacts, such as stigma and discrimination manifesting in a range of discriminatory and stigmatising attitudes and behaviours of family, community members and healthcare providers are also the common negative consequences experienced by both women and men following their HIV diagnosis. The fear of contracting HIV is reported as the main driver of these attitudes and behaviours of others towards them. The literature also shows that stigma and discrimination have further negative influences on the sexual and health-seeking behaviours of MLHIV, and lead to the concealment of their HIV status, self-isolation and disengagement in social activities or interactions to avoid the possibility of HIV status disclosure. The literature also suggests that an HIV diagnosis in women and men leads to stigma by association towards their family members, manifested in children being rejected, mocked by peers, denied school admission and negatively labelled, and family members being avoided, excluded and discriminated against by relatives, neighbours and other community members.

The literature shows that an HIV diagnosis has economic or financial consequences on women and men at the individual level through several mechanisms such as decreased income, job loss and increased health expenditure. Such consequences have further negative impacts on their families, such as family food insecurity, poor nutritional intakes among children and an unaffordability of children's school levies. This can negatively affect children's educational performance, and can lead to the sale of family assets and a vicious cycle of poverty.

Limited evidence suggests that an HIV diagnosis in women negatively influences the social lives of their children due to them taking on additional responsibilities for household chores and their sick mothers, which prevents them from engaging in activities such as socialising with friends. An HIV diagnosis in women also causes family separation, such as the removal of their children by other family members, or WLHIV voluntarily sending their children to live with other families, and being abandoned or divorced by partners or spouses due to the unacceptance of their HIV status.

Facilitators of and barriers to the accessibility of HIV care services among PLHIV

The review of the literature reports several factors that facilitate the accessibility of HIV care services from the perspectives and experiences of PLHIV and healthcare providers. These factors are categorised into healthcare service-related factors and demand-related factors. On the healthcare service side, the availability of HIV care services, healthcare facilities, health devices and HIV-trained healthcare staff, determines the accessibility of the services. The approachability of the services or the well-known information about the services to PLHIV, the affordability of the prices of the services and the appropriateness of the services in meeting or addressing the health needs of PLHIV, are also healthcare service-related factors that facilitate the accessibility of the services for them. On the demand side, the literature shows that the ability of PLHIV to perceive their need for health care, which also reflects their understanding about HIV or the health problem they face, the positive outcomes or benefits of HIV treatment and their acceptance of their HIV status, can determine their access to HIV care services. The abilities of PLHIV to reach healthcare facilities and access the services, to pay for the costs (e.g., medical and transport costs), and to engage and retain the services or treatments, are also factors that facilitate their access to the services. The literature also shows that positive and respectful social relationships and interactions between PLHIV and healthcare professionals, as well as social supports from families and friends, are facilitators for PLHIV to access HIV care services.

Furthermore, the literature reports a range of barriers to the accessibility of HIV care services from both sides. On the healthcare service side, the barriers are the limited availability of HIV care services as reflected in logistical constraints, inadequate number of healthcare facilities providing the services, the lack of medical equipment and antiretroviral medicines, and the shortage of HIV-trained healthcare professionals. These barriers lead to staff feeling overwhelmed and overloaded with work, the inability of clinics to serve HIV patients efficiently, the long waiting hours at the clinics and the delay in patients' enrolment and service provision. The high costs of medical treatment and transport and the inadequacy of HIV care services to address the health needs of PLHIV are also healthcare service-related barriers to the accessibility of HIV care services. On the demand side, the inability of PLHIV to afford the costs for opportunistic infection treatment and laboratory tests to support their HIV treatment and to reach healthcare facilities providing HIV care services due to financial hardship, lack of income, time constraints, fear of losing income or jobs, poor transport infrastructure and long distances to healthcare facilities are barriers to their access to the services. The inability of PLHIV to perceive their needs for HIV care due to poor health literacy about HIV and its impact, and HIV care or ART and its positive outcomes, and to engage in HIV care services due to stigma and discrimination are also significant barriers to their access to services.

The literature also reports that stigma, discrimination, lack of social supports, mental illnesses, substance abuse, concerns about spoiling their relationships and social identity, mobility and internal migration to other places for work or economic purposes, and food insecurity are also barriers to their access to HIV care services. Evidence from a few studies shows that belief in religious ‘cures’ (prayers and holy water ‘therapy’) and the influence of religious leaders who encourage PLHIV to stop taking ART and rely on healing through faith and prayer are also barriers to the access of PLHIV to HIV care services.

2.7 Gaps in the literature

The review of the literature suggests that previous studies have mainly focused on a single group of women or men living with HIV in a single setting; none has compared HIV risk factors, HIV impact and the accessibility to HIV care services for women or men living with HIV in two different settings in any country. Such comparisons are important as they can help understand how similar or different factors in different settings influence HIV transmission, HIV impact and the accessibility to HIV care services among different groups of women or men living with HIV. Although Yogyakarta and Belu are parts of the same country, and appear to be similar with regards to the prevalence of HIV infection, each has several specific characteristics in terms of culture, religion, HIV-related health facilities and services, HIV-related social supports, geographical location and, presumably, HIV-related information dissemination within their respective communities, and community acceptance towards PLHIV.

Yogyakarta municipality is a traditionally Muslim area occupied predominantly by people of the Javanese culture, while Belu district is a traditionally Christian area with the majority of people originating from several tribes, including, *Tetun*, *Marae*, *Kemak* and *Atoni*. In terms of geographical location, Yogyakarta is an urban area with a better infrastructure including health facilities and transportation systems compared to Belu, which comprises rural areas with an underdeveloped infrastructure, such as healthcare facilities and transportation systems. The availability of HIV-related healthcare facilities and services is very limited in Belu (189) compared to Yogyakarta (190). Similarly, HIV-related social supports, including peer support groups and AIDS care groups, are more available within communities in Yogyakarta than in Belu. This may lead to a logical assumption that presumably the dissemination of information about HIV and HIV care services, and community acceptance towards PLHIV might be much better in Yogyakarta than in Belu. Thus, this study provides an opportunity for meaningful comparisons about how the specific characteristics between these two areas have influenced HIV transmission, HIV impact and the accessibility of HIV care services for women and men living with HIV.

The review of the literature shows that although a few studies have addressed and linked some aspects of culture to HIV transmission among women, there is limited evidence and understanding about the influence of cultural practices, norms and values on the sexual relations, practices, and behaviours of women and men, and on HIV transmission among them. Similarly, there is a lack of evidence regarding the influence of religious beliefs on the sexual relations, practices, behaviours and condom use by women and men, and how these influences may put them at risk for HIV transmission and acquisition.

A range of the impacts of HIV on both women and men following the diagnosis have been reported in the literature. However, there is a paucity of evidence regarding the influence of socio-cultural and religious factors on the impact of HIV faced by women and men living with HIV. Also, there is a limited focus in the existing literature on stigma and discrimination towards PLHIV as a process of social influence among family and community members.

The literature has reported a range of the dimensions of healthcare services and individual-related factors (e.g., the abilities of PLHIV) as either facilitators of or barriers to the accessibility of HIV care services among PLHIV. Social supports from healthcare providers, friends and families have also been identified as supporting factors for access to the services among PLHIV. Meanwhile, factors such as stigma, discrimination, food insecurity and religious beliefs have also been reported as potential barriers to the access of PLHIV to HIV care services. However, the literature suggests that evidence on the influence of cultural practices (e.g., the traditional treatment of HIV using traditional medicines from traditional healers) and social factors (e.g., the influence of family members, relatives, friends and neighbours in determining HIV treatment) on the access to HIV care services among PLHIV is still limited.

This study seeks to address these gaps in evidence. It attempts to understand and compare HIV risk factors, HIV impact, facilitators of and barriers to access to HIV care services among women and men living with HIV in the two different areas (Yogyakarta and Belu) in Indonesia. It also attempts to understand and compare the views, perspectives and experiences of women and men living with HIV and healthcare providers about the accessibility of HIV care services in these settings. In addition, it also attempts to understand and compare the views and perspectives of policy makers in Yogyakarta and Belu about the

HIV-related policies and programs that are in place, and what responses or solutions need to be undertaken in the future to halt HIV transmission, and to address the HIV impact on PLHIV and their families in these settings.

CHAPTER THREE

THEORETICAL FRAMEWORK

3.1 Overview

This chapter presents several conceptual frameworks employed to inform the study design, guide the development of interview guide (see Section 4.3.1 and Table 2) and data collection and analysis, and enhance the interpretation of the findings. It begins with the presentation of the logical model for behavioural and environmental determinants diagnosis which guided the exploration of HIV-risk factors among PLHIV. Next, it presents the conceptual framework for the socio-economic impacts of the HIV epidemic on individuals and households and the HIV stigma framework, which guided the exploration of HIV impact on women and men living with HIV and their families. Finally, it presents the access to healthcare framework which guided the exploration of facilitators of and barriers to the access for HIV care services among PLHIV in Yogyakarta and Belu.

3.2 Logical model for behavioural and environmental determinants diagnosis

This logical model was developed to diagnose behavioural and environmental determinants of a health problem that has adverse impact on the quality of life (191-193). In this study, it was used to explore and understand factors that may have supported or contributed to HIV transmission among both women and men living with HIV.

The model suggests that a health problem is determined by behavioural factors (191, 194). For example, behavioural factors that can cause HIV infection include the lack of or inconsistent use of condoms, engagement in unprotected sex with multiple sex partners or HIV-positive partners, engagement in sex work, sexual coercion or violence by intimate partners that lead to unprotected sex, and IDU which often involves needle sharing (56, 115, 191). The model suggests that an individual's behaviours are also determined by other factors, such as their knowledge, attitudes, beliefs, perceptions and education. In the case of HIV infections, factors that could influence an individual's behaviours or contribute to such risky behaviours may include a lack of knowledge about HIV (e.g., how HIV is transmitted and prevented) and condoms (e.g., the protective function of condoms and where to access them), then inability to access condoms, and negative personal attitudes and perceptions regarding condom use in relationships (191, 195, 196). Social networks, peer norms and influences which lead to engagement in sex with multiple sex partners, sex work, unprotected sex and IDU practices are social factors that determine an individual's behaviours (130, 131, 191, 197, 198).

The model also suggests that environmental factors are key determinants of health, and therefore the multifaceted and dynamic nature of people's environment should be considered in effort to understand their health behaviours and problems (191, 199). Thus, it suggests that health problems are also determined by environmental factors that influence an individual's behaviours or the behaviours of at-risk populations (191, 200). In the case of HIV infections, environmental factors or conditions that can influence an individual's risky behaviours (e.g., engagement in unprotected sex, IDU or sex work, which facilitate HIV transmission among them) may include the conditions where condoms are not available, sex work practices exist, and illicit drugs are available and easily accessible (191, 196).

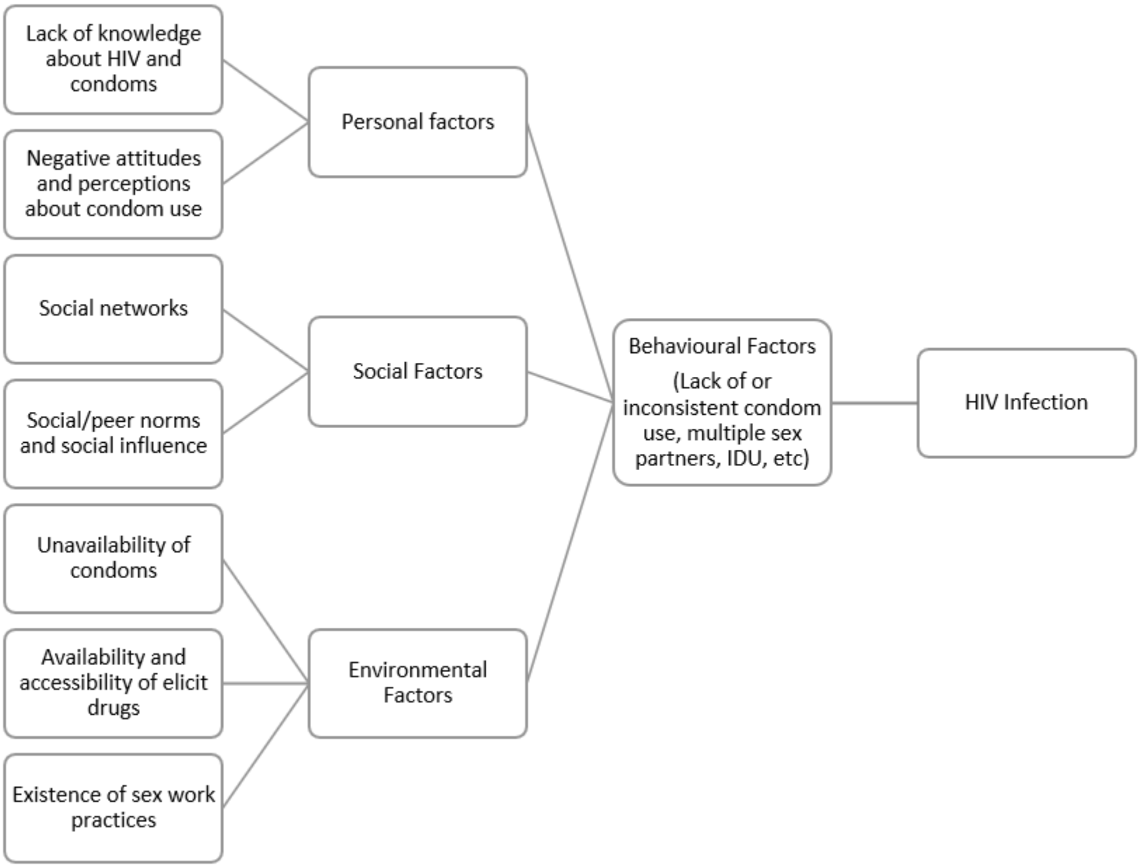

Figure 2: Logical model for behavioural and environmental factors

3.3 Conceptual framework for the socio-economic impact of the HIV epidemic on households

This framework (201) was used to explore the impact of HIV on PLHIV and their families. The framework suggests that HIV-related illness in family members affects households economically (202). It can impact directly by causing a loss of income (203, 204) and increasing expenditures to cover any medical costs (205, 206). It can also have indirect cost which results from the absenteeism of family members from work or school to care for a family member living with HIV (202). The illness of family members, especially ones who are family's breadwinners, may result in their absence from work and lead to a decrease in or loss of an individual and family income (203, 204). Likewise, the health expenditure for HIV-related care and treatment may increase, and this could lead to the use of family savings or the sale of family properties to cover the expenses for healthcare and daily needs (206, 207). This could lead to a family's food insecurity, hunger and poor nutritional food intake of family members, especially children, which is a risk factor for malnutrition (207). In effect, mounting expenses and the reduced or loss of income of a person living with HIV may result in the destitution of the family (202).

The framework also describes the social implications of HIV faced the affected families. These can include the withdrawal of children from school due to the inability of parents to pay school fees and buy supplies, and due to the need for the children's help at home, on the farm or in the market place (202, 208-211). Other social implications are the change in the structure of families and children being sent to live with or taken care of by extended families, relatives or grandparents due to the poor health or the death of their parents (202, 212). Older children may act as the head of families to take care of their younger siblings following the death of their parents (213). These social and economic consequences can lead to the deterioration of the psychological and physical health conditions of PLHIV and other family members (34-36).

3.4 HIV stigma framework

The HIV stigma framework by Earnshaw and Chaudoir (214) was used to guide the exploration of the participants' views and experiences of HIV stigma and discrimination. The framework defines stigma as a devalued attribute that has a negative impact on both HIV-positive and negative people within communities. The impact may occur through a range of stigma mechanisms which reflect people's psychological responses to the fact or knowledge that they are either infected (have the devalued attribute) or not infected with HIV (do not have the devalued attribute).

For HIV-negative people, stigma mechanisms represent their psychological responses to the knowledge about the HIV-positive status of other people living around them and who may transmit the virus to them (214, 215). Their responses towards PLHIV are mainly manifested in three predominant ways, including prejudice, stereotyping and discrimination (214, 216, 217). Prejudice refers to various negative emotions or feelings (e.g., fear, disgust, anger) that HIV-negative people have towards PLHIV (214, 216). Stereotypes refer to the beliefs HIV-negative people have about PLHIV, and such beliefs are often applied to specific individuals living with HIV (214, 218). Discrimination is the behavioural expression of prejudice towards PLHIV by HIV-negative people (214, 216).

For PLHIV, stigma mechanisms represent their psychological responses to the knowledge that they are infected with HIV, and may experience negative treatment from others or non-infected people (214). Such knowledge is experienced by PLHIV through several stigma mechanisms such as external or enacted stigma, anticipated stigma, perceived stigma, and self-stigma, which can negatively influence their behaviour, psychological state, social life and health outcomes (214, 217, 219). External or enacted stigma refers to the experiences of unfair treatment by others or the beliefs of PLHIV about their experience of prejudice and discrimination by non-infected people (214, 217, 219). Anticipated stigma refers to the belief of PLHIV about the possibility of experiencing prejudice and discrimination in the future due to their HIV status (214, 217, 219). Perceived stigma refers to the awareness of PLHIV about the existence prejudice and discrimination towards them, and self-stigma refers to the degree to which PLHIV endorse HIV-related negative labels, perceptions and feelings about themselves (214, 217, 219).

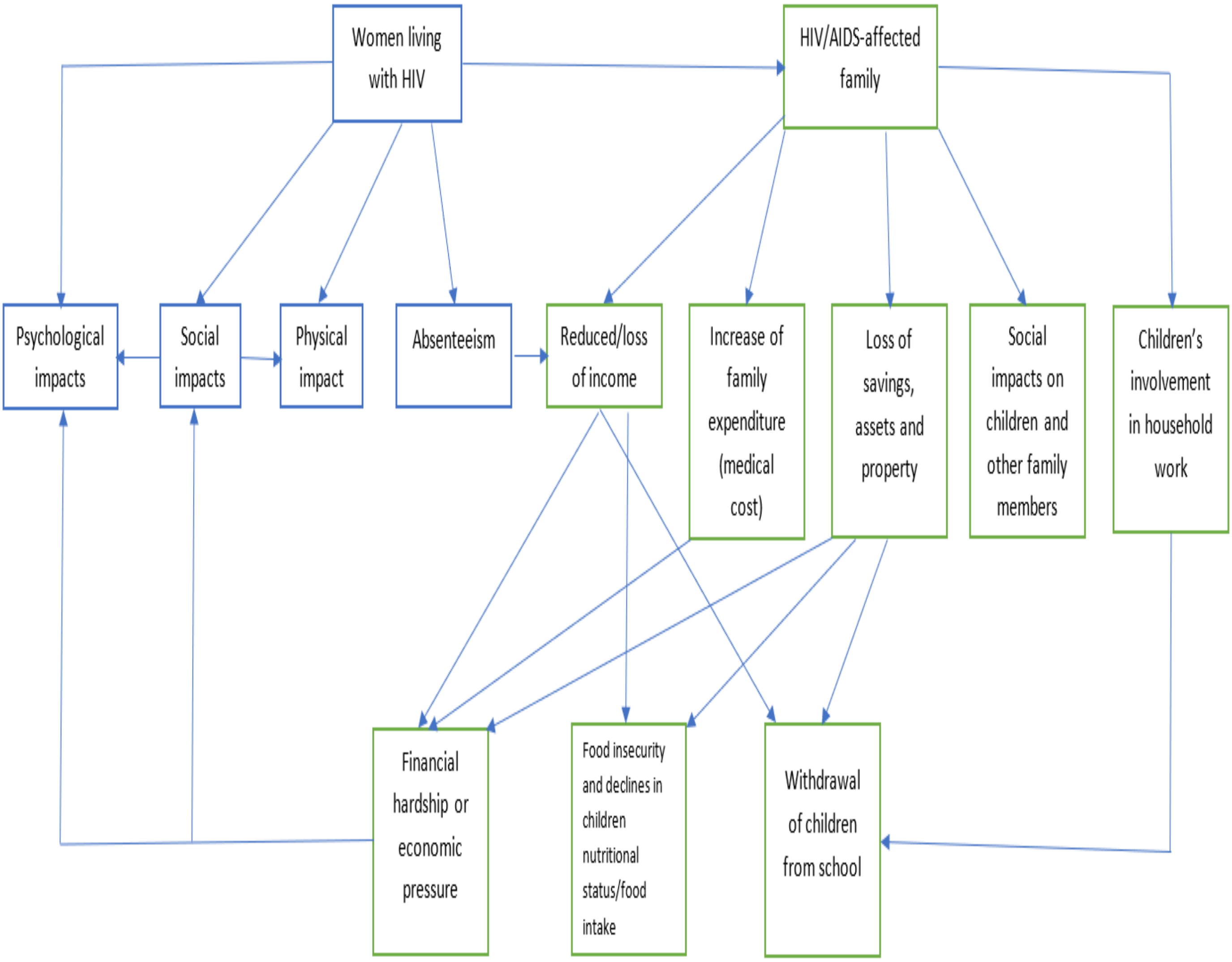

Figure 3: Conceptual framework for the impact of HIV on PLHIV and their family

3.5 Access to healthcare framework

Access to healthcare framework (220) was employed to explore the views and experiences of PLHIV and healthcare professionals about the accessibility of HIV care in Yogyakarta and Belu. The framework suggests that access to healthcare services is determined by the characteristics of both the supply side, such as the healthcare providers or healthcare organisations or institutions or systems, and the demand side, such as populations or communities or households or individuals (220-222).

The framework proposes five dimensions of accessibility to healthcare services from the supply side, which include availability, approachability, affordability, appropriateness and acceptability of healthcare services (220-222). *Availability* refers to the existence of healthcare services that can be reached by people in need of healthcare. It relates to whether or not the healthcare facilities have sufficient resources and health professionals available to produce health services. *Approachability* refers to whether or not the information about the healthcare services is made known to the people within the groups and communities. It is about how well known the services are to people in need for healthcare. *Affordability* reflects the costs of the healthcare services and other expenses related to access to the services, and the capacity of people to spend their resources and time on the services. *Appropriateness* refers to the extent to which the healthcare services serve the needs of the people. It relates to what services are delivered and the quality or the way they are delivered, the healthcare providers who deliver the services, their trust in the healthcare providers, and whether the services are the ones that the people need. *Acceptability* relates to the social and cultural factors that determine or may influence the acceptability of the health services or aspects of the health services. Relevant factors could be the mechanisms or procedures of the service delivery or the sex of the healthcare providers who deliver the healthcare services.

To generate the access, the framework suggests that these five dimensions of healthcare accessibility should interact with the five corresponding abilities of the people in need of the healthcare. The five corresponding abilities include ability to reach, ability to perceive, ability to pay, ability to engage and ability to seek the healthcare services (220-222). *Ability to reach* relates to factors that enable people to reach the healthcare facilities and healthcare services. These factors could be personal mobility, the availability of transportation, occupational flexibility and the availability of time, which would enable people in health need to reach the healthcare providers and services. *Ability to perceive* refers to the knowledge people have about their need for healthcare, the availability of the healthcare services and how to access the services. It is therefore considered as a complementary notion of the approachability of the healthcare services. *Ability to pay* refers to the economic capacity of people to pay for their medical costs, transport costs and other expenses that may facilitate their access to the healthcare services. The ability to pay is determined by an individuals' financial condition or resources that can be used to access to the healthcare services. A*bility to engage* is about the decision of individuals to access the healthcare services available to them. Such decision is determined by other factors, including their motivation to access healthcare services, health literacy, knowledge of the availability of health services, self-efficacy, etc. Lastly, *Ability to seek* relates to the concept of personal autonomy and an individuals' capacity to seek the healthcare services, their knowledge about the healthcare services they may access to, and their rights to access the services.

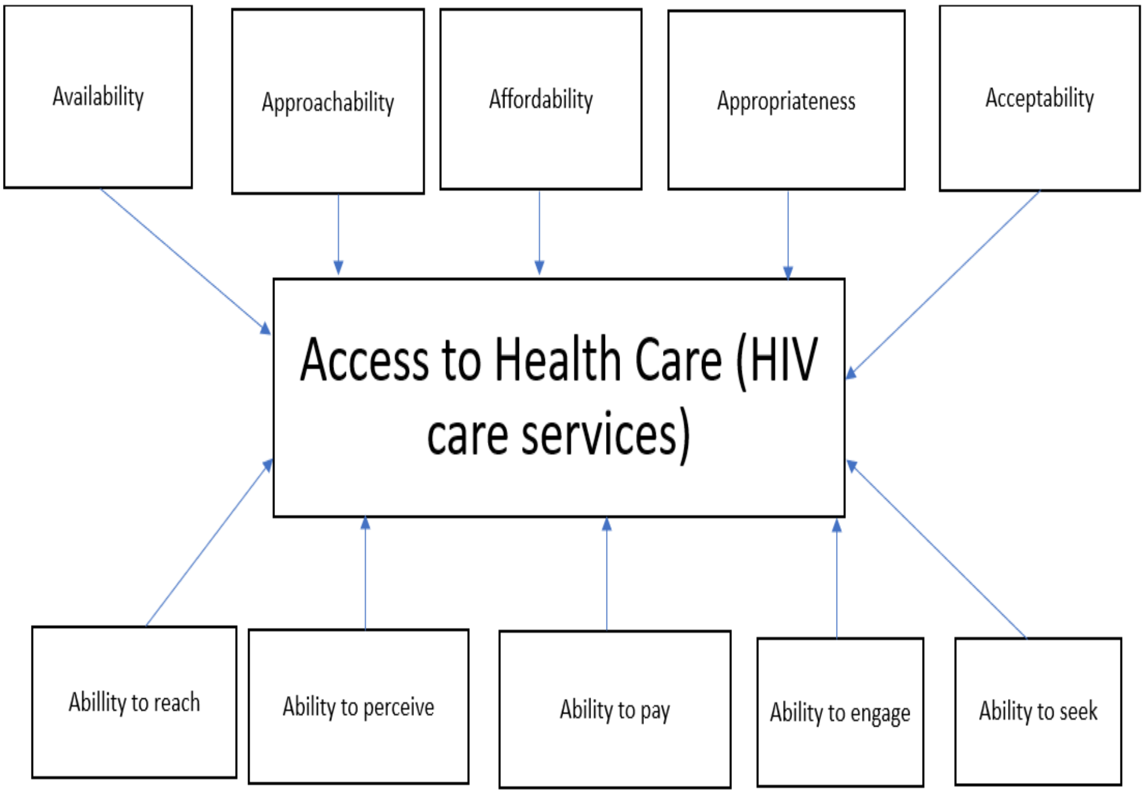

Figure 4: Access to health care framework

CHAPTER FOUR

RESEARCH METHODOLOGY

4.1 Study Settings

The study was carried out from June to November 2019 in Yogyakarta municipality and Belu district, Indonesia. Yogyakarta municipality is located in the Special Region of Yogyakarta province, Java Island, Indonesia. It occupied by a total population of 402,679 people, comprising 195.712 males and 206.967 females (223). It covers an area of 32.50 Km^2 and consists of 14 sub-districts and 45 urban villages. It has nine hospitals, 18 community health centres (CHCs), 14 mobile CHCs, 9 sub-CHCs, 12 maternity units and 58 clinics (223, 224). HIV care services are provided in some of these hospitals (4 hospitals) and CHCs (10 CHCs) (190). The services include information sessions on both HIV and its related services, and counselling and HIV testing and CD4, viral load, liver and kidney function tests, and antiretroviral medicines. HIV-related health information services are provided through regular focus group discussion with PLHIV and workshops for PLHIV and general communities in the area.

Belu is in the eastern part on Indonesia and shares a border with East Timor on the East side, *Timor Tengah Utara* district on the West, and Malaka district on the South (225). Belu and Malaka districts were one district called Belu, prior to their separation in 2012. Belu district covers an area of 1,284,94 km^2 and is occupied by 204,541 people comprising 100,922 males and 171,079 females (225). It comprises 12 sub-districts and has three hospitals, 17 CHCs, 21 sub-CHCs, 71 village maternity posts and village health posts, and one voluntary counselling and testing (VCT) clinic which is located in the city of Atambua (225). HIV-related health services available in this HIV clinic are VCT and ART.

4.2 Study design

This study used a qualitative design and in-depth interview method for data collection (226). The use of a qualitative design was useful as it helped to explore the participants' own views, values, meanings and interpretations about the topics being studied and the settings and situations where they lived and interacted (227-229). This approach allowed the voice of the participants to be heard, and helped the researcher to have a deeper understanding about the participants' knowledge and experiences from their perspectives and contexts. In other words, this approach provided an insight into how the participants made sense of their experiences and situations in relation to HIV, HIV-related healthcare services, policies and programs, and helped the researcher to know about the contexts or settings where this study was conducted (227, 230, 231).

The consolidated criteria for reporting qualitative research (COREQ) with a 32-item checklist was also employed to represent best-practice in qualitative research and support the transparency and comprehensiveness of the report of this qualitative study (232). The 32 items in the checklist are grouped into three domains: (i) the research team and reflexivity (the researcher's personal characteristics and relationships with the participants), (ii) the study design (theoretical framework, setting, participant selection, data collection), and (iii) the analysis and findings (data analysis and reporting). The full list of the 32 items is provided in Appendix 6, and the details of how these items were met or exceeded in this study were presented and integrated into the next sections of this chapter, and into chapter 3 (item 9), chapters 5 to 8 (items 29 to 31) and chapter 9 (item 32).

4.3 Methods

This following section presents the methods used for data collection and comprises the development of an interview guide, the participants, the recruitment of participants, and data collection.

4.3.1 Development of the interview guide

The interview guide was developed based the research objectives and guided by the concepts from the theoretical frameworks applied in this study. The details of the concepts, method and data collection tools or interview questions are presented in table 2. The interview guide was developed for each category of participant, and focused on different aspects. The interview guide for women as well as for men living with HIV focused on exploring their perceptions about behavioural, personal, environmental, economic, socio-cultural and religious factors that may have contributed to HIV transmission among them, their lived experience with the impact of HIV on themselves individually and their families, and their perceptions and experiences on the accessibility of HIV care services. The interview guide was then refined with input from supervisors and the Social and Behavioural Research Ethics Committee, Flinders University. The main concern of the Research Ethics Committee on the interview guide was about some sensitive questions regarding the participants' past sexual behaviours and experiences following their HIV diagnosis which may have a negative psychological impact on them during or after the interviews. Those questions were then revised to avoid the possibility of any negative impacts on them. The interview guide was further developed as the interviews progressed based on the information provided by earlier interviewees. The final interview guide is provided in Appendix 7.

The interview guide for the healthcare providers focused on exploring their perceptions about the HIV care services available in their settings and the facilitators of and barriers to access to the services by PLHIV. Some information regarding HIV care services and accessibility which had been gathered from earlier interviews with PLHIV in the fieldwork, was also carried on to the interviews with healthcare providers. The interview guide for policy makers was designed to explore their views and perspectives about HIV-related policies and programs in place, and what responses or solutions needed to be undertaken in the future to halt HIV transmission in the study settings, and also to address the impact of HIV on PLHIV and their families. Again, information provided by earlier participants (PLHIV) was carried on and used to develop more contextualised interview questions for policy makers in each setting. The details of the interview guide for each category of participant are presented in Appendix 7. The entire process of the development of the interview guide for each category of participant indicates that the interview guide was flexible and adapted to the context of each setting to achieve the research objectives (227, 233).

4.3.2 Participants

There were three distinct participant groups in both study settings: women and men living with HIV, the healthcare providers and the policy makers. This study was initially designed to focus on understanding the HIV-risk factors among WLHIV in Yogyakarta and Belu, the impact of HIV on themselves and their families, and the facilitators of and barriers to their access to HIV care services. The decision to include men MLHIV was based on the recommendation provided by the supervisors and assessor during the PhD confirmation of candidature presentation. The perceptions of MLHIV on HIV-risk factors, the impact of HIV and HIV care services were considered necessary as they could be used as comparative or triangulating elements to WLHIV. It would help to understand or identify HIV-risk factors, the impact of HIV and the experience of HIV care services, which were specific to or only experienced by WLHIV due to their gender, and the ones experienced by both women and me due to their HIV-positive status. The reason for including healthcare providers was to gain broader information from their perspectives about HIV care services and the facilitators of and barriers to the access to the services among PLHIV in the study settings. Their perspectives enriched the information about the same aspects provided by the women and men living with HIV, and which helped the researcher to draw conclusions on issues pertaining to the accessibility of the services among women and men living with HIV in the study settings. Similarly, the reason for the inclusion of policy makers was to help the researcher to have a broader understanding from their perspective on how HIV problems have been addressed at policy level and put into programs and practices in both settings.

Eligible participants were (i) women and men living with HIV aged 18 years old or above living in Belu or Yogyakarta; (ii) healthcare providers aged 18 years old or older who were healthcare professionals (doctors, nurses and counsellors) working in healthcare facilities providing HIV care services in Yogyakarta and Belu; and (iii) policy makers who were individuals holding a position of policy making or decision making, especially in HIV-related matters or were involved in the development of HIV-related programs or interventions and activities in the study settings.

4.3.3 Recruitment of participants

4.3.3.1 Women and men living with HIV

Women and men living with HIV in Yogyakarta and Belu were recruited to participate in this study using a combination of purposive and snowball sampling techniques (227). At the initial stage the researcher (a male PhD student in Public Health) purposively approached and enlisted the help of receptionists at VCT clinics in Yogyakarta and Belu. They were asked to distribute the study information packs (Appendix 8) containing a brief explanation of the study, and the contact details of the researcher to their clients or women and men with HIV who accessed HIV care services at the clinics.

Prior to the distribution of the study information packs a permission letter was solicited from these clinics (Appendix 9), which would indicate their agreement to distribute the information packs to their clients. To obtain the permission letter from the VCT clinic in Yogyakarta (privately owned), several documents needed to be submitted. These included ethics approvals from Social and Behavioural Research Ethics Committee (SBREC), Flinders University, and the Health Research Ethics Committee, Duta Wacana Christian University, Yogyakarta, Indonesia (Appendix 10), and the research proposal and the study information packs. The ethics approval from Health Research Ethics Committee, Duta Wacana Christian University, Yogyakarta, was submitted afterwards as an additional document because it was issued after two weeks of the researcher’s arrival in the field, Yogyakarta, and this caused a-two-week delay in the participants’ recruitment commencement. The permission letter from this clinic was granted within a day after the researcher submitted the additional document.

The permission letter from the VCT clinic in Belu was obtained from the general hospital of Belu (government owned) as the clinic is a part of it. This permission letter was granted within two days after the researcher provided all the required documents. These included the permission letters from the National Unity and Politics Agency (Badan Kesatuan Bangsa and Politik or KESBANGPOL) at the district level and the local Health Department as well as the ethics approval from SBREC, Flinders University and Health Research Ethics

Committee, Duta Wacana Christian University, Yogyakarta. Prior to the application for the permission letter from this hospital, the researcher had already reported to the National Unity and Politics Agency of East Nusa Tenggara province and to the local government of Belu district about the research on his arrival in the study setting. The researcher was then asked by the staff at the local government of Belu district to apply for a permission letter from the local government, which was handled by the National Unity and Politics Agency of Belu district.

After the study information packs were submitted to the receptionists of both clinics, the researcher received two calls from two potential female participants (WLHIV) in Yogyakarta the next day and one call from a potential female participant (WLHIV) in Belu on the same day. These potential participants who called and stated their intention to participate were recruited, and the researcher and participants decided on an agreed place and time for the interviews. After the interviews with these initial participants in both study settings, a snowball sampling technique was used through which they were asked to help distribute the study information packs to other potential participants or their colleagues and friends (both women and men) who might be willing to take part in the study. The same help was again sought from each new participant, and the recruitment of the participants ceased once the researcher felt that the information they provided had been rich enough to address the topics under investigation or answer the research questions and objectives, and that data saturation had been reached. The indication of data saturation in each group of participants was reflected in the similarity of answers of the last few interviewees to those of previous interviewees. Finally, 26 WLHIV and 20 MLHIV in each study setting were recruited to take part in this study, which indicated that the initial expectation of 20 – 30 WLHIV and 20 – 25 MLHIV to be recruited in each study location was fulfilled.

4.3.3.2. Healthcare providers

Healthcare providers were recruited from healthcare facilities, such as public hospitals, VCT clinics and CHCs providing HIV care services in Yogyakarta and Belu. The snowball sampling technique was used to recruit the healthcare providers. The procedure to recruit them was that the researcher was required to firstly report to and obtain a permission letter from each local health department in the study settings (Appendix 9). This permission letter needed to be provided to the head of each government-owned healthcare facility from which a healthcare professional would be recruited for an interview. The researcher was initially informed about this procedure and requirement by a staff member at the local health department in Yogyakarta. The permission letter from each local health department in Yogyakarta and Belu was obtained after seven days and three days, respectively, of submitting the application.

Once granted, the permission letter and the copies of the study information packs (Appendix 8) were distributed to the healthcare professionals by the researcher through the administration staff at some of the healthcare facilities providing the HIV care services Yogyakarta and Belu. The information about the study was also posted by some healthcare professionals on the WhatsApp groups of healthcare professionals who handled the HIV programs in each healthcare facility in Yogyakarta and Belu. Those who called the researcher and confirmed to participate in the study were recruited and interviewed. Similar to the recruitment process for women and men living with HIV, the recruitment of healthcare professionals ceased when the researcher felt that the data had been rich enough to address research questions and objectives, and an indication of data saturation had been reached. From the initial expectation of 10 – 20 participants in a group to be interviewed in each study setting, 10 participants in each setting were finally recruited and interviewed.

4.3.3.3. Policy makers

Policy makers were recruited from relevant local government institutions and NGOs in Yogyakarta and Belu. Policy makers in Yogyakarta were recruited from the local Health Department, especially from the Disease Prevention Unit which handled the HIV programs, the Social Department, and three NGOs providing HIV-related services and supports for PLHIV. Information about the relevant government institutions and NGOs in Yogyakarta was obtained from some women and men with HIV who had previously been interviewed, and from friends of the researcher who worked in the health sector in Yogyakarta. The study information sheets, letters of introduction and consent forms were distributed at these institutions through the administration staff. Those who contacted the researcher and agreed to take part in this study were recruited, and were asked to suggest a time and a place for the interview.

The recruitment of policy makers from the local Health Department and Social Department in Yogyakarta faced some procedural obstacles due to a misunderstanding of the permission letter which would allow staff at the department level in the local government to take part in a study. The current regulation from the Ministry of Home Affairs has stipulated that overseas researchers who plan to conduct research covering more than one province in Indonesia would need to obtain a permission letter from the national government of Indonesia, which is the Ministry of Home Affairs. They would not need to obtain a permission letter from the local government at provincial level, which is the National Unity and Politics

Agency. The researcher had obtained this permission letter (Appendix 9) prior to the commencement of the study, and as required in this letter, the researcher had reported to this agency at the province level in Yogyakarta about the research and had presented a copy of the permission letter from the national government on his arrival in the study setting. However, the researcher was asked by the local Health Department and Social Department at the municipality level in Yogyakarta to provide a permission letter from this agency at the provincial level. This led to the researcher returning to the agency's office at the provincial level and asking for help or a direct explanation from their side to the local Health Department and Social Department at the municipal level. This process took one and a half weeks, and finally the researcher was allowed to distribute the study information packs and recruit policy makers from the local Health Department and Social Department to participate in the study.

Policy makers in Yogyakarta were also recruited from three NGOs after a permission letter was granted by the head of each NGO. The recruitment process of a policy maker from one of the NGOs took longer than expected. This was due to the concern of the head of the NGO about the possible negative impacts that may arise as a consequence of their participation in this study. The concern was due to previous reports of journalists about the work they did, which were considered misleading and created a negative image about their organisation. After a few weeks of this initial contact, the researcher was invited to meet the head of the NGO, and explain about the aims of the study and how the data or information provided would be used. Finally, the head of this NGO agreed and gave the researcher a permission letter, and one of this NGO staff was recruited to participate in this study. Six policy makers comprising two from the local government and four from NGOs in Yogyakarta were finally recruited and interviewed.

It was intended that policy makers in Belu district would be recruited from the local Health Department, local AIDS Commission, Social Department and Women and Child Protection Department. However, on the day the researcher distributed the study information packs and the permission letters to each of these departments and commission, the researcher was informed by the heads of the Social Department and the Women and Child Protection Department that their departments did not have any HIV/AIDS-related programs at all, hence no participants from these departments were recruited as initially intended. There were not any NGOs providing HIV-related services or supports for PLHIV in Belu district. Finally, a total of three policy makers from the local Health Department, especially the Diseases Prevention Unit and AIDS Commission which was a sub-unit of the Diseases Prevention Unit, were recruited for this study.

4.3.3.4. Conclusion

Prior to the commencement of this study in Indonesia, ethics approvals were also obtained from the SBREC, Flinders University, and Health Research Ethics Committee, Duta Wacana Christian University, Yogyakarta, Indonesia. A permission letter was also solicited from the Ministry of Home Affairs in the National Government of Indonesia. These ethics approvals and permission letters were presented to the local governments of Yogyakarta municipality and Belu district, as well as to their relevant institutions, and to NGOs and HIV clinics to obtain permission letters from each of them for the commencement of the study and the recruitment of participants. It was apparent that the procedures for research in Indonesia by overseas researchers, as had been stipulated by the Ministry of Home Affairs at the national level, were applied differently by the local governments in the study settings as they had their own procedures that needed to be followed. These were issues that the researcher was not aware of, and resulted in the delay of the commencement of the study in the study settings.

Table 1: Study participants

Participant Type / Group	**Population Pool**	**Numbers to be approached**	**Expected / Required No.**	**Actual number of recruited participants**
Women living with HIV (age≥18) in Belu district	Approximately 477	Approximately 50 of them will be approached for the in-depth interviews	20 – 30 or the final number of participants will be determined based on data saturation	26 people
Women living with HIV (age≥18) in Yogyakarta municipality	Approximately 399	Approximately 50 of them will be approached for the in-depth interviews	20 – 30 or the final number of participants will be determined based on data saturation	26 people
Men living with HIV (age≥18) in Belu district	Approximately 485	Approximately 30 of them will be approached for the in-depth interviews	20 – 25 or the final number of participants will be determined based on data saturation	20 people
Men living with HIV (age≥18) in Yogyakarta municipality	Approximately 925	Approximately 30 of them will be approached for the in-depth interviews	20 – 25 or the final number of participants will be determined based on data saturation	20 people
Healthcare providers in Belu	Approximately 812	Approximately 30 of them will be approached for the in-depth interviews	10 – 20 or the final number of participants will be determined based on data saturation	10 people (7 women and 3 men)
Healthcare providers in Yogyakarta	Approximately 478	Approximately 30 of them will be approached for the in-depth interviews	10 – 20 or the final number of participants will be determined based on data saturation	10 people (6 women and 4 men)
Policy makers in Belu district	Approximately 15	All 15 policy makers	5-10 or until data saturation is reached	3 people (2 women and 1 man)

Participant Type / Group	Population Pool	Numbers to be approached	Expected / Required No.	Actual number of recruited participants
Policy makers in Yogyakarta municipality	Approximately 15	All 15 policy makers	5-10 or until data saturation is reached	6 people (4 women and 2 men)

4.3.4 Data Collection

4.3.4.1 Interviews with women and men living with HIV

Data collection with women and men living with HIV in both Yogyakarta and Belu was carried out using one-on-one and face-to-face in-depth interview method (226). Interviews with the participants in Yogyakarta took place in the middle room of a house rented by the researcher during the fieldwork. Interviews with the participants in Belu were carried out in a private room at the VCT clinic. The place and time for the interview were discussed and mutually agreed upon by both the researcher and the participants once they called to confirm their intention to participate in the study. Most interviews with the participants in Belu were conducted on the day they accessed their antiretroviral medicines at the VCT clinic. This choice of the time and place was suggested by the participants in this setting as a strategy for preventing extra time spent and double costs associated with transport to the VCT clinic for collecting the medicines as well as the interview. Interviews with one man and two women participants in Belu were stopped after 10-15 minutes from the start. The women seemed reluctant about providing information or engaging in the conversation, while a young man seemed uncomfortable talking about his sexual behaviour. The researcher was aware of the situation, and asked them whether they would like to continue the interview or withdraw their participation. When they decided to withdraw, the researcher further deleted and excluded their audio recordings. Meanwhile, interviews with the participants in Yogyakarta were conducted on the day they collected their antiretroviral medicines, or in the afternoon after working hours, or on the weekend as they suggested.

Only the researcher and each participant were present in the interview room in both settings. The interview duration with the participants in both settings ranged from 35 to 87 minutes. Interviews were digitally audio recorded, and notes were taken once it was felt necessary during the interviews. None of the participants and the researcher knew each other, or had an established relationship prior to this study. Interviews were conducted in Bahasa, the Indonesian national language, which is widely spoken by people in Yogyakarta and Belu and the primary language of the researcher. No repeated interview was conducted with any of the participants. No opportunity was offered to these participants to read the interview transcript prior to the researcher analysing it. This was due to the sensitivity of the topics being explored in this study and the possibility of negative consequences on the ones who had not disclosed their status to their family members.

The interviews with the participants focused on several key areas:

(i) Factors that may have led to the HIV transmission among the participants, such as behavioural, personal, economic, environmental, socio-cultural and religious factors. The interview guide to explore the views of these participants on these factors was informed by the Logical model for behavioural and environmental determinants diagnosis (191) (see Table 2 and Appendix 7);

(ii) The psychosocial, physical, health, educational and economic impact of HIV on the participants and their families. The conceptual framework for the socio-economic impact of the HIV/AIDS epidemic on households (201) and the HIV stigma framework

(214) were used to develop interview guide exploring the views of these participants on these HIV impacts on themselves and their families (see Table 2 and Appendix 7).

(iii) HIV care services and the access of the participants to the services. The access to healthcare service framework (220) was used to inform the development of the interview guide to explore the participants' views on these aspects (see Table 2 and Appendix 7).

4.3.4.2 Interviews with the healthcare providers

The interviews with the healthcare providers in both settings were conducted using one-on-one and face-to-face in-depth interview method during the same period as above (226). Interviews with each of them were carried out in a private room during working hours at the healthcare facility where the participant worked and during working hours. The time and place for the interviews were mutually agreed upon by both the researcher and the participant on the day they called and confirmed their participation. Only the researcher and each participant were present in the interview room during the interview. Interviews with healthcare providers in both settings lasted between 35 to 57 minutes. The researcher and the healthcare providers did not know each other or have established relationships prior to the study. Interviews were also carried out in Bahasa and digitally audio recorded. Notes were taken, if felt necessary, during the interviews. No repeated interview was undertaken with any of the participants. They were offered an opportunity to read and correct the interview transcript, but no one took it. None of the potential participants who called and confirmed to take part in this study withdrew their participation prior to or during the interviews.

Interviews with healthcare providers focused on topics about the HIV care services in the study settings, and the facilitators of and barriers to the access of PLHIV to the services. The development of the interview guide exploring their views on these aspects was guided by access to healthcare service framework (220) (see Table 2 and Appendix 7).

3.4.4.3 Interviews with policy makers

One-on-one and face-to-face in-depth interviews were also employed to explore the views and perspectives of policy makers about HIV-related policies and programs in place in Belu and Yogyakarta (226). The interviews with these participants were conducted during the same period as with other groups of participants, and took place in their office or a private room at their institutions. The interviews with the policy makers were also carried out in Bahasa and only the researcher and each interviewee were present in the interview room. Interviews were digitally audio recorded, and notes were taken during the interviews if felt necessary. There was not a repeated interview with any of the participants. The duration of the interviews ranged between 30 and 73 minutes. There was not any relationship between any of these participants and the researcher prior to the interviews. These participants were also offered an opportunity to read and correct the interview transcript before the researcher analysed it, but no one took it.

The interviews with policy makers focused on exploring their views and perspectives on HIV-related policies and programs in the study settings, and on the responses or solutions they thought needed to be taken into consideration and implemented in the future to halt HIV transmission, and to address the impact of HIV facing women and men with HIV and their families in Yogyakarta and Belu (see Table 2 and Appendix 7).

Table 2: Concepts, methods and data collection tools

KNOWLEDGE, BEHAVIOURAL, ECONOMIC, SOCIO-ENVIRONMENTAL, CULTURAL AND RELIGIOUS FACTORS THAT SUPPORT HIV TRANSMISSION			
CONCEPTS		**METHODS**	**DATA COLLECTION TOOLS**
Knowledge	- Knowledge of HIV: • Sources of HIV knowledge • Means of HIV transmission -Knowledge of condom and its protective functions: -Self-efficacy in accessing and using condoms - Perceived barriers to condom use - Trust between husband and wife, partner's rejection, feeling uncomfortable, unavailability of condom can lead to lack of condom use	Interview with women and men living with HIV	**Interview questions:** When did you first hear about HIV? And how? Who told you? What do you know about HIV? • How HIV is transmitted and prevented? • Is HIV or AIDS a serious infection or disease or not? Why? Tell me more about it. • How does knowledge or a lack of knowledge about HIV influence your sexual behaviour? Please explore more about it. Before you were diagnosed with HIV, were you aware that you have the possibility to contract HIV infection? Is it possible for to you to identify how you got HIV infection? What do you know about condoms or protected sex? • What are the functions of condoms or benefits of using condoms? • Do you know where to access condoms?

			- What are the challenges of accessing condoms? - What do you know about the perceptions or reactions of other people when seeing someone accessing or buying condoms? Tell me about it. What are, if any, other factors that you think have an influence on condom use practice in your sexual relation?
Behavioural factors	- Lack of or inconsistent condom use - Engagement in unprotected sex with multiple sex partners other than their partners or spouses -Unprotected sex with HIV-positive partners or spouses -Partners' or spouses' engagement in sexual behaviours with other women or men -Engagement of IDU	Interview with women and men living with HIV	**Interview questions:** Would you describe a little bit about condom use in your sexual relation? - How do you discuss condom use or protected sex with your partner or spouse? Explain about it. - How regular is it? Why? - What do you think about condom use in your sexual relation with your partner or spouse? Is it necessary or not? Why? Do you know about your partner or spouse's HIV status? What do you know about your partner or spouse's sexual relation or behaviour with other women or men? Would you mind describing a little bit about your sexual relation with your partner(s) other than your current partner or spouse, if any?

			• What are the reasons or motivating factors that lead you to engage in sexual relation with casual partner(s)? Have you ever been involved in IDU? Tell me more about.
Economic factors	-Low economic status / economically depending on husbands • Inability to negotiate condom use • Indulging sexual interest of husbands -Sexual decision making -Lack of money to buy condoms • Lack of or inconsistent condom use -Economic needs • Engagement in sex work -Mobilisation / migration of women or men for work • Supporting their engagement in unprotected sex with	Interview with women and men living with HIV	**Interview questions:** Can you explain to me about your economic or financial condition? • Do you have your own income? How much is it per month? • Are you economically or financially supporting yourself or depending on your partner or husbands? ○ How does it influence of your relationship? How? Tell me more about it. • Would you describe how your economic or financial condition influences your sexual relation or sexual behaviour? ○ Do you feel it disempowers or hampers you to negotiate or talk about condom use/safe sex with your husband? Tell me about it. • Have you ever engaged in sex work? Why/for what reasons? • Do you think your economic condition has an influence on the sexual decision making in your spousal relation? How? Please explain more about it.

	multiple partners in the host community or country - Partners' migration supports the engagement of the left behind women or wives in sex with multiple sex partners for sexual satisfaction or money		○ Do you think you are more entitled to sexual decision making and your wife should follow you decision? Why? Please explain more about it? Have you ever moved or migrated to other places in Indonesia or to other places/countries for work or any other purposes? - Did it influence your sexual relationship? (How? Tell me more about it). - Did you have other sex partner(s) during the work period? What led you to engage in sexual relation with other sex partner(s)? Tell me more about it. Does your partner or spouse often travel? Or has your partner ever migrated to other place such as for work purposes? - How often does your partner travel? Or how long does your partner migrate? - What do you know/think about your partner's sexual behaviour while away? Tell me about it. - Do you think it influences your sexual behaviour? How? Tell me more about.
Socio-environmental factors	- Social influence - Social perceptions about PLHIV		**Interview questions:** Do you feel that your social relationship with friends or colleagues influence your sexual relation or behaviour? How? Tell me more about it.

	- The influence of the environment or communities where people live, work and interact on risky behaviours		• Sex with multiple partners • Engagement on IDU Would you describe more about the environment or community where you live or work? • Are brothels or illicit drugs available in the places or communities where you live or work? • Do they have an influence on you or your partner or spouse? How? Tell me more about it. What do you know about the social perceptions here (Belu/Yogyakarta) about PLHIV? • How do people within your community look at you or what are their views about PLHIV? ○ Bad woman/man, Unfaithful woman/man, Trouble makers, Stubborn woman/man. Please explain more about these. • How do you feel about these negative perceptions? Tell me more about it. • How do these perceptions influence your behaviour? Tell me more about it.

Cultural factors	-Husband-wife status/position in marriage - Husband-wife sexual decision making - Acceptance of male promiscuity and polygamy by women or wives - Sexual obedience of women to their husbands -Verbal and physical abuse, and sexual coercion or violence by sex partners	Interview with women and men living with HIV	**Interview questions:** What do you think about husband-wife relationship in your culture? • Are there any culture norms that govern husband-wife relationship in your culture? Tell me more about it. • Are any cultural values that are highly upheld by women and men in marriage life? Tell me more about it. • What do you think about rights and power between husband and wife in your marriage life? Please explain about it. • Is husband-wife conversation about sex a common cultural practice in the community you live (in Belu / Yogyakarta)? Please tell me about your experience related to this. • When it comes to sex or decision about when and under what condition to have sex, who makes the decision? (Your husband/wife only or you only or both of you). Tell me more about it. ○ Have ever refused sex with your partner or spouse or proposed condom use? Any consequences? • What are the cultural perspectives in regard to extramarital sexual relation? If any, please tell me more about it.

			Would you describe more about decision making about other aspects in your family? (E.g.: accessing health services and social services, applying for jobs, going out with friends, involving in social activities, etc). • Who makes the decision or has much stronger influence on decision about these aspects? Why? • How does this has impacted on your life psychologically and socially? Tell me more about it What do you know about the cultural perspectives here about condom use in marriage or outside of marriage? • Do they influence you? Tell me about it.
Religious factors	- Husband-wife marital relationship • Position in marriage life • Rights in marriage life • Decision making about sex - Condom use - Sexual behaviour and sexual relation of husband and wife in marriage life	Interview with women and men living with HIV	**Interview questions:** What do you think about husband-wife relationship in your religion? • Are there religious thoughts and values that govern husband-wife relationship? Tell me more about it. • Are there religious values that are highly upheld by women and men in marriage life? Tell me more about them. • Based on your religious beliefs, norms and values, do you feel you have equal rights or power to your spouse in your marriage life? ○ In what matters? Please explain about it.

			• Based on your religious beliefs, norms and values, when it comes to sex or decision about when and under what condition to have sex, who makes the decision? (Your spouse only or you only or both of you). Tell me more about it. o Have you ever refused sex with your partner or spouse due to some reason? o Do you think your wife is obliged to serve you sexually? Why? Please explain more about it. What do you know about religious beliefs in relation to condoms? • Do they influence you? Tell me about it. What are the religious beliefs in relation to extramarital sexual relation? • Do you think it is unacceptable or not? Why? Based on the beliefs, norms and values in your religion, is it acceptable to have sex before marriage or not? Why? Please explain more about this. • Is it a kind of hinderance for you to buy condoms? Why? Would you describe more about beliefs and norms in your religion about the position of husbands and wife within a marriage life? Tell me more about it. • Decision making What do you know about religious perspectives about PLHIV?

STIGMA AND DISCRIMINATION, PSYCHOLOGICAL, PHYSICAL HEALTH AND ECONOMIC IMPACT OF HIV ON WOMEN AND MEN LIVING WITH HIV AND THEIR FAMILIES			
CONCEPTS		**METHODS**	**DATA COLLECTION TOOLS**
Stigma and discrimination towards women and men living with HIV and their families			
Stigma and discrimination against women and men living with HIV from family members	- Family members attitudes and behaviours towards women and men living with HIV - Relationships between family members and women/men living with HIV	Interview with women and men living with HIV	**Interview questions:** Do your family members or relatives know about your HIV status? • What was their reaction or response when they first heard about your status? Please explain. • Are there any differences you notice in the way they interact with you or treat you after they know about your status? • Do you feel your status affect your relationship with your family members? Tell me more about it. How? Is there any change you notice in the relationship between your children and you and your husband due to your HIV status? Are you still involved in family activities with parents, siblings, children, husbands? Tell me more about it.
Stigma and discrimination against women and men living	- Attitude and behaviour of community members towards women and men living with HIV	Interview with women and	**Interview questions:** Do your neighbours and friends in the community you live know about your HIV status?

with HIV from community members	- Social relations of women and men living with HIV with other community members - Acceptance of women and men living with HIV within community where they live	men living with HIV	• What was their reaction or response once they know about your status? ○ Positive or negative reactions, tell me more about it. • Are there any changes in their relationship with you? ○ Being rejected, neglected or avoided by neighbours and friends • Do you feel they treat you differently after knowing your status? Please explain about it. ○ Refused to share foods and drinks, physically assaulted, being labelled negatively or verbally abused with discriminatory words, ridiculed, insulted or harassed, excluded from usual activities or social functions, refused to enter or removed from public places. Are you still involved in social activities with neighbour, friends and relatives? Tell me about it. • Community acceptance towards you
Stigma and discrimination against women and men living with HIV from healthcare professionals or	- Attitude and behaviour of healthcare professionals in delivering healthcare services to women and men living with HIV - Acceptance of women and men living with HIV within healthcare professionals	Interview with women and men living with HIV	**Interview questions:** Would you mind describing about your experiences in accessing HIV-related healthcare services? • Do you feel welcomed by healthcare professionals once accessing healthcare services? Why?

in healthcare settings	- The influence of the attitudes and behaviours of healthcare professional on the access of women and men living with HIV to healthcare services		- Would you describe more about their attitudes and behaviours in delivering the services? - Have ever experienced healthcare service delivery that you might think disappointed or discriminative? ○ Why do you think so? Please explain more about it. - Have you ever experienced discriminatory and stigmatising attitudes and behaviours from healthcare professionals or in healthcare settings? Please tell me more about those. - How do the experiences of discriminatory and stigmatising attitudes and behaviours influence your health-seeking behaviour or access to healthcare services?
Stigma and discrimination against women and men living with HIV from colleagues and employers	- Attitudes and behaviours of colleagues and employers towards women and men living with HIV - Social relationship of women and men living with HIV with colleagues and employers - Employment status of women and men living with HIV	Interview with women and men living with HIV	**Interview questions:** Do your colleagues and employer know about your HIV status? - What was their reactions once they knew about your HIV status? - Are there any changes in how they relate or interact with you? Tell me more about it. ○ Being rejected, neglected, avoided, etc. - Does your status affect your position or job descriptions assigned to you? How? Tell me more about it.

Stigma and discrimination against HIV affected family members from community members	- Attitude and behaviour of community members towards HIV affected family members - Social relationship between HIV affected family members and community members - Children's education and social life - Acceptance of HIV affected family members within the community where they live	Interview with women and men living with HIV	**Interview questions:** What do you think about the relationship or interaction between your neighbours or friends or relatives and your family members after they knew about your status? • Are there any changes you notice? How? Tell me more about it. What do you think about social life or social relation of your family members (parents, siblings, husband, children)? • Are there any changes you notice since you were diagnosed with the infection? • Are they still involved in their social activities as they used to do? Tell me about it. *For women and men living with HIV who are married*: What do you think about your children's social life or relation with their friends within community where you live or at school after you were diagnosed with the infection? • Are there any changes? Tell me more about it. Would you describe about how your HIV status may have influenced your children's education? Tell me more about it.

Psychological impact of HIV on women and men living with HIV and their families			
Psychological impact on women and men living with HIV	- Feelings about HIV-positive status: • Stress, depression, anxiety, fear, anger, worry, shame, etc	Interview with women and men living with HIV	**Interview questions:** What did you feel when you were first informed that you are infected with HIV? • Did you feel scared, stressful, angry, afraid, depressed, or ashamed? ○ Would you describe more about the reasons why you had those feelings? • Do you still feel the same or different? ○ Would you describe more about the reasons why you still have / do not have those feelings?
Psychological impact of HIV on their family members	- Feeling ashamed, stressful, angry, upset, worried, hurt	Interview with women and men living with HIV	**Interview questions:** Do you feel your status psychologically affects your family members as well (parents, siblings, husband or children? • Do they feel ashamed, stressful, angry, upset, worried, hurt, etc.? Why? Tell me more about it). Have you ever seen any of them showing any kind of psychological distress due to your status? Who? Why do you think that happened to him/her? Tell me more about it.

Physical impacts of HIV on women men living with HIV			
Physical impact of HIV on women and men living with HIV	- Physical health condition and experience - The influence of poor physical health condition on daily life - Physical activities	Interview with women and men living with HIV	**Interview questions:** Would you tell me about your physical health experience since you were diagnosed with the infection? • Do you feel healthy or easily get sick? Tell me more about it. Would you describe about your current physical strength? • Are you still active in doing activities that you used to do? Tell me more about it. Would you describe about how your physical health condition influences your daily activities?
Economic impact of HIV on women and men living with HIV and their families			
Economic impact of HIV on women and men living with HIV	- Absenteeism - Reduced working hours - Reduced/loss of income	Interview with women and men living with HIV	**Interview questions:** Would you describe a bit more about your physical strength to work since you were diagnosed with the infection? • Are there any changes? Tell me more about it. • Are your working hours still the same or changes? Why? Tell me about it. Would you describe about your financial condition now compared to the time before you have the infection?

			• Are there any changes? Why? Tell me about it. • What about your income? How do you cope with your needs and the needs of your family? Tell me your experience about this. Would you mind describing about costs associated with your access to healthcare services? • How do you cope with financial difficulties, if any, associated with access to treatment for HIV infection?
Economic impact of HIV on the families of women and men living with HIV	- Absenteeism - Reduced family income • Difficulties to meet basic needs • Children's school levies and involvement in labour and household chores - Family health expenditure	Interview with women and men living with HIV	**Interview questions:** Would you describe about economic or financial condition of your family since you were diagnosed with the infection? • Are there any changes? Tell me more about it. ○ Reduced family income Would you describe about how you as a family cope with your family needs? Tell me your experience about it). Would you share your experience related to your family health expenditure after you were diagnosed with HIV? Does your economic or financial condition affect your extended families? Please expand more about it.

ACCESS TO HIV CARE SERVICES			
CONCEPTS		**METHODS**	**DATA COLLECTIONS TOOLS**
Interviews with women and men living with HIV			
Availability and ability to reach	- Availability of HIV care health services - Ability of women and men living with HIV to reach HIV care services at healthcare facilities	Interview with women and men living with HIV	**Interview questions:** What do you know about HIV care services here (in Belu or Yogyakarta)? • What types of HIV care services are available? • At which healthcare facilities are they available/offered? ○ Are the services available every time you access or limitedly available? • Do you think healthcare professionals providing the services are trained in the field? Tell me what you know about them. How often do you access HIV care services? • Rarely/regularly/monthly? Why? • What kinds of HIV-related health services have you accessed? • How do you get to any of the health facilities to access HIV-related health services? ○ What kind of transport do you use?

			▪ How far is it from your house to the healthcare facility to access the services? (…..in km) Do you think the transportation systems here facilitate you or make it easier for you to access the services or not? Tell me about it.
Approachability and ability to perceive	- Approachability of HIV care services - Dissemination of information about the services - Ability of women and living with HIV to perceive their need for care / services	Interview with women and men living with HIV	**Interview questions:** What do you think about approachability of HIV care services? What do you think about dissemination of information about the services here? • Is the information well disseminated within communities? How? If not, why? • Do you think all or the majority of PLHIV are aware of the availability of the services or not? Why? How did you first hear or know about the availability of HIV-related healthcare services? Tell me more about it. • Through television, newspapers, friends, health professionals.
Affordability and ability to pay	- Affordability of HIV care services - Ability of women and men living with HIV to pay for the services and transport to access the services	Interview with women and men living with HIV	**Interview questions:** • Are the HIV care services free or not? • How much money do you spend on the services and transport every time you access them? Tell me more about it.

			○ What do you think about these costs? ▪ Do you think you can afford to pay the costs? ▪ What sorts of resources do you spend on the costs? ▪ Are they burdensome? Why? ○ Do these expenditures hamper you from accessing the services? Tell me more about it. ○ How do you and your family cope with the health expenditures?
Appropriateness and ability to engage	- Appropriateness of HIV care services: • Meeting the needs of women and men living with HIV • The delivery of the services • Attitude and behaviour of health service providers - Motivation of women and men living with HIV to access the services	Interview with women and men living with HIV	**Interview questions:** Please describe about your experiences related to the access to HIV care services at any health facility here. • Do you think the services available here are appropriate or the ones that you need? Explain about it. • Do you think the services are delivered in a good way by qualified healthcare professionals? Please tell me more about this. • What motivates you to access the services? ○ Are you aware of the benefits of utilising the services? Tell me more about it.

			What do you think about the attitudes of health service providers who provide HIV care services? • Who often provide the services? (doctors, nurses, men, women? ○ Do you trust the health service providers? Why? Please explain more about this. • Do you think they treat you differently or the same other patients who do not have the infection? Why? • How do you feel about the way they interact with you or speak to you every time you access the services?
Acceptability and ability to seek	- Acceptability of HIV care services: • Procedure to access the services • Health service providers providing the services - Ability of women and men living with HIV to seek the services • Decision making related to access to the services	Interview with women and men living with HIV	**Interview questions:** What are the procedures to access HIV care services? • Do you think the procedures enable and hamper you to access the services? Why? Please explain about it. ○ Do you think the procedures are acceptable? Why? Tell me more about it. • Who are the healthcare professionals who serve you? ○ Men or women ○ If the health service provider is a man (or women): do you think it is socially and culturally acceptable? Why?

			○ Does it influence you to seek HIV services? • Are you the one who makes decision about seeking HIV care services or someone else? Tell me more about it. ○ Does this influence your access to the services? How? Tell me more about this.
Interviews with healthcare providers			
Availability and ability to reach	- Availability of HIV care services - Ability of women and men living with HIV to reach healthcare facilities and services	Interview with healthcare providers	**Interview questions:** Please tell me about HIV care services here (in Belu or Yogyakarta) • What types of services are available? • At which healthcare facilities are they available/offered? ○ What about in your healthcare facility? • Are the services available all the time or limitedly available/sometime unavailable? • What is HIV-related training or education have you received? ○ How many trained HIV staff in your healthcare facility? ○ Do you think the number is enough to service PLHIV here? Why?

			• What do you think about the access of women and men living with HIV to the services? ○ Do you think they are able to reach the healthcare facilities or services? ○ What are the factors that you think hamper them from reaching healthcare facilities and services? Please explain more about it. • Are they living nearby or far away from the healthcare facility you are working at? ○ How do they get to the healthcare facility to access the services? ○ Do you think the transportation system here facilitates them to or hampers them from accessing the services or not? Tell me about it.
Approachability and ability to perceive	- Approachability of HIV care services - Ability of women and men living with to perceive the services	Interview with healthcare providers	**Interview questions:** Do you think HIV care services here are known to PLHIV or general population in this area? Tell me more about it. • How do you disseminate information about the services to PLHIV and general community members? ○ What kinds of dissemination strategies or activities do you use?

			• Would you describe more about the access of women and men living with HIV to the services at the healthcare facility you are working at? ○ Rarely/regularly/monthly? ○ What kinds of the services do they access?
Affordability and ability to pay	- Affordability of HIV care services - Ability of women and men living with HIV to pay for costs related to their access to the services	Interview with healthcare providers	**Interview questions:** Do you think HIV care services are affordable to PLHIV? • Do PLHIV need to pay for the services they access? ○ How much is it? ○ Do you think they can afford to pay the services? Tell me more about it. ○ Do you have any experience of patients (PLHIV) could not being able to pay for medical cost as well as transportation cost? Tell me about it. ○ Do you think medical cost and transportation cost are burdensome for PLHIV and hamper them from accessing the services? Tell me more about it. ○ What are the supports that have been undertaken by your institution (healthcare facility) to help them?

Appropriateness and ability to engage	- Appropriateness of HIV care services - Ability of women and men living with HIV to engage in the services	Interview with healthcare providers	**Interview questions:** Please tell me about HIV care services provided for PLHIV: • Do you think the available services meet the needs of PLHIV? Why do you think so? Explain about it. • Please tell me more about your experience in providing the services for PLHIV: o How do you deliver the services and interact with PLHIV? ▪ Are they served differently or in the same way as general populations? Tell me about this. o What do you think motivates PLHIV to access the services? o Do you think they trust you and feel comfortable talking to you about their HIV status and health condition? Why? o What do you think about their adherence to the treatment? Tell me more about your experience related to this. o How do you feel about your relationship as a healthcare professional with them as your patients?
Acceptability and ability to seek	- Acceptability of HIV care services - Ability of women and men living with HIV to seek the services	Interview with healthcare providers	**Interview questions:** What are the procedures that need to be followed to access HIV care services?

			• What do you think about the procedures? ○ Are they supportive of the access to the services? Please explain about your experience related to this. ○ Are there any aspects of the procedures that you think might hamper PLHIV from accessing the services? Why? • Do you think the sex of a healthcare professional (male/female) who provides the services for PLHIV matters? Why? Tell me more about it. What do you think about the decision of PLHIV to access HIV care services? • Are they the ones who make the decision or other people in the family? Who? • Do you think PLHIV have enough courage to access the services at healthcare facilities? Why? Tell me more about it.
HIV POLICY AND PROGRAM			
CONCEPTS		**METHODS**	**DATA COLLECTION TOOLS**
HIV policy	- Policy making - Policy objectives	Interview with policy makers	**Interview questions:** What is the HIV-related policy in Belu/Yogyakarta? • Policy: • Would you explain more about it?

			○ How was the policy made? ○ Who were involved? What are the focuses or objectives of the policy? • Objectives: • Do they address factors leading to HIV infection among PLHIV? ○ What are the factors addressed? Tell me more about them? • Do they address the impact of HIV on PLHIV and their families? ○ What are the impacts addressed in the policy? Tell me more about them? What are the things that you think need to be addressed in future policies on HIV?
HIV program	- HIV strategies and program - Program implementation - Expectation of PLHIV for HIV-related programs or interventions	Interview with policy makers	**Interview questions:** How has the policy been translated into HIV-related strategies and programs? • What are the strategies or programs? ○ Who were involved in the development of the strategies and programs? ○ What were the challenges in translating HIV-related policy into strategies and programs? Tell me more about these.

			How have the HIV-related strategies and programs been put into practice (program implementation)? • So far, is the implementation going well? Tell me more about these. • What are the challenges faced during the implementation of the programs? Please explain more about them. Would you describe more about budget or fund for the implementation of HIV/AIDS? • What is the source of fund? • How much is the annual amount allocated HIV/AIDS-related activities or programs? • Who decide the amount and on what basis? Tell me more about it. • Do you think such amount is enough? Why? Tell me more about it. What are the things you think need to be considered in the future to halt HIV transmission among women and men as well as general population in Belu/Yogyakarta? Why? Please explain more about these.

4.4 Data Analysis

The researcher transcribed verbatim in Bahasa the audio recordings of the interviews for further analysis. The transcription started alongside with the data collection process in the field work, which helped the researcher to directly incorporate notes taken during the interviews into the transcripts of the audio recordings. The transcriptions were imported into NVivo 12 software program where a comprehensive data coding and identification of themes and sub themes were performed. The entire data analysis was performed in Bahasa, the language used by all the participants during the interviews. As Bahasa is the researcher's first language, the researcher felt more confident and credible to conducting the data analysis which involved interpretation and coding in Bahasa. Performing data analysis in Bahasa was also considered helpful in maintaining socio-cultural meanings that are often attached to the information provided by the participants. The risk of losing these meanings and the underlying context attached to the idiomatic expressions used by participants would be high if the data analysis was performed after the translation of the interview transcripts into English (234). The relevant data extracts or quotations from each data item or transcript from each individual participant, which had been grouped under each theme or sub-theme, were translated into English for this dissertation and peer-reviewed publications.

The data analysis was guided by Ritchie and Spencer's (235) analysis framework for qualitative data. This framework offers a systematic approach to data management, and provides coherence and structure to qualitative data analysis (235, 236). This framework provides several guiding steps for qualitative data analysis to ensure the identification of the issues pertinent to the topics being researched. In this data analysis, it guided the identification of HIV-risk factors, the impact of HIV, HIV care service accessibility and HIV programs and activities as perceived or experienced by the participants. This framework was initially developed in the context of qualitative research in applied social policy, but it has been used in many other fields, including health (235, 237).

The steps of data analysis presented in this framework include familiarisation with the data, identification of a thematic framework, indexing the data, charting the data, and mapping and interpretating the data (235). Although, this framework seems to offer a step by step qualitative data analysis, the actual process of data analysis was often not linear, as these steps were interconnected and often performed simultaneously (235).

4.4.1 Familiarisation with the data

The first step of data analysis presented in this framework is familiarisation with the data or transcripts. This was performed by the researcher through listening to the audio recordings, reading the transcripts line by line repeatedly, revisiting notes taken during the interviews, and listing key ideas from the transcripts (235). This process is also called immersion in the data which helped the researcher to gain an overview of the data (235). The process of familiarisation with the data or transcripts started since the transcription of the first audio recording once the researcher was still in the fieldwork. The transcription of the digital audio recordings was done manually using a laptop and began alongside with the data collection process. In so doing, the data analysis was also started along with the process of data collection, because once listening to and transcribing each audio recording the researcher also made some initial codes to each interview data by highlighting words and listing ideas. Some of these initial aspects or ideas coded in this phase were guided or informed by the conceptual frameworks used in this study (see Chapter 3), while others newly emerged from the data, which were not part of the frameworks (238). For example, socio-cultural and religious factors identified from the data as factors that supported HIV transmission or contributed to the impact of on the participants (PLHIV) or influenced traditional treatments of HIV using traditional medicines, but were not parts of the frameworks, were also coded. As the researcher moved from one audio recording to another during the transcription process, the researcher also identified some similarities and differences emerging from the data, and started creating some initial notes or comments which showed the comparisons between one interview data wand another. These initial comparisons were informed or guided by the research questions and objectives (further explanations about the comparisons are presented in the next (coding) section) (235, 238). After the transcription, each audio recording was deleted as required by the ethics committees who gave the permission for this study, and familiarisation with the data was done mainly by reading the transcripts that had been imported to NVivo 12.

4.4.2 Identifying a thematic framework and indexing the data

The second phase of data analysis was the identification of a thematic framework. After importing each interview transcript with the initial codes, listed ideas, notes and comments to NVivo, the researcher continued with the identification of the thematic framework by again making notes or comments and memos on each individual transcript entirely, and breaking down the transcript of each interview into chunks of data. Through this process the researcher identified key issues, concepts and themes from the data to set up a thematic framework within which the data were sifted and sorted (235). The thematic framework was not set up in a one-time activity, but more an iterative process which involved changes and refinements of the themes. The themes that formed this thematic framework were derived from both the conceptual frameworks applied in this study and from the collected data. What the researcher meant by themes derived from the collected data was the newly identified themes that were not part of or fell outside the conceptual frameworks (238).

The process of identifying a thematic framework was conducted simultaneously with the process of indexing (coding) the data or interview transcripts. The comprehensive coding of the data was conducted using NVivo. In this coding phase, the researcher firstly performed an open coding through which all aspects or ideas or themes identified from each interview transcript and which fit the conceptual frameworks or newly emerged from the data, were coded into free nodes (239). This process led to the collection of a long list of free nodes or codes, where each node or code contained data extracts from each individual transcript (data item) being analysed. This was followed by a close coding process through which the researcher collated or grouped together the free nodes or codes which were similar or redundant into a group of free nodes as a hierarchy of nodes (parent nodes, children nodes, grandchildren nodes and so on) to reduce the long list of free nodes into a manageable number. In other words, similar or redundant codes were grouped under the same theme (and sub-theme) derived from the conceptual frameworks used in this study or newly created. In this phase, the creation of new themes or themes that fell outside the conceptual frameworks were informed by the codes that had been made to the data. Both themes that were derived from the conceptual frameworks and newly created, formed the basis of the thematic framework.

Once performing the coding and then grouping the codes with their data extracts into separate themes, the researcher also continued to make comparisons between one interview data and another. This helped identify similarities and differences in perceptions or accounts about the HIV-risk factors and in experiences with the impact of HIV or the access to healthcare services between the participants. For example, differences in perceptions or accounts about barriers to the use of condoms between married and non-married participants, or differences in experiences with access to healthcare services between participants in Yogyakarta and Belu, and so on, were identified. Aspects that were compared between the collected data were driven by the research questions and objectives (235, 238). Both the identification of the thematic framework and the coding activity were iterative processes, and were developed alongside the progress of the data analysis, and involved refining and changing to the nodes or codes and thematic framework (235).

As indicated above, this data analysis was both deductive, with themes derived using conceptual frameworks, and inductive, with themes that newly emerged from the data or fell outside the frameworks (238, 239). The analysis of data from each category of participants resulted in several core themes about the topics being researched. The analysis of the data from the women's category resulted in (i) six core themes about HIV-risk factors: HIV knowledge, behavioural factors, socio-environmental factors, financial factors, intimate partner violence and religious and cultural factors; (ii) four core themes about the impact of HIV on the participants and their families: stigma and discrimination, psychological impact, family disputes and separation, and the physical impact; and (iii) five core themes about access to HIV care services: the availability of the services and ability to reach them, the approachability of the services and ability to perceive the need for care, the affordability of the services and ability to pay, the appropriateness of the services and ability to engage, and the acceptability and ability to seek. The complete records of the thematic framework of data analysis for each category of participants is presented in Appendix 12.

4.4.3 Charting the data

In this step the researcher reorganised all the chunks of transcripts that had been indexed or coded in the previous step into charts of themes. Firstly, charts for the nodes across the participants were generated in NVivo. These charts were then reviewed and summarised manually by the researcher using his own words in a theme chart for each category of participant (women and men living with HIV, healthcare providers, and policy makers). The chart manually created by the researcher contained a list of the participants in the left-hand column and the themes in the rows. The codes that had been made to each transcript, which had been grouped into separate themes in the previous step, were reorganised and summarised by the researcher using his own words and put together under each theme in the chart. So, this chart was created to build up a picture the whole data as it contained all themes and a summary of the codes identified from each interview transcript (235). This manual process of reviewing and summarising the data codes in the chart involved the abstraction and synthesis to the data by the researcher using his own words. Hence this process lifted the data from their original textual context, but the original texts were referenced, and could be traced back and revisited if needed (235). Through this process the researcher also reflected on the patterns identified from the data, and could begin the interpretation and explanation process.

4.4.4 Mapping and interpretation

The final step of the analysis was the mapping and interpretation of the data set as a whole. These were done by systematically pulling together the key characteristics of the data that had been indexed and charted in the previous phases (235). It was the most difficult analytical process to describe because the process of pulling up together the overall picture of the data was not simply by aggregating patterns and multiplicity of evidence but requiring weighing up the salience and dynamics of the issues and searching for structure. Again, this was an iterative analytical process where the researcher revisited the indexed (coded) data extracts and reviewed the summary of the data in the charts back and forward repeatedly. This was to make final comprehensive comparisons between the perceptions, accounts and experiences of participants about HIV-risk factors, the impact of HIV and the facilitators of and barriers to access to HIV care services as identified in this study (235). The comparisons were driven by the research questions used to guide this study, and the main purpose of this analytical process was to address these research questions (235, 238).

The focus of this analytical process was to identify typologies from the data, or to see whether two or more dimensions or themes identified in previous stages were linked at different points, or fell within certain typologies (235). To develop the typologies the researcher identified patterns and interpreted the connections or associations of themes that had been identified. Thus, this process was a creative pathway which depended on the researcher's familiarity with the data and experience in qualitative data analysis (236). The interpretation of the associations of the themes was both deductive, guided by the conceptual frameworks used in this study, and inductive, based on arguments or patterns that emerged from the data (238, 239).

The use of these data analysis steps increased the trustworthiness of the findings as these steps ensured a consistent and structured way of qualitative data management, and supported rigour, transparency and validity of the analytic process (235, 237, 240, 241). The maintenance of the accuracy of the translation and credibility of the findings was also performed to increase the trustworthiness of this study's findings. This was carried out by checking and rechecking transcripts against the translated interpretations or examination of meaning in both source (Bahasa) and target (English) language during the analysis (242, 243). The clarity and accuracy of the translation were also checked and improved by supervisors. Although, data analysis was primarily undertaken by the student, team-based analysis was undertaken at regular supervision meetings during the PhD project whereby comments and suggestions for improvement were provided by supervisors. These helped maintain the reliability and validity of the findings (final themes) and interpretation, and increased the trustworthiness of the findings (243). Thus, the trustworthiness of the findings was maintained through the transparent reporting of the stages of the research project: preparation phase, data collection and analysis, and the report and interpretation of the findings (241).

4.5 Ethical considerations and permissions from the Indonesian government

The study was conducted based on human ethics principles. Ethics approvals were solicited from SBREC, Flinders University, Australia (No. 8286) and the Health Research Ethics Committee, Duta Wacana Christian University, Yogyakarta, Indonesia (No. 1005/C.16/FK/2019). The ethics approval from SBREC was obtained before the researchers headed for the fieldwork, while the one from Duta Wacana University was obtained after two weeks of the researcher's arrival in the fieldwork, Yogyakarta. A permission letter for the study was also obtained from the national government of Indonesia: The Ministry of Home Affairs, which was applied for and granted while the researcher was still in Adelaide, Australia. Permission letters were also obtained from the VCT clinic in Yogyakarta and Belu, which indicated their agreement to distribute the study information packs to the women and men living with HIV who accessed the HIV care services at the clinics. Permission letters were also solicited from the local governments of Yogyakarta and Belu or the relevant departments of these local governments. Permission letters were also solicited from three NGOs in Yogyakarta prior to the recruitment and participation of their staff in the interviews.

Prior to the interviews, participants were again advised that the study had obtained ethical approvals from the Ethics Committees, as well as permissions from relevant institutions at national and local level. They also received a verbal explanation by the interviewer about the purpose of the study and the voluntary nature of their participation. They were also advised that they had the rights to withdraw their participation during the interview without any consequences. They were also advised that the interview may take approximately 45 to 90 minutes for women and men living with HIV, 30 to 60 minutes for healthcare providers and 30 to 45 minutes for policy makers, and would be digitally recorded, and that the researcher would make notes during the interviews. Participants were assured that the data or information they provided in the interviews would be treated anonymously and confidentially. These would be done by providing a study identification letter and number for each participant (e.g., FP1, FP2 (Female Participant), ... or MP1, MP2 (Male Participant), …. or HCP1, HCP2 (Healthcare Professional), …. or PM1, PM2 (Policy Maker), ….) to ensure that the data or information provided would not link back to an individual in the future. A consent form was provided for each participant to read and if needed, could ask for clarification from the researcher. Prior to singing the consent form, three women participants in Belu asked the researcher to make sure that signing the form would not have any negative impact on them or their family. Each participant signed and returned the consent form to the researcher before participating in the interview (Appendix 11).

4.6 The socio-demographic profile of the participant

4.6.1 Women living with HIV

A total of 52 WLHIV, comprising 26 women from Yogyakarta and 26 women from Belu, participated in this study. The age of the women ranged from 19 to 60 years old, with the majority in the age group of 30 to 39 years and 40 to 49 years. Nearly half of the women were married or had re-married, and the others were divorced, widowed or never married (non-married). Most women had been diagnosed or living with HIV for about one to five years, and a few had been living with the virus for a much longer time between a range of six to ten years or eleven to fifteen years. Several women had also been diagnosed with other STIs, such as herpes and candidiasis and tuberculosis (TB) (See Table 3). All the women participants in both settings were on ART.

The education backgrounds of these women varied, with half of the women in Yogyakarta graduating from senior high school, while nine in Belu had dropped out or graduated from elementary school. Only five in Belu had graduated from senior high school. A few women in both settings had graduated from junior high school and university. Nearly half of the women in both settings were housewives, and the others were engaged in different professions, such as health worker, private employee, NGO worker, entrepreneur, civil servant, tailor, shop keeper, sex worker, banker and laundress. Most women in Yogyakarta and Belu were Muslim and Christians, respectively (See Table 3).

4.6.2 Men living with HIV

A total of 40 MLHIV, consisting of 20 men from Yogyakarta and 20 men from Belu, participated in this study. The age range of the men were between 22 to 60 years old, with the majority in the age groups of 30 to 39 years and 40 to 49 years. The majority of the men were married or had re-married, and the rest were non-married (divorced or widowers or never married).

Half of the men had been diagnosed with HIV for a much longer time between a range of six to ten years or eleven to fifteen years, and the others had been diagnosed with HIV within the last five years. Half of the participants had also been diagnosed with TB, and several men had also been diagnosed with other STIs, such as herpes, syphilis and gonorrhoea. All the participants in both settings were on ART at the time of this study.

The participants in Yogyakarta had a relatively better education background than the ones in Belu, with seven graduating from university, eleven from senior high school and only two from junior high school. Meanwhile, half of the men in Belu graduated from elementary school or junior high school, eight from senior high school and only two from university. Most men in Yogyakarta were entrepreneurs and private employees and three were unemployed. Men in Belu engaged in different kinds of jobs, such as a truck driver or motorbike taxi driver, an iron welder, teacher, police, farmer, entrepreneur, and private employee. One man in Belu was a university student (See Table 3).

Table 3: Sociodemographic profile of female and male participants (PLHIV)

Characteristics	**Women living with HIV**		**Men living with HIV**	
	Yogyakarta (n=26)	Belu (N=26)	Yogyakarta (N=20)	Belu (N=20)
Age				
18 - 19		2		
20 - 29	6	4		7
30 - 39	12	12	10	5

40 - 49	8	6	10	5
50 - 59		1		2
60 - 69		1		1
Marital status				
Single	5	3	5	7
Divorced	5	1	2	
Widowed/r	3	12		1
(Re)Married	13	10	13	12
HIV diagnosis				
1 - 5 years ago	16	18	6	15
6 - 10 years ago	7	7	7	4
11 - 15 years ago	3	1	7	1
Other infections				
Herpes	2		2	1
Candidiasis	1	3		
Syphilis			2	
Gonorrhoea			2	1
TB	4	5	10	9
Religion				
Islam	23	1	17	
Catholic	2	25	3	19
Protestant	1			1
Hindu				
Other				
Education				

University graduate/Diploma	6	6	7	2
Senior High school graduate	13	5	11	8
Junior High school graduate	6	6	2	4
Elementary school graduate	1	8		6
Elementary school dropout		1		
Occupation				
Housewife	10	11		
Entrepreneur	3	6	10	1
Tailor	1			
Sex worker	1			
NGO worker	3			
Laundress	1			
Teacher				2
Farmer				3
Police				1
Nurse / health worker	1	2		
Shop keeper	1			
Private employee	2	2	5	1
Banker	1			
Retired civil servant		1		1
Civil servant		1		
University student	1			1

Taxi/truck/ Motorbike taxi driver			1	8
Iron welder				2
Mechanic			1	
Unemployed	1	3	3	

4.6.3 The healthcare providers

The healthcare providers (n=20) who participated in this study were from Yogyakarta (10 people) and Belu (10 people). The ones in Yogyakarta were three counsellors (who were also nurses), two nurses and five medical doctors. The ones in Belu included eight nurses who were also trained to take on roles as counsellors for PLHIV and two medical doctors. The healthcare providers from both study settings had been involved in HIV care service delivery to PLHIV for many years during their careers (See Table 4).

4.6.4 The policy makers

Nine policy makers participated in this study, including six and three people from Yogyakarta and Belu, respectively. Four of the policy makers in Yogyakarta were recruited from three NGOs providing HIV-related services for PLHIV. They were the director, the companions of PLHIV and the heads of outreach and VCT unit of the NGOs. Two others were recruited from the local governments, including the head of the disease prevention unit at local health department, and the head of social department in the Yogyakarta municipality. Three policy makers in Belu were recruited from the local health department. They were the head and secretary of the disease prevention unit and the coordinator of the local AIDS commission (See Table 4).

Table 4: Sociodemographic profile of the healthcare providers and the policy makers

Characteristics	**Healthcare providers**		**Policy makers**	
	Yogyakarta (N=10)	Belu (N=10)	Yogyakarta (N=6)	Belu (N=3)
Age				
30 - 39	2	4	1	1
40 - 49	6	4	4	2
50 - 59	2	2	1	
Sex				
Male	4	3	2	1
Female	6	7	4	2
Religion				
Islam	5		5	
Catholic	5	10	1	3
Education				
Doctorate	1			
Postgraduate	2			
University graduate/Diploma	7	10	3	3
Senior High school graduate			3	
Involvement in HIV service delivery				
1 – 5 years	4	6		
6 – 10 years		4		
11 – 15 years	6			

Involvement in		
Decision making		
1 – 5 years	1	2
6 – 10 years	4	1
11 – 11 years	1	

CHAPTER FIVE

HIV RISK FACTORS AND IMPACT AMONG WOMEN LIVING WITH HIV AND THEIR FAMILIES, AND THE WOMEN'S ACCESS TO HIV CARE SERVICES

5.1 Overview

This chapter comprises three sections: risk factors for HIV transmission among WLHIV in Yogyakarta (n=26) and Belu (n=26), the impact of HIV on themselves and their families, and their access to HIV care services. The majority of the participants were unmarried (n=29) and others were married (n=23). The participants' ages ranged from 19 to 60 years old. The first section presents WLHIV's accounts about factors that facilitated or supported HIV transmission among them, and some parts of the findings on culutral and religious factors have been published in PLoS ONE (48) (The details of author contributions are presented in the article: Appendix 1). The exploration of the women's views and experiences about HIV-risk factors was guided by the logical model for behavioural and environmental determinants diagnosis (See section 3.2 for a discussion of the framework). The second section presents the women's views and experiences of the impact of HIV on themselves and their families following the HIV diagnosis. Some parts of the findings on HIV stigma and discrimination have been published in the International Journal of Environmental Research and Public Health (49) (The details of author contributions are presented in the article: Appendix 2). The exploration of their views and experiences of the impact of HIV was guided by the conceptual framework for the impact of HIV on individuals and families, and the HIV stigma framework (See section 3.3 and 3.4 for a discussion of the frameworks). The third section presents the accounts of WLHIV about their experience with their access to HIV care services. Access to the healthcare framework was used to guide an exploration of the women's views regarding their experiences with their access to the HIV care services in the study settings. The framework suggests five characteristics or dimensions of the supply side, and five corresponding abilities of the demand side (see section 3.5 for a discussion of the framework).

5.2 HIV transmission risk factors

The HIV-risk factors described by the WLHIV are grouped into HIV knowledge, behavioural factors (e.g., condom use and perception, multiple sex partners and sex partner's behaviours), socio-environmental factors, financial factors, intimate partner violence, and religious and cultural factors.

5.2.1 HIV knowledge

Although the breadth of knowledge about HIV varied among participants, all the females interviewed across both settings demonstrated a good, basic knowledge of HIV infection, including how it is transmitted and how it can be prevented. However, most of them acknowledged that they did not know about HIV prior to their diagnosis, and started learning about it after their diagnosis:

> *"I did not know about HIV before the diagnosis, did not know at all about the means of transmission and prevention. I heard about it after I was tested positive in 2016 because I was asked (by the companion of people with HIV who was also HIV-positive) to attend HIV information sessions" (FP23, single, Yogyakarta).*
>
> *"I had never heard of HIV at all (prior to the diagnosis). The doctor told me about it once I was tested positive. That was the time heard about this disease (infection). Before the diagnosis and the explanation from the doctor, I did not know at all about how HIV is transmitted" (FP18, married, Belu).*

Several women across both study settings described that they were unaware that HIV could be transmitted by sexual intercourse, and had not thought of engaging in protected sexual behaviour. For these women, the lack of knowledge and access to information about HIV seemed to be the underlying reason for their engagement in unprotected sex with their partners, including the ones who were HIV-positive, because they were unaware of the possibility of HIV transmission from their sex partners:

> *"Because I did not have information about HIV, I had sex with my ex-boyfriend without using condoms at all. So, I was pregnant and both my child and me are HIV-positive" (FP16, divorced, Yogyakarta).*
>
> *"My husband and I never used condoms at all in our intimate (sexual) relation. Never thought of the possibility of contracting HIV because at that time I did not know about HIV at all" (FP5, widowed, Belu).*

5.2.2 Behavioural factors

5.2.2.1 Condom use and perception

Lack of condom use practices

Lack of condom use appeared to be one of the behavioural factors that facilitated the transmission of HIV infection among female participants in both study settings. Most participants (n=46) described how they engaged in sex without condoms at all (used interchangeably with 'unprotected sex') for years prior to their HIV diagnosis, with either their 'ex-boyfriend or ex-husband or current husband or sex client' (referred to as 'sex partner' from here):

> *"Never used condoms once having sex with my ex-boyfriends (one of her ex-boyfriends died from AIDS) when I was in college" (FP12, married, Yogyakarta).*
>
> *"I do not really know about condoms and never used (them), that made me got HIV from my ex-boyfriend" (FP11, single, Belu)*

A few women interviewed from both study settings (n=6) reported the use of condoms in sexual relations with their sex partner. However, they acknowledged that the use of condoms was inconsistent:

> *"I had a boyfriend from Jakarta. We had sex, but sometimes we used condoms, sometimes we did not use condoms. …. With my husband we never used condoms. Both have passed away" (FP21, widowed, Yogyakarta).*
>
> *"There was condom use in my intimate (sexual) relations with my ex-boyfriend but that was very rare. I once asked him to use (them) so that I did not get pregnant" (FP26, single, Belu)*

Condom perception or knowledge

Most women interviewed in both study settings reported that prior to their HIV diagnosis they did not know about condoms and their function in preventing the transmission of HIV and other STIs:

> *"Before I was diagnosed (with HIV) in 2009, I did not know at all about protection or condoms. After the diagnosis, I started to hear about condoms from the doctor and my peers (who are also HIV-positive) during the peer support group meetings, that condoms can be used to prevent HIV and other (sexually transmitted) infections" (FP9, married, Yogyakarta).*
>
> *"I did not know about condoms at all, just heard about it after I contracted HIV because the nurses said that condoms should be used if I have intimate (sexual) relation, that was the time I heard about it" (FP7, remarried, Belu)*

The lack of knowledge and information about condoms and their susceptibility to HIV infection through unprotected sex prior to their HIV diagnosis, were supporting factors for the women's unprotected sexual behaviour. The majority described that they did not have any knowledge and information about condoms as a means of HIV prevention, which was why they did not think of or use condoms in their sexual relations prior to their HIV diagnosis:

> *"…. I did not know yet about condoms, so (there was) no condom use at all every time I had sex with my (ex) boyfriend, …. I did not know about the function of condoms" (FP5, married, Yogyakarta).*
>
> *"At time (when she dated her ex-boyfriend) I did not know what a condom looked like, did not know at all, never heard about it. That was why I never thought of condoms*

> *every time having sex with him (ex-boyfriend). Besides, I did not have information about this HIV" (FP16, divorced, Yogyakarta).*
>
> *"We (the woman and her late husband who was HIV positive) never used condoms in our intimate relation. We did not about condoms, so we never used. We were told about it after the (HIV) test" (FP22, widowed, Belu)*

However, even knowledge of condoms did not guarantee condom use or protected sexual behaviour. The women interviewed in both study settings who had been aware of condoms and their protective functions following their HIV diagnosis continued to engage in unprotected sex or inconsistent condom use practice with their sex partners. Being an HIV positive couple, feeling uncomfortable and unaccustomed to condom use, husbands being drunk, their sex partner's objection to condom use due to a perceived less pleasurable experience, and a lack of knowledge about where to access condoms, were the barriers for condom use, and the underlying reasons for these women's continuous engagement in unprotected sex:

> *"Both of us (the women and her husband) are positive, why should we use (condoms)" (FP1, remarried women from Yogyakarta).*
>
> *"My (ex) husband did not want to use condoms because every time we made love, he was drunk, he could not be asked to use (condoms). …" (FP16, divorced, Yogyakarta).*
>
> *"We (the woman and her husband) never used condoms after knowing our HIV status. My husband did not want to use because he said he was not accustomed to using condom, he said it was unpleasurable" (FP4, widowed, Belu).*
>
> *"After my husband and I were diagnosed (with HIV), the doctor told us to use condom once we have husband-wife relation (have sex) but we never used because we do not know where to get that thing (condom)" (FP18, married, Belu).*

The lack of, or inconsistent condom use, was indicated as the main route for HIV transmission among the women interviewed across the study settings. Most of them firmly stated that they were infected by their sex partner through unprotected sex. Such statements were made due to the fact that their sex partner had either been previously diagnosed with HIV or had died from AIDS:

> *"He (an HIV counsellor at the hospital where she was admitted to) told me that my husband died from AIDS. …. I got it (HIV) from my husband because we did not know about HIV, so we had sex without protection (condom)" (FP3, remarried, Yogyakarta).*
>
> *"We (the woman and her husband) never used condoms at all every time we had sex. …. After my husband was diagnosed with HIV (husband already died from AIDS), I was also tested, and I have it (HIV) too. My husband transmitted it to me" (FP4, widowed, Belu)*

Lack of any other HIV-risk factors was also another strong reason for the women's firm acknowledgement of having contracted the HIV infection through sexual intercourse with their partner. For instance, the majority of the women interviewed in both settings commented that they had never been involved in sex with men other than their partner, or had never injected drugs, as described below:

> *"I am sure I got HIV from my (late) husband because I never had sex with other men, I did not use injecting drugs. So, there was no other risk factors that could put me at risk for HIV, but intimate (sexual) relations with my husband" (FP2, widowed, Yogyakarta).*
>
> *"I am sure I got it (HIV) from my husband because I never had extramarital (sexual) relations during our marriage. We (the woman and her husband) never used condoms …." (FP18, married, Belu).*

Of the women interviewed, four in Yogyakarta clearly stated that their sex partners deliberately transmitted the virus to them. This conclusion was made because their ex-boyfriend or ex-husband was aware of his HIV status, but hid it from them and continued to engage in unprotected sex with them, as illustrated in the following quotes:

> *"One day I decided to break up with him (her ex-boyfriend) because there was a problem. I wanted to leave him and then he told me: 'you cannot leave me, I am infected with HIV'. 'Does that mean I am infected too?' I asked him. 'Yes, that is why you cannot leave me', he said" (FP25, single, Yogyakarta).*

> *"He (her ex-husband) knew that he was HIV positive but did not have courage to tell me, and finally transmitted it to me, deliberately spread the infection to me. …." (FP24, divorced, Yogyakarta).*

Women's trust in their sex partners

Trust in their sex partner was a personal factor that seemed to play a role in the transmission of HIV among the women participants. Trust was indicated as a barrier to condom use or a supporting reason for the lack of condom use and unprotected sex practices between the women and their sex partner from whom they had contracted HIV. Several women (n=8) interviewed in both settings revealed that they had trusted their sex partners, hence considered it unnecessary to use condoms in their sexual relationship. This seemed to correlate with a lack of knowledge about the HIV status of their sex partner:

> *"At that time, I never thought of condom use …. I trusted my (late) husband, he was kind and loved me, but I did not know that he was infected with HIV" (FP2, widowed, Yogyakarta).*
>
> *"As husband and wife, I trusted him. So, once he came back from Bali, we had sex without condoms. Surely, we never used condoms during our marriage because we are husband and wife and trusted each other. The fact was that he (her husband) had sex with other girls (FSWs) and got the infection over there (Bali) and then transmitted it to me (she was diagnosed with HIV a month prior to the interview)" (FP19, married, Belu).*

5.2.2.2 Multiple sex partners

Several women interviewed in both study settings reported changing sex partners over time, which contributed to the transmission of HIV infection among them. They acknowledged as having engaged in such sexual practice for years prior to their HIV diagnosis, and this seemed to have been a facilitator for the transmission of HIV among them, as the sexual encounters were often without condoms:

> *“I used to like to have sex with different guys (prior to the HIV diagnosis). …. Before I got married, I often changed my sex partner. If I felt bored with a sex partner, then left him and changed to another one. I was (had sex) with about eight different men. …. Never used protection (condoms) at all in sex with all of them” (FP12, married, Yogyakarta).*
>
> *“Intimate (sexual) relations with my husband (she was remarried 3 times) are without condom at all. But I also had sex with other men (before remarried)” (FP1, remarried, Belu).*

A few of them in both study settings (n=5) also reported engaging in sex with multiple sex partners within a time period which was driven by their involvement in sex work practices. They acknowledged engaging in sex with multiple clients every night where condoms were inconsistently used:

> *“Now I limit the number of (sex) clients to four or five person per night. I used to serve more than this (number) before. …. Condom use depended on the (sex) clients. It was up to them, if they did not want to use condoms, it was okay for me” (FP4, single, Yogyakarta).*
>
> *“I used to have multiple sex clients from everywhere. …. At that time, I was still working as a sex worker at X and XX hotels. …. Never used condoms because those men did not want. …. I did not know the reason why they did not want (to use condom) but if I offer (condoms) they always rejected it” (FP9, Widowed, Belu)*

5.2.2.3 Sex partner’s behaviours

The sexual behaviours of the women’s sex partners (ex-boyfriends or ex-husbands or husbands) seemed to play a role in supporting the transmission of HIV among the women participants. Their sex partners’ engagement in sex with other women, including FSWs or women whose HIV status was unknown, could have been the route of HIV transmission to the study participants’ sex partners, who then transmitted it to them. Most women interviewed in both study settings acknowledged their sex partner’s involvement in sex with multiple female sex partners:

> *"He (ex-husband) had sex with many women, had multiple sex partners, many wives, and for sure he had sex with the girls at brothels (FSWs) as well and that is why he got HIV" (FP14, remarried, Yogyakarta).*
>
> *"My ex-boyfriend previously worked in Kalimantan for two years. And I heard that he often had sex with 'naughty girls' (FSWs) over there. So, I am sure he was already infected over there, brought it here and then spread it to me. He was also tested positive" (FP11, single, Belu).*

The women's sex partners' engagement in sex with multiple female partners seemed to be driven largely by mobility and migration for work purposes, as well as the environment where their sex partners lived, worked and interacted during the mobility and migration period. The majority of female participants in Belu and a few in Yogyakarta acknowledged that their sex partners moved from one place to another, and migrated to other places within or outside of Belu or Yogyakarta for work, where they met and engaged in sex with other women, including FSWs:

> *"He (her ex-husband) used to move from one place to another for work …. And in every place he went to he had another woman: a new girlfriend or new wife, or visited brothels (had sex with FSWs)" (FP14, remarried, Yogyakarta)*
>
> *"He (her ex-husband) was a motorbike taxi driver. He went out in the morning and came back in the evening. He visited (had sex with) 'naughty girls' (FSWs). He still did that after we had been diagnosed with HIV. He knows those women because he often drives them (as passengers)" (FP20, divorced, Belu)*
>
> *"My (late) husband migrated to work in Kalimantan. He worked for companies and he moved from one place to another. Those 'naughty girls' (FSWs) often came to the locations of the companies and waited for clients. So, maybe my (late) husband often had sex with them" (FP22, widowed, Belu).*

Women's acknowledgement of their sex partners' sexual behaviours, including engagement in sex with multiple female partners, was based on conversations with their sex partners. Some women in both study settings commented that they were told about the sexual behaviours their sex partners had engaged in, which were believed to have contributed to the HIV transmission among them:

> *"…. He (her ex-husband) told me that he often visited brothels (had sex with FSWs) …. One of his ex-girlfriends died from AIDS …." (FP24, divorced, Yogyakarta).*
>
> *"…. I got the infection from my husband because my husband used to have sex with 'naughty girls' (FSWs). …. He himself told me that he used to play (had sex) with 'naughty girls', who are usually called 'ayam' (ayam is a local term for FSWs, literally means chicken)" (FP10, married, Belu).*

However, several women across both study settings described that they did not discuss the sexual behaviours of their husband irrespective of their awareness of contracting the virus from their husband. Fear of physical and verbal violence, feeling inappropriate in raising questions that investigated their husband's sexual behaviours and avoidance of spousal dispute, were reported as the main reasons for the lack of discussion about such a topic:

> *"I got HIV from him (ex-husband) but I did not ask about his sexual relations with other women because I was scared of him beating me up. I would have got scolded and beaten up if I asked about what he did outside which made him contract HIV" (FP6, remarried, Yogyakarta).*
>
> *"I know that he transmitted HIV to me but I do not have the courage to ask him about how he got it. I feel like it is not appropriate and can lead to dispute because it can make him feel embarrassed. I do not feel comfortable to open a talk about it, so I keep quiet up to now and just listen to the doctors who encourage us (the women and her husband who is also HIV-positive) to focus on the treatment" (FP13, married, Belu).*

IDU by sex partners of the female participants was identified as another supporting behavioural factor for the spread of HIV infection. Half of the women participants in Yogyakarta and one participant in Belu, reported that their sex partners were injecting drug users, and might have got their HIV infection through sharing needles with other users:

> *"…. Finally, he (her late husband) told me that he used drugs, injecting drugs. …. He said he got HIV through sharing needle with his friends" (FP2, widowed, Yogyakarta).*

> *"My (late) husband was an injecting drug user. It seemed like he got (HIV) from injecting drugs before we got married. He used illicit drugs for very long time. …. I know that he was a former injecting drug user because he told me that (before marriage). So, I thought he was a good man (because he told her his background)" (FP3, widowed, Belu).*

The engagement of the women's sex partners in IDU practices was indicated as influenced by the environment where they lived, and the social relationships they engaged in. The stories of several women presented below showed that living in prison and in environments where illicit drugs could be easily solicited, plus mingling with other drug users, were the supporting factors for their sex partners' engagement in IDU practices through which their sex partners' contracted HIV:

> *"He (her ex-boyfriend who died from AIDS) was an injecting drug user. He was diagnosed with HIV just after a few months of his release from prison. In the prison, one needle is used together, so it is possible that he got HIV through it" (FP12, married, Yogyakarta).*
>
> *"He (her husband who died from AIDS) told me that once he was in senior high school in Jakarta, he was a drug dealer, he was jailed for eight years. …. The social environment in Jakarta dragged him into the use of illicit drugs, many of his friends used. He was also a drug dealer, so it was easy for him to get drugs" (FP3, widowed, Belu).*

5.2.3 Socio-environmental factors

A few women in both study settings (n=5), who reported on engaging in sex work practices, commented that the social influence of friends or other FSWs was a supporting factor in their involvement in such practices which facilitated HIV transmission among them:

> *"A friend of mine worked here (Yogyakarta) as a sex worker, she invited me to come here with her. I came with her and joined with many other friends who were like this (FSWs), and I continue it up to now" (FP4, single, Yogyakarta).*
>
> *"Initially, I started to work as a sex worker because I was invited by my friends (who were also FSWs). …. Nearly all my friends in (my) village work like that, as sex workers.*

> *…. Initially they invited me to work in Atambua (the name of the only town in Belu district). So, my mother and father also agreed. I came here and I had (sex) clients every day" (FP9, widowed, Belu).*

The environment where the women lived and interacted was also indicated as a supporting factor for the women to continue to engage in sex work. These women described how they felt comfortable with this social environment as there were many other FSWs with whom they shared their stories:

> *"I was living with other friends (FSWs) nearby the 'lokalisasi' (the place to meet sex clients). So, we shared stories with each other. The social environment was really supportive because other friends also do the same job (as her) every day. That made me feel comfortable to work like this, but I moved and now live a bit far from the 'lokalisasi'. I go there just in the evening" (FP17, divorced, Yogyakarta).*

5.2.4 Financial Factors

A few women who reported on engaging in sex work also raised issues about financial factors which drove their involvement in such practices prior to them being diagnosed with HIV. The lack of or need for money to support current and future personal and family needs, were reported as the supporting reasons for their engagement in sex work. Selling sex in exchange for money included regular instances of unprotected sexual intercourse with multiple clients on a daily basis, which in turn led to HIV exposure and other infections for these women:

> *"I chose (started) to work like this (FSW) due to difficult financial condition, and also because I did not continue my study (after graduating from elementary school). …. It was difficult for me to get a job (other than being a sex worker) because I did not have a school certificate" (FP4, single, Yogyakarta).*
>
> *"At that time, it was because I was poor financially and could not get any jobs. So, to support our daily life and fulfil the needs of my children I got involved in sex work" (FP1, remarried, Belu).*

These women also indicated that financial factors had an influence on their use of condoms with clients, which they described as being dependent upon the preference of the client.

Many clients were reported as refusing to use condoms, but they were charged a higher rate than the normal price:

> *…. I am sure I have got the infection from the (sex) clients because condom use is always dependent on them, and many do not want to use a condom even though I provided one" (FP17, divorced, Yogyakarta).*
>
> *"After my husband passed away, I started to have visitors (engaged in sex work, but she stopped being a sex worker). Those men did not want to use condoms at all, but I could not force them to use (condoms) because they paid (me) and I also needed money. Sometimes I offered condoms, but no one wanted to use (condoms). I think I got it (HIV) from one of those men (sex clients) because lately I found out that he is HIV-positive" (FP16, widowed, Belu).*

Some of the Belu women who were not FSWs also commented that being financially dependent on their husbands had an influence on their sexual relationships. They described how it led to their husbands dominating all decision-making, including in sexual matters, and the women's inability to reject the sexual demands of their husbands stemmed from the threat of withdrawal of financial support from their husbands:

> *"In our family, my (late) husband decided everything, including in the matter of our intimate relations. If he wanted to have sex then it should happen, I had to serve. …. I was depending on my husband economically. …. If he asked (for sex) and I did not want, then he would say: 'I earned money for you'. So, whether I am tired or not, I had to serve him, if not, then he would not give me money" (FP4, widowed, Belu).*

5.2.5 Intimate partner violence

IPV against women by their sex partners emerged during the interviews, and seemed to contribute to the transmission of HIV infection among several women participants in both study settings (n=10). IPV against women, both physically and sexually, caused fear and the inability among the women to discuss the need for protected sex or condom use with their husbands. This led to the women voluntarily indulging the sexual desires of their husbands, as portrayed in the following examples:

> *"When I was pregnant for my second child, I was so weak because I was harassed (physically by her former husband). …. I almost aborted my child because I was so stressful, often beaten. …. He was a temperamental person. That was because he often consumed alcohol and used drugs. For instance, if he was drunk and wanted to have sex but I did not want, then I would be beaten badly, even though I was pregnant. …. He often forced me to have sex with him. …. I had to serve him, if not it would be like that, I got beaten. In such condition, how could I talk about safe sex or condom use, I could get beaten" (FP14, remarried, Yogyakarta).*
>
> *"I was often beaten up (by her late husband) and forced to have sex. …. Sometimes he came back home in the evening and asked (for sex), but if I did not want to because I am tired, tired of taking care of the kids and household chores. …. I was beaten up" (FP5, widowed, Belu).*

IPV against women also had a negative impact on women's involvement in spousal sexual decision making. It prevented the women from taking part in the decision of when and under what conditions to have sex with their husband. The examples of stories of several women below portrayed how IPV made them feel powerless and unable to discuss with their husbands about their spousal sexual relations:

> *"My (ex) husband was dominant in deciding sexual matters because I think our sexual relations as husband and wife was unhealthy. I served him and he was in a condition of not being fully aware, he was drunk. We never discussed our sexual relation, I always served him because he was often drunk, and I was afraid of physical violence. He asked for sex once he was drunk" (FP16, divorced, Yogyakarta).*
>
> *"We (the women and her late husband) never discussed about our intimate relations. So, even if I was tired, I was not brave to let him know or talk to him that I was tired. …. I wanted to talk to him, but I was scared that he would get mad or be rude at me" (FP4, widowed, Belu).*

Some of these women in Belu revealed that rejecting the sexual demands of their husbands not only led to IPV, but also suspicions and accusations of having sexual affairs with other men, factors which were not raised by the women interviewed in Yogyakarta. The women felt they had no other choice but to indulge the sexual desires of their husbands:

> *"I was accused of cheating (by her late husband who worked as a motorbike taxi driver), saying 'You sleep (have sex) with other men once I go searching for passengers in the morning, therefore you do not give (serve him sexually) me in the evening' so I often just served him if he wanted" (FP5, widowed, Belu).*
>
> *"If he wanted to have sex then I must serve him. If I did not (serve him) then he would be suspicious of me having other men out there" (FP9, widowed, Belu).*

Being raped by a boyfriend or husband was an extreme type of sexual violence which was indicated as contributing to the transmission of HIV infection among some of the women participants. A few women interviewed in Yogyakarta shared their experiences of being raped, through which they were infected with HIV:

> *"I had sex only once in my life. At that time, it was like I was raped by my (ex) boyfriend because we both were alone in his house and he asked to have sex but I refused and he threatened to kill me. Because of that I contracted (HIV). …. I was forced, threatened, beaten, so I could not avoid (having sex). And where to get a condom in such a situation, it was not possible to use condom, and the result was that I am now infected with HIV" (FP26, single, Yogyakarta).*
>
> *"I think my (ex) husband had a sexual disorder, I was often forced to have sex even though my child was there, it was crazy. I was forced to have sex. Sometimes I was strangled to serve him, I was raped. I tried to refuse, I did not want it because my child was there with us but I was strangled and unable to refuse" (FP16, divorced, Yogyakarta).*

Some of the women reported that IPV prevented them from being able to discuss the sexual behaviour of their husbands outside of their marriage. Several women who experienced IPV in both study settings were aware of the high-risk sexual behaviour of their husbands, but were reluctant to discuss it with them due to the fear of physical violence, a situation which seemed to play a role in HIV acquisition among the women:

> *"I knew he (her former husband) often visited brothels (had sex with FSWs) in those nights he went out of home but how could I ask about it? I did not ask because I often got beaten. So, if I asked and made him felt offended then I would be beaten up so badly. After I tested positive (for HIV), my child and I ran away to my mom's house and left him because I knew he infected me. I did not have sex with anybody else, did not*

> *inject drugs, did not receive a blood donation, so how could I get the infection?" (FP6, remarried, Yogyakarta).*
>
> *"I knew he (her late husband) had sex with 'naughty girls' in Atambua or Ainiba (names of places). There were many (FSWs) over there, I heard he often visited those places. …. There was a thought to ask (him) but I was scared of being beaten up, so I keep quiet" (FP4, widowed, Belu).*

5.2.6 Religious and cultural factors

5.2.6.1 Javanese (Yogyakarta)

Religious beliefs in Islam that prohibit sex for unmarried people, seemed to indirectly affect the practice of condom use amongst unmarried participants in Yogyakarta, factors which were not raised by the interviewees in Belu. Although they were not practising or following such beliefs because they engaged in premarital sex, their awareness of such beliefs seemed to lead to the fear of the possibility of stigma and negative labelling by other people if their engagement in premarital sex practices was known. Such fear led to women feeling ashamed and unwilling to access condoms, as it may lead to other people knowing of their engagement in premarital sex, and labelling them as sinners. Consequentially, these women continued to engage in unprotected sex practices which placed them at high-risk for HIV acquisition:

> *"It is also the same in religion (Islam), people have to get married first and they can have sex after they are officially husband and wife. …. That is the reason I feel ashamed to buy condoms because if my neighbours see me buying condoms then I will be labelled negatively. They could label me as a sinner" (FP23, Muslim woman, single, Yogyakarta).*
>
> *"The religious thought in Islam is that there are to be no sexual encounters prior to marriage. I am still single, if I buy condoms and it is seen by other people who know me, then what would happen?" (FP19, Muslim woman, single, Yogyakarta).*

Similarly, the participants' interpretation of their religious beliefs in Islam, that prohibit condom use among married people, also influenced their condom use practices. Several married Muslim women interviewed in Yogyakarta, commented that the lack of condom use in sexual relations with their husbands was partly due to the reason that condom use is prohibited in Islam. The following narrative of a Muslim woman who acknowledged be infected by her husband through unprotected sex illustrate this assertion:

> *"Since the very beginning (of her marriage) up to now we have never used condoms. I contracted HIV because of that, I was infected by my husband. Condom use is prohibited in Islam. Condom use in marriage is not in accordance with our religious belief, which I obey by never using condoms" (FP8, Muslim woman, widowed, Yogyakarta).*

The stories of the majority of Muslim women in Yogyakarta showed that religion played a role in their sexual practices. For example, the religious beliefs that sexually serving a husband in marriage is a sign of worship in the wife, and refusing to do so is a sin which makes the angels angry, and a husband is the one who can bring a wife to heaven, seemed to shape the women's concepts about sex, and their sexual relations and practices with their husbands, which contributed to HIV transmission:

> *"In sexual matters, if he (her late husband) wanted (to have sex) then I had to serve him. I could not refuse because it is a wife's duty to serve her husband. In Islam, if I refuse (to serve her husband sexually) then it is a sin for me …. Refusing to have sex with your husband makes the angels angry. …. I obey my husband and it is written that serving your husband (including sexually) is a worship" (FP2, Muslim woman, widowed, Yogyakarta).*
>
> *"The religious thought in Islam is that a woman (wife) who serves her husband sexually is doing worship. …. In my religion (Islam), if a husband wants to have sex (with his wife), then that is the same as a wife that worships together with her husband. …. I try to practice this in my life as a wife because I believe in my religion that my husband is the door for me to heaven. He is the one who can bring me to heaven" (FP14, Muslim woman, remarried, Yogyakarta).*

Such religious beliefs seemed similar to the Javanese cultural concept about an 'ideal wife', which was reported to play an important role in spousal relationships within the family of the women participants in Yogyakarta. Half of the women interviewed in this setting described that in Javanese culture an 'ideal wife' is one who has certain characteristics, such as serving, obeying and listening to her husband. These women revealed that they lived and practised such cultural concepts in their relationships with their husbands as illustrated in a following narrative:

> *"An ideal wife (in the Javanese culture) is the one who serves her husband, submits to her husband, listens to her husband, does whatever her husband says, is not against her husband, and takes care of household chores, and her children and husband. I live these cultural values in my life as a wife" (FP15, married, Yogyakarta).*

These cultural concepts also include the notion that the man is the head of the family, and part of a woman's duty and loyalty is to sexually serve her husband. This enforced sexual submission of women, which is a known risk factor for HIV:

> *"In the Javanese culture, the position of the husband is higher (than the wife). …. A husband has the authority and makes decisions in everything. In the matters of sex, I must always be ready, if he wants then I must serve him. My experience is like that, if my husband wants sex then I am always ready to submit to my husband" (FP13, married, Yogyakarta).*
>
> *"I am aware that my husband is the head of the family, and in the Javanese culture a wife must serve her husband sexually. A wife who is devoted to her husband is a wife who serves her husband (including sexually)" (FP1, remarried, Yogyakarta).*

However, the Muslim women explained that they could refuse to sexually serve a husband under several conditions. For example, being sick or menstruating were considered to be valid reasons, as sex is prohibited by Islam under these conditions:

> *"In Islam, a wife must serve if her husband wants to have sex, …. (She) cannot refuse with made up reasons, unless she is on her period or sick" (FP15, Muslim woman, married, Yogyakarta).*

Some of the Muslim women reported that whilst they mostly followed their religion in terms of their sexual practices and beliefs, they did take into consideration their own physical and emotional needs, and built good communications with their husbands:

> *"In Hadith there is a religious thought that serving your husband (sexually) is a worship and refusing to have sex with your husband is a sin. But it depends, if my physical condition is fit and I am not tired, then I want to serve, but if I am not feeling well or not in the mood to have sex, then I will say no. My husband understands, he knows if I am tired, he does not force me (to have sex). We have built good communications in regards to our sexual need, and understand each other" (FP1, Muslim woman, remarried, Yogyakarta).*

5.2.6.2 Belu

Cultural practices in Belu were also indicated as having an important role in the marriages of the participants. The cultural practice of bride wealth paid by groom and his family to the bride's family in some tribes in Belu, for instance, was described by nearly half of the women as having an influence on the way they interacted sexually with their spouse. This cultural practice seemed to place them in the position where they felt obliged to serve their husbands, who had paid the bride wealth. The women felt they had no choice but to indulge the sexual demands of their husbands, as illustrated in the following narrative of a woman whose family received the bride wealth from her late husband:

> *"There is bride wealth (in her tribe). …. My father was a royal descendant, so the bride wealth was expensive. As a wife I was not against my (late) husband, I obeyed him. If I did not obey what he said, then he would ask: 'Why? Haven't I paid your bride wealth?' …. So, what happened was that I fulfilled everything he wanted, especially his sexual demands. It was difficult to resist him because he has already paid the bride wealth. He could beat me up. I could not go back to my family (parents) because he has already paid the bride wealth. I was sure that my family would send me back. If I do not go back (to her husband) and live with my parents, then my husband can sue them (her parents) to return the bride wealth" (FP22, widowed, Belu).*

Furthermore, in Belu, the cultural norms and practices that regard spousal disputes as an embarrassment to themselves and the families of both sides, and that promote sanctions towards such disputes, were revealed as also influencing the sexual behaviour and relations of the women with their husbands. Several women expressed an inability to say “no” to sexual advances, and felt they had no choice, but to oblige their husbands’ sexual demands in order to avoid verbal and physical disputes which could be embarrassing if known to other family members or neighbours and lead to cultural sanctions. The cultural sanctions require them to provide sacrificial animals and a dozen bottles of alcohol, which are used to serve traditional male leaders within a tribe, who then gather to teach and provide cultural advice to the couples in disputes. Avoidance of these disputes, feelings of embarrassment and shame, and the risk of cultural sanctions were reported to prevent the women from questioning their husband’s risky sexual behaviour with other women, including FSWs:

> *“I do not like (spousal) dispute. It is embarrassing if the neighbours hear about it. It is an embarrassment not only for us (the woman and her husband) but more for our parents, uncles and extended families…. If we (the woman and her husband) have a dispute verbally or physically and they (the neighbours) know about it, we could get cultural sanction. We have got cultural sanction once: a pig and dozens of bottles of alcohol. So, I try not to get involved in spousal dispute. Thus, sometimes if he (her husband) wants (to have sex) then I have to serve him even though I do not want to or I am suspicious that he has had sex with other women (FSWs). It is because I do not want to fight and get cultural sanction. That is our culture, spousal dispute within family which is known to other people is an embarrassment, especially for our parents and uncles because it can be regarded as an indication that they have not taught us well enough. And it is even more embarrassing for us who have already got the sanction if we get it for the second time” (FP18, married, Yogyakarta).*

> *“I was suspicious that he (he ex-husband) had sex with other women. …. So, if he asked to have sex then I was so mad because I knew that he had sex with other women but sometimes I still had to serve him to avoid dispute. …. ‘Kemak’ culture is like that, spousal dispute which is known to neighbours is an embarrassment. Our family will become a subject of conversation and gossip for neighbours or other community*

> *members. It is an embarrassment for our parents and uncles, and can cause cultural sanctions to us (the woman and her husband)" (FP20, divorced, Belu).*

The purpose of marriage in culture in Belu is to produce offspring. This was clearly a source of influence in relation to condom use and unprotected sex among the women. Several women explained that even though they were aware of their husband's risky sexual behaviour with other people (before and/or during the marriage), they never thought of condom use due to this cultural perception and the family expectation for them to have children. The following story of a woman who acknowledge to acquire HIV from her late husband illustrate these assertions:

> *"My (late) husband and I wanted to have children so (we) did not think of using condoms. In our culture here, getting married is to have children, and our family, especially parents, wanted to have grandchildren. So, it was never in my mind to use condom even though I was aware that my husband had risky sexual behaviour" (FP9, widowed, Belu).*

In addition, several women interviewed in Belu perceived that condom use was not a practice that existed in their culture, or that was passed down by their ancestors. Such perception seemed to also influence their condom use practices:

> *"Never used condoms. It is not a common thing. I never heard of any parents talking about this thing (condom use). I just heard about condom from the nurses, but it is a strange thing in family life (spousal relations). It is not something passed down by our parents or grandparents" (FP10, married, Belu).*

5.3 The impact of HIV on women and their families

After looking at the range of risk factors for HIV transmission among women, as presented in previous sections (section 5.2), this section presents the views and experiences of women about various impacts of HIV on themselves and their families following an HIV diagnosis. This section comprises stigma and discrimination, psychological impacts, family disputes or separation, being left by a boyfriend or fiancée, economic impacts and physical impacts.

5.3.1 Stigma and discrimination

5.3.1.1 Internal stigma

Perceived and anticipated stigma

Perceived and anticipated stigma associated with HIV infection were negative challenges facing the women interviewed across the study settings. Perceived stigma refers to the awareness of the existence of stigma and discrimination, or negative attitudes and behaviours of HIV negative people toward PLHIV. Anticipated stigma refers to the belief about the possibility of experiencing stigma and discrimination in the future due to an HIV-positive status. Although these concepts are considered conceptually distinct, it was difficult to differentiate between them in this study as the stories of participants about these aspects were interconnected (see Section 3.5 for a discussion of the stigma concepts). Perceived and anticipated stigma were experienced by the participants due to their beliefs about the existence of HIV stigma and discrimination, and the possibility of negative attitudes and behaviours against them if their HIV status was known to other people. Most participants described how HIV stigma and discrimination towards PLHIV often occurred, and so there was a possibility that they could be stigmatised and discriminated against if their HIV status was known to other people:

> *"I know that negative attitudes and behaviours towards PLWHA (people living with HIV/AIDS. In Bahasa it is called ODHA (Orang Dengan HIV/AIDS), an acronym used by the participants and common in Indonesia) still exist and often happen. So, I am very careful about my (HIV) status, I do not want people in my community to know about it because they might stigmatise and discriminate against me" (FP12, married, Yogyakarta).*

> *“Stigma and discrimination can happen to any person like me (HIV-positive). I have heard several times that some PLWHA were treated negatively by others (HIV-negative people). This can also happen to me if people find out about my status. So, I do not talk about it (HIV status) to other people” (FP7, remarried, Belu).*

The women’s beliefs about the existence of HIV stigma and discrimination, and the possibility of being stigmatised, discriminated against, avoided, rejected or ostracised by other people due to their HIV-positive status, seemed to be corroborated by discriminatory and stigmatising attitudes and behaviours previously experienced by other PLHIV:

> *“People who contracted HIV are considered the worst. Sometimes, their eating utensils and personal belongings are separated. …. I often hear such discriminations against people living with HIV, they are real and may also happen to me” (FP4, single, Yogyakarta)*
>
> *“(I) once saw with my eyes people did not want to eat at the house of someone who is infected with HIV. It was here in Atambua. …. At that time, he was not dead yet, but nobody wanted to take care of him because he was sick of this (HIV). I am scared, if people know that I have HIV then they could avoid me” (FP25, widowed, Belu).*

Negative perceptions and labels the women had about other PLHIV prior to their HIV diagnosis were reported to also reinforce perceived or anticipated stigma among them. Several women interviewed in Belu acknowledged that they had stigmatising attitudes towards other PLHIV before they were diagnosed with the infection, which made them assume that other people would have the same negative attitudes towards them if their HIV status was known to others:

> *“When I was still healthy (before her HIV diagnosis) I thought that people who got HIV would die soon. I had negative thoughts about them: I thought they had immoral behaviour, had multiple sex partners. Sometimes, if I saw PLWHA who were single women then I thought they might be ‘naughty’ (FSWs). Once I was diagnosed with this HIV, I think people will think the same about me” (FP17, married, Belu).*
>
> *“I feared PLWHA, if someone died from it (AIDS), then I would not visit that person, even though other people ask me to visit together. I would say ‘you can go, I cannot’. Others once said to me ‘it is fine, if someone died then that thing (the virus) is already*

> *gone but I still did not want to go. That is why I think if people know that I am infected then they will not want to be close to me, they will avoid me" (FP19, married, Belu).*

Self-stigma

Self-stigma associated with HIV was also experienced by both married and non-married women interviewed in both study settings. It was reflected in how these women reacted to the negative perceptions or labels other people had about PLHIV. Women's endorsement of negative perceptions and labels given to PLHIV and the application of those perceptions and labels to themselves, such as 'I am dirty, disgusting', 'I am a damned person', 'I am a bad person' were instances of the self-stigma identified among several women interviewed in Yogyakarta and Belu:

> *"People consider PLWHA as dirty, disgusting and naughty women. It hurts a lot to be considered as a dirty or disgusting person. Even though nobody knows about my (HIV) status, but this sometimes makes me feel: 'Yes, I am dirty, disgusting for many people' …." (FP11, widowed, Yogyakarta).*
>
> *"I once talked to my grandmother about HIV, she said: 'That is their (PLWHA) own mistakes, they must be dirty, like to 'jajan' outside ('Jajan' is a term used to refer to a person who likes to have sex with different sex partners. It applies to women who engage in free sex or sex work or men who have sex with FSWs. It literally means eating snack). She said that. It is very pity to be an HIV-positive person. I feel about my own body: 'I am dirty'. If she knows (about her HIV status), I could be chased away from home" (FP22, divorced, Yogyakarta).*
>
> *"As far as I know, people here (in Belu) still think negatively about PLWHA, it is difficult for them to accept (PLWHA). Sometimes if I remember other people's negative perceptions about PLWHA, I feel like I am a very bad person in their eyes due to my HIV-positive status. It is so sad" (FP12, widowed, Belu).*

Hiding HIV status and self-isolation

Perceived, anticipated and self-stigma experienced by the women were reported to lead to the decision to hide their HIV status from others. Most married and non-married women interviewed across the study settings commented that they hid their status from family members, neighbours and friends due to the fear of the possibility of being stigmatised and discriminated against by others due to their HIV status:

> *"I hide my (HIV) status because people have negative views about PLWHA. I feel scared if my family know and they can ostracise me, where I will stay" (FP23, single, Yogyakarta).*
>
> *"Only my husband (who is also HIV-positive) and I who know about my status. Other family members do not know. …. My children do not know either. …. Neighbours do not know. My husband and I have decided to hide it so that nobody knows about it. This is to avoid the possibility of negative impact because many people do not know about HIV and everybody has different perceptions about it. Some people avoid (PLHIV), others say that people get HIV due to being naughty (having multiple sex partners), engaging in free sex" (FP14, married, Belu).*

Non-disclosure of their HIV status was also considered by the women as a way to avoid courtesy stigma or stigma by association towards their family members. Fears about the possibility of family members being avoided, children being discriminated against or rejected at school, and embarrassment for the family, were some of the concerns raised by several women interviewed in Yogyakarta, and which also supported their non-disclosure of their HIV status to other people:

> *"They (members of the community where she lives) do not know about HIV, if they suddenly know about my HIV status, then they will discriminate me. Not only me who will be discriminated against but also my parents, siblings and my child. So, I decided not to disclose it to other people within the community where I live" (FP12, married, Yogyakarta).*
>
> *"I am afraid of disclosing my (HIV) status because my child is at the elementary school. I am afraid my child will be discriminated against at school. …. I once read on a newspaper and also heard that children who are HIV-positive were kicked out from school. I am afraid if people know about my (HIV-positive) status then my child will be kicked out from school. Thus, I do not want anybody to know (about her HIV status)" (FP17, divorced, Yogyakarta).*

Perceived, anticipated and self-stigma experienced by the women was also reported to lead to the self-isolation of a few them interviewed in Belu. Avoiding other people and sitting alone were some instances of the self-isolation experienced by these women due to the fear of their HIV status being known to other people, and of discrimination. The following narratives of two women who have been living with HIV for a year and six years respectively prior to this interview, reflect such experiences:

> *"I try to avoid other people, do not gather with the surrounding neighbours because I am afraid, they can know (about her HIV status) if I continue mingling with them. If they sit together, I do not join them, but sit alone" (FP7, remarried, Belu).*
>
> *"After the death of my husband (died from AIDS) if I went to buy fish (at the beach and again re-sell it in the city market) and saw the others sitting together I often thought that they must be talking about me saying that I am having this disease (HIV infection). So, while waiting for the fish I always sat alone. I avoided and did not want to talk to them" (FP4, widowed, Belu).*

5.3.1.2 External or enacted stigma

Stigma and discrimination within the family

HIV stigma and discrimination were reported to occur within the families of the participants. Several married and non-married women (n=9) interviewed across the study settings reported having experienced discriminatory and stigmatising attitudes and behaviours within their families at a certain point of time following their HIV diagnosis. The separation of personal belongings, such as clothes and eating utensils, from those of other family members, being labelled as FSWs, and being asked to stay away or live in other places, were some examples of the discriminatory and stigmatising attitudes and behaviours of close family members against these women:

> *"My parents asked me 'what kind of medicine are you taking every day and at the same time?' And then I told my mom that it is HIV medicine. …. She was shocked and kept silent for a few hours, and then said to me 'you are comfortable living in Yogyakarta and with your job over there, it is better you do not come back to Semarang. In our family there is no one like you, …., no one who has the same disease*

> *(HIV infection). …. It is better if you stay in there and do not come back here. I never go back home up to now" (FP4, single, Yogyakarta).*
>
> *"At that time (early HIV diagnosis) they (her family) were scared of me and did not want to eat together. My plates, spoons and clothes were separated. I was asked to sleep in a separated room" (FP22, widowed, Belu).*

The participants also commented that they experienced stigma and discrimination from their extended family members. Keeping distance, avoidance, neglect and rejection were some instances of discriminatory and stigmatising attitudes and behaviours by extended family members towards some women (n= 5) interviewed across the study settings, as illustrated in the following stories:

> *"My niece also keeps distance, …. She used to come into my house but after I get HIV, she is not allowed by her husband to come into my house. …. They do not want to enter my house or eat any foods I give them" (FP8, remarried, Yogyakarta).*
>
> *"There is a relative of mine who avoids me after I was diagnosed with HIV. …. My younger cousin. She even told my other relatives saying 'do not get close to her because she is infected with HIV" (FP11, single, Belu).*

Stigma and discrimination against WLHIV also came from their in-laws or the family of their husbands. Being asked to leave the house or separated from their children, and the separation of the women's eating utensils from those of others were some instances of the discriminatory attitudes and behaviours of in-laws against some married female participants (n=6) within their husband's family:

> *"My sister-in-law seemed so scared of this disease (HIV infection). She asked us (the women and her daughter) to go back to my parents (after her HIV diagnosis and the death of her husband)" (FP2, widowed, Yogyakarta).*
>
> *"I was separated from my child (by her sister-in-law). My child slept with her aunty. My eating utensils were given a sign. The relatives of my husband also said to my sisters-in-law: 'the spoon she used should be separated, you can be infected'. They were nice in front me but felt disgusted about me at the back. They asked my sisters-*

> *in-law to chase me and my husband (her husband was HIV-negative) away from the house" (FP5, married, Yogyakarta).*
>
> *"They (the family of her husband) felt disgusted to enter our room, did not want to drink and eat in our house. I did feel these (discriminatory behaviours) once my husband condition was getting worse and once he died. The treatment of the entire family of my husband was very unpleasant" (FP4, widowed, Belu).*

Fear of contracting HIV was reported by the participants as the main factor that resulted in unfair treatment or discrimination by family members toward them. Such fear was reported to be supported by the lack of knowledge of family members about HIV, or the means of HIV transmission, as well as the influence among family members about the perils of HIV:

> *"We (the woman and her husband who was also HIV-positive and had died from AIDS) were avoided nearly all the family members of my husband except my parents-in-law (they lived together with her parents-in-law in one house) because they were scared of getting HIV, they did not know how it transmits. They thought they would get it if they have physical contact with us. A relative of my husband was the one who spread this misleading information to all the family members my husband, she told all of them this wrong knowledge, hence they were influenced by this" (FP4, widowed, Belu).*
>
> *"My food was given to me (by her mom) through the bottom of the door, just like you would do for a dog. It was very painful and if I remember this, I sometimes still feel the pain. But she is my mom, she knew very little about HIV. Other people in the community (where the woman and her mom lived) have the same understanding. …. What she knows about HIV is just based information she has heard from neighbours and other people around us in the community. The information and perceptions from others influenced her reaction towards me once I told her I have HIV (FP24, divorced, Yogyakarta).*

Stigma and discrimination within communities

HIV stigma and discrimination towards WLHIV who participated in this study were reported to occur within communities where they lived and interacted. Refusal of direct physical contact, such as shaking hands and eating food they had touched, exclusion from community activities, gossip about their HIV status, and accusations about wearing veil to cover up their HIV status or disgrace, were some instances of discriminatory and stigmatising attitudes and behaviours of neighbours against some of these women (n=15) within their communities in both study settings due to their HIV-positive status:

> *"I got discrimination in the community where I lived before. If I have touched any foods, then people would not eat those foods. Some (community members) spread information that I am HIV-positive. I experienced this for about two years. Some avoided me, did not even want to shake hands with me" (FP17, divorced, Yogyakarta).*
>
> *"I heard some said that I am wearing the veil just to cover up this disease (HIV), this disgrace" (FP10, remarried, Yogyakarta).*
>
> *"The neighbours talk about me at the back, they said 'she gets this disease (HIV infection)'. So, my HIV status becomes a topic of discussion among the neighbours. They search for information about my (health) condition. The information they get about my condition (being infected with HIV) is discussed with other neighbours" (FP21, widowed, Belu)*

The women interviewed across the study settings commented that social perceptions which associated HIV infection with immoral behaviours (e.g., sex with multiple sex partners or engagement in non-marital sexual relations) or engagement in sex work, were amongst other factors that supported stigma and discrimination by community members towards PLHIV in general. The following quotes from two women who were diagnosed with HIV 12 and 6 years ago, respectively, reflect such social perceptions:

> *"Social perceptions about HIV are very negative, a disease (infection) of people with negative behaviours, such as women who sell sex (FSWs), have multiple sex partners or non-marital sex. …. They perceive HIV as a disgrace for family. Such perceptions influence how other people look at or react towards people who are diagnosed with HIV…. To be honest, I feel uncomfortable with these perceptions (FP12, married, Yogyakarta).*
>
> *"I keep it (her HIV status) secret so that other people do not know because I am ashamed and afraid that people do not want to mingle with me, feel disgusted about me. …. People might think that my first husband left me because I am naughty (a naughty woman means a FSW) and have had sex multiple sex partners or different men outside of my marriage, and now I get HIV. That is what people think about HIV. They associate it with bad or immoral behaviours. Such perception is common, and it*

> *makes people think that all people who are diagnosed with HIV have immoral behaviours" (FP7, remarried, Belu).*

Javanese cultural practices about husband-wife relationships were reported to be firmly held by family and community members within the communities in Yogyakarta where some women lived, and were also indicated as supporting factors for stigma and discrimination towards them. For example, cultural practices that a wife should submit, be loyal to her husband and do everything her husband says and wants, were reported to influence the way their family members regarded them and their HIV status:

> *"Both my HIV status and the fact that I am divorced became a subject of gossip for my neighbours and other community members, and made disdained me. In our (Javanese) culture, a wife is expected to be loyal, submit to her husband, listen and do what her husband says. That is why I heard some said that we were divorced because I was not a good wife, my husband left me because I did not listen or submit to him. That fact that I am infected with HIV reinforced their perception that I am not a good wife because I might have slept (have sex) with other men" (FP17, divorced, Yogyakarta).*

> "*In Javanese culture a wife should totally submit and be loyal to her husband. Now I have HIV, but my husband does not have it. That means I am not a good wife and have done wrong things. I am a naughty woman in their eyes (her sisters-in-law). HIV is considered a disease (infection) that someone gets due to bad behaviour (having sex with multiple sex partners or engaging in free sex or sex work). That is why they hated me very much" (FP5, married, Yogyakarta).*

Religious beliefs about sex and HIV were also reported by the participants in Yogyakarta as supporting factors for discriminatory and stigmatising attitudes and behaviours towards PLHIV in general by people or community members. For example, religious beliefs in Islam that non-marital sex and sex with multiple sex partners are a sin, and that HIV infection is a curse as it is acquired through sex and IDU. These were mentioned by some women in Yogyakarta as supporting factors for HIV stigma and discrimination, factors that were not raised by the women interviewed in Belu:

> *"The religious thoughts in Islam do not allow sexual intercourse before marriage. …. I am still thinking of what my grandmother said. She said people contract HIV because they have dirty behaviours and like 'jajan' (to have non-marital sex with multiple or different sex partners). She said this (jajan) is not allowed in Islam and a sin. I think that is the reason why she labels people living with HIV negatively" (FP22, divorced, Yogyakarta).*
>
> *"Many people think that the ones who contract HIV are dirty because it is a disgusting disease (infection). They are drug users and selling sex. HIV is a curse from God to them because their behaviours are not right. That is why many people, including my mom are discriminative towards people like me (her mother was very discriminative to her during the first few months after the HIV diagnosis)" (FP24, divorced, Yogyakarta).*

Stigma and discrimination within healthcare settings

HIV stigma and discrimination towards WLHIV interviewed in both study settings were also reported to occur within healthcare settings where they accessed healthcare services. Negative labelling or cynical questions raised by healthcare professionals, the spread of their HIV status by healthcare professionals, and the delay of services due to their HIV status, were instances of discriminatory and stigmatising attitudes and behaviours of healthcare professionals against both married and non-married women (n=13) who participated in this study:

> *"I underwent medical check-up, the laboratory staff (a healthcare professional) asked me: 'how did you get it (HIV)?' I got it from my (late) husband, I said. 'Is your husband dead?' Yes, I replied. 'Did your husband like 'jajan'?' In their mind, people who contracted HIV must be naughty (FSWS or have sex with multiple sex partners). I got the same questions before: are you 'naughty'? Do you like jajan?' (FP3, remarried, Yogyakarta).*
>
> *"I asked a nurse: 'madam I know that HIV status of patients is kept secretly but why did nurse X told other people that I get HIV? She said: are you serious? Yes, people told me that she told them so" (FP23, single, Yogyakarta).*
>
> *"I have repeatedly experienced rejection, stigma and discrimination at healthcare facilities. Once I went to hospital to treat my teeth. …. Once he (a nurse) saw my status which is B20 (HIV-positive), he put down my health record and whispered to his friend*

> *(another nurse). His friend came to me, stood a bit far from me, wore mask and said 'madam, were you a female migrant worker?' I said no, I was not. 'Where did you 'mangkal' before?' ('Mangkal' literally means to wait. It is a term used to refer to the activity of FSWs waiting for clients at a certain spot). I said I did not 'mangkal'. Then they asked me to wait outside or sat at the corner. …. I saw the other patients who were in the same queue as me had been served, then I asked why I was not served, he (the nurse) said because the doctor has not come yet. …. I said: 'sir, the doctor has been serving these patients, how come you said he has not come?' I came earlier than the other patients, but I was not served. …. I felt very humiliated in that room. Their questions and treatments made me feel very small in that room" (FP3, widowed, Belu).*

Consequently, women felt traumatised about accessing healthcare services, disappointed with healthcare professionals and reluctant to access healthcare services at the same healthcare facilities where they had experienced stigma and discrimination. They also decided to access healthcare services in other healthcare facilities, or only consult certain healthcare professionals who they expected to give good treatment, or to receive non-discriminatory and stigmatising attitudes and behaviours. The following comments of several married and non-married women from both study settings describe their perceptions about these aspects:

> *"I need lots of courage just to come to hospital. I was traumatised with hospitals, and my body gets cold if I see hospitals. I was treated very badly by the doctor in the previous hospital. My child was not provided with the (antiretroviral) medicines due to the reason that there should be a healthy (HIV-negative) family member who accompanied her, otherwise the medicines would not be provided. Once a healthy family member of mine accompanied her (to access the medicines), the doctor said 'wait until her dad is fully recovered'. My husband was sick (HIV-positive and hospitalised). My child who is HIV-positive was not allowed to pup (use the toilet) in the hospital" (FP2, widowed, Yogyakarta).*
>
> *"I access the healthcare services as a general patient (who does not use health insurance) and do not use the National Health Insurance because I do not want to access referral letter (from the community health centre in the community where she lived). If I access the referral letter from community health centre, then people will know about my status because there is a friend of mine who works for that community health centre. I am afraid she will tell other friends, then it (her status) could be spread out. It often happens that healthcare professionals spread the HIV status of patients*

> *to other people. It could be very stressful if my HIV status is known to other people" (FP26, single, Belu).*

5.3.2 The psychological impact of HIV on WLHIV and their families

The participants across the study settings reported as having experienced a range of psychological challenges following their HIV diagnosis. The psychological challenges facing the participants were due to their HIV positive status, mother-to-child transmission, fear of death and concern for the future of their children, shame for their family, feeling guilty towards their parents, self-blaming and blaming their husband, fear of being rejected or left by their boyfriend, and thinking of suicide. An HIV diagnosis among the participants also had a psychological impact on their families.

5.3.2.1 An HIV-positive status

An HIV diagnosis was reported to cause negative psychological challenges on the majority of both married and non-married women interviewed across the study settings. The psychological challenges were experienced by these women at a certain point following their HIV diagnosis, and reflected in a range of negative feelings or emotions, such as feelings stressed, shocked, broken down and desperate. The following quotes illustrate the feelings or emotions experienced by these women after their HIV diagnosis:

> *"At that time (once she was diagnosed with HIV) I was shocked and very much stressed out. …. I cried every day because I was stressed out thinking of this (HIV). I felt like my future was blurred already. I felt broken. If I remember that moment I still cry" (FP9, married, Yogyakarta).*

> *"The first time I was diagnosed with HIV, I was broken and desperate. I felt like the world was dark. …. I was very much depressed, and it took long time to recover. I was still desperate after starting the medication (ART)" (FP21, widowed, Yogyakarta).*

> *"When I was told (about her HIV positive status) I was shocked and cried. I could not sleep and kept crying for about two to three months. I was stressed out, sometimes I could not eat" (FP7, remarried, Belu).*

Women's limited knowledge of HIV was indicated as contributing to such negative feelings or emotions facing them following diagnosis. For example, the perception that HIV is a dreadful, horrific and deadly infection, and that they would die soon due to contracting the infection, reflected their limited knowledge on HIV, which led to those negative feelings or emotions:

> *"The first time I was informed that I contracted HIV I felt broken, did not believe it. At the time I had very limited knowledge on HIV. I thought I did not have future anymore and would die soon. That was in my mind. I thought I did not have hope for the future. I was very much depressed at that time because I did not know much about HIV" (FP22, divorced, Yogyakarta).*
>
> *"Once I was told (about her HIV status) I felt broken. If the earth was separated into two pieces, then I would like to jump into the hole and disappear. My body felt weak, I could not walk. I thought I would die soon. I was really stressed out. It was because I did not understand anything at all about this HIV, what was in mind was I am done, I am going to die soon" (FP1, remarried, Belu).*

Questions from neighbours about a woman's health condition and plans to get married were also indicated as contributors for those negative psychological challenges facing them. A few women interviewed in Yogyakarta commented that they felt uncomfortable, worried, burdened and stressed out when receiving those questions from their neighbours:

> *"Sometimes I feel very uncomfortable and depressed because my neighbours keep on asking about what I am sick of. It is not possible for me to tell them the truth because I am afraid of what they may think about me. Every time I think about my condition I just cry. I feel burdened with this (HIV status) because I feel like I am not free, always worried" (FP18, married, Yogyakarta).*
>
> *"I am not married yet, this makes me feel stressed out until now because it is always a matter of question of people around me, my neighbours. If I am open to them about who I am (HIV status), they may have different thoughts about me and think that I am not a good woman because I have had sex before marriage. I feel stressed and awry" (FP19, single, Yogyakarta).*

5.3.2.2 Fear of HIV transmission to children

The negative psychological challenges facing the participants was also induced by the fear of mother-to-child transmission, as they were aware of the possibility that such a mode of transmission could have happened during the delivery process or breastfeeding period. Such fears were reported by women across the study settings, and who were diagnosed with HIV during the pregnancy period (n=9) or after several years of giving birth (n=17). These were acknowledged to cause stress and worry prior to the HIV test for their child, as illustrated in the following comments:

> *"To be honest, I was confused and scared of whether my baby was also infected or not. This fear started once I met several women who were also HIV-positive at the clinic. Their children were also HIV-positive. I asked them: 'did you give birth normally?' 'Normal and breastfeeding', they said. I was frightened because I gave birth normally and breastfed my child. I was so worried for several years before the (HIV) test, but luckily my child is HIV-negative" (FP3, remarried, Yogyakarta).*
>
> *"Sometimes I cry because I have been thinking of my children: one is still little and another one is still in my womb (7 months). What would happen if they get (HIV)? Hope I bear this burden myself" (FP10, remarried, Belu).*

Several other women interviewed in both study settings (n=14) reported having transmitted the virus to their child or baby. This made them feel regretful, broken and guilty for their child leading to very much stress, worry and sadness. The following stories represented the feelings of the women whose children were HIV positive:

> *"I am very sad. I often cry in the night once looking at my second child. I can only say 'forgive mom, because of mom you get HIV'. I feel very much guilty to my child. My child carries the impact of my fault. I am so worried about my child" (FP23, single, Yogyakarta).*
>
> *"It was really heavy at that time (beginning of her HIV diagnosis). I was very much stressed out. Once I knew about my (HIV) status it felt like the world was broken down, but I could accept it. What I could not accept was that my second child was also positive*

> *(her second child passed away). That was the hardest hit for me which made me broken. The sadness in my heart does not completely go away" (FP3, widowed, Belu).*

5.3.2.3 Fear of death and concern for the future of the children

Fear of death was another negative psychological challenge facing the women interviewed in this study. Such fear, as described by the women, was triggered by the death of a boyfriend and friends, or other people with HIV, and seeing the weak or poor physical conditions of other PLHIV:

> *"When I was told by the doctor that I am HIV-positive, I was so scared. What was in my mind was that I would die very soon …. I once went to X hospital and met others (PLHIV) with very weak physical condition, I was so shocked. For two year I was broken, depressed and scared because I thought my condition would be like their condition" (FP16, divorced, Yogyakarta).*
>
> *"The thing that makes me scared and stressed out is that there have been many people died from this (HIV/AIDS). So, I think that maybe it is my time to die. Fear of death is number one for me. I do not want to die. I feel so scared if I think of this" (FP7, married, Belu).*

The women in both study settings also described that they felt sad, pressured and worried about the future for their children. Such feelings were experienced by the participants due to the awareness of their own health condition, and the possibility of being ill or physically weak or passing away at any time. The stories of several women below portrayed how their condition of living with HIV influenced their feelings and thoughts, and increased their worries about the future for their children:

> *"I still feel worried about the future of my children until now because I could fall sick any time and my children still need me, especially the youngest one. He is still at high school, and I do not know how long I can hold on" (FP17, divorced, Yogyakarta).*
>
> *"Knowing that I am infected with HIV stresses me out. I am worried about my children because they are still kids. If I am not with them anymore (die), who will look after them? This makes me very much worried and sad" (FP14, married, Belu).*

5.3.2.4 Shame for family

The women across the study settings also described that an HIV diagnosis was shameful for their family due to the negative conversations about HIV in their communities and the common perception that associated HIV with sex work. Thinking of the possibility of shame for family members due to their HIV diagnosis was indicated as a supporting reason for a range of negative feelings facing them, as explained in the following quotes:

> *"I feel stressed and scared up to now. If people know about my (HIV) status, then it can be shameful for family. …. I am sure my parents will not accept it (her HIV status) because it is shameful for family" (FP12, widowed, Belu).*
>
> *"Having HIV is shameful for family if other people know about it because of the negative perceptions related to how HIV spreads, such as through free sex or sex work. I am sometimes stressed out thinking about what might happen if other people know (about her HIV status)" (FP14, married, Belu).*
>
> *"This (HIV status) can make them (her family) feel ashamed if other people know because people must think that I have got it from sex while I am not married. Thinking of this makes me stressed out and depressed" (FP19, single, Yogyakarta).*

The participants' perception that their HIV status would be shameful for their families seemed to be influenced by the negative reactions and perceptions of their own family members about HIV and PLHIV. For example, several participants described how their family members perceived HIV as a shameful infection for the family, and were cynical towards PLHIV as they associated HIV with negative sexual behaviours (e.g., engagement in sex with multiple sex partners or sex work):

> *"I think it (her HIV status) will be shameful for them (her parents) because once my sister was diagnosed with HIV (her sister died from AIDS), it was obvious that my mom could not to accept the fact that her daughter was infected. She kept on blaming my brother in-law and asked us (family members) to keep it secret because she said it is shameful for our family. That is why I hardly go back home because I feel scared of my*

> *parents or other people finding out about my status. If they know about mu status then it will be very complicated and stressful for me …." (FP26, single, Yogyakarta).*
>
> *"It will be embarrassing for my family if my HIV status spreads among people within our community. I remember my mom and sister once talked about a woman who is HIV-positive. My mom said the woman's HIV status must be shameful for her parents because people know that the woman must have engaged in free sex. She was very cynical once talking about the HIV status of the women. I am sure my HIV status will make them (family members) feel embarrassed. This makes me worried and sometimes scared if someone finds out (about her HIV status) and spreads it…." (FP26, single, Belu).*

5.3.2.5 Feeling guilty towards parents, self-blaming and blaming the husband

Feeling guilty towards parents was another psychological impact of HIV experienced by women interviewed in Yogyakarta. Several women described how they felt guilty towards their parents due to their HIV diagnosis and being a burden on their parents. Such feelings were supported by their perception that they should have been the ones taking care of both their parents and children and not vice versa, as described in the following quotes:

> *"I feel guilty towards my mom and dad. …. I would like to take care of them, but what happens is like this (her parents look after her and her children). I am sad and feel guilty not because I am sick, but because I am a burden to them" (FP2, widowed, Yogyakarta).*
>
> *"I kept silent (after her HIV diagnosis). I did not talk to my dad and mom because I have hurt their feelings once I was pregnant outside of marriage. Now I am diagnosed with HIV, how it feels to them. I hurt them again, but they have to take care of me because of this infection" (FP16, divorced, Yogyakarta).*

Most women interviewed in Yogyakarta also blamed themselves for what they had done in the past, which they acknowledged as a supporting factor for HIV transmission amongst them. The neglect of their parents' advice, and engagement in non-marital sex and sex without condoms through which they had contracted HIV, were some instances of the things they had done, and the supporting reasons for self-blaming among both married and non-married women:

> *"I blame myself because I did not obey the advice of my parents. My mom said 'you can mingle with anybody but you should know the limit, you need to filter whether they are good people or not'. When I was in senior high school, I got acquainted with drug users and engaged in free sex. …. I feel sad now, if I listened to my parents' advices, then perhaps I am a better person now" (FP12, married, Yogyakarta).*
>
> *"Why I wanted to have sex without condoms, if I used condoms, perhaps I would not have contracted HIV, I am very much regretful" (FP23, single, Yogyakarta).*

Several participants in Belu described how they blamed and got mad at their husbands for transmitting the virus to them. The belief that their husband may have got the infection from other women, and feeling disappointed and sad about the sexual behaviour of their husband, were the supporting reasons for the blaming and anger they women had towards their husband. The following narrative of a 40-year-old woman, who was diagnosed with HIV a few months prior to this interview and acknowledged to get it from her husband, illustrates such feelings:

> *"I am mad at my husband because I got it (HIV) from him. …. I do blame him because I know I get (HIV) from him. I never slept (had sex) with other men. If I get from him then that means he got it from other women. Therefore, I am disappointed with him and do blame him" (FP18, married, Belu).*

5.3.2.6 Fear of being rejected or left by boyfriend

The concern about future relationships, and fear of being rejected or left by their boyfriend due to their HIV positive status, were other psychological challenges facing non-married women in both study settings. Such concerns and fears were described as rendering further negative psychological effects, such as desperation, sadness, worry and stress, as illustrated in the following statements of these participants:

> *"I am fearful thinking of this: if I have a relationship with a guy and get married and then he knows that I am HIV-positive. What would happen next? Would he accept me or not? This makes me worried. It is stressful to be in a situation like this" (FP24, divorced, Yogyakarta).*
>
> *"I am often stressed out because of this condition (having HIV-positive status) and fear whether there would be a man who accepts and wants to have a relationship with me. What I am thinking of is that there would not be a man who wants to marry a woman with HIV like me. This makes me scared of my future" (FP11, single, Belu).*

Such concerns and fears were indicated to be underpinned by the women's previous experiences, or other PLHIV's experiences of being left by someone they loved due to their HIV-positive status. Such experiences seemed to make them confused and reluctant to start a new relationship due to the fear of ending up having the same experiences:

> *"There was a guy who was close to me (in relationship with her). We were serious in the relationship but once he knew about my (HIV) status he avoided me step by step and finally we lost contact. Because of this experience, I am scared and worried of having a relationship with any other men. I am often confused, on the one hand I am scared of having a new relationship with a guy because of the fear of being left, but on the other hand, I think: should I live like this (not having a relationship with a man) for the rest of my life?" (FP19, single, Yogyakarta).*
>
> *"There are families who do not accept (PLHIV). …. Sometimes the husband has HIV and the wife's family does not accept or the wife has HIV and the family of the husband does not accept. This makes me worried. Would I be accepted if I get married?" (FP5, widowed, Belu).*

5.3.2.7 Thinking of suicide

Thinking of suicide was another psychological impact experienced by several married and non-married women across the study settings after their HIV diagnosis. Such thoughts were triggered by a range of psychological challenges facing them following their HIV diagnosis, such as stress, desperation, hopelessness, and feeling broken and burdensome due to rejection. The stories of the women below portray that at a certain point in their life after the diagnosis they thought of attempting suicide due to their HIV status:

> *"It felt very much burdensome being rejected by my mom. I felt like I did not want to live anymore, I just wanted to finish my life" (FP24, divorced, Yogyakarta).*
>
> *"When I was told (by her ex-boyfriend) that I must have contracted HIV I felt broken, stressed out. I felt like I could not breath anymore. I told him 'you destroy my life'. I was broken and wanted to commit suicide. …. I took a lot of medicines (pills), I bought many types of medicine and took them at once" (FP25, single, Yogyakarta).*
>
> *"After my son passed away (died from AIDS) and I was tested positive with HIV (her son was first diagnosed with HIV once he was critically ill), I locked up myself in my room for a while and during the time I sometimes thought of ending my life because the burden I felt was so heavy" (FP12, widowed, Belu).*

Some participants described that not knowing what to do, or having a lack of solutions that needed to be undertaken following their HIV diagnosis, made them feel trapped in their own negative thoughts and considered ending their life. Similarly, having no one to talk to and thinking about any possible consequences that could happen to them due to the infection, were also reported as triggering their thoughts of suicide:

> *"During the early period of the diagnosis, I did not know what to do. Many thoughts came to my mind and I felt like I was trapped in my own thoughts. Sometimes all negative thoughts of any possible consequences that could happen to me next made me think that it is better to end my life" (FP26, single, Yogyakarta).*
>
> *"The thought about ending my life came across my mind every time I thought about a range of consequences to face later in life due to this infection. I felt overwhelmed with all those thoughts. It was very difficult moments, sometimes I held the knife (to commit suicide) but then threw it away because I felt scared of doing that (suicide)" (FP5, married, Yogyakarta).*
>
> *"I was struggling alone after I was diagnosed with HIV. I had nobody who I really trusted to talk to. I was on my own. I could not tell my family (parents and siblings) or my close friends because I was scared. It felt like I was stuck, and this made me think it is better to die, just die and the problem will be gone. I thought of that (ending her life) but I did not try to do it. Now, I live with my brother, and he fully supports me" (FP26, single, Belu).*

5.3.2.8 The psychological impact of HIV on the women's families

An HIV diagnosis among women not only caused negative psychological impacts on themselves but also on their family members, such as parents and siblings. Several interviewees in both study settings described how their family members also felt sad, shocked, stressed and ashamed of their HIV status:

> *"My parents were very much disturbed psychologically. They were stressed out because of me getting HIV and my child who was also admitted to hospital (her child was also HIV-positive). Every day they came to hospital even though they came a long way from Magelang (a city in Central Java). I thought they were stressed out and did not know where to go, …. I thought they felt the same stress as I did" (FP13, married, Yogyakarta).*
>
> *"My family was stressed out more than I was. …. My older brother cried a lot, perhaps he was afraid that I might die soon. …. My mother was very much stressed out, cried every day, and maybe feel ashamed. For very long time I saw my mother stressed out due to this infection, my HIV status" (FP15, widowed, Belu).*

5.3.3 Family disputes and separation

Being infected with HIV was described as having a negative impact on the women's families or relationships within their families. Family disputes and husband-wife separation or divorce were examples of the of impact HIV on their families, and which occurred due to the women's HIV diagnosis or status. Several women in both study settings commented that family disputes and husband-wife separation or divorce occurred due to the unacceptance of the women's HIV status by their husbands, and accusations from the extended families against the women or their husbands about who first transmitted the virus:

> *"The family of my husband said (to her family) that I was not a good woman (after her child died from AIDS), my family said (to her husband family) 'your son is not a good man'. They blamed each other. …. After my child passed away, my husband's parents separated him from me, it was so stressful (the woman was tested positive for HIV, but*

> *her husband did not want to test and died from a motorbike accident)" (FP15, widowed, Belu).*
>
> *"My husband and I divorced before he passed away. He died one and a half year after we divorced. He looked healthy and there was not any physical sign that he was sick. …. We did not get along after my HIV diagnosis. He did not accept it (the woman's HIV status) and did not want to test either. It is highly likely that I got (HIV) from him and he knew that I have been infected with HIV, therefore he did not want to get tested. Because we did not get along, so we divorced" (FP21, widowed, Yogyakarta).*

Mother-child separation was another negative impact of HIV facing the families of the women following their HIV diagnosis. Several women interviewed in Yogyakarta described how their children were separated from them by their mothers and in-laws due to the fear of transmitting the infection to their children. Some commented that they gave away their children to be taken care of by their sisters or parents-in-law so that they can take care of their health and due to the fear that they would die soon:

> *"My child was kept away from me (by her mother). She said 'do not get close to your child, you could transmit the virus to your child'. I was not allowed to touch my child for three months" (FP24, divorced, Yogyakarta).*
>
> *"My children are with my parents-in-law. The family of my husband said: 'now you need to focus on medication so that you can be healthy'. So, the needs of my children: school-related needs, food and everything are taken care of by my parents-in-law" (FP20, remarried, Yogyakarta).*
>
> *"I thought I would die soon, so I gave my three children to my sisters. It was because I thought I would be like my friends, I would die in the next few months" (FP17, divorced, Yogyakarta).*

5.3.4 Physical Impact

Having the HIV infection was reported to have a negative physical impact on the participants across the study settings. The majority of the women interviewed acknowledged having experienced poor physical health conditions due to the infection. These were indicated by the loss of weight and being regularly sick prior to the diagnosis:

> *"I was physically getting weak, but I was not sick. I was admitted to hospital, but it was not known what I was sick from. At the end I attended VCT. In the next day I got the result which was HIV-positive. My body weight decreased from 90 kg to 36 kg. My cheeks looked very small, I was so weak physically, could not do anything. I gave up, I thought I would die" (FP10, remarried, Yogyakarta).*
>
> *"I have been very weak physically for a year. I feel like my body is not strong enough, very weak. I am still feeling weak, sometimes I feel pain on my body" (FP21, widowed, Belu).*

The weak physical condition experienced by the women due to their HIV infection was also reported as influencing their ability to work. Several women interviewed in both study settings commented how they have not been working after the HIV diagnosis due to their weak physical condition, as illustrated in the following stories:

> *"My husband works but I do not work because I do not feel strong physically" (FP8, remarried, Yogyakarta).*
>
> *"I stay at home for most of the time. I feel that my body is not strong enough as it was, so I cannot farm anymore" (FP18, married, Belu).*
>
> *"I quitted teaching (because) I do not feel strong enough to stand up to teach" (FP21, widowed, Belu).*

5.4 Women's access to HIV care services

This section presents the views and experiences of WLHIV about their access to HIV care services in Yogyakarta and Belu. The exploration of the participants' views and experiences on this aspect was guided by access to healthcare framework (see section 3.4 for a discussion of the framework). Guided by this framework, this section presents the characteristics or dimensions of the supply side (healthcare providers) and the corresponding abilities of the demand side (WLHIV), which determine the accessibility of HIV care services.

5.4.1 Availability of healthcare services and ability to reach the services

The availability of the HIV care services in the healthcare facilities was an important facilitator of the women's access to the services. All the women interviewed in Yogyakarta acknowledged that the health services for HIV treatment, which included the provisions of antiretroviral medicines, CD4 and viral load tests, and other medical tests associated with HIV treatment, were available in several public and private hospitals and community health centres around the city of Yogyakarta. They also reported having easily accessed the treatment in these healthcare facilities in this setting, as illustrated the following narratives of two women who had been on ART for eight and three years, respectively, at the time of this study:

> *"It is easy to access HIV care services here (Yogyakarta). In X hospital the services are complete. The (antiretroviral) medicines and other medical tests are also available in community health centres" (FP8, remarried, Yogyakarta).*
>
> *"I did the (HIV) treatment for three months in X hospital and moved to XX community health centre. I asked (healthcare professionals in X hospital) to refer me to the community health centre because it is closer to my house. HIV care services, such as medicines and other medical tests (CD4, viral load, kidney tests, etc) to support HIV treatment are available over there" (FP4, single, Yogyakarta).*

All the women interviewed in Belu also reported that healthcare services for HIV treatment were available for them. However, they commented that the services for HIV treatment were very limited, and only available in an HIV clinic which was a part of a public hospital located in Atambua town. The participants also revealed that the only HIV treatment service they regularly accessed every month was antiretroviral medicines:

> *"I undergo the (HIV) treatment in this public hospital, this VCT clinic (VCT clinic is a part of the hospital). This is the only place where the (antiretroviral) medicines are available. I collect the medicines and meet the doctor in this hospital" (FP8, widowed, Belu).*

> *"Only (antiretroviral) medicines are provided here (VCT clinic). Other tests like CD4 and viral load tests are not available" (FP2, married, Belu).*

The women in both study settings also explained that healthcare professionals, such as doctors and nurses who were trained in HIV topics, were available in the healthcare facilities providing HIV services, and could be reached in person or by phone. The availability of these healthcare professionals to listen to the patients' health complaints and provide healthcare services, was acknowledged by the women interviewed. The availability of healthcare professionals and the good services they provided seemed to support the women's access to HIV care services:

> *"Doctors and nurses in HIV clinic are trained in HIV. They do understand what the patients (PLHIV) are going through. They always help and give me advices in relation to health complaints or problems I tell them. They are assigned to provide the services at the (HIV) clinic, so they are always there every working day" (FP9, married, Yogyakarta).*

> *"Sometimes if I feel unwell in the evening due to stomach-ache or fever which are not related to HIV, I can just text the doctor and the doctor will text me the name of medicines that I can buy. So, we do not have to meet. The doctor and nurses always encourage me to access healthcare services" (FP3, widowed, Belu).*

The ability of the women to reach the healthcare facilities providing HIV care services was indicated as another facilitator for their access to the services. All the women interviewed in Yogyakarta, and half of women in Belu, commented that they were able to reach hospitals or community health centres providing the services. Their proximity to healthcare facilities, the availability of time, and the availability of private and public transport such as motorbike and bus, seemed to be the factors that supported their ability to reach those healthcare facilities:

> *"The distance (from her house) to the hospital is not far, it takes approximately 10 minutes by motorbike, very close. I use my own motorbike" (FP6, remarried, Yogyakarta).*

> *"I live in XX (name of her place). …. If I go by public bus, then it takes 15 minutes from my house to X hospital. It is not far, still within the town and very reachable" (FP17, remarried).*
>
> *"I walk from my house to this hospital (VCT clinic), if I have money then I go by motorbike taxi, it is just IDR 2,000, very close" (FP10, married, Belu).*
>
> *"The distance from my house to this VCT clinic is very close. It takes me five minutes, I usually go by my own motorbike" (FP15, widowed, Belu).*

However, nearly half of the women interviewed in Belu, who lived far from the only HIV clinic in the district, described that they had difficulties in reaching the clinic due to the distance and lack of public transportation. The use of a motorbike taxi seemed to be the only transportation option available for them and as a consequence the costs were high, which seemed to be financially burdensome:

> *"I feel very much burdensome with the transportation cost. Every month if I have some amount of money I safe it to pay motorbike taxi because there is no public transportation available from my village to this clinic. Therefore, I have to use motorbike taxi and it is expensive" (FP7, remarried, Belu).*
>
> *"I usually come to this hospital to collect the (antiretroviral) medicines using motorbike taxi. Motorbike taxi is available but there is no public transportation. I feel that this burdens me because the cost of motorbike taxi is too expensive for me" (FP11, single, Belu).*

Occupational flexibility and the availability of time were factors that supported the ability of the participants in both settings to reach the healthcare facilities that provided HIV services. Several women interviewed in both study settings commented that as they were self-employed, or had their own business, they could manage their own time to access the services. Others reported of having to get permission from their employers to go to the healthcare facilities, and the others could easily reach the healthcare facilities due to their work as companions of PLHIV:

> *"I am self-employed and have my own business. So, I can easily manage my time to go to hospital to collect (antiretroviral) medicines and do medical check-up" (FP7, divorced, Yogyakarta).*
>
> *"I usually ask for permission from my boss (employer) every time I want to collect (antiretroviral) medicines (from hospital) but I never told my boss what medicines I access. I hide it (her HIV status) from my boss and colleagues" (FP6, remarried, Yogyakarta).*
>
> *"I arrange my working schedule and the schedule to collect the medicines here so that they do not collide. If I work in the evening, then I can come to collect medicines in the morning. Sometimes I swop my working schedule with my colleagues if the schedule to collect medicines collides with my working schedule" (FP17, married, Belu).*

5.4.2 Approachability of healthcare services and ability to perceive the need for healthcare

The approachability of the HIV care services or treatments played a crucial role in supporting the women's access to the services or treatments. As acknowledged by all the women interviewed in Yogyakarta, the approachability of the services was reflected in the widespread dissemination of information among the participants regarding the availability of HIV care services. This seemed to have enabled them to identify the existence of the services and access them:

> *"Information regarding HIV care services has been widespread in Yogyakarta, at least many PLWHA know about the services" (FP12, married, Yogyakarta).*
>
> *"Information regarding HIV care services is easy to get, I can get it from community health centres or hospitals. It is also disseminated through WhatsApp groups of peer support groups. If there is information regarding healthcare services, then it will be instantly disseminated among us (PLHIV)" (FP21, widowed, Yogyakarta).*

A few women interviewed in Belu also stated that information about HIV care services was available and had been disseminated. However, they commented that dissemination of the information had not reached many communities in Belu, hence many people in the area were not yet informed and aware of HIV and the services:

> *"Information about HIV care services has been spread out and it is easy to get. I am working for the local AIDS commission and visiting this VCT clinic every day, so I know information about the available health services. Yet, it is true that many community members (in Belu) do not know information about HIV care services and HIV" (FP3, widowed, Belu).*
>
> *"I know about this VCT clinic before I was diagnosed with HIV because as a health worker I often accompany (HIV) patients to this clinic. I also inform patients about this VCT, but I am sure most people in Belu do not know about this clinic and HIV care services it provides" (FP17, married, Belu).*

HIV care services information seemed relatively well-disseminated in Yogyakarta due to the active collaborative roles played by the health sector of the local government and the NGOs in conducting outreach activities such as HIV information sessions and testing to target populations and general communities. This aspect was lacking in Belu district. All the women interviewed in Yogyakarta acknowledged these roles and activities performed by these sectors, through which they gained information about HIV and the related healthcare services:

> *"Information regarding HIV care services is widespread, sometimes I ask healthcare professionals at HIV ward (HIV clinic in a hospital), sometimes I ask the companion of PLWHA from X NGO. Healthcare information is easy to access here. The staff from X NGO and healthcare professionals (from the local health department) often carry out HIV information sessions for high-risk groups and general communities. So, I think many people should have known about HIV care services" (FP14, remarried, Yogyakarta).*
>
> *"Dissemination of information about HIV care services is very good here. The companions of PLWHA from X NGO have good networks with the (local) heath department, community health centres and hospitals, so they know a lot about healthcare services and disseminate the information to us" (FP23, single. Yogyakarta).*

Peer support groups of PLHIV were another element that played a very important role in the dissemination of information about HIV and healthcare services among PLHIV in Yogyakarta. Regular peer support group meetings (where some doctors, nurses and NGO staff were also present) and announcements through WhatsApp groups by the companions of PLHIV, were instances of activities through which information about HIV, healthcare services and healthcare access procedures were disseminated among the women and other PLHIV in Yogyakarta:

> *"Information regarding healthcare services is available and widespread among us. The companions of PLWHA always update us with information on healthcare services. We (PLWHA) have WhatsApp group, so the companions of PLWHA always disseminate important information related to the services through the group, and everybody in the group reminds each other" (FP5, married, Yogyakarta).*
>
> *"I get information about HIV care services from miss X (name of the person), the companion of PLWHA. She always shares information about what needs to be prepared to access the medicines or to undergo CD4, viral load, and liver and kidney tests" (FP23, single, Yogyakarta).*
>
> *"Information about HIV care services usually comes from X NGO staff who are the companions of PLWHA. All the procedures or steps related to how to access the services are shared with us through WhatsApp group" (FP7, divorced, Yogyakarta).*

A similar peer support group of PLHIV was reported to have just been established in Belu, and a group meeting had been conducted a few times. However, it seemed that not many PLHIV were aware of the existence of this group and the activities or meetings. Some were unable to participate in the activities or attend the meetings due to the fear of their HIV status being disclosed as well as geographical constraints:

> *"I know information about HIV and its related healthcare services from the (staff of) local AIDS commission and the companion of PLWHA. …. We have regular meeting every three months at the AIDS commission office. I always attend even though I have already known (about HIV and the services), I can meet other friends" (FP8, widowed, Belu).*
>
> *"I never attend the peer support group meeting. I once heard about it, but I do not really know. The distance from my place to here (the local AIDS commission office where the meeting usually takes place) is too far, and the cost for motorbike taxi is expensive. Besides, I do not want other people know (about her HIV status), they might spread it (information about her status) (FP7, remarried, Belu).*

It should be acknowledged that most participants across the study settings became aware of the existence of HIV care services at the time when they or their husbands fell sick, were diagnosed with HIV and told by healthcare professionals:

> *"Initially I know about HIV care services because my husband was diagnosed with HIV. The outreach group (comprising healthcare professionals and NGOs staff) tested him and after that they told us about healthcare services for HIV" (FP9, married, Yogyakarta).*
>
> *"I know about this VCT clinic and HIV services provided here because the nurses told me and brought me here (when she was sick and admitted to hospital). They told me to do the (HIV) test so that if I have (HIV) then I could start the treatment, they said there are medicines for it (HIV)" (FP19, married, Belu).*

The ability to perceive the need for healthcare was another supporting factor for the access to HIV care services among all the women in both study settings. The ability to perceive was reflected in the women's knowledge or awareness of their health needs and the services they needed to access and when to access. The quotes provided below illustrate how the women perceived their needs for healthcare:

> *"I memorise the date I have to collect the medicines every month and the month I have to check my viral load and CD4. These are just like my daily need for food" (FP15, married, Yogyakarta).*
>
> *"I access the medicines every month at X hospital because I need the medicines to fight against the virus. I did a test for other STIs yesterday and the results were very good. …. CD4 test is every six moth and viral test is every 12 months" (FP19, single, Yogyakarta).*
>
> *"I come to collect the medicines every month because the date to access the medicines for the next month is written (by the nurses at HIV clinic on her healthcare card record), so I always remember it. I have been routinely coming to this clinic every month. The medicines have become my main need every month" (FP22, widowed, Belu).*

5.4.3 Affordability of healthcare services and ability to pay the services

The affordability of the HIV care services was another important supporting factor for women's access to the services. The majority of the women interviewed in Yogyakarta and several in Belu described that they had free access to the services as they held the National Health Insurance, commonly known as the Social Insurance Administration Organisation (*Badan Penyelenggara Jaminan Sosial* or BPJS). This was either the fully government subsidised type, commonly known as Indonesian Health Card (*Kartu Indonesia Sehat* or *KIS*) or the independent (*mandiri*) type, which required them to pay a certain monthly fee:

> *"All healthcare services are free of charge because I use the BPJS (KIS), which is fully subsidised by the government" (FP18, married, Yogyakarta).*
>
> *"I use the BPJS (KIS), so all healthcare services are free. I do not pay anything at all, the government pays for me. It is very helpful" (FP7, remarried, Belu).*
>
> *"I do not have any difficulties with the costs for healthcare services because I use the BPJS (mandiri type). I only need to pay the monthly fee of IDR 25,000, which is affordable" (FP1, remarried, Belu)*

The participants seemed aware of the expensive costs of healthcare services if they had to pay by themselves. Therefore, all the women interviewed in Yogyakarta and a few in Belu acknowledged that the National Health Insurance was very helpful, reduced the burden of medical expenses and supported their access to the healthcare services:

> *"Healthcare services are free of charge because I use the BPJS (mandiri type), I feel that it is very helpful. The services are very expensive If I have to pay by myself. Viral load test, for example, is 1.8 million rupiahs" (FP3, remarried, Yogyakarta).*
>
> *"Since I started the ART, I come (to HIV clinic) to collect the medicines every month. …. I use the KIS, so I do not need to pay anything, including the administration costs. …. This is very helpful. It is expensive if I have to pay healthcare costs by myself. With this insurance, I can access all healthcare services for free. I have got this type of insurance long time ago. It is Jokowi's (the name of the president of Indonesia) program" (FP14, married, Belu).*

The ability of the majority of the women who held the *mandiri* type of the insurance to pay the monthly fee and the transport costs was also indicated as playing a role in supporting their access to the available healthcare services. Comments by the majority of women interviewed in Yogyakarta and several women in Belu revealed that they could afford to pay the monthly insurance fee for themselves and/or their family members as well as the transport costs to the healthcare facilities:

> *"I just need to pay the monthly fee of IDR 25,000 to the BPJS. I work and have my own salary, so I have no difficulties in paying the monthly fee of the insurance" (FP12, widowed, Belu).*
>
> *"My husband and I just need to spend money on one or two litters of gasoline (for their motorbike), it is not much, we can afford it. In addition, we go to the hospital once a month, not every day" (FP20, remarried, Yogyakarta).*
>
> *"The costs for transportation (to VCT clinic) are probably IDR 20,000. This amount is enough to buy fuel for my motorbike so that I can go to VCT clinic and return home. …. For the sake of my health, I feel it is not burdensome" (FP21, widowed, Belu).*

Similarly, the ability of women, who did not use the BPJS and who paid for their medical costs by themselves, was also a supporting factor for their access to the healthcare services. A few women interviewed across the study settings, who did not use the insurance, described that they could afford to pay the costs associated with access to healthcare services. The women's own financial capacity and financial support from family members were mentioned as the supporting reasons for not using the insurance:

> *"I pay (for healthcare services). I do not have the BPJS but I can afford to pay for the healthcare services" (FP13, remarried, Yogyakarta).*
>
> *"I access healthcare services as a general patient (not as a patient using the BPJS). …. So, I pay (the costs associated with healthcare services) by myself. The costs are IDR 35,000 for the administration (registration) fee every month I collect the (antiretroviral) medicines. It is affordable and not burdensome, I can afford IDR 35,000 a month" (FP4, widowed, Belu).*

> *"My (extended) families are very supportive. Three of us (the women and her husband and child) use the BPJS but they said if we use the BPJS then we need a referral letter from the community health centre to collect the medicines and this might be time consuming for us. So, both families from my side and my husband's side decided for us not to use the BPJS and they pay for three of us every month we access the medicines. We can pay the costs by ourselves, but they said they want to help us with the expenses" (FP17, married, Belu)*

However, nearly half of the women interviewed in Belu, who used the BPJS reported having experienced difficulties or felt burdened with the monthly fee of the insurance and the transport costs to access the services. As a consequence, as explained by a few of these women, they had to borrow money from others or rely on the support of their family members in order to be able to access the needed healthcare services:

> *"Sometimes, if I do not have money to come (to VCT clinic) to collect the medicines, then I borrow from my friends and will return it once I have money. I have to pay the BPJS fee for me and my child, and for the transport to collect the medicines. These are routine expenses every month. I feel these are very much burdensome" (FP5, widowed, Belu).*

> *"I usually come to this hospital to collect the medicines by motorbike taxi. The costs from X (the name of her village) to this hospital are IDR 20,000. …. I feel burdened very much because I do not income at all. I can come to collect the medicines because I am supported financially by my older sister, she gives me money" (FP11, single, Belu).*

Another consequence of their financial difficulties and inability to pay the costs associated with access the HIV care services was the postponement of their access to the services or the collection of antiretroviral medicines. A few women interviewed in Belu described that they were financially poor and dependent on the support of their parents or siblings, which sometimes led to not being able to collect the medicines as scheduled:

> *"Sometimes if I do not have money at all and my older sisters have not yet given me money to pay the Ojek (transport) and administration fee (at the hospital) then I postpone to collect the medicines. I am dependent on them" (FP20, divorced, Belu).*

> *"Sometimes, if I do not have money at all, then I am not able to come to collect the medicines here (VCT clinic). I was late to collect the medicines for a few days several times because I did not have money for the transportation costs" (FP23, married, Belu).*

These women in Belu also reported having to rely on support from parents or families to fulfil their basic needs, a condition indicating the impact of HIV on families:

> *"At that time (when her husband was still alive), we (the women and her child and husband) lived with my parents-in-law, so we were fully depending on them. They fed us because my husband did not have income at all. We both were sick and did not have money at all. I felt that they carried our burden" (FP4, widowed, Belu).*
>
> *"My mother and father take care of me and my child because once I was diagnosed with HIV my husband already passed away and I could not work. So, I do not have money at all. Foods, drinks and all my needs were supported by my mother and father. I can see that my condition creates another burden for my parents" (FP9, widowed, Belu).*

In addition, although at the time of the study, all female participants in Yogyakarta setting seemed able to afford the medical and transport costs associated with their access to the healthcare services, several of them, both married and non-married women, experienced financial difficulties at the beginning of their diagnosis. These women described how expensive the healthcare costs, and the non-existence of or not having the national health insurance subsidised by the national government in the beginning of their HIV diagnosis had led to an economic burden for them. These also led to the sale of property and the use of savings to cover the costs of health treatment:

> *"In the beginning (of her HIV diagnosis in 2014) it was very difficult financially because the national health insurance subsidised by the government that many of us (PLHIV) now use did not exist. …. I sold my car to cover the medical costs and other expenses" (FP13, married, Yogyakarta).*
>
> *"I had savings, so I used the savings (to cover healthcare costs) but the savings diminished over time because every time (monthly) I wanted to do the medical check-up I have to withdraw from my savings. …. It was in 2016 and I did not have the national health insurance" (FP4, single, Yogyakarta).*

It was apparent that an HIV diagnosis in women in both study settings had economic consequences for themselves and their families through different mechanisms. One of them was that the infection caused poor physical health condition from them which prevented or reduced their engagement in work or in income generating activities, leading to the experience of financial hardship within their families. For example, most non-married women interviewed across the study settings reported having experienced financial difficulties following their HIV diagnosis or in the beginning of their HIV diagnosis due to quitting their job and the reduced or loss of income, leading to an inability to provide for the necessities for their family and having to use savings:

> *"In the beginning (after HIV diagnosis), it (HIV infection) influenced me very much financially because I stopped working. I did experience difficulties to provide the needs of my family. So, nearly all the savings I had were spent" (FP7, divorced, Yogyakarta).*
>
> *"So far I stop working because of this (HIV infection). So, I do not have income at all. My (older) brother gives me money for medication and my daily needs. All my needs are supported by my brother because personally I do not have anything left" (FP26, single, Belu).*

The economic difficulties associated with HIV seemed to be worse among the married women whose husbands were also HIV positive. The majority of the married women interviewed in both study settings commented that both they and their husbands resigned from their jobs for a certain period of time following their HIV diagnosis, lost incomes and spent savings to cover daily needs and expenditures, a condition that caused economic hardships for their families:

> *"My (former) husband and I did not work at all at that time (after their HIV diagnosis). So, we did not have incomes for more than a year and for sure the economic condition of our family was very difficult at that time" (FP13, remarried, Yogyakarta).*
>
> *"At the moment we (the women and her husband) do not have income at all because my husband has stopped 'Ojek' (motorbike taxi driver). I do not work so far, I am just*

> *a housewife. It feels so difficult if we both are sick like this, and we face many difficulties because we do not have income. We need foods and drinks, and we need to provide the needs of the children. These are very much burdensome for our family" (FP18, married, Belu).*

5.4.4 Appropriateness of healthcare services and ability to engage in the services

The appropriateness of the HIV care services reflected in the adequacy of the services provided and the need of PLHIV was reported by all women interviewed in Yogyakarta. The participants described that HIV care services available, such as antiretroviral medicines, viral load, CD4, kidney and liver function tests had met their health needs and seemed to support their access to the health services. These are illustrated in the following narratives of two women who had been on ART for eight and three years, respectively:

> *"In my opinion, HIV care services do fit my (health) needs. What I need is the medicines and the tests like viral load, CD4, and kidney and liver function tests. All these services are provided (in healthcare facilities)" (FP1, remarried, Yogyakarta).*
>
> *"I think the existing HIV care services fully meet my (health) needs. The medicines are available. Blood test and other medical check-ups are also available. These are the services I need" (FP4, single, Yogyakarta).*

The appropriateness of healthcare services was also reflected in the quality (the way in which the services were provided) of healthcare service delivery. All women interviewed in both study settings commented that the services were delivered in a professional manner and a friendly attitude by the healthcare professionals at HIV clinics, and these seemed to facilitate their access to the services:

> *"Doctors and nurses are very kind. They are friendly and professional, and willing to help if I have any health complaints" (FP21, married, Yogyakarta).*
>
> *"The attitudes of doctors and nurses in the VCT clinic are very nice. They serve me well. I see that they serve professionally. The way they handle patients like me shows that they are very well-trained and professional" (FP19, married, Belu).*

However, it was acknowledged by the participants in Belu, who were aware of the HIV care services needed by PLHIV, that the services provided in the VCT clinic in this setting did not fully meet the needs of the patients. Antiretroviral medicines were the only HIV care service provided in the setting, which was only available in one VCT clinic located in Atambua town:

> *"The (antiretroviral) medicines are in this clinic, only the medicines. Other tests to know viral load and CD4 are not available in this clinic. Hopefully, the (medical) devices are available in the future so that we (PLHIV) can da the test to know our CD4 counts and the viral load in our body" (FP10, married, Belu).*
>
> *"To my opinion, the services for HIV treatment are still lacking here (Belu). I hope the medicines are also provided in community health centres to make the services closer to us so that we do not have to spend money on transportation which is expensive" (FP7, remarried, Belu).*

The women's ability to engage in the HIV care services also played a role in supporting their access to the services. Their ability to engage in HIV treatment was supported by several enabling or motivating factors, such as their willingness to stay healthy and keep working, their expectations about living longer and taking care of their children, and the fear of death. The following stories of women across the study settings provide some instances illustrating their motivations to participate in the healthcare services provided for them:

> *"I do the treatment so that I stay healthy and continue working. These motivate me to consistently undergo the treatment and take care of my health" (FP4, single, Yogyakarta).*
>
> *"What motivates me the most to undergo the treatment, get healthy and try to overcome all the stress, is my child. I mean I have one child only. So, I must try to raise up him and make him happy. The second (what motivates her for treatment) is my little brothers and sisters (the woman is an orphan and responsible for the life of her young brothers and sisters)" (FP4, widowed, Belu).*
>
> *"Fear of death is the number one motivation (to engage in HIV treatment). I do not want to die, if I think of it (death) I feel scared. Fear of death motivates me to do the treatment" (FP7, remarried, Belu).*

5.4.5 Acceptability of healthcare services and ability to seek the services

The acceptability of the HIV care services provided by the healthcare professionals was another factor that supported the women's access to the services. The acceptability of the services was indicated in the women's acceptance of the healthcare professionals and the way they delivered the services. The positive and supportive attitudes and behaviours of the healthcare professionals in HIV clinics or wards for PLHIV were factors that seemed to support the acceptance of the services by most women interviewed in both study settings, as illustrated in the following quotes:

> *"Healthcare professionals are very nice and supportive. I feel encouraged to access the services" (FP6, remarried, Yogyakarta).*
>
> *"Doctors and nurses in this VCT clinic are always friendly. They are very good in delivering the service. I like the way they treat me" (FP13, married, Belu).*

Talking openly to the healthcare professionals who delivered the HIV care services was another indication of the acceptability of and access to the services by the participants. As described by most women interviewed across the study settings, this was supported by their belief that the healthcare professionals knew about their health condition and were willing to help them:

> *"I am very open to doctors and nurses. I tell them any health complaints I have because I believe they understand my condition. I have often shared (about her health condition) to them" (FP8, remarried, Yogyakarta).*
>
> *"I am very open with doctors and nurses. …. I am open because they already know about the disease (infection) I have. They know why I come here (VCT clinic), so I am open to them" (FP18, married, Belu).*

The belief that the healthcare professionals had a better knowledge and understanding about HIV and could provide advices or solutions, and the expectation to stay healthy, were other supporting reasons for the open talk between most women in both study settings with doctors and nurses in HIV clinics:

> *"I am always open to doctors and nurses in the VCT clinic because I want to stay healthy. They have the knowledge about this disease (infection), hence I am open to them so that they can provide me with correct advices or solutions. I do trust them, they know me well" (FP5, married, Yogyakarta).*
>
> *"I am very open to doctors and nurses in the CVT clinic. …. I am open about what I experience (health condition) so that they can provide me with advices and I can feel calm. …. I trust them, they know better about health. So, in my opinion it is better to be open to them in order to get help. …. Because of their help I am still be alive up to now" (FP10, married, Belu).*

Social relationship between the participants and healthcare professionals at the HIV clinics was another factor that encouraged them to talk openly to the healthcare professionals about their health condition. Most women interviewed in Yogyakarta and a few in Belu described that they had a close relationship with doctors or nurses who treated them, and openly shared their health needs with them. It seemed to support the acceptability of and access to the services among these women:

> *"Doctors and nurses are very nice; they serve me well and friendly. We know each other and are close. So, if I have a health complaint, I do not hide it from them, I openly tell them and do not feel ashamed" (FP14, remarried, Yogyakarta).*
>
> *"Doctors and nurses at the VCT clinic and I know each other very well. We are just like friends because we often meet. I am now working for an HIV program, so I often meet them. If I have any health complaints I directly speak to a doctor or nurse (at the HIV clinic) without any hesitation because we have known each other very well" (FP3, widowed, Belu)*

The ease of access to the HIV care services was another factor that supported the acceptability and accessibility of the services among the women who participated in this study. All participants in Yogyakarta and several in Belu stated that the services were easy to access. They just needed to collect a referral letter from the hospital or community health centre where they were registered or as indicated in their health insurance (BPJS), and then provide it to the healthcare professionals in the HIV clinic that provided the services. They also needed to be registered, which could be done from home via an online system, or manually in a healthcare facility before they accessed the services, or ask for the help of a companion of PLHIV to access the services, such as antiretroviral medicines, on their behalf if they were unable to do it in person:

> *"Procedures to access the services are very simple. I go to the city community health centre to collect the referral letter, bring it to this VCT clinic and then collect the medicines" (FP5, widowed, Belu).*
>
> *"The process to access the services is very easy. Sometimes if I am busy and do not have any health complaints, then I ask for help (of a companion of PLHIV) to collect the medicines for me" (FP10, remarried, Yogyakarta).*

The ability to seek the HIV care services, which refers to the participant's personal autonomy, capacity to choose to seek care and treatment, and knowledge about the healthcare options or services available for them, was also another supporting factor for access to the services among the participants in both study settings. This was because the participants had the knowledge about the healthcare facilities providing the services and had the capacity to decide when to access the services. However, the stories of some women in Belu showed that their capacity to decide when to access the services was restricted or influenced by other factors such as poor financial conditions, long distances to HIV clinics, and a limited availability of transportation modes:

> *"I know all the healthcare facilities providing HIV care and the types of care each of them provides, so I can access anytime I want and as scheduled. I use my own motorbike, so no need for help from other people to drive me there" (FP16, widowed, Yogyakarta).*
>
> *"I know that the medicines are only available in this (HIV) clinic, so I have to come here to collect the medicines anytime I need. My driver drives me here (the clinic) but*

> *sometimes I come here by motorbike taxi, no barriers for me to access the services here" (FP14, married, Belu).*
>
> *"I was told by the doctor to collect the medicines here (HIV clinic), so I have known about this clinic since the day I was diagnosed with HIV. I know when to collect the medicines because the date is written here (showing her health record) but as I told you before, the problem is that sometimes I do not have money for transport. My place is far from this clinic and I have to take motorbike taxi because there is no public transportation" (FP7, remarried, Belu).*

5.4.5.1 Cultural practice of traditional medicines

The use of traditional medicines to treat any kinds of disease, including HIV/AIDS, seemed to have an influence on the acceptability of and the access to HIV treatment among the women interviewed in Belu, a factor which was not identified in the interviews with participants in Yogyakarta. The participants in Belu acknowledged that the use of traditional medicines provided by traditional healers was a common practice passed down from one generation to another:

> *"The use of traditional medicines has been a common practice in our culture since long time ago, passed down from our ancestors. If people get sick then they would firstly seek for traditional medicines" (FP15, widowed, Belu).*
>
> *"It is common that traditional healers provide traditional medicines for people who are sick. The one who gave me the (traditional) medicine is also a traditional healer, and there have been many people who do the treatment with him" (FP23, married, Belu).*

The cultural practice of traditional treatment was reported to influence or delay the acceptability of and access to HIV care services among the women in Belu. It influenced the initiation of and retention in ART. Nearly half of the women interviewed in this setting described that they did not start the ART straightaway following their HIV diagnosis or stopped the ART due to undergoing traditional treatment using traditional medicines:

> *"After the HIV diagnosis, the doctor told us (the women and her husband) that the medicines for HIV treatment are available at this hospital (HIV clinic) but we did not*

> *access the medicines directly. We did the treatment using traditional medicines provided by a traditional healer in XX (name of a place)" (FP8, widowed, Belu).*
>
> *"So, after collecting the (antiretroviral) medicines at the first time, I stopped collecting the medicines. It was because at that time I used traditional medicines for the treatment" (FP7, remarried, Belu).*

The use of traditional medicines was reported to have financial consequences for PLHIV in Belu. Some women interviewed in this setting acknowledged that they had to pay a certain amount of money and give sacrificial animal to traditional healers who provided the traditional medicines. The amount of money and the animal seemed to differ from one traditional healer to another and had to be provided by the women prior to the commencement of the treatment. Meanwhile some other women revealed that they had the traditional treatment for free as the traditional healers were in their families:

> *"My husband and I took traditional medicines from three different traditional healers and wasted a lot of money which was up to two million rupiahs for each of them and one goat, but we did not get better" (FP5, widowed, Belu).*
>
> *"I used traditional medicines from my relatives, they (husband and wife) knew that I am infected with HIV, and offered the medicines to me. …. I did not pay them, they are my family, they just wanted to help me and did not ask for money" (FP7, remarried, Belu).*

5.4.5.2 The role of family in the use of traditional medicines for HIV treatment

Family members were reported to have an important role in determining the HIV treatment for these women. The comments of several women participants in Belu indicated that they underwent HIV treatment using traditional medicines due to this being asked for or suggested by their family members, such as parents or in-laws:

> *"After he (her late husband) was diagnosed with HIV, at first the doctor gave him cotrimoxazole for two weeks, but they (her husband's family) told him to take traditional medicines. …. They asked him and me to use the traditional medicines for bathing as well. My husband and I took the traditional medicines, but after a while my*

> *husband's condition got worse, so we went back to hospital (to start ART but her husband died)" (FP4, widowed, Belu).*
>
> *"Once diagnosed (with HIV), my family encouraged us (the women and her late husband) that the person (traditional healer) could heal (HIV). Once we arrived at her place, she (traditional healer) also convinced us that she could heal it, so we underwent the traditional treatment" (FP8, widowed, Belu).*

The family members' decisions for the use of traditional medicines for HIV treatment of their sick family member was reported to be influenced by their experience of the use of traditional medicines in treating other health issues. The participants described how their family members were accustomed to using traditional medicines and had used them regularly, hence suggesting them to use traditional medicines for the treatment of HIV. This also seemed to be supported by the lack of knowledge among their family members about medical treatment for HIV or ART as provided in healthcare facilities:

> *"My parents and grandparents are very familiar with traditional medicines and these are number one medicines for them. Every time they feel sick or unwell, they use traditional medicines to treat their body. So, they recommended me to use traditional medicines to treat HIV as well. They do not know anything about medical treatment like these (showing her medicines she just collected)" (FP5, widowed, Belu).*
>
> *"Many people, including my families, regularly use traditional medicines to treat themselves or any family members who are sick. So, once they know that I am sick they recommended me to use traditional medicines. I think it was also because they did not understand about the medical treatment (ART), so what was in their mind for the treatment was traditional medicines, not ART" (FP7, remarried, Belu).*

Extended family members and neighbours were also reported to have an influence on the decision of the participants' family members for the use of traditional medicines to treat HIV infection. Providing information about traditional medicines for HIV treatment, and encouraging the participants' family members about the effectiveness of traditional medicines to treat HIV infection, were in some instances reflecting the influences of others towards the participants' family members regarding the use of traditional medicines:

> *"My parents and siblings asked me to take traditional medicines as well. They were told by the family members of my husband about the traditional medicines to treat HIV, and were encouraged that the medicines are effective to cure HIV. So, I still take traditional medicines up to now every morning and ART in the evening. My sister-in-law sends it (the traditional medicine) every month" (FP17, married, Belu).*

> *"My family members encouraged us (the women and her late husband who died from AIDS) to use traditional medicines because they have been encouraged by our extended family members and neighbours that traditional medicines can cure HIV (FP8, widowed, Belu).*

Besides, the stories of some women showed that by being physically weak, being taken care of by their family members, their desire to quickly get cured and their lack of knowledge about HIV treatment using antiretroviral medicines, appeared to be the supporting factors that made them accept and follow the recommendations of their family members for the use of traditional medicines:

> *"At that time (the beginning of their HIV diagnosis), my husband and I were very weak physically, and we were taken care of by the family of my parents-in-law. We lived together with them in the same house. So, we just listened to what they said. Once we got back home (from healthcare facility after being tested positive with HIV) my parents-in-law started talking about traditional medicines. They recommended us to use traditional medicines and provided the medicines for us. We were in a very weak condition and wanted to get healthy or cured, so we used the traditional medicines they provided. At that time, my husband and I did not really understand much about the medical therapy (ART) even though the doctor told us about it. My parents-in-law did not know anything at all about it either" (FP4, widowed, Belu).*

CHAPTER SIX

HIV RISK FACTORS AND IMPACT AMONG MEN LIVING WITH HIV AND THEIR FAMILIES, AND THE MEN'S ACCESS TO HIV CARE SERVICES

6.1 Overview

This chapter presents the views and experience of MLHIV in Yogyakarta (n=20) and Belu (n=20) about HIV risk factors among them, the impact of HIV on themselves and their families, and their access to HIV-related healthcare services. The majority of the participants were married (n=25) and others were unmarried (n=15) and their ages ranged between 22 to 60 years old. This section consists of three main parts. The first part presents the accounts of MLHIV about factors that had facilitated or played supporting roles for the transmission of HIV among them. Some parts of the findings on culutral and religious factors have been published in PloS ONE (48) (The details of author contributions are presented in the article: Appendix 1). The exploration of their views or perceptions on this topic was guided by the logical model for behavioural and environmental determinants diagnosis (see section 3.2 for a discussion of the framework). The second part presents the accounts of MLHIV about their experiences of the impact of HIV facing them and their families following their HIV diagnosis. Some parts of the findings on HIV stigma and discrimiination have also been published in the International Journal of Environmental Research and Public Helath (49) (The details of author contributions are presented in the article: Appendix 2). The exploration of the participants' individual accounts on their lived experience of the impact of HIV was guided by the conceptual framework for the impact of HIV/AIDS on individuals and families and the HIV stigma framework (See section 3.3 and 3.4 for a discussion of the frameworks). The third part presents the accounts of the participants about their experiences with access to HIV care services. Guided by access to healthcare framework (See section 3.5 for a discussion of the framework), the focus was on exploring the characteristics or dimensions of both the supply side (healthcare providers) and the demand side (MLHIV), which determined the accessibility of the HIV care services.

6.2 HIV transmission risk factors

This section presents the accounts of MLHIV about the risk factors for HIV transmission among them. The risk factors described by MLHIV were grouped into several themes, including HIV knowledge, behavioural factors, the social influence on drug use, sex and condom use, environmental factors, economic factors, religious thoughts about sex, condom use and husband-wife relationships, and cultural factors in regard to spousal relationships and bride wealth in marriage.

6.2.1 HIV knowledge

The male participants interviewed across the study settings had a basic understanding of HIV or the means of HIV transmission and prevention at the time the study was conducted. However, most of the participants (n=32) described that they did not have knowledge or information about HIV prior to their diagnosis and started learning or were told by healthcare professionals about it after they were diagnosed with the infection:

> *"I heard about HIV at the time I was in Jakarta, I was sick (diagnosed with HIV) and the doctor explained to me (about HIV). I did not know at all before I was diagnosed with HIV" (MP7, married, Yogyakarta).*
>
> *"I know about HIV after the diagnosis because I searched for information about how it spreads, its impact and treatment. After the diagnosis I intensively searched on the internet and also got information from the doctor. My younger brother's wife is a nurse and she also provided me with information about it" (MP6, single, Belu).*

The lack of or limited knowledge about HIV was reported to play a role in supporting unprotected sexual behaviour or sex without condom use through which HIV was transmitted among the participants. The stories of the majority of the participants across the study settings (n=22 out of 26 people), who reported having acquired the infection through unprotected sex, showed the lack of or limited knowledge about HIV as one of the supporting factors for their engagement in sex without condoms:

> *"I know about HIV after I was diagnosed. I have heard of HIV, but I did not know how it is transmitted, how it is treated. I started to know about the (HIV) transmission and prevention after I was diagnosed. That was why I did not use condoms at all and got this infection" (MP15, single, Yogyakarta).*
>
> *"I did not know about HIV at all prior to the diagnosis, that was the reason I had sex with them (FSWs) without any fear of contracting this disease (infection). If I knew about the danger of this disease (infection), I would have been careful and using condoms. But what to say, I know that HIV is dangerous after I am infected with it" (MP7, married, Belu).*

The lack of knowledge about HIV was also reported as a supporting factor for the participants' engagement with IDU through which they acquired HIV infection. Most of the participants in the Yogyakarta setting (n=10 out 14 people), who reported contracting HIV through IDU, described that they were not aware of the possibility of HIV transmission through sharing needles at the time they engaged in such practice:

> *"…. At that time, I used injecting drugs, but I did not know the risk of getting HIV. I did not know at all about the spread of HIV through needles. The doctor explained to me about it after I was tested positive with HIV" (MP6, remarried, Yogyakarta).*
>
> *"I got information about HIV in 2005 even though it was very limited. At that time, I was in prison and there was an information session about HIV in prison. I felt that I was at risk and decided to do voluntary counselling and testing, and the result was that I am HIV-positive. I felt I was at risk because I used injecting drugs with my friends, but before that (prior to the information session) I did know that I could get HIV through injecting drug use" (MP13, married, Yogyakarta).*

However, the stories of several participants indicated that their knowledge of HIV did not guarantee translation into safe sex practices or condom use behaviour, and stopping needle sharing practices among the participants. Several male participants interviewed across the study settings (n=8) described that they had been aware of HIV and the means of the transmission prior to their HIV diagnosis, but kept on engaging in risky behaviours, including sex without condoms and needle sharing for drug use, through which they acquired HIV. Sexual desire and addiction to drugs were some of the underlying reasons for their continuous engagement in such risky behaviours:

> *"I have known about HIV since I was in senior high school in the 90s. I have heard information about HIV at that time even though it was limited, not exhaustive. I know it (HIV) transmits through sexual contacts. …. I know it spreads through free sex but because I could not handle my biological demand (sexual desire), I often had sex with those girls (FSWS). I got HIV because I did not use condoms every time I visited (had sex with) them" (MP9, single, Yogyakarta).*

> *"I have heard about HIV a few years before my HIV diagnosis. I heard about it through HIV information sessions when I was in junior high school and senior high school, but I did not think that I could get it through sexual intercourses with the girls (FSWs). I fulfilled my (sexual) desire with them but did not think of this (getting the infection" (MP8, single, Belu).*

> *"I have got the knowledge about HIV since I was in senior high school. The problem was I was addicted to drugs and shared needles (with other users). I did not really think of the consequences of sharing needles. Finally, I contracted it. I was addicted to drugs until the end of 2008. I started using drugs in 1997, it was about 11 years. I quitted in 2008 …." (MP8, married, Yogyakarta).*

6.2.2 Behavioural factors

6.2.2.1 Lack of or inconsistent condom use

Lack of condom use was a behavioural factor that facilitated the transmission of HIV among MLHIV who participated in this study. It was reported as a common practice among these participants across the study settings. Most of them (n=34) described that they had engaged in sex without condoms with their sex partners for years prior to their HIV diagnosis and being told by healthcare professionals about condom use, a high-risk practice for the transmission of HIV among them:

> *"I had sex without condoms at all prior to the (HIV) diagnosis. …. I did not know about the function of condoms (to protect HIV transmission) before I was diagnosed with HIV. I did not use condom at all" (MP16, single, Yogyakarta).*
>
> *"I never used condoms once I had sex with my (ex) girlfriends or those women (FSWs) because I knew nothing about condoms at that time. I started to know about these things (condoms) after I was diagnosed with HIV, but prior to that I did not have any information about this thing. After the diagnosis, the doctor said I have to use condoms …." (MP13, single, Belu).*
>
> *"I never used condoms at all before the doctor and nurse told me to use (condoms). They suggested that after I was diagnosed with HIV" (MP17, married, Belu).*

However, it seemed that knowledge of condoms did not guarantee the translation into consistent condom use behaviour or protected sex practices among all the male participants. A few participants interviewed across the study settings, who had knowledge about condom as the means of HIV prevention prior to their HIV diagnosis, described that they used condoms inconsistently or did not use condoms at all in their sexual encounters with their sex partners or wife. An unwillingness to use condoms, feeling ashamed and lazy about buying condoms, their intention to hide their premarital sexual relationships, and reduced sexual pleasure were some of the underlying reasons for the lack of or inconsistent condom use among these participants:

> *"I know the places where condoms are sold, such as pharmacies or other places. I have known these places long time ago, but I just do not want to buy, I feel ashamed and lazy to buy condoms (he bought condoms once)" (MP6, remarried, Yogyakarta).*
>
> *"I have known about condoms since I was single, but using condoms makes it (sexual intercourse) less pleasurable, thus I hardly used condoms once having sex with the girls (FSWs) (before marriage). That is why I got the virus. I also felt ashamed to buy condoms, people might know that I engaged in free sex" (MP2, married, Belu).*

Similarly, the majority of the participants across the study settings who had been informed about condoms and their function by healthcare professionals and peers following their HIV diagnosis, and who were suggested to use condoms in sexual encounters with their sex partners, reported continuing to engage in unprotected sex or be inconsistent in using condoms. Reduced sexual pleasure or feeling uncomfortable using condoms, being an HIV positive couple, knowing the experience of other discordant couples who did not use condoms, their wife's rejection of condom use and the unavailability of condoms, were some of the underlying reasons for the lack of or inconsistent condom use among these participants:

> *"I know about it (condom use) now (after he was diagnosed with HIV), I was told to use condoms to be safe. I was told about condom use in our peer support group meetings, but we (the man and his wife) do not use condoms. My wife (who is HIV-negative) asks me not to use condoms: she said 'why we need to use condoms, if I got it (HIV), that is fine, just live with it. But luckily since 2011 up to now she is (tested) negative (for HIV)" (MP12, remarried, Yogyakarta).*
>
> *"After I know about HIV and condoms, we (the man and his wife: both HIV-positive) do not consistently use condoms. The doctor said we need to use condoms, so we do not mix up the virus (co-infections), but there are many husbands and wives (who are both HIV-positive) do not use condoms. There is also a friend of mine (who is HIV-positive), her husband does not get HIV even though they do not use condoms and they have a child. Her husband is still negative up to now" (MP4, married, Yogyakarta).*
>
> *"After we (the man and his wife) were tested positive with HIV, we never used condoms because we think we are both HIV-positive and on ART. The doctor often said that we need to use (condoms) even though we are both positive, but I feel uncomfortable using condoms. We do not have those things (condoms) at home" (MP1, married, Belu).*

The physical appearance of sex partners or FSWs was another factor that supported the participants' engagement in unprotected sex with their sex partners or FSWs. The comments of several participants across the study settings (n=9) revealed that clean, healthy, and the good-looking physical appearances of sex partners or FSWs were factors that made them rule out the possibility of HIV transmission from these women, and influenced the lack of condom use among them:

> *"Prior to the HIV diagnosis I never used condoms at all every time I had sex with them (FSWs). I saw that they looked physically healthy and had good looking appearances. I did not think that any of them was sick (HIV-positive) because what was in mind was that people who have HIV are skinny. I did not know that the HIV status cannot be judged through the physical appearance. …. Because they have good looking physical appearances, I did not think that they were infected with HIV and did not think of condom use" (MP2, single, Yogyakarta).*
>
> *"The girl (a massager at a massage parlour) asked me to use condoms but I did not want to use because she looked very clean and fresh and had good looking physical appearance. So, I did not think that she had any diseases (the participant reported having sexual intercourses with one girl only at the massage parlour during his three months holiday in Bali after retirement)" (MP14, married, 60 years old, Belu).*

A lack of or inconsistent condom use with multiple sex partners were acknowledged by the majority of the participants across the study settings as the means through which they had acquired HIV. Such acknowledgements were made by the participants due to their awareness that such practices were the only means of HIV transmission they had engaged in, as indicated in the following quotes:

> *"I got the infection due to 'jajan' factor (jajan is a term used to indicate men having sex with FSWs). I often visited (had sex with FSWs) XXX (the name of a place in West Java where there are many brothels) and I am sure they got it from any of them because I did not use condoms" (MP9, single, Yogyakarta).*
>
> *"I realise that my (sexual) behaviour prior to the (HIV) test was wild. I often changed sex partners and did not use condoms. I do not know when I got the infection, but the fact is that my wife and child are not infected. This means that I got infected after we have our child and this was because I often changed sex partners, or people call it 'jajan' (MP10, separated, Yogyakarta).*
>
> *"At that time (before getting married), I never used condoms once having sex with those girls (FSWs), that is why I contracted HIV. I might not have got HIV if I used condoms because I am sure this (lack of condom use) is the only way through which I got the infection" (MP19, married, Belu).*

Such practices were also reported as facilitators for the transmission of HIV to their wives. Several married men across the study settings (n=16) described that they engaged in sex without condoms with their wives prior to their HIV diagnosis, and acknowledged such practice as the means through which they had transmitted the virus to their wives, as illustrated in the following quotes:

> *"I transmitted it (HV) to my wife before I was tested. Prior to the diagnosis we never used condoms in our intimate relations, thus she got it too" (MP11, married, Yogyakarta).*
>
> *"Never used condoms after getting married with my wife, so I am sure my wife got it (HIV) from me through spousal intimate relations" (MP20, married, Belu).*

Despite having transmitted the virus to their wives, most of these men (n=13) reported a lack of discussion between them and their wives or ex-wives about their sexual behaviour. These participants described that their wives did not talk and raise questions about their sexual behaviour through which they may have acquired HIV. Avoidance of spousal dispute, feeling uncomfortable asking about sexual behaviour-related questions, fear of being scolded by their husband, and suggestions from healthcare professionals to focus on treatment and avoid blaming each other, were mentioned by these participants as the possible reasons which prevented their wives from proposing such talk or asking questions:

> *"I am sure that my (ex)wife knew about how I have got the infection, but she did not talk about it. I could see her suspicion, but she kept it in her heart to avoid dispute, perhaps. Also, the doctor told us to focus on the treatment and not to blame each other" (MP10, separated, Yogyakarta).*
>
> *"We (the man and his wife) never talked about sex in our family. My wife never asked how I got HIV. She may be suspicious, but she never asked. I think she does not feel comfortable asking or talking about it" (MP2, married, Belu).*
>
> *"We (the man and his wife) never discussed about this HIV. My wife never asked what I did once I was in other places (he used to work in other places outside of Belu) and how I was infected (HIV). She may be feeling uncomfortable asking me that or scared*

> *of getting scolded. She never talked about that topic and just kept quiet. The doctor also suggest that it is better to focus on the treatment and avoid looking for mistakes to blame each other" (MP11, married, Belu).*

6.2.2.2 Injecting drug use

IDU was another high-risk behavioural factor that facilitated HIV transmission among the male participants in Yogyakarta, a factor that was not raised among the ones interviewed in Belu. The majority of the participants interviewed in Yogyakarta (n=14) described that they had engaged in IDU for years prior to their HIV diagnosis, a practice that was acknowledged as a means through which they had acquired the infection:

> *"I got HIV through needles, I used injecting drugs for five years (prior to marriage). I started using in 2000 and continued to 2004" (MP6, married, Yogyakarta).*
>
> *"I got it (HIV) through drugs, needles. I used injecting drugs for many years (prior to marriage), that is why I got it. I was sick and admitted to hospital, and then the doctor told me that I got this (HIV)" (MP7, married, Yogyakarta).*

Interviews with these participants revealed that IDU was a practice that they often performed with their friends. These participants described that they often engaged in such practice with friends in a group, where they often shared needles, a practice that facilitated the spread of HIV among them:

> *"I met my friends who were drug users in 1997, and there were many friends of mine used injecting drugs. We often used needles and drugs together (prior to marriage)" (MP8, married, Yogyakarta).*
>
> *"I actively used injecting drug in 1998. I had tried them (illicit drugs) since 1994 but started using injecting drugs in 1998 together with my friends and we used (shared) needles together. In 1999, a friend of mine was tested positive for HIV, and he told me to get tested but I did not want to do it. In 2004, I fell sick and was physically weak and tested positive with HIV (prior to marriage)" (MP4, married, Yogyakarta).*

Of these participants, two acknowledged to also engage in unprotected sex with FSWs or girlfriends prior to marriage and their HIV diagnosis. They seemed to have multiple risks for

HIV transmission both through sex and IDU, even though they reported to have acquired the infection through IDU:

> *"I was sexually active and engaged in injecting drug use. I sometimes had sex with the girls at brothels (FSWs), but more often with my (ex)girlfriends. …. During those times, I did not use condoms at all but I think I got the infection injecting drugs because I often shared the needles with my friends" (MP4 married, Yogyakarta).*
>
> *"At that time (he was still actively using injecting drugs), sometimes after injecting drugs we had sex among us (drug users). At that time we did not know about condoms, so we never used condoms. The girls (who they had sex with) were our friends who were also injecting drug users. We used drugs together very often, so I am sure that we transmitted HIV to each other through the needles we shared" (MP17, married, Yogyakarta)*

6.2.3 Social factors: the social influences on drug use, sex and condom use

The social influence of peers was indicated as playing a supporting role for the engagement of the male participants in IDU. The participants in Yogyakarta, who reported being infected with HIV through IDU, described that they were initially introduced to injecting drugs by their friends, and engaged in such practices together with them. These were some instances of the social influence which supported participants' engagement in IDU through which they acquired HIV:

> *"I used to use injecting drugs together with my friends, we were close friends. We used drugs every time we got together at our meeting spots. …. We always invited each other to use (drugs together). …. I got to know about illicit drugs through social relations, through my friends. They were the ones who introduced injecting drugs to me at the first time" (MP1, married, Yogyakarta).*
>
> *"Initially, I injected drugs because my friend invited me to do it together, my friend is from Jakarta. After a few times doing the injecting drugs, I enjoyed it and then continued to use and even got addicted to it" (MP5, married, Yogyakarta).*

Purchasing drugs together with friends, who were also drug users, was another social factor supporting the participants' continuous engagement in illicit drug use which had facilitated

HIV transmission among them. The participants described that they and their friends, or other drug users, often had to contribute some amount of money to buy drugs together when they could not afford to buy drugs individually. This seemed to be a common strategy used by the participants to support their engagement in IDU practice:

> *"I always used (injecting drugs) together with my friends. …. We contributed money together to buy (drugs) if each of us did not have enough money to buy drugs individually. We always invited each other, our friends (to buy and use)" (MP1, married, Yogyakarta).*
>
> *"In the prison, if we did not have enough money then we bought the drugs together and then used together" (MP12, married, Yogyakarta).*

The engagement of these participants in IDU seemed to also be influenced by the social situations in the places where they lived. Some participants described that illicit drugs were popular at the time they started getting involved in drug use, and using drugs made them popular among their friends:

> *"I used heroin for three years, injecting drug. At that time, I was (studying) at a university in Bandung, and heroin was so popular at that time. …. Back in those time, getting drank and using drugs made you feel cool and popular among friends. I used to get together with friends from wealthy families. At the beginning they often bought the drugs and we used together" (MP11, married, Yogyakarta).*

The social influence of peers was also a supporting factor for the participants' engagement in sex with multiple partners, including with FSWs. The stories of the male participants interviewed across the study settings showed that their peers had an important influence on their sexual behaviour or engagement in sex with FSWs, a practice through which they acquired HIV:

> *"We (the man and his male friends) were from different countries and worked together (he worked in oil palm plantation in Malaysia). During the weekend my friends often asked me to hang out looking for the girls (either female migrant workers or FSWs) to*

> *have sex with, and finally I felt accustomed to it and every weekend we always went out to have sex" (MP10, married, Yogyakarta).*
>
> *"At that time (he worked in Papua, a province of Indonesia, for several years) I lived together with my friends who liked to 'play women' (have sex with FSWs). So, if one of us wants, then he would invite others to visit the women together. I engaged in such practice for five years of working period over there" (MP5, single, Belu).*

The social influence of peers about condom use was also a factor that influenced condom use among the male participants. The descriptions of several participants (n=9) across the study settings, who were aware of condoms prior to their HIV diagnosis, illustrated the influence of peers as a factor that supported these participants' engagement in sex without condoms or unprotected sexual behaviour:

> *"I have heard about condoms when I was working in Irian (Papua) but I never used them every time I visited those girls (had sex with FSWs) because my friends said that it hurts and makes you feel uncomfortable during the sex" (MP20, married, Belu).*
>
> *"I have heard about condoms (before he was diagnosed with HIV), I have not started using condoms because my friends said using condoms make it (sexual intercourse) less pleasurable and I just believed in what they said and never tried to use every time I had sex" (MP2, single, Yogyakarta).*

6.2.4 Environmental factors

Environmental factors were also reported to have an important influence on or contribute to high-risk behaviours that facilitated HIV transmission among the male participants. For example, the environment or the surroundings in which they lived where illicit drugs were available and accessible were described in the stories of all male participants who were drug users, as one of the supporting factors for their engagement in IDU practices through which they acquired HIV infection:

> *"I used injecting drugs for nine years. The place where I used to live was called drug village. People sold drugs in every alley. So, there were people who distributed drugs every day. It was not difficult to find drugs" (MP14, married, Yogyakarta).*

> *"The environment where I lived when I was in senior high school and the school environment were very supportive. I mean drugs were easy to get. So, if I wanted to use then I could just buy or ask from friends" (MP7, married, Yogyakarta).*

The workplace environment which was far away from family was another supporting factor for the use of injecting drugs among the participants. This was due to the absence of supervision and restrictions from parents and other family members at the places where the participants worked and lived. Such absence was described as supporting their involvement in the use of illicit or injecting drugs, as they were not afraid of anybody and did not feel like being watched by family members or other people around them:

> *"It was free (to use drugs) at the place where I was busking, there were not my parents or any other family members. So, I was not afraid of anybody. There were only my friends who were also (drug) users. After using (injecting drugs) I was busking and after busking if we (the man and his friends) still had (drugs) then we again injected" (MP3, married, Yogyakarta).*
>
> *"I have known illicit drugs before 1998 when I was still sailing. There were many friends who used injecting drugs on the ship. We (the man and his friends) often sailed, so I just enjoyed it (using drugs). Nobody forbade or kept eye on us, so every night we got together and used, injected" (MP4, married, Yogyakarta).*
>
> *"I used injecting drugs for the first time in Kalimantan. At that time, I moved over there and worked at oil palm plantation for a year. I had many friends at the plantation who were injecting drug users. We were alone, nobody cared about what we did, and we were not afraid of anybody" (MP5, married, Yogyakarta).*

Similarly, the place where the participants were detained was also an environmental factor that supported their engagement in IDU. A few male participants interviewed in Yogyakarta (n=4) described that the prison environment was very supportive of drug use due to the availability and accessibility of drugs. This was indicated as supporting the transmission of HIV infection among them due to the practice of needle sharing and non-disclosure of their HIV status among drug users:

> *"Never run out of stock (of drugs) in the prison. You can use whatever (drugs) you want in the prison, they are available. The environment was very supportive, drugs were available and easily accessible, thus I used it nearly every day. …. Every night, there was music in every room just like in a discotheque. It was highly likely to get HIV in prison if we did not have information about it. Some deliberately spread it (HIV) because we shared the same needles. …. We did not know who was infected. It was not possible to ask about it, while the ones who were (HIV) positive did not want to disclose their status due to the fear discrimination in prison" (MP13, married, Yogyakarta).*

The surroundings or conditions where needles were hardly available or difficult to access were also environmental factors that supported the needle-sharing practice among injecting drug users, which facilitated HIV transmission among them. All the male participants interviewed in Yogyakarta, who acknowledged contracting HIV through IDU, described how needles or injecting devices were limited and difficult to buy back in the 90s and 2000s, a condition reported to support the practice of needle-sharing which was high-risk for HIV transmission among them:

> *"Because of a limited availability of needles at that time (when he was in senior high school) I shared needles (with other drug users). …. It was not easy to find needles. A letter of explanation from a medical doctor was required to buy new needles from pharmacies. We needed to provide our identity card and the letter from the medical doctor to the pharmacist" (MP8, married, Yogyakarta).*
>
> *"I shared needle (with other drug users) because it was difficult to buy a new one. No pharmacies could give you needles if you wanted to buy. So, sometimes I sharpened syringes that were no longer sharp, and we reused it together" (MP11, married, Yogyakarta).*
>
> *"It was difficult to get needles in the prison, so one needle was often used together. I was in prison for two years and eight months and I used drugs nearly every day. If there was not a new needle, then we used together the old one. We just needed to clean it up with water and then reused, we took turn using the same needle. …." (MP12, married, Yogyakarta).*

The environment where the participants lived and worked was also reported as playing an important role in supporting their engagement in sex with multiple sex partners, or changing sex partners over time, a factor that facilitated HIV transmission among them. The availability of brothels and FSWs within the places or communities where they lived and worked, and the workplace environment which allowed men and women to live together, such as in plantation areas, were described by the male participants across the study settings (n=17), who contracted HIV infection through sex, as the supporting environmental factors for their engagement in sex with multiple or different sex partners:

> *"There was a brothel in the place where I lived. ….. I had sex with some of the girls (FSWs). …. I realised that environmental factor had a big influence on my engagement in sex with them. When I was still in senior high school, my house was close to the brothel, only one kilometer, and every night the girls stood on the side of the road. Clients could choose any girls they liked. That was the time I initially engaged in sex and after that I often had sex with them (FSWs)" (MP9, single, Yogyakarta).*
>
> *"I often had sex with different women at the workplace (he used to work at oil palm plantation in Malaysia) because there were many female workers, and many were widowed. …. I often had sex with different women because the environment was supportive. I could meet women (female workers) from different countries, and we, both women and men, stayed together in the plantation area. So, every week I had sex with different women, nobody watched us, so nothing to be worried about. Everybody looked for a sex partner to satisfy their sexual desire every weekend" (MP10, separated, Yogyakarta).*
>
> *"There were many girls (FSWs) from around the world over there (Thailand. He worked in Thailand for several years). It (Thailand) is like the centre, they (FSWs) were from around the world. So, it was easy for me to find them and I just needed to choose the ones I liked" (MP4, single, Belu).*

6.2.5 Financial factors

Financial factors were reported as having a supporting role in the participants' engagement in high-risk behaviours for the transmission of HIV infection among them. For example, as reported by the male participants interviewed in Yogyakarta (n=14) who acquired the infection through drug use, having their own income or savings, and getting financial support from family and friends were some instances indicating a financial condition that enabled their involvement in IDU:

> *"I worked for a ship and had saved a lot. At that time, I already had savings, but all was gone due to drugs. …. I lost everything, spent all the money I had saved for years for drugs" (MP4, married, Yogyakarta).*
>
> *"I worked before (had salary). I also worked (part time) in the evening, taking care of a parking place, I had a parking area. So, I had my own income. It was not difficult for me to get one or two hundred thousand rupiahs (USD 1 = ±IDR 14,000) every day. All the income was used for pleasure, drugs. I used to sell drugs too. So, I have some to sell but I used the rest myself. I do this for years" (MP6, married, Yogyakarta).*

The use of school-related financial support from parents or budget for other needs was also an enabling factor for the participants' engagement in IDU. The male participants in Yogyakarta (n=8) who engaged in IDU since they were in high school or university, described spending tuition fees and other school-related budgets and pocket money for drugs, a strategy used to support their continuous involvement in IDU practices which facilitated HIV transmission among them:

> *"The money to buy drugs was from my parents. Sometimes, I asked money from my parents to buy this and that or for school or university-related needs, but I used it to buy drugs. At that time (when he was at senior high school and university), my parents always supported me financially, and every time I asked money they always gave. So, I never run out of money" (MP7, married, Yogyakarta).*
>
> *"It (using drugs) was financially disadvantageous. My parents were shocked, I asked money for other needs but used it for drugs. The money my parents gave me for whatever purpose, for school fees, and so forth, was used to buy drugs" (MP17, married, Yogyakarta).*

The financial condition of the participants was also indicated as support for their engagement in sex with multiple sex partners. As described by most of the participants across the study settings (n=23) who reported contracting HIV infection through unprotected sexual behaviour, having an individual income and money enabled them to buy sex from FSWs, from whom they might have contracted HIV infection:

> *"At the time I had sex with different women (including FSWs), I worked and had my own incomes and money. So, every time I wanted (to have sex) I just needed to look for the girls, negotiate the prices, pay and have sex. …. I was there (working overseas) for three years. After I came back to Indonesia, I still had sex with them (FSWs) because I still had money. But after the HIV diagnosis I rarely do it, if I do it, I use condoms to protect myself" (MP10, separated, Yogyakarta).*
>
> *"I have my own money because I have a job, and I spend my money just for my own needs. That is why every time I need (sex) I just do it (buy it from FSWs). At that time and also now I do not have a girlfriend, what I can do is buying (sex from FSWs)" (MP9, single, Yogyakarta).*
>
> *"I was working when I was there (in Malaysia) and had income. So, every time I wanted (to have sex with FSWs) I could buy it" (MP1, married, Belu).*

The low price for sex with FSWs was another enabling factor for these participants' engagement in sex with FSWs. They described how they did not care about, or have trouble with spending money for buying sex due to the low prices for sex with FSWs:

> *"The prices for sex with them (FSWs) were very cheap. Initially, I just wanted to try once but after that I got addicted to it and did it again and again. But I did not feel having trouble with money because at that time the prices were cheap, and I worked and had my own salary" (MP9, single, Yogyakarta).*
>
> *"The prices (for sex with FSWs) were around IDR 50,000 to IDR 200,000. These were cheap to me because I was a minibus driver and had money (income) every day. So, I did not care about spending money. I always did (had sex) every time I wanted" (MP20, married, Belu).*

6.2.6 Religious and cultural factors

6.2.6.1 Javanese (Yogyakarta)

The Islamic religious beliefs and Javanese cultural practices of husband and wife relationships in marriage seemed similar, and influenced the sexual relationships of some participants interviewed in Yogyakarta and their wives. For example, in Islam and Javanese culture a wife is obliged to respect, submit to her husband, obey, and do everything her husband says, as well as serve her husband well including sexually. Failing to do so is a sin for her. Such religious beliefs and cultural practices were enacted in their marriage or spousal sexual relations, and seemed to put husbands in a position of power over their wives:

> *"In Islam, it is a sin for a wife if she refuses to have sex with her husband. A wife must do what her husband wants. If her husband wants to have sex then the wife must serve him. The religious thought (in Islam) is like that and we (the man and her wife) try to live such religious thought in our family life. These are similar to our culture. The culture in Jogja or Java says that a wife must submit to her husband. A wife must do everything her husband says. It must be like that. A wife who submits to her husband is the one who serves her husband and her husband's needs, including intimate (sexual) need. We live in our culture, so it should be like that" (MP6, remarried, Yogyakarta).*
>
> *"In Islam, a wife must obey and treat her husband well. She must obey everything her husband says. Whatever a wife wants to do she must firstly get the permission from her husband. She must ask her husband as the head of the family, if her husband does not allow and she insists on doing it, then it is a mistake, a sin for her because she does not obey her husband, she is against her husband. It is also the same in sex matter, as a husband if I want to have sex then my wife must serve me, otherwise it is a sin for her. …. In Javanese culture, a wife must 'ngajeni' her husband. 'Ngajeni' means respect and appreciate. So, in Javanese culture everything a husband says must be obeyed by his wife. As a husband, my wife must do what I say, including about husband-wife intimate relation because that means she is obedient to me" (MP3, married, Yogyakarta).*

However, several other male participants in the setting, who were also aware of these religious beliefs and cultural practices, reported that they adapted these beliefs and practices to their wife's condition, and did not force their wives to just listen to them or do everything they said or wanted. Good spousal communication and understanding seemed to help them adjust these thoughts to their situation, and lead to collaborative decision making in their spousal relationships and family life:

> *"In my experience, I do not fully rely on religious beliefs (that a wife must serve her husband). So, for example, I ask my wife to have sex, but she does not want it because she is tired, that is fine for me. We communicate and understand each other" (MP17, married, Yogyakarta).*

> *"The Javanese culture is very similar to the religious beliefs in Islam, a wife must listen, obey and submit to her husband. I do not do that in my family or my relationship with my wife because we understand each other. My wife and I complement each other. She does not have to do everything I want. We always talk to each other. For example, if I want something from her but she cannot do it because she is tired or not feeling well, she will tell me" (MP1, married, Yogyakarta).*

Similarly, some participants in the area (n=4), whose wives were not infected with HIV, reported that Islamic religious beliefs that prohibit the use of condoms in husband-wife sexual relationships did not influence their sexual behaviour. They started using condoms consistently in their sexual relations with their wives following their HIV diagnosis, even though they were aware that condom use is prohibited in Islam. The practice of condom use was employed as a means to prevent husband-to-wife HIV transmission:

> *"I use condoms after being diagnosed with HIV because I am afraid of transmitting it to my wife. …. We (the man and his wife) know that condom use is not allowed in Islam, but this is for our benefit and health, my wife can get it (HIV) if I do not use condoms" (MP7, married, Yogyakarta).*

> *"In Islam, condoms and other contraception methods are not allowed. My wife and I are aware of that but after the diagnosis I always use condoms in sexual relation with my current wife because I fear of transmitting it (HIV) to my wife" (MP19, remarried, Yogyakarta).*

Furthermore, Islamic religious beliefs about sex were also indicated as having indirect consequences for condom use behaviour of some unmarried participants in Yogyakarta, which was not raised by the interviewees in Belu. These consequences were indicated in the stories of some participants, which illustrated their awareness of Islamic religious beliefs that premarital or non-marital sex is not allowed and is a sin. Such an awareness seemed to lead the fear of being stigmatised by other people who saw them access condoms, as condoms were associated with sex. Such fears prevented them from buying condoms so as to avoid being seen by other people, a factor that influenced their condom use practice, or supported their engagement in unprotected sex:

> *"I hesitated to buy condoms and felt ashamed. I was scared that people who know me might see me buying condoms. I am not married, if they see me buying condoms then they will know that I engage in free sex. In Islam, free sex or sex before marriage is a sin. People may think negatively about me. Therefore, I do not buy condoms and often do not use condoms once having sex with my girlfriend or those girls at brothels (FSWs) (now, he sometimes accesses it for free from HIV clinic). …. I am sure I got it (HIV) from them (FSWs) because I did not use condoms" (MP9, Muslim man, single, Yogyakarta).*
>
> *"After the HIV diagnosis I did not directly used condoms because I was embarrassed to buy condoms, I was embarrassed toward other people. I thought if other people see me buying condoms, what they would say about me because condoms are associated with sex. If they know that I am not married, then they would look at me negatively. It is a sin, because that is what is in our religion (Islam)" (MP 15, single, Yogyakarta).*

6.2.6.2 Belu

Cultural practices in Belu were reported to have an influence on spousal relationships among the male participants. For example, the practice of bride wealth paid by the groom and his family to the bride's family obliged women or wives to submit to their husbands, and put men or husbands in a position of power over women. The description of a few married men (n=5) from some tribes in Belu that applied bride wealth showed that wives were culturally obliged to submit, listen to, serve including sexually and obey their husband who had paid the bride wealth:

> *"From the cultural view, I have paid the bride wealth. So, my wife must submit to me and she cannot go against me because I have paid the bride wealth and she cannot go back to her parents. If she goes back to her parents then I can sue her parents to return the bride wealth I have paid" (MP9, married, Belu).*
>
> *"Husband is the one who has the power in a household. So, a wife must listen to her husband as the one who has the power. A wife must serve her husband, including in*

> *husband – wife (sexual) relation. In our culture, if the bride wealth has been paid then the wife must submit to her husband, all the decision-making in the household is at the hand of the husband as the head of the household. I have paid the bride wealth, so my wife must submit to me as her husband and the head of the household" (MP11, married, Belu).*

The purpose of marriage in the participants' culture, which is to have children, was also reported as a barrier to condom use practices among them. Several married men interviewed in this setting commented that the purpose of marriage is to have children, which is a common perception in their culture. Similarly, expectation of families towards couples to have children seemed to also have an influence on their condom use practices. Thus, condom use in spousal sexual relations was considered unnecessary, as illustrated in the following assertions:

> *"My wife and I never used condoms because I think the consequence of using condoms is that we will not have children. We get married to have children. This is our culture, getting married is to have children. The families will continuously ask 'is your wife already pregnant?' If we use condoms then this (pregnancy) will not happen" (MP2, married, Belu).*
>
> *"I do not use condoms because I want to have children. In our culture, if you are married, that means you have to have children. If not, then families, neighbours and everybody who knows you will continuously ask you about when you will have a child. Sometimes it (not having a child) becomes a subject of discussion among others" (MP16, married, Belu).*

The perception that condom use was not a common practice in marriage was also one of the factors that influenced condom use practices among the married men interviewed in Belu. The majority of married men interviewed in this setting (n=9) stated that they did not think of using condoms in their spousal sexual relations even though condom use was suggested by healthcare professionals. The reasons were that condom use was not a common practice in spousal relationships, unrecognised in marriage and was not introduced by their parents or ancestors. Such perceptions seemed to support their consistent engagement in unprotected sex after their HIV diagnosis, a high-risk factor for HIV transmission among husbands and wives:

> *"So far, I never used condoms because condom use is not a common practice in spousal relationship. Condom use is not recognised in the life of husband and wife. Our parents or ancestors never talked about condoms. After I was diagnosed with HIV, the doctor advised me to use condoms, but I do not really think about using condoms" (MP7, married, Belu).*
>
> *"We (the man and his wife) are not accustomed to using these things (condoms) in spousal intimate relationship. So, how could we suddenly be told to use (condoms)? During our marriage we have never used condoms in our intimate relationship. Condom use is not common in spousal intimated relationships. So, I never thought about condoms in intimate relationships with my wife" (MP14, married, Belu).*

6.3 The impact of HIV on men living with HIV and their families

This section presents the views or perceptions of participants about their experience of the impact of HIV on themselves and their families. This section comprises stigma and discrimination, psychological impact, family separation and spousal divorce, economic impact on the men and their families, and physical impact.

6.3.1 Stigma and discrimination

6.3.1.1 Internal stigma

Perceived and anticipated stigma

The participants' awareness of the existence of HIV stigma and discrimination, and belief about the possibility of experiencing stigma and discrimination due to their HIV-positive status, were the supporting factors for the perceived and anticipated stigma they felt. Most participants across the study settings described how stigma and discrimination were prevalent within community where they lived, which made them believed that they could be stigmatised or discriminated against by family members, relatives, and neighbours or community members if their HIV status was known:

> *"Stigma and discrimination against (HIV) positive people often occur, and that is why I do not want my family (parents and siblings) and relatives to know about it (his HIV status), none of them knows. …. I am afraid my family members do not accept me or feel embarrassed. If so, then it would be complicated, they may chase me away from home" (MP15, single, Yogyakarta).*
>
> *"There are still many (HIV-negative) people who give negative labels towards the ones infected with HIV or avoid them. They do not want to get close (to PLHIV) because they are afraid of getting HIV. This makes me worried because if the community members know that I have HIV then there may be some people who do not want to get close to me, or label me negatively" (MP18, married, Belu).*

The real experiences of stigma and discrimination encountered by other PLHIV were factors that supported the perceived or anticipated stigma felt by the participants. Several participants (n=11) across the study settings stated that stigma and discrimination experienced by other PLHIV, such as being avoided and rejected by other people and family members, and children being rejected in schools due to their parents' HIV-positive status, made them think that they would experience the same treatment if their status was known to other people:

> *"Discrimination still happens a lot. …. A friend of mine (who is HIV-positive) enrolled his child to a school but the school did not accept the child due to his (the father's) HIV-positive status. So, I am scared if my neighbours and other people know about my HIV status, it can have negative impact on my family, and my children could be discriminated against" (MP19, remarried, Yogyakarta).*
>
> *"It (HIV-related stigma) once happened to a (HIV-positive) woman in X (the name of his place of origin), she was avoided by everybody. Healthcare professionals also seemed reluctant to get close to her. I saw that she was very depressed. I am scared because stigma and discrimination are still high, and I can also be stigmatised or avoided if people know that I have HIV" (MP6, single, Belu).*

Self-stigma

Self-stigma referring to an individual's endorsement of negative beliefs or perceptions about HIV and PLHIV was also experienced by the participants following their HIV diagnosis. Self-stigma, as described by several participants across the study settings (n=13), was reflected in their feelings of shame towards their families, neighbours, friends and other people due to having contracted HIV or having HIV-positive status. Such feelings seemed to be supported by the negative social perceptions of HIV as a disgrace, a bad and shameful infection, which they seemed to endorse and project on to themselves:

> *"I am afraid if I get sick and the neighbours know it (his HIV status), I am still scared of that. HIV is a disgrace. It is shameful if people know that I have HIV because it is a disgrace not only for me but also my family" (MP15, single, Yogyakarta).*
>
> *"In our community, this (HIV infection) is a disgrace, disgusting disease (infection) which makes people scared, and I have it. That is why I feel ashamed very much. I still feel ashamed up to now if I meet my friends" (MP12, widower, Belu).*

The social perception that associated HIV infection with engagement in free sex or sex with FSWs was also a factor that supported self-stigma among the participants. The stories of several participants interviewed in Belu (n=5) showed that they were aware of the social perception associating HIV infection with engagement in free sex or sex with FSWs, which considered as shameful behaviour for a married man. These participants endorsed or applied this perception to themselves:

> *"I feel inferior because I know that some of the families of my wife know that I have HIV. I feel inferior and ashamed if I meet them, especially the ones working in health sector because I know I am a bad person and I have done shameful things (sex with FSWs). Everybody knows that people get HIV because of free sex with those girls (FSWs)" (MP2, married, Belu).*
>
> *"People like me who get HIV feel inferior and ashamed. (HIV negative) People might not know that I have HIV but inside my heart I always feel ashamed and inferior*

> *because I am an old man (60 years old) and now get this shameful disease (HIV infection). People might think negatively about me and my wife. Here, most people know that this is a disease (infection) of 'naughty people' who engage in free sex and I have this shameful behaviour, that is why I got HIV" (MP14, married, Belu).*

Hiding HIV status and delaying access to treatment

The perceived or anticipated stigma and self-stigma associated with HIV felt by the participants were reported to lead to the participants hiding their HIV status from family members, neighbours or other people. Most participants across the study settings were concerned with the possibility of experiencing stigma and discrimination, and hence decided to hide their HIV status from others:

> *"I do not want other people to know my (HIV) status because I may get stigma and discrimination. …. It is better to keep it secret from others because many people do not have knowledge about HIV, and stigma and discrimination against PLWHA often happen. …." (MP8, married, Yogyakarta).*
>
> *"If others know that I have HIV then they may not want to get close to me, so it is better not to let other people know (about his HIV status). I might be seen like an outcast in people's eyes if they know about this (his HIV status)" (MP2, married, Belu).*

Hiding their HIV status from other people was also used by the participants as a strategy to prevent stigma by association, which could also be experienced by their family members. Several participants interviewed across the study settings (n=11) stated that HIV stigma and discrimination may not only happen to themselves but also to their family members if their HIV status was known to others. Hence, they decided to hide it from others:

> *"I still hide my HIV status. …. It is not a problem for me to disclose and if people around me know that I am HIV-positive, but what I am concerned about is my children. I am scared of my children getting discrimination. If the neighbours know that I am positive, would they accept my children or not?" (MP3, married, Yogyakarta).*
>
> *"I keep it (his HIV status) secret because I fear the possibility of stigma and discrimination against me and my family. If the neighbours know that I have HIV they*

> *may not come to our house and avoid me and my parents because they are afraid of getting HIV" (MP6, single, Belu).*

Perceived stigma was also reported to influence the participants' access to healthcare services. The stories of a few male participants in Yogyakarta and Belu (n=5) revealed that the fear of stigma and discrimination from other people caused them to delay the initiation of HIV treatment or the decision to access healthcare services in other healthcare facilities which were far from the community where they lived. Such decisions were made to avoid the possibility of meeting neighbours or people who knew them, which might lead to the disclosure of their HIV status and stigma and discrimination:

> *"The fear of discrimination was so high (in the early stage of his HIV diagnosis), thus I did not directly undergo the treatment. I was afraid that people would know about my HIV status. I was so sad and broken. I did not think of anything but getting drunk to forget this (his HIV status)" (MP13, married, Yogyakarta).*

> *"I do not access healthcare services at the community health centre in my place and decide to access them here (hospital). The problem is that the healthcare professionals in my place are my relatives and friends, if they know that I have HIV, then the information about my (HIV) status will spread everywhere" (MP6, single, Belu).*

6.3.1.2 External or enacted stigma

Stigma and discrimination within family

External or enacted stigma referring to unfair treatment or discrimination by others due to their HIV infection was reported as occurring within the family of the participants in this study. Several participants across the study settings (n=11) stated that due to their HIV-positive status they experienced discriminatory and stigmatising attitudes and behaviours from their parents, siblings and in-laws. These behaviours included ostracism, avoidance, separation of eating utensils and clothes, and the spread of their HIV status:

> *"I experienced it (discrimination), it felt painful here (pointing to his chest). I was ostracised by family: my father, mother, brothers and sisters. At that time, I did not have the spirit to live anymore because I was ostracised like that. It took place for a long period of time till I remarried. …. At the first time I told them that I contracted HIV, everybody was shocked and angry at me. I was nearly chased away from home. …. I was scolded and asked not to use the toilet, if I used it then I had to clean it up afterwards (the man and his second wife lived apart from his family after they got married)" (MP19, remarried, Yogyakarta).*
>
> *"My father, mother and nephew know about my (HIV) status. My eating utensils, food and water are separated from those of other family members. They separate all of these, I feel so painful and sad, but I can do anything and just accept it. I feel like my family members do not really care about me. They do not care whether I eat or not and this makes me cry sometimes" (MP5, single, Belu).*
>
> *"My mother in-law is very cynical to me even up to now. Her words hurt so much. She once said I am useless and bring unfortune because I get this HIV. My mother in-law hates me very much. She has spread information to other people in the community and mosque that I have HIV" (MP14, divorced, Yogyakarta).*

Fear of contracting HIV was reported by the participants as the main factor that supported the unfair treatment or discrimination by family members toward them. Such fear was reported to be supported by the lack of knowledge of family members about HIV, or the means of HIV transmission and the influence among family members about the perils of HIV:

> *"I was discriminated against by my parents. My father collected all my clothes and boiled them with hot water. He was asked by his second wife to do so. His second wife do not want to accept me. It is apparent that they are scared of me transmitting the virus to them because they do not know that HIV does not transmit through clothes" (MP4, married, Yogyakarta).*
>
> *"I feel that my extended family leaves me. There is no love from them. None of them really care about me. I feel that they avoid me. My aunties will not use any glass I have touched, and this makes me very sad. They are afraid that I may transmit it (HIV) to them. To be honest, some family of mine (extended family) do not accept me in their house because they are scared that people may not come to their house if I have come to their house and used their stuff. They do not understand about HIV and fear contracting it from me. You know families here are very close to each other, so if some have such kind of feeling (scared) then they might talk to each other and influence each other" (MP9, married, Belu).*

Stigma and discrimination within the community

Unfair treatment and discrimination by others toward the participants also occurred within the communities where they lived. Keeping distance, avoiding handshakes and disallowing children to come to their house, were some instances of the discriminatory behaviours of community members or neighbours and friends against several of them (n=11) across the study settings:

> *"Our neighbours know my status …. They do not allow their children to come and play in my house anymore, they keep distance. Some of them do not want to talk to me or shake hands with" (MP8, married, Yogyakarta).*
>
> *"There are neighbours who keep distance, do not want to close to me (physically). They do not want to get this disease (infection). Some of my friends who know (about his HIV status) also leave me" (MP10, single, Belu).*

Fear of the possibility of contracting HIV infection was reported by the participants as a major supporting factor for the discriminatory behaviours of the community members toward them. The participants described that such fear was supported by the social perception about HIV as a dangerous, deadly, disgusting and embarrassing infection which had no cure, and their lack of knowledge about HIV. These were also acknowledged as supporting factors for stigma and discrimination toward PLHIV in general:

> *"It seems that people in the mosque do not like me (due to his HIV status). During the Friday prayer I sit in the middle and the ones who come after me will shake hand with others but not with me. They are scared of getting HIV. I know that they do not know much about HIV. What they know is that HIV is deadly and there is cure for it. This kind of information spreads in the community and influences the way people (community members) see or interact with me" (MP14, divorced, Yogyakarta).*
>
> *"Many people do not know about HIV and they think that HIV is a disease (infection) of people who have sex with multiple sex partners. They think people get HIV because they change sex partners over, which is something that many people do not accept. That is why people like me look bad, negative to their eyes. Perceptions like this spread*

> *from mouth to mouth among community members and people are easily influenced by what they hear" (MP8, single, Belu).*

Religious and moral-related perceptions in Islam about HIV were also brought up by the participants in Yogyakarta as contributors for the stigma and discrimination toward PLHIV in general, factors which were not identified in interviews with the participants in Belu. For example, religious-related perceptions in Islam about HIV as a curse, disgrace and a sin, and the moral perceptions about PLHIV as the ones with a low moral standing, were reported to contribute to stigma and discrimination toward PLHIV:

> *"There are still many people who look at HIV as a curse, the worst disease (infection) because it is acquired through free sex. People think it is a disgrace because it is acquired through sexual behaviour that deviates from the religious thoughts. There are still lots of people who have such thoughts and I have heard people said those things. Such perceptions are very much disturbing because HIV stigma and discrimination towards PLWHA often happen due to perceptions like these" (MP1, married, Yogyakarta).*
>
> *"As I know, for Muslim people, HIV is a disease (infection) of people of Sodom and Gomorrah, cities that were cursed by God because most people in these cities practised free sex and sodomy. …. Therefore, many Muslim people very much disdain people who contract HIV and look at them as sinners" (MP16, single, Yogyakarta).*
>
> *"Many people still look at them (PLHIV) as the ones who have low moral standing compared to the others (HIV-negative people)" (MP11, married, Yogyakarta).*

Stigma and discrimination within healthcare settings

Discriminatory and stigmatising attitudes and behaviours by others were also experienced by the participants within the healthcare facilities. Several participants in Belu and Yogyakarta (n=14) described how they experienced stigma and discrimination from healthcare professionals in healthcare facilities where they accessed non-HIV related healthcare services. An unwillingness to touch or treat them, keeping distance from them, leaving them untreated, showing fear and disgust towards them, refusing to shake hands with them, and spreading their HIV status, were the examples of discriminatory and stigmatising attitudes and behaviours of healthcare professionals toward these participants:

> *"I experienced discrimination in healthcare facility, but it was in another ward (dental ward), not in HIV ward (clinic). At that time, I wanted to check my teeth. …. I was honest, I told the dentist that I am HIV-positive. The dentist was shocked and nervous, perhaps she never had patients with HIV. She said to me: 'please give me a moment, I will talk to my boss (head of the ward)'. She came back and said: 'I cannot take the decision (to serve him) because we have to have a meeting first. I was told to come back in four days. After four days, I came back and received the same treatment. I was not served, and she said the decision has not been made. …." (MP10, separated, Yogyakarta).*
>
> *"I once experienced it (discrimination) at the community health centre. The nurses kept distance from me once they know that I am HIV-positive. They avoided to shake hand with me or touch my body" (MP3, married, Belu).*
>
> *"The nurses (in community health centre) were the ones who spread the information that I have HIV, that is why some friends of mine know about my (HIV) status" (MP5 single, Belu).*

A few of these participants in both study settings (N=5) also reported that they were verbally discriminated against by healthcare professionals in non-HIV wards or clinics. Calling out a patient's HIV status in front of other patients and telling each other in front of a patient to use disposable gloves due to the HIV-positive status of a patient, were some instances of verbal discrimination by healthcare professionals toward these participants:

> *"I had experienced discrimination. I went to healthcare facility where I was registered (as indicated in his health insurance) to ask for referral letter (to access HIV care services in other healthcare facility where the services are available), the nurse called out my HIV status. She mentioned it clearly which made other patients surprised. So, it was like my status was open to other people" (MP11, married, Yogyakarta).*
>
> *"Once my child was admitted to hospital, the nurses told each other in front me to use disposal gloves and said: 'this kid's dad is HIV-positive'. What they said made me feel very sad and angry at the same time, but I could not do anything" (MP9, married, Belu).*

As a consequence, some of these men avoided meeting healthcare professionals who were discriminative against them, and decided to access healthcare services in other healthcare facilities and hide their HIV status from healthcare professionals:

> *"After I was rejected (he was not served for tooth extraction in a dental clinic due to his HIV status), I decided not to tell my (HIV) status to any healthcare professionals every time I access (non-HIV related) healthcare services in any healthcare facilities other than HIV clinic and I do not want to go to that (dental) clinic anymore" (MP10, separated, Yogyakarta).*
>
> *"I do not want to see her face anymore (a nurse who spread his HIV status to other community members). I do not want to go the community health centre either because I might meet her there. So, this (HIV clinic which is a part of a public hospital) is the only place I access healthcare services" (MP10, single, Belu).*

6.3.2 The psychological impact of HIV on men living with HIV

All male participants interviewed across the study settings reported having experienced psychological challenges due to their HIV-positive status, the fear of transmitting HIV to wives and children, the fear of death and the concerns they had with the future of their family.

6.3.2.1 HIV-positive status and fear of transmitting HIV to wives and children

An HIV diagnosis was reported to cause negative psychological challenges, reflected in a range of negative feelings and emotions, on the participants across the study settings. Feeling broken, regretful, desperate and stressed, losing the spirit to live, and easily getting angry or the inability to control anger, were some instances of the negative feelings or emotions experienced by the participants (n=16) at certain points in their lives following the HIV diagnosis, as described below:

> *"I could not control my emotion after the HIV diagnosis. One day I was in the office, I took my medicines at 9 in the morning and a friend of mine said: 'oh you take HIV medicine' and I threw the glass on him. I could not control the stress I experienced. I was easily getting angry" (MP18, single, Yogyakarta).*

> *"I feel very much pressured with my condition (he was diagnosed with HIV two months prior to the interview). Getting infected with HIV has extreme impact on me. All negative thoughts and feelings always come to my mind, I feel very regretful with what is happening to me and my wife (he transmitted the virus to his wife). It is very stressful and I am desperate due to this infection" (MP14, married, Belu).*

Fear of the possibility of transmitting HIV to their wives or children was another negative feeling or emotion experienced by the participants after their HIV diagnosis. A couple of participants in Yogyakarta reported that they felt scared for a long period of time because of the awareness of the possibility of transmitting the virus to their wives and children:

> *"I was scared of transmitting the infection to my child. I did the HIV test for my child since he was born until he was at the third year of elementary school. I felt scared of the possibility of my child getting infected for about 7 years. Feeling scared and stressed were mixed up for years because my wife breastfed my child and at that time my wife and I had not done the HIV test (his wife is also HIV positive)" (MP3, married, Yogyakarta).*
>
> *"To be honest I feel scared about husband-wife intimate relations. Thus, now we (the man and his wife) hardly have sex, perhaps once or twice a month. I am scared of transmitting the virus to my wife even though we use condoms. My wife already did the (HIV) test three times and the results are negative, but I am still scared. I feel scared every time we have sex" (MP5, married, Yogyakarta).*

6.3.2.2 Fear of death and concerned with the life and future of the family

Fear of death was another negative feeling experienced by the male participants in the study during the early stages of their HIV diagnosis. As reported by several participants across the study settings (n=12), fear of death was felt mainly due to the thought that they would not live long or get a full recovery from HIV, and their experiences of seeing other people die from HIV/AIDS:

> *"At the beginning of the infection, I was so scared because I know that I will not fully recover. The doctor told me so. I thought that my life was over, I would die soon. It was a very stressful period I have ever had in my life" (MP6, remarried, Yogyakarta).*

> *"My biggest fear was death. Once I was tested positive, I directly thought about death. I would die soon. I was very scared because I have heard and seen people die from this disease which was terrifying for me" (MP17, married, Belu).*

Feeling worried and frustrated due to the concerns about their own lives, the lives of their parents and the future of their children were also psychological impacts experienced by the participants (n=8) after they were diagnosed with HIV. Such feelings and concerns were experienced by the participants due to the thought that they might not be able to live a normal life or to live longer following their HIV diagnosis, as described in the following assertions:

> *"Once I knew that I am HIV-positive, I felt down and so worried. The feelings were mixed up. I thought a lot about my life, how many days or months I still have. What about my family if I die? I was responsible for my parents; I am the only one in the family who takes care of them. If I die, who would take care of them, who would help them. This made me scared and even now I still feel worried sometimes" (MP10, separated, Yogyakarta).*
>
> *"I am worried and concerned a lot with the future of my children. I feel sorry for my children, if I die then they would not go to school, they would not have a bright future" (MP7, married, Belu).*

6.3.2.3 Feeling guilty and self-blaming

Feeling guilty towards their wives, brothers and sisters was another psychological consequence experienced by the participants after their HIV diagnosis. As explained by several participants across the study settings (n=11), such feelings were experienced because they had transmitted the virus to their wives, and had caused HIV-related burdens to their wives, brothers and sisters. They acknowledged the extra efforts being made by their wives or sisters and brothers to take care of them and support their lives and futures due to their HIV diagnosis:

> *"I feel guilty to my wife because I transmitted the virus to her. When I was sick (hospitalised) she took care of our children. My wife gets the virus from me, but she still has to take care of me, I feel very much guilty because of that. She carries the burden I have caused" (MP1, married, Yogyakarta).*
>
> *"Since I knew that I have HIV, I feel guilty to my brothers and sisters. I am regretful. My brothers and sisters try very hard to support my life and future (his life and study at university was supported by his older brothers and sisters). I feel guilty to them because they support my life entirely and since last year, I have added another burden (He was diagnosed in 2018, a year before this interview was conducted)" (MP8, single, Belu).*

Self-blaming was another psychological impact experienced by the participants following their HIV diagnosis. A few participants in both study settings (n=4) reported that they blamed themselves due to their engagement in risky behaviours such as unprotected sex and IDU, through which they had acquired HIV:

> *"I blame myself. Why I engaged in the bad behaviour (IDU) which makes me feel the impact now. I blame myself because if I did not use (injecting) drugs, then maybe I am not like this now" (MP17, married, Yogyakarta).*
>
> *"I am regretful very much and blame myself, why I got involved in risky behaviour (unprotected sex and change sex partners over time). Now I must live with this disease (HIV infection) for the rest of my life" (MP1, married, Belu).*

6.3.3 Family separation and spousal divorce

A diagnosis of HIV in the male participants was reported to have a negative impact on their family and spousal relations. A few of them in both study settings (n=4) described how they were scolded by their wives and their wives' families, and asked by in-laws to divorce or leave their wife and children following their HIV diagnosis, as illustrated in the stories below:

> *"At the beginning of the HIV diagnosis my father-in-law took care of me and helped me to undergo medical treatment, but he passed away. A few years after he passed away, I was asked to divorce with my wife because this HIV. …. My mother in-law asked me to do that, she separated us. She separated my wife and child from me" (MP14, divorce, Yogyakarta).*

> *"After my wife and I were tested positive with HIV, my wife and her family scolded me and asked me to go back to my parents and leave my wife and children. So, my parents and bothers came and took me home for about six months. I started taking the medicines in my parents' house. We were separated for about six months (he came back to his wife and children after his health condition got better)" (MP1, married, Belu).*

Family separation and husband-wife divorce occurred or were experienced by these participants because of the anger and accusations of their wives and their wives' families. They were accused of having other female sex partners from whom they got the virus and transmitting it to their wives, and were seen as unlucky bearers in the family due to their HIV positive status. The wives' fear of the possibility of contracting HIV from their HIV-infected husbands was also raised as a supporting factor for husband-wife divorce:

> *"The reason my wife's family was so mad at me and told me to go back to my parents was because I transmitted the virus to their daughter (his wife). (The man admitted that he transmitted the virus to his wife)" (MP1, married, Belu).*
>
> *"My mother-in-law considered me as a bad luck for their family, she hated me very much. Therefore, after the death of the father-in-law she separated us (the man and his wife and child)" (MP14, divorce, Yogyakarta).*
>
> *"We (the man and his ex-wife) divorced because she knows I get HIV. Perhaps she is scared of getting HIV from me. …. She left me and the reason was because I have HIV" (MP19, remarried, Yogyakarta).*

6.3.4 Physical Impact

Most male participants interviewed across the study settings (n=35) reported as having experienced a poor physical condition due to the infection. Decreased body weight, getting skinnier, having a very low CD4 count and feeling physically tired and weak, were the signs of their poor physical health condition mentioned by the participants as a consequence of having the HIV infection:

> *"I was very weak physically. My CD4 count was one. My body was just the skin and skeleton and was very black all over. My body weight decreased from 72 Kg to 40 Kg" (MP17, married, Yogyakarta).*
>
> *"I have been losing body weight and getting skinnier like this (point to his body). I feel weak physically. Hope this medicine can help (he was diagnosed with HIV a month prior to the interview)" (MP10, single, Belu).*

A late diagnosis of HIV, the delay of initiating medical treatment, and the condition of having the TB infection seemed to worsen the physical and health conditions of these participants. Nearly all the male participants across the study settings reported that they were diagnosed with HIV once they fell sick or were admitted to hospital, which indicated a late HIV diagnosis as well as treatment. Besides, having another infection such as TB seemed to also worsen their physical and health condition. Nearly half of the male participants across the study settings reported being infected with TB as well:

> *"Once I was diagnosed with HIV my physical condition was already very weak, I fell sick and was admitted to hospital and tested positive with HIV. Before I started ART I was also diagnosed with TB. So, I took TB medicine first and experienced negative side effect of the medicine, I became deaf and nearly paralysed" (MP8, married, Yogyakarta).*
>
> *"I did the HIV test because I was sick, and my physical condition was getting weaker drastically. I was also infected with TB. My body weight decreased, and I became very skinny" (MP18, single, Yogyakarta).*
>
> *"I know about my HIV status once I fell sick and was admitted to hospital, and the doctor told me that I have HIV and TB. So, I was diagnosed with HIV once I was already very weak physically" (MP5, married, Belu).*

6.4 Men's access to HIV care services

This section presents the accounts of the participants about their experience with their access to HIV care services. Guided by access to healthcare framework (see section 3.4 for a discussion of the framework), this section presents the characteristics or dimensions of the supply side (healthcare providers) and the corresponding abilities of the demand side (men living with HIV), which determine the accessibility of the HIV care services. The dimensions of the supply side and the corresponding abilities of the demand side are the availability of the healthcare services and the ability to reach the healthcare facilities providing the services; the approachability of the healthcare services and the ability to perceive the need for the services; the affordability of the healthcare services and the ability to pay for the services; the appropriateness of the healthcare services and the ability to engage in the services; and the acceptability of the healthcare services and the ability to seek the services.

6.4.1 Availability of healthcare services and ability to reach the services

The availability dimension which refers to the physical existence of the HIV care services in the healthcare facilities, such as hospitals and community health centres that could be reached, was indicated as a supporting factor for accessing the services among all the male participants interviewed in Yogyakarta. Antiretroviral medicines, CD4 and viral load tests, and kidney and liver function tests, were some instances of HIV care services available in the healthcare facilities and accessible to the participants in Yogyakarta:

> *"I usually collect the (antiretroviral) medicines and do CD4, viral load, kidney and liver function tests in X hospital. …. All these services are available here (Yogyakarta) and I just need to access them" (MP3, married, Yogyakarta).*
>
> *"The medicines and medical tests like CD4 and viral load tests are available in hospitals and community health centres here (Yogyakarta). I have accessed all these services. All patients like me (HIV-positive) can access these services here" (MP7, married, Yogyakarta).*

However, the availability of HIV care services for PLHIV in Belu was very limited. All the participants reported that ART was the only treatment service available for PLHIV in Belu, and this service was only available in an HIV clinic located in the town of Atambua:

> *"HIV service is available here but only the (antiretroviral) medicines. Other services like viral load and CD4 test are not available. If (HIV) patients want to know about their viral load or CD4 counts then they have to go to Kupang (hospital at provincial level, which is about 300km and takes 7-8 hours travel by bus) but even in Kupang those tests are not always available. So, what I access every month is the medicines" (MP13, single, Belu).*

The availability of healthcare professionals, such as nurses and doctors who were trained in HIV services, to deliver the healthcare services to PLHIV was acknowledged by the participants. All male participants in both study settings described that HIV-trained healthcare professionals were available in the healthcare facilities providing HIV care services, and could be reached at HIV clinics or through their mobile phones and be consulted at any time. The availability of healthcare professionals with their help, support and encouragement seemed to be enabling factors for the participants' access to the services as illustrated below:

> *"The doctor and nurses are very professional. They know well about HIV and serve patients living with HIV very well. They always available in the HIV clinic, so I can meet and talk to them any time. Every time I collect my medicines if I have any health issues then I always talk to the doctor. She is very supportive. She encourages me to adhere to the medication" (MP8, married, Yogyakarta).*
>
> *"I also have the WhatsApp number of the doctor (Medical doctors at the HIV clinics gave their mobile numbers to their patients living with HIV for online consultation). So, if I have any health issues then I can directly consult with the doctor. I feel that the doctor who serves patients (PLHIV) is very helpful" (MP6, remarried, Yogyakarta).*
>
> *"Doctors and nurses in this clinic are very supportive. I think there are three doctors and three nurses. The nurses and one of the doctors are always here (in the HIV clinic) every day. They are very professional in handling patients with HIV like me. So, if I come here like now, I can consult with one of the doctors or nurses if I have any health concerns" (MP8, single, Belu).*

The ability to reach the services, which refers to personal mobility, the availability of transportation and occupational flexibility, was indicated as another facilitator for access to the services among the participants across the study settings. Most male participants (n=18) in Yogyakarta and nearly half of those in Belu (n=9) commented that they could reach the healthcare facilities to access HIV-related healthcare services without any difficulties. Proximity to healthcare facilities and the availability of a private vehicle for transportation were the enabling factors for these participants to reach the healthcare facilities:

> *"I live nearby the hospital where I access the (antiretroviral) medicines for the treatment every month, probably six kilometres from my house. It is reachable and I use my own motorbike" (MP5, married, Yogyakarta).*
>
> *"It is probably five kilometres from my house to this clinic, very close, and I use my own motorbike. So, I do not have any problems to reach this clinic" (MP4, single, Belu).*
>
> *"I come here by car (his own car) and the driver drives me here. I do not feel strong to drive motorbike. It is just a few kilometres and very fast using car to arrive here (HIV clinic)" (MP14, married, Belu).*

However, just over half of the male participants interviewed in Belu reported that they felt burdened or experienced difficulties in reaching the healthcare facilities providing HIV services. Distance to an HIV clinic and the lack of private and public transportation were some instances of the barriers for the participants to reach the healthcare facilities and access antiretroviral medicines:

> *"Public transport from my house to community health centre and to this clinic is not available. I do not have motorbike. This is difficult for me and I feel burdened every time I come here to collect medicine because I have to use motorbike taxi (Ojek) and it is expensive" (MP3, married, Belu).*
>
> *"I live far from away from here (HIV clinic). It is about 70 kilometres from my house to this clinic, that means 140 kilometres for two ways: come here and return home. I come here by minibus (mikrolet: a public transport that carries 8 to 10 passengers) but the space (seat for passenger) is not always available. If it is full of passengers then I have to wait until midday or afternoon or the next day" (MP7, married, Belu).*

The availability of time and flexibility in their working schedule were also enabling factors for their access to the services among the male participants across the study settings. Some participants stated that they could get permission from their employers, while others could schedule their own time to collect their medicines every month as they were unemployed or self-employed or retired or had flexible working schedules. These were indicated as support for their access to the HIV care services:

> *"I am self-employed. I have my own business, a few villas, so I can manage my own time to come to X hospital every month. It is not a problem for me" (MP16, single, Yogyakarta).*
>
> *"I ask permission from my boss every time I come to collect the medicines at X clinic (name of the HIV clinic at X hospital) and so far, it is not a problem. …." (MP5, married, Yogyakarta).*
>
> *"I can come here to access healthcare services at any time because I am now free, I have just retired, I have plenty of time" (MP14, married, Belu).*
>
> *"I work as a motorbike taxi driver, so I manage my own time. My time is very flexible. Sometimes I drive my wife here to collect the medicine and I go back to look for passenger or we come here together and then after collecting the medicines I drive her back home and continue my work" (MP2, married, Belu).*

6.4.2 Approachability of healthcare services and ability to perceive need for healthcare

The approachability of the HIV care services, which was reflected in how well disseminated the information about the services was among people living with HIV, was another factor that supported the access to the services among the male participants. All the male participants interviewed in Yogyakarta described how information about the services was available and well-disseminated among them through HIV information sessions provided by the healthcare professionals and the companions of PLHIV in collaboration with NGOs, and through regular peer support group meetings and WhatsApp groups:

> *"Information about healthcare services is widespread among PLWHA, it is also updated through WhatsApp group of peer support groups. For example, if there are free tests (viral load or CD4 tests) then the information will be shared by the companions of PLWHA through WhatsApp groups. We (PLWHA) can also ask doctors and nurses in healthcare facilities" (MP4, married, Yogyakarta).*

> *"Information about HIV care services is disseminated through socialisation (HIV information sessions) at sub-district and urban village levels by healthcare professionals in collaboration with NGOs. I was an outreach staff (of an NGO) and a companion of PLWHA. We also delivered HIV information sessions at schools and universities" (MP8, married, Yogyakarta).*

For the male participants in Belu, healthcare professionals were mentioned as the only source of information through whom they acquired information about the HIV care services available for them. All the participants in this setting stated that they heard information about the services from doctors and nurses once they were diagnosed with HIV, and every time they accessed the services. Besides, they also reported as not having heard of or participated in HIV information sessions from healthcare professionals or any NGOs or become part of peer support groups in the study setting:

> *"I firstly knew about HIV care services from nurses and doctor here (HIV clinic). I was tested positive with HIV here and then they told me that there are medicines for this disease (HIV infection) and if I take the medicines then I will be fine. I knew nothing about the medicines prior to the diagnosis because there have never been any information sessions from healthcare professionals about HIV services in the community where I live. …. I do not know about peer support group meeting" (MP6, single, Belu).*

> *"So far, I get information about this clinic and the treatment for patients (PLHIV) from nurses and doctors here (HIV clinic). They told me about these when I was diagnosed with HIV, and every time I come here to collect the medicines, they always remind me to come back in the next month. I have not heard of any information socialisation from healthcare professionals or NGOs about the treatment for HIV" (MP12, widower, Belu).*

Although information on the HIV care services had been disseminated among the participants or known to them at the time the study was conducted, nearly all of them across the study settings acknowledged that they only became aware of the availability of the services once they were diagnosed with HIV. The participants described that they started receiving information and advice from doctors, nurses and companions of PLHIV about the availability of HIV treatment in healthcare facilities after their HIV diagnosis:

> *"I know about the healthcare services for patients like me after the diagnosis. I was advised by a nurse and she took me to the doctor. They (the nurse and doctor) told me about the treatment and I was advised to start ART" (MP1, married, Belu).*
>
> *"At the beginning I got information about HIV care services from a companion of PLWHA in an HIV information session and then in the peer support group meetings. I did not know anything about the services prior to the diagnosis. Once I was tested positive with HIV, I was guided and supported by a companion of PLWHA from an NGO to start the medication" (MP13, married, Yogyakarta).*

The ability of the participants to perceive their need for healthcare or treatment was determined by their knowledge of the existence of and belief about the care or treatment, and was another supporting factor for their access to the available HIV care services. All the participants across the study settings stated that they were aware of their need for the treatment and deemed antiretroviral medicines as their basic need, which seemed to support their regular access to the services:

> *"I am aware that the treatment for HIV is just like my basic need. So, it is compulsory for me to access the medicines every month" (MP2, single, Yogyakarta).*
>
> *"Since the beginning of the treatment I am aware that the medicines are just like my food every day and I need to collect them here every month" (MP9, married, Belu).*

The participants' ability to perceive their need for and access to the healthcare services available for them seemed to be supported by the healthcare professionals and companions of PLHIV. All the participants across the study settings described that they received supports from and were reminded and encouraged by companions and healthcare professionals who provided the HIV services to continue accessing the services:

> *"Doctor and nurse always remind me every time I collect the (antiretroviral) medicines, if I do not collect it as scheduled, they will give me a call to remind me. The companions of PLWHA also remind us through our WhatsApp group" (MP15, single, Yogyakarta).*
>
> *"I come here to collect the medicines every month because I need it. The doctors and nurses always remind and encourage me to collect the medicines on time here and always come back here next month to collect it again. The nurse has written the date*

> *for the next month (on his patient's card), the date I have to come here to get the medicine" (MP16, married, Belu).*

6.4.3 Affordability of healthcare services and ability to pay for the services

The affordability of the healthcare services, which reflects the economic capacity of participants to spend their resources to access the HIV care services, was another supporting factor for accessing to the services among the participants across the study settings. Most participants interviewed in Yogyakarta (n=17) and just over a half of those in Belu (n=11) stated that the HIV care services were affordable as they had the National Health Insurance (BPJS), which was acknowledged to facilitate their access to the services:

> *"All the healthcare services are free because I have the National Health Insurance (KIS type). It is very helpful. It helps me undergo the treatment for free. If I do not have the insurance, then it would be very complicated for me because the regular health expense every month will be very much burdensome" (MP13, married, Yogyakarta).*

> *"We (the man and his wife) have the KIS card (fully government subsidised insurance), so we do not pay anything every time we access the medicines. All healthcare services are free, we just need to provide the care. It is very helpful for us and because of this (insurance) we still access the medicines up to now" (MP1, married, Belu).*

> *"I use BPJS (the independent type) every time I access the medicines. It helps me a lot. I just need to pay the monthly fee to the insurance" (MP6, single, Belu).*

The ability of the participants to generate an income to pay the monthly fee of the insurance and transportation-related costs to healthcare facilities was also an important supporting factor for their access to the services. Most participant in Yogyakarta (n=17) and several in Belu (n=8) reported that they were able to pay the healthcare services or the monthly fee of the insurance and the transport costs because they had their own income:

> *"I pay sixty thousand rupiahs if I am not mistaken, so it is one hundred and twenty thousand rupiahs for me and my wife (the monthly fee of the insurance, second class). I can still handle it because I work (have income) and my wife also has income, so it is not a problem to pay that amount, we can afford it. For the transport, we spend about fifty thousand rupiahs for the gasoline for my motorbike. It is not a problem either, we can afford it because we have income every month" (MP1, married, Yogyakarta).*

> *"I used to use BPJS (the independent type) but I have time constraint to collect the referral letter from community health centre, so I directly come here and choose to pay the service costs by myself, it is not much. I have my own salary" (MP4, single, Belu).*

However, more than half of the participants in Belu (n=12) and a few in Yogyakarta experienced difficulties in paying the monthly fee of the insurance or the cost for healthcare and transportation to the healthcare facilities. These participants stated that they were unemployed, lacked income and depended on the support from family and other people. These were circumstances which reflected the inability of these participants to afford the monthly fee of health insurance, healthcare expenses and transportation costs:

> *"I use the BPJS (independent type), so I can access healthcare services for free, but I have to pay the monthly fee of insurance. Now, I can afford it because I am helped by people in the Mosque. What would happen to me if they do not support me anymore? I feel burdened very much because my life fully depends on the support from other people. I do not work and do not have income. How long they would keep on helping me. I feel uncomfortable and insecure" (MP14, divorce, Yogyakarta).*
>
> *"I feel burdened with the healthcare costs. Although, the treatment is free, but I have to pay the amount of IDR 25,000 (±USD 2) to the insurance (monthly fee) and also spend about IDR 70,000 for transportation every month, excluding the costs for food and drink. I need to eat because it is a long way to come here and return home. It is difficult to get such amount of money every month because I am not working at the moment" (MP5, single, Belu).*

The inability to afford these healthcare-related costs or the monthly fee of health insurance was reported to lead to the termination of their health insurance, loan and delay in accessing healthcare services or ART among the participants interviewed in Belu. A few participants (n=4) reported having their health insurance terminated due to arrears in their monthly insurance instalments, and the others (n=8) reported borrowing money from friends or relatives or being dependent on financial support from family to help them access the services. As a consequence, participants delayed access to the healthcare services:

> *"We (the man and his wife) spend about IDR 100,000 every month to collect the (antiretroviral) medicines here. We do not use the BPJS (insurance) because we have arrears of monthly insurance instalments. We have to pay those arrears in order to reactivate it, but I cannot afford to pay the arrears. I feel very much burdened with transportation and administration costs here. These are routine expenses every month, and I feel burdened" (MP20, married, Belu).*
>
> *"Sometimes, I borrow money from my friends if I do not have money at all to come here (HIV clinic), but sometimes, I just delay collecting the medicine" (MP7, married, Belu)*
>
> *"My sisters are the ones who support me financially for the healthcare and transport expenses because I do not have income at all. Sometimes, I am late to come here to collect the medicines because they have not given me money" (MP10, single, Belu).*

Economic hardship facing these participants across the study settings seemed to be a negative consequence of HIV following their diagnosis. Their poor physical and health conditions which prevented the participants from working or caused a reduction in their working hours were the mechanisms through which the HIV infection negatively influenced the economic condition of the participants and their families:

> *"Now it (his economic condition) is not like it was. I used to work and had my own salary and could buy everything I wanted. Now I have to think twice if I want to buy something, I have to think whether the money I have is enough or not. I know how it feels when you do not have income at all. I stop working due to this (HIV infection, and his physical and health conditions were still weak) and have nothing" (MP2, single, Yogyakarta).*
>
> *"Having HIV disturbs me very much economically because I cannot work as I used to, I do not feel strong. Before I get this HIV, as a construction worker I could work both during daytime and night-time. Now I cannot do the construction work, which was my source of income, because I do not feel strong (physically)" (MP3, married, Belu).*

Increased family health expenditure was another mechanism through which HIV infection influenced the economic condition of the participants. They described that being diagnosed with HIV was financially burdensome as it not only influenced their work or employment status but also increased the family's health expenses. The stories of the participants portrayed how they experienced an increase in their healthcare expenses, which inflicted financial difficulties on them and their family:

> *"It (being diagnosed with HIV) was very much burdensome financially. I was weak, both my physical and health conditions were weak. So, I did not work and had no income. At the same time, we (the man and his wife who is also HIV-positive) had to spend money on the treatment. We did not experience such health expenditure before, it felt like an extra burden for us" (MP17, married, Yogyakarta).*
>
> *"Having HIV is financially burdensome because I have to come here (HIV clinic) regularly. Now I do not have a job, but I must pay for the monthly fee of the insurance. I have not paid it for several months because I do not have money. I feel burdened due to the routine expense for treatment. It is often difficult for me to fulfil the need of my family" (MP18, married, Belu).*

The economic hardships associated with the HIV problem also had further consequences for the male participants and their families. As reported by several participants across the study settings (n=11), it led to the sale of family properties, the use of savings and loans to cover daily costs and healthcare expenditures at the early stage of their HIV diagnosis. This seemed to also lead to the participants being dependent on the support of their close family members such as parents:

> *"I sold our (family) motorbike and some jewelleries gold I had (neckless and ring) to cover healthcare expense and family need. After that I got nothing else to sell and finally, we (the man and his wife and children) were dependent on the support of my parents" (MP17, married, Yogyakarta).*
>
> *"I used all the savings I had to cover healthcare expense and my daily needs. I sold my motorbike and other valuable things I had like laptop to cover the treatment expenses" (MP13, single, Belu).*
>
> *"We (the man and his wife) sometimes borrowed from friends because I did not have income at all" (MP20, married, Belu).*

The negative economic consequences associated with an HIV diagnosis facing the male participants interviewed across the study settings were also experienced by their close and extended families, such as parents, siblings and in-laws. The participants in both settings (n=19) who reported the experience of economic hardship following their HIV diagnosis commented that they relied on the support of their close or extended family members to cover their healthcare costs, daily needs and the needs of their children at the early stages of the HIV diagnosis:

> *"The economic impact was very much burdensome at the early stages of the HIV diagnosis because I could not do anything (could not work). So, my sister-in-law, my older siter and parents supported my family needs. I did not have income at all. My wife was also sick (HIV-positive) and took care of me. …. They sent us money because my children were still little, at kindergarten, and to buy food and vitamin for them, and to pay for their tuition fees" (MP1, married, Yogyakarta).*
>
> *"At that time, I did not have income at all (he quitted working due to his HIV diagnosis). I was helped by my sister. She supported me to get healthy, she supported me financially to fulfil all my needs" (MP4, single, Belu).*

These participants were aware that their dependence on the financial support from their close or extended families to cover the costs for their treatment and daily needs put a burden on their families. This was reported to have led to some parents of a few participants in Yogyakarta and Belu selling off their house, jewelleries and other valuables or using the savings they had to support the needs of the participants:

> *"I got full support from my mom. She paid my medical costs. It was not cheap at that time (he was diagnosed with HIV in 2008 and other health issues), it was 60 million rupiahs (±USD 4,200). My mom did not have enough money at that time, and she had to sell her jewelleries to support my medical treatment. …. At that time my mom was responsible for everything: my daily needs such as foods, and healthcare costs. The economic burden on my mom was heavy. My dad already passed away, so it was my mom who took care of me" (MP8, married, Yogyakarta).*
>
> *"At the time when I was sick (HIV and other health issues) my dad sold his house because the costs for the treatment were expensive. It costed my dad bout 60 million rupiahs. It was a huge amount back in those days (2006). There was not BPJS (government health insurance) like now, so my dad had to sell his house. He built a small one for him next to it and sold the big house. I feel that it was a big burden for*

> *my dad, and he had to sell his house because of me. Luckily, all my brothers and sisters do not question that" (MP11, married, Yogyakarta).*
>
> *"My sister owned a kiosk business where she sold goods for daily necessities. She used all her money from the business as well as her savings to support all my needs because my parents had nothing. She took care of me completely. After a year and a half of taking care of me her kiosk business stopped because she ran out of capital" (MP4, single, Belu).*

6.4.4 Appropriateness of healthcare services and ability to engage in the services

The appropriateness of the healthcare services, which was reflected in the adequacy between the HIV care services provided and the health needs of the participants, and in the quality of the services, was a supporting factor for the participants' access to the HIV services. For example, all the participants interviewed in Yogyakarta commented that the HIV care services provided in the healthcare facilities in the setting, such as antiretroviral medicines, CD4 and viral load tests and other medical tests were adequate or had met their health needs:

> *"To me the healthcare services meet my health needs in relation HIV treatment. Antiretroviral medicines, viral load and CD4 tests and other medical check-ups, such as kidney and liver function tests are available in X hospital" (MP4, married, Yogyakarta).*
>
> *"I think the existing health services fulfil what I need and are very good. The medicines and all kinds of medical tests related to HIV are available (MP16, single, Yogyakarta)*

The quality of the healthcare service delivery or the way the services were provided, which also reflected the appropriateness of the healthcare services, was also indicated as another supporting factor for their access to the HIV care services. All the male participants across the study settings stated that the services were delivered in a professional manner by the doctors and nurses:

> *"In my opinion, the healthcare services are delivered in professional manners by trained healthcare professionals. I feel that doctor and nurses in the (HIV) clinics do care about my condition. They treat me very well. They give the medicines, talk to me*

> *about my health condition, and always make sure that I adhere to the treatment" (MP11, married, Yogyakarta).*
>
> *"I feel that doctors and nurses in this clinic are very professional. Every time I come here to collect the medicines, the nurse at the front desk registers my name and starts talking to me, asking about my condition, how I feel, and encouraging me to adhere to ART. The doctors also say the same if I consult with them. I am sure that they are very professional in helping us (HIV-positive patients) and very friendly" (MP13, single, Belu).*

However, several participants interviewed in Belu (n=8) who understood about the HIV care services needed by PLHIV, reported that the HIV-related healthcare services in the study setting did not fully meet their health needs. Antiretroviral medicines were the only HIV-related healthcare service provided for them, which was only available in one HIV clinic in the setting. However, none of these participants pointed out the inadequacy as a barrier or factor that influenced their access to the available healthcare services. Meanwhile, the other participants (n=12) reported that they did not know about the HIV care services that were appropriate or needed by PLHIV:

> *"Other medical tests, such as CD4 and viral load tests, are not available here. The healthcare services are not complete in this clinic. We (PLHIV) need those tests but we cannot do the tests here. The doctor said that these tests are not available" (MP11, married, Belu).*
>
> *"I do not know the healthcare services needed by patients (PLHIV). I come here every month just to collect the medicines, the doctor and nurses just told me that" (MP4, single, Belu).*

The ability of the participants to engage in treatment which was determined by their motivation was also a facilitator of their access to the HIV care services. The desire to stay healthy, live longer, keep working and support the family, and the intention to make the family happy, were some examples of the motivations that supported the access of the participants across the study settings to the services:

> *"What is now in my mind is my children and wife. I strive to undergo the medication to stay healthy and can support my parents, wife and children" (MP17, married, Yogyakarta).*
>
> *"I regularly access the (antiretroviral) medicines and adhere to the therapy (ART) because I am scared of death and want to live longer" (MP7, married, Yogyakarta).*
>
> *"I undergo the medication so that I am healthy and keep working. It will be very difficult for my family if I am sick because I am providing for my family needs" (MP11, married, Belu).*
>
> *"I want to make my brothers and sisters happy, that is my biggest motivation to undergo the treatment. We are nine siblings; I am number seven. My first sister is the one who takes care of me, others (siblings) also help me sometimes. I do the treatment so that I can get healthy, find a job and can do something for them to make them happy" (MP8, single, Belu).*

The prevention of husband-to-wife HIV transmission and the intention to reduce or avoid stigma, discrimination and stereotyping associated with HIV were also factors that motivated the participants' access to the healthcare services. Several participants interviewed in Yogyakarta (n=5) reported that they engaged in the treatment in order to prevent transmitting the virus to their wives which could increase their health burden and also to avoid HIV stigma and discrimination and stereotyping against PLHIV as skinny and sickly:

> *"I regularly access antiretroviral medicines because I do not want to transmit the virus to my wife. I do not want her to get it because if she gets it too then the burden on our shoulders will be heavier. The doctor said that if I adhere to medication, I will be healthy dan less likely to transmit it to my wife" (MP5, married, Yogyakarta).*
>
> *"I have been regularly accessing antiretroviral medicines since I was diagnosed with HIV. I am aware that my body has HIV and needs medication. I do not want to fail in medication because I want to stay healthy and avoid stigma and discrimination. People always say that the ones who get HIV are skinny and sickly, I do not want those stereotypes, that is why I undergo the treatment" (MP15, single, Yogyakarta).*

6.4.5 Acceptability of healthcare services and ability to seek the services

The acceptability of the HIV care services was reflected in the participants' acknowledgement of the good health service delivery by the healthcare professionals. The kind, encouraging, supporting and non-discriminatory attitudes and behaviours of the healthcare professionals providing the services were acknowledged by all the participants across the study settings. Such acknowledgement reflected good health service deliveries and the participants' acceptance of the services. The acceptability of the service deliveries supported their access to the services, as illustrated in the following assertions:

> *"Nurses and doctors who serve patients with HIV are very good. They are very gentle in providing the services and not discriminative. I feel accepted and encouraged to be healthier. Their attitudes and the way they treat me and other patients (PLHIV) is very good. Thanks to them" (MP8, married, Yogyakarta).*
>
> *"Doctors and nurses in this clinic are very nice. They serve me kindly and are very supportive of me to adhere to the treatment, so that I can get well soon. I think they have done a great job and I feel supported to undergo this treatment. I accept the treatment and everything they ask me to do for the sake of my health" (MP7, married, Belu).*
>
> *"Attitudes and behaviours of doctors and nurses here are very good. They serve patients kindly and no discrimination. They are not afraid of us (PLHIV). I appreciate their support for me to do the treatment" (MP10, single, Belu).*

Talking openly to the healthcare professionals about their health condition was another factor reflecting the participants acceptance of the healthcare services. Most of the participants across the study settings stated that they talked openly to the nurses and doctors about their health condition due to the belief that the healthcare professionals were knowledgeable and the ones to provide health-related advice and medicines to help them get better:

> *"I am very open talking about my health condition to doctors and nurses who serve me every time I access the services. It is because I think they have to know it so that they can provide me with the right advices and medicines to support my health. If they do*

> *not know about my health condition, then I am the one who loses ….” (MP3, married, Yogyakarta).*
>
> *“I talk openly to the doctors and nurses here (HIV clinic). Whatever they ask about my health I will tell them. I am sick and in need for medication, and they know better about HIV because they study that thing, so I believe they can help me” (MP4, single, Belu).*

Social relationships with the healthcare professionals were indicated as a supporting factor for participants being open with the healthcare professionals and their acceptance of the healthcare services. Several participants across the study settings (n=8) described how they and the healthcare professionals in the healthcare facilities where they accessed the services had known each other for several years, which seemed to encourage them to talk openly about their health condition and access the healthcare services:

> *“I access the healthcare services at X community health centre. The healthcare professionals at the community health centre and I have known each other very well, so I feel comfortable to talk to them openly about my health condition and I collect the medicines every month” (MP17, married, Yogyakarta).*
>
> *“They (doctors and nurses in the HIV clinic) have known me very well. Since the first time I started the medication here and up to know I am very close to them. I mean I can talk to them everything about my condition with no hesitation” (MP13, single, Belu).*

Ease of access to the HIV care services was another factor that supported the acceptability of and access to the services. The majority of the participants across the study settings stated that to access the services they just needed to collect a referral letter from a community health centre or hospital as indicated in their health insurance (BPJS) every three months and take it with them to a healthcare facility providing the HIV services. They would then do the registration which could also be done online and collect the medicines:

> *“It is very simple to access the healthcare services, I just need to collect the referral letter from the community health centre as indicated in BPJS, provide it to the nurse at the hospital, register my name and collect the medicines. Sometimes, I have to wait a*

> *little bit if there are many patients in queue. I can also do the registration online from home" (MP4, married, Yogyakarta).*
>
> *"To collect the medicines, I just need to come here and present my card (health record) to the nurse to register me and then collect the medicines. If I do not have any health issues then I do not need to see the doctor, I can directly go back home. I also need to provide a referral letter from community health centre, one for every three months" (MP2, married, Belu).*

However, several participants interviewed in Belu (n=12) who lived far away from the HIV clinic, commented that the procedure that entailed them to access antiretroviral medicines only in the HIV clinic located in the town of Atambua was burdensome due to the long distance of travel and the high costs of transport. These participants also expected that the antiretroviral medicines could be made available in the community health centres which would be much closer to them and reduce their transportation costs:

> *"Patients (PLHIV) must come to this clinic to collect antiretroviral medicines every month. My place is very far from here and I have to spend money on transport. I think if it is also available at every community health centre then it would be very helpful because I would spend less time and money on transport" (MP18, married, Belu).*
>
> *"I come here (HIV clinic) every month to collect the (antiretroviral) medicines because this is the procedure. This is costly and a burden for me. I hope that in the future ART is also provided in community health centres" (MP10, single, Belu).*

The ability to seek the healthcare services was also another supporting factor for access to the services. This was reflected in the accounts of most participants across the study settings, which showed that they knew about the HIV care services and the healthcare facilities providing the services, and were able to choose to access the services at any of the healthcare facilities where the services were available:

> *"My wife and I have been told about healthcare facilities that provide HIV care services for patients after the HIV diagnosis. So, we started the treatment (ART) at the hospital until now. We know other healthcare facilities that provide the same services, but we chose to continue the medication at X hospital until now because we feel comfortable*

> *and familiar with healthcare professionals and the hospital environment" (FWP1, married, Yogyakarta).*
>
> *"Every time I want to access healthcare services, I can just do it, no barriers at all. …. I have already known where to collect the medicines and do viral load or CD4 tests, so I can just go by myself with my motorbike" (MP9, single, Yogyakarta).*
>
> *"My wife and I have already known this place (HIV clinic) and this the only place for patients like us to get the (antiretroviral) medicines. So, we can just come here at the date scheduled for us to collect the medicines. I often come here by car (his own car)" (MP14, married, Belu).*
>
> *"It has been a few years I undergo the (HIV) treatment, so I know what to do. I can come here anytime I want if I have any health issues, it is just a few minutes with motorbike (his own motorbike)" (MP13, single, Belu).*

6.4.5.1 The use of traditional medicines for HIV treatment

The stories of the participants in Belu showed that the acceptability of the HIV care services was influenced by the practice of traditional treatment of HIV using traditional medicines provided by traditional healers in the setting, a factor which was not reported by the participants in Yogyakarta. All the participants in Belu acknowledged that traditional treatment using traditional medicines for various diseases, including HIV/AIDS, was a common practice passed down from one generation to another:

> *"The traditional treatment using traditional medicines is a common practice here. If people get sick, then their family will firstly look for traditional medicines from traditional healers. People use traditional medicines to treat HIV too. It is a hereditary practice from our ancestors" (MP4, single, Belu).*
>
> *"Here, the use of traditional medicines for treatment of any diseases, including HIV is a very common practice" (MP9, married, Belu).*

The use of traditional medicines to treat HIV was indicated as a barrier to the acceptability of or the access to the HIV care services. It prevented the early initiation of ART after their HIV diagnosis and influenced access to HIV care services and adherence to ART. A few participants in Belu (n=4) stated that they delayed access to the healthcare services and the initiation of ART due to the use of traditional medicines after their HIV diagnosis. Other participants (n=7) also reported that they did not adhere to ART at the early stages of their treatment or quitted taking antiretroviral medicines due to the use of traditional medicines to cure HIV:

> *"After the diagnosis I did not take the medicines from the doctor but I took traditional medicines. I underwent the traditional treatment of HIV for several months, but I did not get better, and my body weight kept dropping. …. Because I did the therapy using the traditional medicines, I did not think of collecting the (antiretroviral) medicines here (HIV clinic) (he has already restarted ART prior to the interview)" (MP4, single, Belu).*
>
> *"After the diagnosis I accessed the therapy (ART) and then once I finished the medicines (first month), I switched to traditional medicines. I came back here (to restart ART) because my physical condition was getting weaker" (MP9, married, Belu).*

The use of traditional medicines was also reported to have financial consequences for the participants. Some participants in Belu acknowledged that the people who underwent traditional treatment of HIV had to pay certain amounts of money and give sacrificial animals, such as chickens, pigs or goats to the traditional healers. The costs and the accompanied sacrificial animals were paid or given to the traditional healers at the beginning of the treatments and were admittedly very expensive:

> *"The use of traditional medicines for treatment of any kinds of disease is very common here, but it is costly. Patients have to pay some amount of money and take with them a chicken or pig or goat as sacrificial animal. I heard that to get traditional medicines from Marry (pseudonym of the traditional healer), a patient has to pay five million rupiahs and give a chicken or pig to her" (MP16, married, Belu).*
>
> *"To get the traditional medicines and undergo the treatment with the healer, we (the man and his wife who is also HIV-positive) had to pay a lot of money to him (the healer) and give him a goat. It was very expensive, but we had to do it because we wanted to get better. We spent about fifteen million rupiahs for this treatment. This amount had to be paid at once before the start of the treatment, only once. My family: parents and siblings helped me with the payment" (M11, married, Belu).*

6.4.5.2 The role of family in the use of traditional medicines for HIV treatment

The participants' engagement in the traditional treatment of HIV using traditional medicines seemed to be influenced by their family members. The stories of these participants showed that family members played an important role in decision-making for the use of traditional medicines for HIV treatment before or after the initiation of ART. This was indicated as a barrier to the acceptability of and ability to seek HIV-related healthcare services and adherence to ART:

> *"After I got the test result that I am HIV-positive and came back home (he was hospitalised once diagnosed with HIV), I started taking traditional medicines. My parents, brothers and sisters encouraged me to do that because they thought traditional medicines could cure the disease (HIV infection) (He and other participants were already on ART once the study was conducted)" (MP7, married, Belu).*
>
> *"Initially, I had already started ART, but I stopped because my family asked me to take traditional medicines. They heard some people said that those traditional medicines are more effective to cure the disease (HIV infection). So, I took traditional medicines and stopped collecting antiretroviral medicines here" (MP5, single, Belu).*

The decision of family members to choose traditional medicines for HIV treatment over ART seemed to be supported by their experiences with the effectiveness of traditional medicines in treating other health issues and their lack of knowledge about ART. The participants described how their families had been accustomed to and had used traditional medicines for the treatment of any health issues for long time, and had no knowledge at all about ART and how it works:

> *"My parents mostly use traditional medicines every time they get sick or feel unwell. I think their experience of using traditional medicines influenced their decision or thought about HIV infection I have. They have experienced the effectiveness of traditional medicines in treating other health issues, so they think traditional medicines can also cure HIV. That is why they asked me to take traditional medicines even though I had started ART. Besides, they do not know at all about ART and the*

> *effectiveness of the (antiretroviral) medicines. That is why they did not encourage me to continue taking the medicines" (MP10, single, Belu).*
>
> *"My parents do not know anything at all about ART. So, once they know that I am HIV-positive, they started looking for traditional medicines from traditional healers and asked me to use them for my HIV treatment. They did not think of seeking medical treatment (ART). I think it was because they themselves are familiar with and have been using traditional medicines for long time" (MP4, single, Belu).*

The decision of family members regarding the use of traditional medicines for HIV treatment for their HIV-infected family members was indicated to also be influenced by neighbours, relatives and friends who were aware of the existence of traditional medicines for HIV treatment. A few participants (n=7) who used traditional medicines before or after the initiation of ART stated that their family members suggested traditional treatment due partly to the influence or recommendation and encouragement of neighbours, relatives or friends about the effectiveness of traditional medicines for the treatment of various diseases, including HIV or AIDS:

> *"We (the man and his wife) know about traditional medicines for HIV treatment from a friend of mine. He came to my house and talked to my wife and me about traditional medicines. My wife was convinced with his story that traditional medicines are very good and had cured people from this disease (HIV infection). Then my wife encouraged me to switch (from ART) to that traditional treatment" (MP9, married, Belu).*
>
> *"After the (HIV) diagnosis and I came back from the hospital and then one of my relatives said to my parents that he knows a traditional healer who can cure HIV with her traditional medicines. He and my parents got the traditional medicines from her and asked me to use them for my HIV treatment" (MP15, divorce, Belu).*
>
> *"After I was diagnosed with HIV infection, our neighbours also encouraged my parents that this must be treated using traditional medicines, that is why they asked me to take traditional medicines even though at that time I had started taking antiretroviral medicines" (MP10, single, Belu).*

6.5 Summary

In summary, this chapter presents the views of MLHIV about factors that contributed to HIV transmission among them. Their poor knowledge of HIV and condoms prior to their diagnosis was a supporting factor for their engagement in unprotected sex and IDU practices which facilitated HIV transmission among them. Their engagement in unprotected sex with multiple partners or FSWs, prior to or after being informed about HIV and condom use, was also supported by other factors. These included feeling lazy and ashamed about purchasing condoms, the unavailability of condoms, their intention to cover up their premarital sexual relations, reduced sexual pleasure, being an HIV-positive couple, the influence of the experiences of other HIV-positive couples who did not use condoms and the good-looking physical appearance of casual sex partners or FSWs. Other factors such as the social influence of peers through invitations to look for FSWs, discouragement of condom use, and environments where they lived and worked such as construction sites where brothels and FSWs were available and easily accessible, were also factors that supported their engagement in such risky sexual behaviours. Unprotected sex was also acknowledged as facilitating further HIV transmission from them to their wives. Similarly, their engagement in IDU was also influenced by peers through the introduction and invitation to engage in the practice, the encouragement to purchase illicit drugs together, and environmental factors such as workplace and prison environments where illicit drugs were available and accessible, needles were hardly available, and supervision and restrictions from parents and family members were absent. Relatively good economic conditions reflected in having their own incomes or savings and financial support from family and friends, which enabled the purchase of sex and illicit drugs, was also a factor that supported men’s engagement in such risky behaviours. Finally, religious beliefs and cultural practices in relation to spousal relationships, sex, condom use and bride wealth in marriage were also factors that influenced some men’s sexual behaviours and condom use practices.

This chapter also reports on a range of negative impacts of HIV on the men. Perceived stigma, anticipated stigma, self-stigma, and external stigma and discrimination within families, communities and healthcare facilities, were common negative impacts felt and experienced by men following their HIV diagnosis. A lack of knowledge about how HIV is transmitted which led to the fears about contracting HIV, was a supporting factor for such stigma and discrimination towards MLHIV by family and community members and healthcare providers. Similarly, negative social perceptions about HIV as a disgusting and embarrassing infection, religious beliefs about HIV as a curse, disgrace and a sin, and moral perceptions about PLHIV as the ones with a low moral standing, were supporting factors for such stigma and discrimination towards MLHIV by non-infected people. Stigma and discrimination also caused further negative consequences for MLHIV, such as the non-disclosure of their HIV status and their delay in accessing healthcare services. Psychological challenges such as feeling broken, regretful, desperate, worried and stressed which led to the loss of the spirit to live, self-blaming and anger, were also experienced by men following their diagnosis. These were influenced by concerns the men had about their HIV positive status, the possibility of transmitting HIV to their wives and children, their untimely death, and the future of their children and parents. Family separation and spousal divorce were also experienced by MLHIV following their HIV diagnosis. These were due to anger and accusations from their wives and family members of their wives towards men about their engagement in extramarital sex with FSWs, HIV transmission to their wives, and the wives’ fear of contracting HIV from their infected husbands. Poor physical health conditions due to a late diagnosis, delays in the initiations of medical treatment, and conditions of TB-HIV co-infections, were also negative impacts facing MLHIV.

Finally, this chapter presents different dimensions of the healthcare services and the corresponding abilities of MLHIV which either facilitated or influenced the men’s access to the HIV care services in the study settings. These included the availability of both the HIV care services, such as ART, medical tests, health devices to support HIV treatment and the healthcare professional to deliver the services, and the ability of MLHIV to reach the services. Their ability to reach the services was also determined by the travel distance to the healthcare facilities, the availability of transportation and time, and their occupational flexibility. The approachability of the services which was determined by how well-known information about the services is to MLHIV, and the ability of MLHIV to perceive their need for care, were also factors that determined their access to the services. The ability to perceive need for care was reflected in their level of knowledge about their health needs, the services they needed to access and how to access. The affordability of the services, and the ability of MLHIV spend their resources to pay for the costs of medical treatment, health insurance, and transportation to healthcare facilities, were also factors that determined their access to the services. The appropriateness of the services, which was determined by their judgement about whether or not the services met their needs, and their ability or motivation to access the services, were also factors that facilitated or influenced their access to the services. The acceptability of the services, which was reflected in the men’s acceptance of the healthcare professionals and the way they delivered the services, their trust in the healthcare professionals, were also factors that determined their access to the services. Similarly, the men’s supportive social relationships with the healthcare professionals, their ease of access to the HIV care services, and their ability to seek the services, were also factors that determined their access to the services. For some men, the use of traditional treatments for HIV and the social influence of families, friends and neighbours supporting traditional treatments for HIV, influenced their access to the HIV care services.

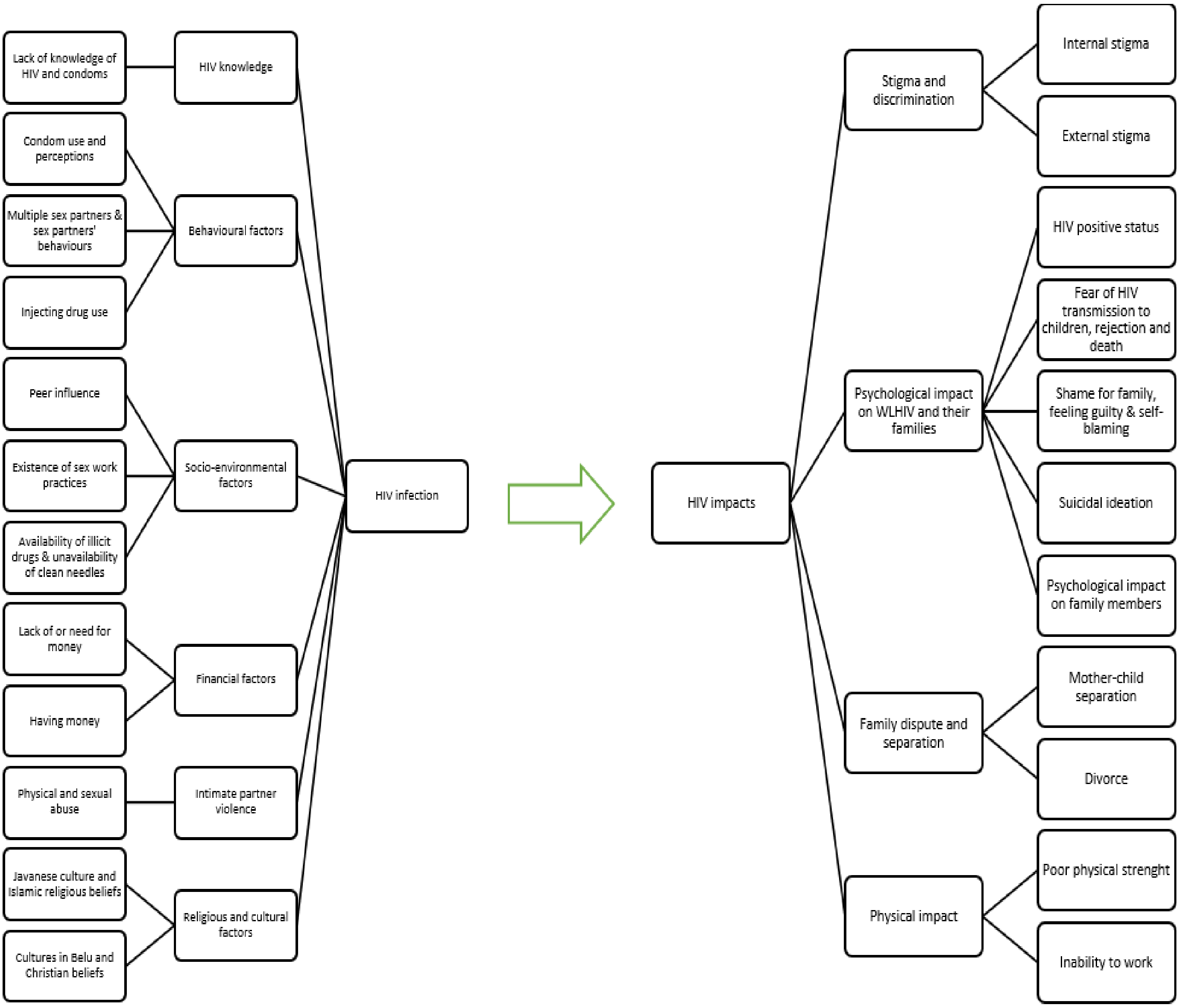

Figure 5: Coding tree for HIV risk factors and impact

CHAPTER SEVEN

PERSPECTIVES OF HEALTHCARE PROVIDERS ABOUT FACILITATORS AND BARRIERS TO ACCESS TO HIV CARE SERVICES BY PLHIV

7.1 Overview

This chapter presents the views and perspectives of healthcare providers in Yogyakarta (n=10) and Belu (n=10) about HIV care services and the access of PLHIV to the services in the study settings. There were no differences between the perspectives of female and male healthcare providers about these aspects. The participants comprised seven medical doctors and 13 nurses, of whom 11 nurses also took on a role as counsellors. Participants were recruited from hospitals (where HIV clinics were located) and community health centres providing HIV health services. The access to the healthcare framework (see section 3.5 for a discussion of the framework), was used to guide the exploration of the participants' views and perspectives about these aspects. The framework suggests that in order to generate access to the healthcare services, there should an interaction between the dimensions of healthcare services and the corresponding abilities of people with health needs. Dimensions of healthcare services are the availability, approachability, affordability, appropriateness, and acceptability of the HIV care services, and the corresponding abilities of people with health needs are the ability of PLHIV to reach, perceive their need for, pay, engage in, and seek the HIV care services. Some parts of the findings on HIV stigma and discrimination as barriers to the access of PLHIV to HIV care services have been published in Frontiers in Medicine (50) (The details of author contributions are presented in the article: Appendix 3).

7.2 Availability and ability to reach healthcare services

Healthcare providers interviewed in Yogyakarta reported that HIV care services were available at several hospitals and community health centres and were regularly accessed by PLHIV. The services included providing antiretroviral medicines, CD4 and viral load tests, liver and kidney function tests and other HIV-related medical tests to support HIV treatment for patients:

> *"HIV care services available in this hospital include antiretroviral medicines and laboratory tests, such as CD4, viral load, nutrition, liver and kidney function tests. These tests are required to support care and treatment for patients (PLHIV)" (HCP4, medical doctor, Yogyakarta).*
>
> *"Care, support and treatment for patients (PLHIV) can be done here (a community health centre). The treatment we provided is not only for HIV infection but also other sexually transmitted infections. We provide antiretroviral medicines, CD4 and viral load tests for the (HIV) patients" (HCP10, medical doctor, Yogyakarta).*

Participants also described that the healthcare facilities providing HIV care services to PLHIV in Yogyakarta were linked to each other. This was reported as facilitating effective communication between healthcare providers in order to provide better services for PLHIV. For example, if an HIV related medical test or laboratory test was not available in a healthcare facility then it could be done in another healthcare facility where it was available. This seemed to support effective healthcare provision to PLHIV:

> *"Healthcare facilities that provide HIV care services are linked to each other and help each other in terms of the service delivery to patients (PLHIV). The services we provide in this community health centre include HIV counselling and testing, antiretroviral medicines, and viral load and CD4 tests. Other medical tests such as liver and kidney function tests, etcetera, are carried out in X hospital or XX medical centre, which are located in this city and close to each other. We take the patients' blood here and send it to X hospital or XX medical centre, so patients do not need to go to any of these places. We inform patients about the results here" (HCP6, nurse and counsellor, Yogyakarta).*

> *"We only provide HIV test and CD4 test here because we get the reagents from the government, but we are linked to other healthcare facilities that provide HIV-related healthcare services. So, if we run out of reagents or need to do other laboratory check-ups such as viral load test, then we send patients' blood to X hospital where tests can be performed" (HCP7, medical doctor, Yogyakarta).*

HIV care services were also reported to be available in healthcare facilities in Belu. However, all the healthcare providers interviewed in this setting acknowledged that the services available and regularly accessed by PLHIV were limited to HIV testing and antiretroviral medicines. While an HIV test was available in all the community health centres in the district, antiretroviral medicines were only available in one HIV clinic located in Atambua town. As a consequence, the effectiveness of ART, including the prevalence of resistant strains of HIV before starting treatment, and treatment failure due to acquired drug resistance in Belu, was unknown due to the unavailability of CD4 and viral load tests:

> *"HIV care services available here (in Belu) are HIV testing and antiretroviral medicines, only these two items. The medicines are available in this (HIV) clinic, so all patients (PLHIV) access the medicines here. It is not possible to do CD4 and viral load tests here (HIV clinic) because so far this clinic gets the support only from the Ministry of Health, no support from the local government" (HCP1, medical doctor, Belu).*
>
> *"At the community health centre level, we can only do HIV testing, that is it. If the tests with first and second reagents show HIV-positive results, then we refer the patients to HIV clinic to undergo the third test and other medical examinations by medical doctors before patients start antiretroviral therapy. All community health centres in Belu can only provide HIV testing. The available health services for HIV treatment in Belu are only HIV testing and ART. The therapy is only available at the HIV clinic in Atambua" (HCP9, nurse and counsellor, Belu).*

These participants further commented that the limited availability of HIV care services for PLHIV was due to the lack of attention and support from the local government. They described the local government as not being proactive in their efforts to improve health services for PLHIV. One of the examples was the lack of effort by the government to procure medical devices and reagents for CD4 and viral load tests, although several recommendations and proposals had been submitted to the local health department by healthcare providers. Conversely, antiretroviral medicines provided for PLHIV were fully supported by the national government:

> *“The local government should have provided medical devices and reagents for CD4 and viral load tests. It appears that the local government is less proactive and has no effort to buy them even though we have repeatedly submitted procurement proposals. The devices and reagents are not yet available until now. The role of the local government is very important for the procurement of medical devices and reagents so that we can provide proper HIV treatment and services to patients. The role of this hospital (where the HIV clinic is located) is only to help facilitate and provide health services. Antiretroviral medicines, reagents for CD4 and viral load tests, and so on are the government programs. These are all programs of the local health department and the ministry of health, and this hospital helps implement and deliver the services, (HCP2, medical doctor, Belu).*

> *“In my opinion, HIV care services are the responsibility of the local government. We have repeatedly proposed for the provision of tests like CD4 and viral load tests in order to know the effectiveness of ART, but there have not been any follow ups from the local government. I would say the local government is not proactive to improve the services for patients” (HCP5, nurse and counsellor, Belu).*

The participants across both study settings also reported that HIV-related activities or programs were carried out to reach, detect and treat PLHIV within groups or communities. The activities or programs included HIV information sessions, mobile VCT and support for PLHIV. These were reported to be regularly delivered by healthcare providers for group and community members in the study settings. The participants in Yogyakarta also collaborated with NGOs in supporting PLHIV to start and adhere to HIV treatment:

> *“Healthcare providers from this community health centre also deliver HIV information session and mobile VCT to various groups within the coverage area of this community health centre. …. We also collaborate with companions of PLWHA from an NGO here in supporting the patients to start or adhere to ART. Usually, people who are diagnosed with HIV during the mobile VCT or in this community health centre are referred to the companions of PLWHA so that they get further support. The companions of PLWHA provide psychological support, information about HIV and healthcare services, how to*

> *apply for health insurance from the national government (BPJS), and so on" (HCP9, medical doctor, Yogyakarta).*

> *"We (healthcare providers) carry out HIV information sessions and also mobile VCT. For example, we carry out an integrated service post activity for mothers or pregnant women every month and sometimes we insert information about HIV into the activity. HIV testing is compulsory for pregnant women as stated in the national HIV policy. We also ask them to share the information within their family. For the ones who have started ART, we encourage them and regularly check them to ensure that they adhere to the treatment" (HCP7, nurse and counsellor, Belu).*

The presence of qualified and HIV-trained healthcare providers to deliver these HIV care services in healthcare facilities was another aspect of the availability dimension reported by all the participants across the study settings:

> *"There are several medical doctors and nurses and a counsellor here (HIV clinic) who are specifically trained in health service delivery to the patients (PLHIV). The nurses and counsellor are always here in this clinic every day and the medical doctors take turn because they also work for other wards in this hospital (HIV clinic is part of the hospital)" (HCP4, medical doctor, Yogyakarta).*

> *"I am the one who handles the HIV program in this community health centre. I play a role as both a nurse and a counsellor to serve patients" (HCP4, nurse and counsellor, Belu).*

Telehealth related consultations were reported to be provided through WhatsApp and mobile phones. The participants across the study settings described that they provided their mobile phone and WhatsApp numbers to PLHIV to contact them at any time for consultation if the patients were in need or had any health concerns. However, all participants in Belu stated that even though they made themselves available through these telehealth consultations, most PLHIV did not access these telehealth services, due to either not having a mobile phone, or a reluctance to talk to healthcare providers by phone or WhatsApp:

> *"We, medical doctors in this HIV clinic, give our mobile phone numbers to the patients so that they can consult with any of us if they have any health concerns and cannot come to this clinic. For example, some of them often call or send me WhatsApp*

> *message if they are not feeling well and then I prescribe the medicines to buy at the pharmacy" (HCP4, medical doctor, Yogyakarta).*
>
> *"I give my mobile number to patients (PLHIV) to facilitate them to talk to me if they have any health issues. They do not have to come to this clinic and can just call or send me WhatsApp message. But, so far there are only a few patients who do that. Most patients do not use this medium because they do not a mobile phone or are not accustomed to consulting with a medical doctor through phone or WhatsApp. Some patients once told me that they thought of calling me for consultation, but they hesitated because it (consultation with a medical doctor by phone call) is not a common thing" (HCP2, medical doctor, Belu).*

The ability of PLHIV to reach healthcare facilities was also a facilitator of their access to the HIV care services. The healthcare providers interviewed across the study settings described that most PLHIV in Yogyakarta, but only a small number in Belu, were able to reach the healthcare facilities. Their ability to reach the healthcare facilities seemed to be supported by the availability of public transportation, proximity to the healthcare facilities, being motorbike taxi drivers who were very much mobile, and possessing private vehicles such as cars or motorbikes:

> *"I see that many patients (PLHIV) do not have difficulties to come and access healthcare services in this hospital because public transportation is quite good here and this hospital is just next to the main route, so it is easy to reach by patients. Many patients also come here using their own motorbike, some are escorted by their parents using private car" (HCP1, nurse and counsellor, Yogyakarta).*
>
> *"There are small number of patients (PLHIV) who have private vehicles, such as motorbike or car, or live around Atambua town (where the HIV clinic is located). These patients do not have any difficulties to come here (HIV clinic) to access health services or collect antiretroviral medicines" (HCP1, medical doctor, Belu).*

All healthcare providers interviewed in Belu reported that the majority of PLHIV were unable to reach and access HIV care services at the clinic due to the long distances to the clinic from rural areas and the lack of public transportation. This impacted on adherence to ART:

> *"Many patients (PLHIV) here live far away from this community health centre and the HIV clinic in town, because the coverage area of this community health centre is very large. It covers villages and rural areas, including the ones in the hills, so the distance to this community health centre and HIV clinic is quite far. Public transportation is not available here and even in some areas here motorbike taxi is not available either. These factors also make it difficult for patients to reach and access health services at this community health centre or antiretroviral medicines at the HIV clinic" (HCP9, nurse and counsellor, Belu).*

Patient related factors such as physical weaknesses, and the lack of support from family members were raised by a few participants (n=3) as barriers for PLHIV to access HIV services in Yogyakarta. A late HIV diagnosis, poor adherence to HIV treatment or discontinued attendance to services after the initiation of ART due to an inability to come to the healthcare facilities by themselves and the lack of support from their family members were factors prohibiting effective HIV care:

> *"The reasons why some patients (PLHIV) could not come here to access health services varied. For example, some once told me that they did not come to collect antiretroviral medicines following their HIV diagnosis or after the first month initiation of ART because there were not physically strong enough to come here by themselves and none of their family members offered them help or wanted to accompany them to this hospital" (HCP1, nurse and counsellor, Yogyakarta).*
>
> *"There were a few patients who told me that they faced difficulties in accessing HIV care services because their physical condition was weak. They did not get support from their family members and could not come to this clinic. That happened during the first few months of the treatment, so they did not fully adhere to ART…" (HCP4, medical doctor, Yogyakarta).*

7.3 Approachability and ability to perceive the need for healthcare

Healthcare providers in Yogyakarta perceived that HIV care services were approachable or known to PLHIV in this setting. The reason underlying these perceptions was that information about HIV care services had been regularly disseminated by healthcare providers and companions of PLHIV to PLHIV and general community members, by way of websites, HIV information sessions and mobile VCT, regular peer support group meetings for PLHIV, and WhatsApp groups. Another supporting reason for such perceptions was the fact that the number of PLHIV accessing the services continued to increase over time:

> *"I think health services for patients with HIV in this hospital is known to people. We disseminate information about HIV care services through HIV information sessions and mobile VCT for various groups or communities. For instance, we carry out HIV information sessions in churches, schools and universities and provide this information on our website. There are patients who look for the information about our health services through our website. So, I think information about HIV care services is widespread here and this can be seen from the fact that the number of patients who access the services increases over time" (HCP1, nurse and counsellor, Yogyakarta).*
>
> *"I think HIV-related health services in the city of Yogyakarta are known to them (PLHIV) and general community members because information about the services is disseminated to them regularly. Healthcare providers and companions of PLWHA regularly inform people about the services HIV information sessions, mobile VCT or through WhatsApp groups" (HCP4, medical doctor, Yogyakarta).*

However, in contrast to Yogyakarta, HIV care services seemed unknown to many people within communities in Belu. This was reflected in the fact, as described by the healthcare participants in this setting, that the majority of PLHIV in Belu only came to know about the services once they fell sick, were admitted to hospital and tested positive for HIV. It seemed that a poor participation in HIV-related activities, such as HIV information sessions and mobile VCT activities was the reason HIV care services and information about HIV were unknown to community members in Belu:

> *"Only a small number of people attend activities (HIV information sessions and mobile VCT) we carry out. That is why HIV services and information are still unknown to many people. Patients (PLHIV) here started to know about HIV and HIV treatment or ART once they were sick, admitted to this hospital and tested positive with HIV, and then the counsellor informed them about the treatment or ART" (HCP8, nurse and counsellor, Belu).*
>
> *"I see that antiretroviral therapy service is still unknown to many people in Belu. I think a low participation by community members in HIV information sessions and mobile*

> *VCT is the main reason. Only a few people attend activities like these. This happens in all community health centres, others (healthcare providers in other community health centres) share the same kind of story every time we have a (HIV counsellors, nurses and doctors) meeting. Most of us (PLHIV) started to know about HIV treatment or the therapy once they were admitted to the hospital and tested positive with HIV" (HCP5, nurse and counsellor, Belu).*

Healthcare providers across the study settings also acknowledged that the ability of PLHIV to perceive their need for HIV treatment was a factor that supported their access to the HIV care services. The participants reported that most PLHIV in Yogyakarta and a small number in Belu were able to perceive their need for care, and this was reflected in their regular access of, and adherence to, ART. This awareness seemed to be underpinned by the continuous support and encouragement from healthcare providers in both study settings:

> *"I think most patients (PLHIV) who have done counselling and started antiretroviral therapy are aware of their need for HIV treatment because we have often told them about the benefits and drawbacks of adherence and non-adherence to the treatment. We always try to support and encourage them during the counselling sessions or once we meet on the day they collect the medicines so that they adhere to the treatment for the sake of their own health. I see that most of them regularly access the health services every month" (HCP6, nurse and counsellor, Yogyakarta).*
>
> *"In my opinion, there are a small number of patients (PLHIV) who do understand that they need antiretroviral therapy. It can be seen from our record that these patients always collect antiretroviral medicines every month. The doctors and I have always tried to make them aware that they need the medicines for their health. Every time they collect the medicines, I always talk to them and remind them to come back next month. We, nurses and doctors, do the same for every patient, we encourage them to access and adhere to the therapy" (HCP3, nurse and counsellor, Belu).*

The healthcare participants interviewed in Belu reported that the majority of PLHIV in Belu were not fully aware of their need for HIV treatment. They reported that only half of the people who had been diagnosed with HIV began ART, and again only half of those who had started ART adhered to the treatment. Levels of education of PLHIV were mentioned as having a positive correlation with their level of understanding about their need for ART:

> *"Majority of people (PLHIV) are not fully aware of their need for ART. Of more than a thousand people who have been diagnosed with HIV, nearly half of them do not start antiretroviral therapy. Half of the ones who have started the therapy do not adhere to the treatment. I think majority of them do not understand the long-term benefits of the therapy for their health even though we have talked to them about those benefits. The majority have low level of education, this may also influence their capacity to perceive their need for care" (HCP1, medical doctor, Belu).*

> *"In my opinion, majority of them (PLHIV) have very low level of understanding about the important of antiretroviral therapy for their health. We (healthcare providers) have explained to them following the diagnosis that they need antiretroviral medicines and if they adhere to the therapy then they will be fine. But the fact is that majority of them do not want to undergo the therapy. It is not easy to make them understand about the therapy because majority of patients (PLHIV) never attended any formal education or graduated from elementary school or junior high school. We have explained to them everything about the therapy, but it seems like they do not understand" (HCP4, nurse and counsellor, Belu).*

7.4 Affordability and ability to pay for healthcare services

The affordability of HIV care services for PLHIV varied, depending on whether they possessed national health insurance as well as their economic capacity to spend resources to access the services. The healthcare participants across both study settings reported that the services were affordable for most PLHIV in Yogyakarta but only for a small number of PLHIV in Belu. They were the ones who possessed the national health insurance which covered the costs for all their healthcare services, and were able to afford the monthly fee of the insurance or the full costs of the healthcare services and the transportation costs to reach the healthcare facilities:

> *"Generally, most patients (PLHIV) have BPJS insurance, so the costs for healthcare services are not a problem for them because they are covered by the insurance. There are also patients who do not want to use the insurance and choose to pay the costs by themselves. …. These are the ones who are economically capable" (HCP1, nurse and counsellor, Yogyakarta).*

> *"Based on my experience in serving patients within the coverage area of this community health centre, I can see that HIV care services are affordable to a few patients because they have the insurance (BPJS) from the government. Some (PLHIV) who use the independent type of the insurance can afford the monthly fee of the insurance and the transportation costs" (HCP4, nurse and counsellor, Belu).*

As described by the participants across the study settings, the ability of those patients (PLHIV) to afford medical and transportation related costs was due to the fact that they were able to generate an income because they had paid jobs:

> *"Many patients who I serve in this clinic have paid jobs, I mean permanent jobs. Some are freelance or self-employed. They have their own incomes, so they can afford to pay for the monthly fee of the insurance or the transportation to this clinic" (HCP8, medical doctor, Yogyakarta).*
>
> *"There are only a small number of patients (PLHIV) who have permanent jobs such as civil servants or retired civil servants or who have their own businesses. They are the ones who have monthly or regular incomes and seem to have no problem at all with the monthly insurance fee or transportation costs. But this is just a small number of them. Many do not have jobs and incomes. They are farmers in villages and housewives" (HCP8, nurse and counsellor, Belu).*

The healthcare providers interviewed in Yogyakarta acknowledged that there were some PLHIV who could not afford to pay for healthcare services and transportation to healthcare facilities. These patients were mostly university students from outside of Java who were studying in Yogyakarta. Not having the national health insurance, fully relying on financial support from parents as well as hiding HIV status from family, seemed to lead to the lack of extra financial support from parents for the healthcare expenses and the unaffordability for them to pay for their HIV treatment. Such conditions were reported as being the barriers to access to the services and adherence to ART among these PLHIV:

> *"There are a few patients (PLHIV who access the services at the hospital) who are from outside of Yogyakarta. They are university students. They told me that they have financial difficulty in paying for the healthcare services. They do not have BPJS insurance and we cannot help them apply for the insurance here because they do not*

> *have Yogyakarta's identity card (Kartu Tanda Penduduk Yogyakarta/KTP). They do not want to go back and make one in their place of origin because of fear of their HIV status being known to other people and their parents. Sometimes they do not access the services because they simply do not have money to pay for transport or medical costs" (HCP5, nurse and counsellor, Yogyakarta).*
>
> *"There are patients who do not collect antiretroviral medicines because they do not have money to pay for transport costs. They are mostly single and university students from outside of Java. Their life is depending on the support from their parents, so if their parents have not sent them money or were late sending them monthly living allowance, then they will be late to collect the medicines here (community health centre) (HCP9, medical doctor, Yogyakarta).*

The healthcare providers interviewed in Belu also reported that the majority of PLHIV could not afford the expenses related to access to the healthcare services, including transport costs and monthly insurance fees (BPJS) due to their poor economic conditions. Their poor economic conditions were described as the barrier to them accessing HIV care services:

> *"Economic factor is the main problem among patients. Many of them stopped collecting antiretroviral medicines because of financial difficulties which make them unable to pay for transportation costs to this clinic. Majority of them reside in the villages and rural communities which are far away from here. They have to spend money on transport and food, and also on the services if they do not have the BPJS insurance. There are patients who have the insurance, but it has been terminated because of an inability to pay the monthly fee" (HCP1, medical doctor, Belu).*
>
> *"Economic hardships make them (PLHIV) unable to pay for transport and healthcare expenses, such as registration fee at the hospital and other supporting medical tests before the initiation of antiretroviral therapy or the monthly fee of the BPJS insurance. So, they do not access health services or stop ART" (HCP4, nurse and counsellor, Belu).*

As the solution to help PLHIV in Yogyakarta who could not afford to pay for both their HIV-related and general healthcare services, a collaboration between the healthcare facilities providing HIV care services and an NGO was established. The participants interviewed in Yogyakarta described how the PLHIV who were Yogyakarta residents and experienced financial difficulties in accessing the healthcare services, were linked to the companions of

PLHIV at an NGO in the study setting. The companions then linked these patients to the local Social Department and helped them apply for regional health insurance subsidised by the local government or the BPJS as subsidised by the national government:

> *"This HIV clinic collaborates with XXX NGO in relations to the health service delivery to patients. Those (Yogyakarta residents) who have trouble with the medical expenses and inform us about it, we immediately take action to help. We connect them to the companions of PLWHA from XXX NGO. The companions will link them to the local Social Department and help them apply for health insurance from community health insurance (Jamkesda) provided and subsidised by the local government or BPJS insurance as subsidised by the national government. These can help them access antiretroviral medicines or other health services for free. (HCP3, nurse, Yogyakarta).*

The healthcare participants in Belu also reported that assistance for the PLHIV to apply for the national insurance was also provided. However, as described by the participants, the decision to apply for the insurance had to come from the PLHIV because they were responsible for the monthly fee of the insurance:

> *"We (healthcare providers) always tell patients (PLHIV) to apply for BPJS insurance and offer them help to apply for it. But they are the ones who need to decide because they will need to pay for the monthly fee of the insurance. Besides, they have to apply for it as a family, that is the regulation, which means the monthly fee of the insurance need to be paid for each family member. That makes it even more difficult for many patients (PLHIV). There were patients who had got the insurance (the independent type), but it was terminated because they could afford to pay the monthly fee. There are also many other patients who have heard about it from us but have not decided to apply because of the monthly fee. Some said the fee will be burdensome for them because their family members, such as children who are not sick (HIV-negative) should also be registered" (MP3, nurse and counsellor, Belu).*

7.5 Appropriateness and ability to engage in healthcare services

The appropriateness of the HIV care services for PLHIV, which was reflected in the adequacy between the services and the health needs of PLHIV, was reported by the healthcare providers interviewed in Yogyakarta. The participants stated that the health services had met the needs of PLHIV, with HIV treatment and tests such as CD4 and viral load, liver and kidney function, and other medical tests, available to them and being delivered by qualified healthcare professionals:

> *"I would say HIV-related health services for patients (PLHIV) here (Yogyakarta) are complete, and patients continue to access them until now. This hospital (where the HIV clinic she works for is located) provides antiretroviral medicines and medical tests such as CD4, viral load, liver and kidney functions tests. Other laboratory tests can be done in this hospital. …. All of us in the clinic: nurses, counsellors and I as the medical doctor, have attended HIV trainings held by the ministry of health before we are involved in HIV-related health service delivery to the patients. I am convinced that so far the health services provided meet the needs of the patients and we deliver the services professionally …" (HCP8, medical doctor, Yogyakarta).*

In contrast, the healthcare providers interviewed in Belu reported that HIV care services were less adequate and, in many cases, did not fully meet the needs of PLHIV. Antiretroviral medicines were the only HIV-related healthcare service available in one HIV clinic, with CD4 and viral load tests to check the effectiveness of ART unavailable:

> *"HIV-related health service available in this clinic for the treatment of HIV is only antiretroviral medicines. The service does not meet the need of the patients because other medical tests like CD4 and viral load tests are not available. These are important to know whether antiretroviral therapy increases the patients' CD4 counts or not, or supresses the patients' viral load or not" (HCP1, medical doctor, Belu).*
>
> *"In this community health centre, we can only provide HIV testing and if the result is (HIV) positive, then we refer the patients to the HIV clinic to do one more (HIV) test, confirmation test. All community health centres can only do HIV testing. Antiretroviral medicines are only available in the HIV clinic. I think health service in this community health centre and in Belu is still far from meeting the need of patients (PLHIV)" (HCP10, nurse and counsellor, Belu).*

The ability of PLHIV to engage with the HIV health services or treatment was also acknowledged as a factor regarding the accessibility of services. Healthcare providers in Yogyakarta reported that most PLHIV were able to easily engage with HIV health services or treatment. The participants commented that the ability of PLHIV to engage in the services was reflected in the number of PLHIV who accessed the services every month at the healthcare facilities they worked for. Conversely, the healthcare providers interviewed in Belu reported that the majority of people who had been diagnosed with HIV did not engage in or access the services:

> *"Most patients do engage in the healthcare services and in my opinion their adherence to the treatment is high. This can be seen from the record of the number of patients who access the services every month, more than ninety percent access the services. They collect the medicines and consult with doctors. I always check the ones who consult with me about whether their adherence to the therapy (ART) is good or not" (HCP4, medical doctor, Yogyakarta).*
>
> *"The majority of people who have been diagnosed with HIV here (in Belu) do not engage in HIV services. There are more than a thousand but our data show that only about 600 people started taking ART and only about half of the 600 do actively access antiretroviral medicines every month in this clinic. I would say that their engagement in the services and their adherence to the therapy are low here" (HCP2, medical doctor, Belu).*

The ability to engage seemed to be supported by a range of motivations and reasons. The desire to stay healthy and keep working, a strong spirit to live longer, a positive experience of the effectiveness of ART, and the fear of death, were some instances of the motivations and reasons that supported their ability to engage in the services:

> *"At the beginning (following HIV diagnosis), many (PLHIV) are motivated to undergo ART because of the fear of death. Then, once they have felt the effectiveness of the therapy, they continue to access the medicines and adhere to the therapy because they want to stay healthy, not easily get tired or sick and to work as they used to. Many have said these to me" (HCP9, medical doctor, Yogyakarta).*
>
> *"There are patients who do engage in the services. They adhere to ART because initially their health condition was worse and they were very skinny physically but after starting the therapy their health and physical conditions started to get better and they feel strong and can work" (HCP8, nurse and counsellor, Belu).*

Sustained support and encouragement from family members and healthcare providers were also reported as motivators or supporting factors for increased engagement. Reminding

PLHIV to regularly access health services and adhere to ART, and suggesting they live a healthy lifestyle and stay positive, were some instances of support and encouragement from family members and healthcare providers. These support and encouragement seemed to motivate their engagement in the healthcare services or HIV treatment:

> *"I see that family support is a strong motivator for their engagement in HIV treatment. One of the reasons they adhere to the treatment is because their family members support them: remind them to take the medicines on time and access the medicines every month as scheduled. So, they feel cared for and have strong motivation to undergo the treatment and live a healthy lifestyle" (HCP2, nurse, Yogyakarta).*
>
> *"We (the participant and other healthcare providers in the community health centre) support them in various ways so that they continue to access HIV care services and adhere to HIV treatment. The words we use to talk to them should not offend them. Every time they access the services, we always remind them to come back every month, take medicines on time and motivate them to continue the treatment (HCP10, medical doctor, Yogyakarta).*

However, the healthcare participants across both study settings also reported several factors that hindered the engagement of PLHIV with the healthcare services or influenced their adherence to ART. For example, personal factors such as feeling bored, lazy and being busy with work, and health-related factors such as the side effects of treatment, were described as barriers to the engagement of PLHIV with the health services or their adherence to ART:

> *"There are patients who feel lazy and bored with antiretroviral medicines and do not want to adhere to the treatment. Some said 'I feel very bored to take the medicines every day" (HCP1, medical doctor, Belu).*
>
> *"There are patients who do not access and adhere to the therapy (ART) because of the side effects of the medicines. Taking the medicines influences their concentration during work due to the side effects of the medicines. There are also patients who have to take the medicines twice a day which make them feel bored and then quit. There are also patients who are busy with their work and just simply forget to take the medicines on time. So, the reasons for non-adherence to the treatment vary among the patients" (HCP10, medical doctor, Yogyakarta).*

A lack of understanding about how HIV treatment works, and the psychological impact of HIV were also reported in the interviews across the study settings as factors that influenced their service engagement. The influence included cessation of treatment once feeling healthy and physically strong after several months of undergoing therapy, due to the misconception that they had been fully cured by antiretroviral medicines. Another influence was their unwillingness to access the HIV health services or undergo ART due to the psychological impact of their HIV diagnosis:

> *"There are many patients who drop out of their medication and stop collecting the medicines. I usually call them to check and some said, 'we do not need to take medicines anymore because we are healthy, we are fine'. So, once they feel that they are physical healthy after taking the medicines for a few months, then they stop the therapy (ART). They think they have completely recovered even though we have told them that this treatment must be routine every day for life" (HCP3, nurse and counsellor, Belu).*
>
> *"There are patients who struggle at the beginning of the diagnosis and are psychologically depressed due to the fear of death and fear of being ostracized or avoided by others. Such psychological pressures and fears make them isolate themselves from others and unwilling to access health services or undergo HIV treatment" (HCP6, nurse and counsellor, Yogyakarta).*

The change of residence was also reported across both study settings as another contributing factor for the disengagement in the health services or non-adherence to ART among PLHIV. For example, moving to new places without informing healthcare providers disconnected patients from the HIV health services. Similarly, the inability to access the services in the new places they had moved to due to a lack of understanding of the healthcare system, or the procedures to access the services and the unavailability of antiretroviral medicines hindered their engagement in the services:

> *"Another reason why some patients do not engage in HIV services or treatment is that they move to other places without telling us, thus we cannot link them up to HIV*

> *services that might be available in the places they move into. They are disconnected from the services and HIV treatment. Some patients such as students from outside Java move back to their places of origin in rural areas and could not access or continue the therapy because antiretroviral medicines are not available" (HCP1, nurse and counsellor, Yogyakarta).*
>
> *"There are patients who sell sex for money (FSWs) and they often move from one place to another. The problem is that they do not let us know once they move to other places, so they are disconnected from the services. Some move to places outside of Belu and might not know the health service systems or procedures to access HIV services in the new places. Many of them (FSWs) here do not know the services and the procedures to access the services. The nurses at community health centres regularly visit and explain to them" (HCP3, nurse and counsellor, Belu).*

HIV stigma and discrimination were also reported to hinder their access to the HIV care services. Healthcare providers interviewed in both Yogyakarta and Belu described the prevalent discriminatory and stigmatising attitudes and behaviours from family members, community members and healthcare providers towards PLHIV. These often led to PLHIV concealing their HIV status and self-isolating, which hindered their engagement with the health services and healthcare professionals:

> *"Stigma and discrimination against them (PLHIV) still occur and affect their access to HIV care services. They fear stigma and discrimination from healthcare providers who do not understand about HIV or from the community members if their HIV status is discovered. This is one of the reasons why there are still patients (PLHIV) who do not seek (medical) treatment. Some told me about negative reactions they received from healthcare providers (in non-HIV ward) and from their neighbours who know about their HIV status, that is why at they initially tried to hide their status and did not want to access HIV treatment" (HCP1, nurse and counsellor, Yogyakarta).*
>
> *"One of the things that make them (PLHIV) scared of accessing HIV-related health services is stigma and discrimination from healthcare providers and community members. They do not come to HIV clinic because they do not want other people to know about their status. Also, the ones who get stigma and discrimination from their family members mostly do not access health services because they are not supported by their family members…." (HCP4, nurse and counsellor, Belu).*

The main reported determinant for stigma and discrimination by family and community members, and healthcare providers was the lack of knowledge about HIV which led to the fear of contracting the infection through interaction with PLHIV. These were reflected in a range of discriminatory attitudes and behaviours, such as the separation of personal belongings or eating utensils of PLHIV from those of other family members, the unwillingness of healthcare providers to touch or examine PLHIV physically, and the active avoidance of PLHIV by community members:

> *"There are healthcare professionals who avoid serving (HIV) patients, do not want to be close to or touch patients to carry out physical examination due to a lack of knowledge about HIV and how to treat the patients and the fear of being infected with HIV. These are discriminative and the patients can feel such discriminatory acts. The same thing also happens to them within families and communities where they live. Due to a lack of knowledge about the means of HIV transmission, many family and community members discriminate against them, such as avoiding physical contact with them and separating their personal belongings or eating utensils from those of others" (HCP2, nurse, Yogyakarta).*
>
> *"Many people are still very scared of HIV, and stigma and discrimination towards people who are diagnosed with this infection are still high. If it is known that someone has HIV, people will avoid the person. Many people fear of contracting HIV through social contacts because they do not have enough knowledge about HIV. Even family members are also discriminative against their own (HIV-positive) family members. I often hear that their clothes, plates, spoons, glasses and soap are separated from those of other family members. It is a pity that healthcare providers also avoid them because they are afraid of contracting HIV" (HCP5, nurse and counsellor, Belu).*

Some healthcare participants reported that they themselves had personally stigmatised and discriminated against PLHIV, citing personal values, religious thoughts and socio-cultural values and norms as factors that supported these attitudes and behaviours. For example, personal values regarding loyalty between a husband and wife, or socio-cultural and religious values about premarital or extramarital sex and same sex relations, contributed to a negative judgement of the perceived behaviours of PLHIV, which were assumed to lead to the patients contracting HIV:

> *"I myself used to discriminate against patients (PLHIV). That was because I knew what they did, such as sex and drugs and eventually getting HIV, is against the values I hold. For example, in marriage, the value of loyalty is very important to me, so if there is a husband who gets HIV because of having sex with other women, I do not accept such behaviour because he is cheating on his wife. As a wife, I do not accept such behaviour. That was why I previously did not really care about male patients who were married and got HIV through sex with other women, I did not want to serve them" (HCP3, nurse, Yogyakarta).*

> *"At the beginning, when I served the patients, I felt uncomfortable and disgusted by male patients who got HIV because of free sex while working as migrant workers in Kalimantan or Malaysia. They had wives but were involved in casual sex with other girls (FSWs) and got HIV. I was disgusted because I saw them always go to church every Sunday but apparently their sexual behaviour does not reflect what is taught in religion" (HCP7, nurse and counsellor, Belu).*

> *"Same sex sexual behaviour is not accepted in our society and culture. It is against our social and cultural values and norms. Initially, I felt that treating them (men who have sex with men) medically and teaching them to have safe sex or use condoms, are like supporting such behaviour. I quite struggled with this thought at the beginning of my involvement in HIV care service delivery to (HIV) patients. On the one side I had in mind that they have contaminated sexual behaviours and thought that they deserved the consequences (got infected) but on the other side, I am a doctor who is supposed to focus on helping patients to get healthy. So, at the beginning I always had the tendency to advise them to stop and have normal relationship with girls" (HCP10, female medical doctor, Yogyakarta).*

Fear of stigma and discrimination were also reported by healthcare providers as a factor that led to PLHIV choosing to move from one healthcare facility to another, accessing HIV health services at other healthcare facilities far from the community they lived in, or asking family members to access services on their behalf. This was underpinned by the fear of their HIV status not remaining confidential:

> *"The ones from outside of Yogyakarta access HIV care services here to maintain their privacy or conceal their HIV status. They do not want people from community where*

> *they live to know about their HIV status which could lead to stigma and discrimination against them. They often say that there is a high chance that people who know them could find out or suspect their HIV status if they undergo ART at a hospital or community health centre in their community. A few other patients (from Yogyakarta) ask their family members to collect antiretroviral medicines for them due to the same reason" (HCP6, nurse and counsellor, Yogyakarta).*
>
> *"There are still a number of patients whose antiretroviral medicines are collected by their family members. We allow their family members to collect the medicines on their behalf because they do not want to come here by themselves. They fear that people would find out about their HIV status and stigmatise or discriminate against them. If we do not allow their family members to collect the medicines, then they would not undergo the treatment. There are also patients who decide to access the referral letter every three months from other community health centres which are far from the place where they live because of such fear …." (HCP2, medical doctor, Belu).*

7.6 Acceptability and ability to seek healthcare services

Healthcare providers interviewed across both study settings reported that the HIV care services were accepted by PLHIV, and this was reflected in their access to the services. The healthcare providers reported that the majority of PLHIV in Yogyakarta and a small number of PLHIV in Belu accessed the services and were quite open in talking to healthcare professionals about their health conditions and experiences of living with HIV. Their openness seemed to be supported by the trust and good social relationships established between them and the healthcare providers who served them at the healthcare facilities:

> *"Patients who come here accept the services we provide and are very open to me and also to counsellor and nurses. I think it is because we have established trust between us. I always listen to their stories, treat them like friends and make them feel comfortable and welcomed to share their stories or experiences. We meet every month and that makes us know each other and close to each other. That is why they are open to me and others (healthcare providers)" (CP7, medical doctor, Yogyakarta).*
>
> *"I would say HIV services here are accepted by the patients because half of them who started the treatment in this clinic continue the treatment and do not have any complaints or problems with the services we provide. They are also very open to me or the doctors about their health conditions and problems that prevent them from*

> *collecting the medicines on time or things that make them sad and lose spirit for medication" (HCP3, nurse, counsellor, Belu).*

There were some patients across both study settings who were reportedly reluctant to talk openly about their health or how they had acquired HIV. The healthcare participants surmised that these patients may have felt embarrassed about contracting HIV, and were worried about their HIV status not being kept a secret if they divulged information:

> *"Based on my experience, there are a few patients who access antiretroviral medicines here (HIV clinic) are reluctant to talk openly to me. I can see that they feel embarrassed with what is happening to them because they get the infection through sex before marriage. Some are university students, that is why they seem reluctant to talk about how they get the infection" (HCP4, medical doctor, Yogyakarta).*
>
> *"Here (in Belu), getting HIV is an embarrassment because people will associate it with free sex or sex with many partners. That is why there are patients who do not want to talk at all with us (healthcare providers). They seem avoiding us. For example, if the nurse asks them questions, then they will give very short answers and say: 'sorry I have to go, I get something to do or I am in a hurry'. It also seems to me that they do not want to stay a bit longer in this clinic and talk to us because of the fear that other people or patients might see them (at the HIV clinic) and be suspicious about their HIV status. They want to keep it secret as long as they can" (HCP2, medical doctor, Belu).*

Ease of access to HIV care services was also reported to impact how easily PLHIV accepted services:

> *"It is very simple to access HIV care services here, such as antiretroviral medicines. Patients just need to register at the from desk to get a number and wait for their turn. They can also do the registration online, then collect the medicines and talk to a medical doctor, that is it. The ones who use BPJS insurance need to collect referral letter once per three months from a community health centre they have chosen once they apply for the insurance" (HCP8, medical doctor, Yogyakarta).*
>
> *"I think the procedure to access antiretroviral medicines in clinic is very simple and fast. Patients come here and register at the front desk, provide their health record card and referral letter from community health centre and then collect the medicines. The medicines are available in this clinic, separated from medicines for non-infected patients. If they do not have any health concerns to be talked about, either with me or other medical doctors, then they can go home" (HCP1, medical doctor, Belu).*

However, Belu healthcare providers reported a procedural issue regarding only being able to pick up antiretroviral medicines at one clinic located it town. This was a long distance for many PLHIV, especially with the limited availability of public transportation, and therefore high transportation costs were a barrier for many PLHIV to accessing HIV treatment. Lack of HIV-trained medical doctors to deliver HIV care services to PLHIV was reported as the underlying reason for the provision of the medicines at only one HIV clinic:

> *"What I see is that the procedure that entails patients to collect antiretroviral medicines at the HIV clinic in town hampers their access to the service because the distance from here (the coverage area of community health centre) to the clinic is far and public transportation is not available here. Patients have to go by motorbike taxi which is a bit expensive for them. This is one of the reasons why there are patients who do not access the medicines. The medicines are not provided here (community health centre) because there is no trained medical doctor in HIV field" (HCP10, nurse and counsellor, Belu).*

The ability of PLHIV to seek health services was reflected in their personal autonomy, capacity to choose to seek care and treatment, and their knowledge about the healthcare options or services available for them. These were all reported as supporting factors for access to HIV care services. Healthcare providers interviewed in Yogyakarta stated that most PLHIV had the ability to seek healthcare services because they had already been introduced to the healthcare facilities providing HIV services and could choose to seek care at any of the healthcare facilities:

> *"Most patients are well informed about both HIV-related health services in the city of Yogyakarta and healthcare facilities that provide the services. So far, the patients choose by themselves any healthcare facility at which they want to access the services, and most of them are able to access the services" (HCP6, nurse and counsellor, Yogyakarta).*

In contrast, the healthcare providers interviewed in Belu reported that many PLHIV seemed to have less personal autonomy or capacity to choose to seek the health services. These impacted on their decision to undergo HIV treatment, either medical treatment or ART, or treatment using traditional medicines, which was mainly made by their family members, such as parents or siblings or relatives who took care of them. It was reported that families could have quite a significant impact on patient decisions, especially when there was a lack of knowledge about HIV-related health issues, and ART, a relatively low level of education, when the patient was dealing with poor overall health, and when there was financial stress:

> *"Many patients are taken care of by their families: parents or siblings, thus family members have a very important role in determining the treatment for them. Moreover, most patients have low level of education and lack knowledge about HIV and health matters in general. So, they fully listen to their family members who take care of them" (HCP5, nurse and counsellor, Belu).*
>
> *"I see that many patients are not able to seek HIV treatment for themselves. Family members play a very important role in the treatment for them. When they are sick, physically weak and have no money to support their life, they will do what their parents or siblings say, including being told to stop taking antiretroviral medicines and switch to traditional medicines. So, for many patients, the decision to seek treatment is actually made by their family members" (HCP8, nurse and counsellor, Belu).*

7.6.1 The use of traditional medicines for HIV treatment

Healthcare providers reported that they felt the use of traditional medicines to treat HIV infection influenced the acceptability and accessibility of medical treatment or ART among PLHIV in Belu. Healthcare providers interviewed in this setting described that traditional medicines from traditional healers to cure HIV were widely used among PLHIV, especially the ones residing in rural areas in Belu:

> *"I have often heard that many of them (PLHIV), especially the ones who live in the villages, use traditional medicines to treat HIV. I hear from patients living with HIV. Some said that their friends (who are living with HIV) used traditional medicines to treat HIV and eventually died" (HCP 5, nurse and counsellor, Belu).*

> *"The use of traditional medicines for HIV treatment is very common in Belu. I am sure that most (HIV) infected people, who have known their HIV status but do not start ART, are taking traditional medicines. Patients who consult with me often tell me about this (the use traditional medicines) because I always ask whether or not they use traditional medicines and remind them to adhere to ART …." (HCP1, medical doctor, Belu).*

This was reported to often lead to the late initiation of ART, or a decision to cease the therapy. The participants also described that some PLHIV who had not started ART after their diagnosis or had quitted the therapy due to the use of traditional medicines, sometimes decided to start or restart treatment once their physical and health condition drastically worsened:

> *"Every time a patient is diagnosed with HIV, we always try our best to encourage them to start the medication, antiretroviral therapy here (HIV clinic). Most of the time they said yes in front of us but once they went back home, they never returned to do the follow up tests or medical examination. They use traditional medicines from traditional healers instead. They do not easily accept the medical treatment we offer and rely on traditional medicines" (HCP2, medical doctor, Belu).*
>
> *"There are patients who do not use traditional medicines straightaway after the HIV diagnosis even though we (healthcare professionals) have talked to them and encouraged them to start antiretroviral therapy. There are also patients who have started the therapy (ART) for a few months and then quitted and switched to traditional medicines. Some of these patients came back to this clinic to start or restart the therapy once their physical and health conditions gradually got worse" (HCP3, nurse and counsellor, Belu).*

The desire to recover faster, the belief in the effectiveness of traditional medicines and distrust in HIV test results, were reported as barriers to the acceptance of medical treatment or ART among PLHIV. These were acknowledged by the participants as some of the factors that supported the decision of PLHIV and their families not to undergo ART or to switch from ART to traditional treatment:

> *"One of the reasons they or their families decide to use traditional medicines or switch from antiretroviral therapy to traditional treatment of HIV is because of the desire to get better faster or full recovery. Some patients told me that they wanted to get cured and strong faster, that is why they switched to traditional medicines, even though we*

> *have told them that they will not be completely cured of HIV and therefore they have to take antiretroviral medicines every day for the rest of their lives" (HCP9, nurse and counsellor, Belu).*
>
> *"Some patients switched from antiretroviral medicines to traditional medicines because they think traditional medicines are more effective and can cure HIV" (HCP6, nurse and counsellor, Belu).*

7.6.2 The role of family in the use of traditional medicines for HIV treatment

Family members of PLHIV were reported to play a pivotal role in decision making for the use of traditional medicines in the treatment of HIV, hence also influencing the acceptance of medical treatment. Healthcare providers interviewed in Belu stated that family members were the ones who took care of a person or PLHIV within a family, and they often decided what type of treatment the patient would have, a factor which was not raised by healthcare providers in Yogyakarta. This also included the decision to use traditional medicines or switch from medical therapy to traditional treatment for their HIV infection:

> *"I see that family members have a dominant role in determining treatment for the sick ones (HIV-positive). Often people are diagnosed with HIV while they are in a severe condition and being admitted to hospital. So, once they left the hospital, many of them switched to traditional medicines because their family members asked them to do so and then stopped taking antiretroviral medicines. Family members are the ones who look for traditional medicines for them (PLHIV)" (HCP10, nurse and counsellor, Belu).*

Lack of knowledge of ART and the experience of the effectiveness of traditional medicines to treat other health issues were described by the participants as other possible reasons that influenced family members' decision to choose traditional medicines over ART for the treatment of HIV for sick family members:

> *"In general, (HIV) patients come from families with low level education. Their family members do not have knowledge about ART, do not understand about the function of the therapy to suppress viral load. Besides, I believe their family members have seen and experienced healing from certain ailments or health issues due to the use of*

traditional medicines. I think, these are also the reasons why many families rely on traditional medicines for the treatment of their HIV-positive family member" (HCP3, nurse and counsellor, Belu).

Figure 6: Coding tree for access to HIV care services

CHAPTER EIGHT

THE CURRENT AND FUTURE PERSPECTIVES OF POLICY MAKERS ABOUT POLICIES AND PROGRAMS TO ADDRESS HIV AND ITS IMPACT ON PLHIV AND THEIR FAMILIES

8.1 Overview

This chapter presents the perspectives of policy makers in Yogyakarta (n=6) and Belu (n=3) in relation to HIV policies, programs and activities in place at the time of interview, and their experiences of challenges to implementing them. Their perspectives on future responses and solutions that need to be undertaken to halt HIV transmission and address the impact of HIV on PLHIV and their families, are also presented. There were no differences between the perspectives of female and male policy makers about these aspects. Five policy makers were recruited from local governments across both study settings. They included the heads of the disease prevention units, the coordinator of local AIDS commission, and the head of the local social department. Four policy makers were recruited from NGOs in Yogyakarta. They took different roles or positions at their NGOs as the director, the companions of PLHIV and the head of the outreach and VCT unit. They were individuals who were involved in making HIV-related policies, and designing HIV programs and activities in the study settings. For example, they created ideas or made annual plans to respond to HIV, designed annual HIV programs, activities and estimated budgets.

8.2 HIV policies in Yogyakarta and Belu

Policy makers interviewed across both study settings outlined the HIV policies currently in place for each institution or organisation they worked for. Their stories identified similarities and differences about the focus of HIV policies between local government institutions and

NGOs. Some institutions incorporated both HIV-risk factors and the impact of HIV into their policies, whilst others focused on either tackling HIV-risk factors or addressing the impact of HIV. For example, a participant described a dual focus at the local health department of Yogyakarta municipality. They addressed this through the promotion of HIV information, and HIV prevention, diagnosis, treatment and rehabilitation programs or activities. The aim of the policy was ultimately to prevent the transmission of HIV but also minimise stigma and discrimination towards PLHIV and support them in re-engaging in socially:

> *"The focus of our HIV policy is on addressing both the HIV-risk factors and the impact of HIV through promotion, prevention, diagnosis, treatment and rehabilitation programs or activities. The emphasis is on the promotion of HIV-related knowledge or information and protected sexual behaviours, the provision of condoms to prevent HIV transmission, the provision of HIV testing and treatment, and the rehabilitation for the ones who have been diagnosed with HIV to help them cope with the social and economic impacts following their HIV diagnosis. … It also addresses the social impact of HIV on them, with the aim to minimise stigma and discrimination against them and help them engage in social activities that are empowering. Being infected with HIV often makes them feel inferior, reluctant to interact with other people around them and even isolate themselves. Therefore, we try to bring them back into their social life. We do this in collaboration with the social department" (PM4, health department, Yogyakarta).*

Two participants from Yogyakarta, one from the social department of the local government and one from an NGO, reported a sole focus on the impact of HIV. These policies were focused on rehabilitation and starting ART, minimising HIV-related social and economic impacts facing PLHIV, education to understand and accept an HIV diagnosis, and ensuring HIV-related health services are accessed regularly. The aims of these policies were to rebuild self-confidence, promote social engagement, and support economic capacity:

> *"The HIV policy in this social department specifically focuses on the social and economic rehabilitation aspects. It addresses HIV-related social and economic impacts facing them (PLHIV). The purpose of this policy is to help them get back their self-confidence so that they can again take part in social interactions with others within*

> *community where they live and also have their own income to support their life. This policy is embodied in a range of programs or activities that empower them. We formulate this policy and programs or activities based on our discussions with and recommendations from the companions of PLWHA from an NGO here and with the healthcare professionals from the local health department" (PM5, social department, Yogyakarta).*
>
> *"Regarding HIV policy, we focus on the provision of support for the ones who are referred to us by healthcare professionals at hospitals or community health centres. The aim of the support we provide is to ensure that they understand about HIV, accept themselves or their HIV status, think positively, can manage psychological and social challenges facing them, start the treatment or ART and get emotional and social support from us and others (PLHIV) whom we work with. So, community health centres, hospitals and other NGOs are the ones who deliver the HIV testing for HIV diagnosis and then they send (PLHIV) to us so that we can support and help them to cope with the problem. So, there is a work division between us and them, and we focus only on addressing the impact of HIV" (PM1, XXX NGO, Yogyakarta).*

Participants from two different NGOs in Yogyakarta detailed a specific policy focus on HIV-risk factors only, which were addressed through promotion of HIV information, and HIV prevention, diagnosis and treatment programs, including promotion of safe sexual behaviours and provision of HIV voluntary counselling and testing for as many people as possible within groups and communities in Yogyakarta:

> *"The HIV policy in this organisation only focuses on HIV education for them (PLHIV) who are transgender women. The aim is to help them understand about the means of HIV transmission and prevention, and undergo HIV treatment or antiretroviral therapy" (PM3, X NGO, Yogyakarta).*
>
> *"The focus of HIV policy in this NGO is on the promotion of information about HIV and the prevention of HIV transmission for them (PLHIV) and other people within groups and communities in Yogyakarta. So, the focus is on education or behavioural intervention and HIV testing. The aim of this policy is to make them and community members aware of HIV so that they can change their risky behaviours, and to reach members of groups or communities with HIV testing service. We focus on the HIV diagnosis through VCT and then we refer them to XXX NGO (name of the NGO) that provides further support. All companions of PLWHA are from XXX NGO. They support PLWHA to cope psychologically, access healthcare services, etc" (PM6, XX NGO, Yogyakarta).*

Similarly, the participants from the health department of the local government of Belu described a specific policy focus on HIV-risk factors. Health promotion, prevention of transmission, and provision of both HIV testing and ART were used to address HIV-risk factors in the study settings as reflected in the following quote:

> *"Policy on HIV issue in Belu (health department) covers several aspects, namely health promotion, prevention of HIV transmission, provision of HIV testing, and provision of ART for those who have already been diagnosed with HIV. So, our focus is on addressing HIV-risk factors to halt the transmission of HIV among community members" (PM1, health department, Belu).*

It was apparent HIV policies in Yogyakarta addressed both HIV-risk factors and impact. Compared to Yogyakarta, Belu participants agreed that local health department policy did not address the impact of HIV on PLHIV and their families. They acknowledged that the focus on risk factors and ART was due to inadequate resources within the department, and a lack of involvement by other non-health sectors or departments in addressing HIV in the district:

> *"We have not made any HIV-related policies that address the impact of HIV on this group (PLHIV), which can be translated into programs or activities to help them cope with the impact of HIV. One of the reasons is because the promotion, prevention and diagnosis have not been implemented at the maximum level. Similarly, the HIV treatment services in Belu are not complete and do not fully meet the health need of patients. We can only provide HIV testing and ART but other tests, such as viral load or CD4 tests, are not yet available. We are currently working on the procurement of equipment and reagents" (PM2, health department, Belu).*

> *"The health department seems like a single fighter in addressing the HIV problem in Belu. Other sectors both government and non-government sectors or departments were not involved at all. If other departments of the local government, such as social department and women's empowerment department, are also involved in the response to this problem, then they can take part in addressing the impact of HIV on people who have been diagnosed with HIV and we (health department) can focus on the health aspect" (PM3, health department, Belu).*

8.3 HIV programs or activities

Programs and activities aimed at addressing HIV-risk factors varied across the organisations and institutions in both study settings. Some conducted HIV information sessions and VCT for key or high-risk populations and various group and community members, and ensured that PLHIV were on ART. These were to disseminate information and knowledge about HIV, high-risk behaviours and condom use among key populations and general community members, and to reach as many people as possible for HIV testing and treatment:

> *"HIV policy in this health department is translated into programs or activities, such as information sessions on HIV and mobile VCT for key populations such as the ones who engage in sex work practices, men who have sex with men, transgender women, injecting drug users, as well as the general community members. These activities are generally planned and implemented by the community health centres. The aim is to increase their knowledge about HIV and high-risk behaviours, with the hope that the ones who feel that they have committed risky behaviours would be willing to do HIV testing and if they are positive with HIV, then they would undergo HIV treatment" (PM1, health department, Belu).*

> *"There are two main activities regarding HIV that we carry out, namely the dissemination of information about HIV to key populations (high-risk populations) in brothels, night clubs, theatre and general community members, and the provision of voluntary counselling and HIV testing. So, our task is to educate the public about HIV and reach as many people as possible to get tested for HIV" (PM6, XX NGO, Yogyakarta).*

Programs and activities, specific to Yogyakarta, that addressed the impact of HIV on PLHIV, included skills and business training and the provision of business capital for PLHIV as well as administering the national or regional health insurance for those who could not afford to pay the healthcare services. HIV education to reduce and prevent stigma and discrimination towards PLHIV within their family unit was another program reported. This was carried out through educating families around HIV and encourage acceptance of the HIV-positive status of their family members:

> *"Our HIV policy focuses on social and economic rehabilitations for them (PLHIV), so the program or activity we have designed is training for them. For example, we have conducted massage skills training for them. We hope that through such training they can have the skills and are able to provide massage services so that they can earn their own income. We also provide business training and start-up business capital of two million rupiahs (±USD 150) per person. They are also accompanied by social workers who are assigned by the social department. However, only a small number of them were recruited for the previous trainings because the available funds were very limited. We hope that through activities like these, they can engage in social interactions with other people. In addition, the ones who are unable to engage in any activities at all are financially supported with IDR 300,000 per month for 12 months" (PM5, social department, Yogyakarta).*

> *"There are activities that we carry out to help them (PLHIV). For example, we help the ones who do not have national health insurance (BPJS insurance) and have difficulty in paying healthcare costs. We help connect them to the local social department and together with them prepare all the required documents so that they are eligible for the national or regional health insurance. They are referred to us by the healthcare professionals at the community health centres or hospitals" (PM1, XXX NGO, Yogyakarta).*

> *"We educate their family members and, if necessary, people within the community where they live about HIV to increase the acceptance and reduce discrimination towards them (PLHIV). In general, stigma and discrimination occur because people do not have the correct knowledge about HIV. We use HIV education as a strategy to reduce and prevent stigma and discrimination against them (PLHIV)" (PM2, XXX NGO, Yogyakarta).*

Policy makers interviewed in Yogyakarta reported that these programs were effective because of a strong collaboration among the local health departments, community health centres, hospitals, local social departments, and NGOs, in their response to HIV:

> *"The social department's aid program for people who have been diagnosed with HIV is carried out in collaboration with the companions of PLWHA from an NGO here. The social department cannot carry out the program by itself. The companions are the ones who make the proposal and submit to the social department, and they also report the progress of program implementation to the social department. The social department collaborates with the NGO and the health department since the beginning of the program because they are the ones who have the data about people who have been diagnosed with HIV and know about the ones who are eligible to receive the aid. So,*

> *we discuss about this, and they provide us with the data" (PM5, social department, Yogyakarta).*
>
> *"We collaborate with the Ministry of Social Affairs and the local social department to carry out empowerment programs for PLWHA. We carry out a productive economic business program for them to help them have their own business and income, but the quota is limited, thus the number of the ones who receive the financial aid is very small. The aid programs they received are skills training and funds for business capital" (PM2, XXX NGO, Yogyakarta).*

8.4 Challenges to the implementation of HIV programs or activities

Participants in both study settings reported several challenges in relation to implementing HIV-specific programs or activities, due to issues stemming from both internal and outside institutions and organisations. They stated these challenges had led to nonoptimal rollout of HIV programs, activities and services.

8.4.1 Internal challenges

Participants interviewed in Belu described the limited availability of HIV care services and the limited number of healthcare professionals trained to deliver HIV services to PLHIV as internal challenges which impacted on the effective implementation of HIV programs, activities and services to support PLHIV. These internal challenges were not identified in Yogyakarta setting because HIV care services were available in HIV clinics, community health centres and hospitals within communities throughout Yogyakarta municipality. The following quotes from two policy makers reflect these internal challenges in Belu:

> *"The HIV-related health programs that we provide for patients (PLHIV) have not been running optimally because we have limited HIV-related healthcare services. For example, CD4 and viral load tests cannot be done here (Belu) because the tools and reagents are not available. …. In addition, the antiretroviral medicines are only available in one HIV clinic due to the unavailability of medical doctors who are trained to deliver HIV services to patients with HIV at the community health centres. We have*

> *limited number of medical doctors who have been trained for HIV (only three)" (PM1, health department, Belu)*
>
> *"Human resources, be it healthcare professionals or HIV workers, are still very limited. For example, there is only one nurse who also acts as a counsellor, who takes care of many patients (PLHIV) at each community health centre, and there is no an HIV-trained medical doctor at the community health centres. This has resulted in the nonoptimal health service delivery to the patients or implementation of HIV-related programs or activities. If the healthcare professionals at the community health centres do not regularly monitor the patients' access and adherence to HIV treatment or therapy, then sometimes they stop the treatment and decide to use traditional medicines, or move to other places without notifying the healthcare professionals" (PM2, health department, Belu).*

Participants across both study settings also reported limited human resources and available funds within their organisations. Participants from an NGO in Yogyakarta, for example, outlined the difficulty in organising activities aimed at supporting PLHIV, due to the low level of education and lack of public speaking skills of several companions (who were also HIV positive) of PLHIV who carried out the activities. The limited availability of funds was also acknowledged by participants from another NGO, a local social department in Yogyakarta and a health department in Belu, which impacted the number of communities and PLHIV involved in programs. The following quotes illustrate these challenges:

> *"One of the challenges to the implementation of HIV programs or activities is the low quality of human resources of several companions of PLWHA in our NGO. There are several of them who are elementary school graduates, so their understanding of HIV and public speaking skills are very limited. I see that these influence their performance during the implementation of HIV programs or activities" (PM1, XXX NGO, Yogyakarta).*
>
> *"The Regional Revenue and Expenditure Budget allocated for HIV activities for a year is very limited. Therefore, the number of PLWHA that we support financially in the form of IDR 300,000 per month is only six people. Likewise, only a small number them were recruited to participate in the trainings that we have provided. Together with the companions of PLWHA, we selected and recruited only the ones who were very much in need to receive the aid we provided. However, the fact is that, there are many of them who experience difficulties and meet the requirements to take part in the*

> *trainings and to receive financial support from the government. However, due to limited funds, we could not recruit all of them" (PM5, social department, Yogyakarta).*
>
> *"The funds we receive from the local health department to support HIV programs or activities for a year are very limited. HIV is only one of the many other health problems, and in my opinion, it is not yet a major concern of the government of Belu district. Limited budget is also a main challenge to the implementation of HIV-related activities. Although we (policy makers) have discussed and decided the amount of budget for HIV programs or activities that have been planned but the final decision is at the hand of the 'number one person' (Chief of the district)" (PM3, health department, Belu).*

8.4.2 External challenges

Reports of challenges related to external organisations and institutions were made by participants interviewed in Belu, who stated that the poor economic conditions of PLHIV led to their inability to afford healthcare services, health insurance and transportation costs. Transportation costs were also influenced by the long-distance travel from rural areas to the healthcare facilities or HIV clinics and the unavailability of public transportation. These were reported as having a significant impact on the successful implementation of HIV programs or activities, especially relating to HIV treatment:

> *"In Belu, the main program or activity to help them (PLHIV) is HIV treatment or ART. However, it seems that the implementation of HIV treatment program is not optimal because there are many patients who have not accessed or do not adhere to the treatment. One of the reasons is the poor economic condition of the patients. Most of them are economically poor and do not apply for health insurance because of their inability to pay the monthly fee of the insurance. Some of them have already got the insurance (BPJS) but due to arrears in monthly fee for months, the insurance has been terminated. Moreover, the ones who live in the villages which are far away from the HIV clinic have to spend more money on motorbike taxi (ojek) due to the lack of public transportation. The farther the distance to the HIV clinic, the more expensive motorbike taxi costs. Many of them do not seek the treatment for economic reasons or healthcare and transportation costs which are burdensome. These are challenges to the successful implementation of the HIV treatment programs" (PM3, health department, Belu).*

Community members refusing to be HIV tested, and the decision by PLHIV to discontinue ART were also reported as external challenges to the implementation of HIV treatment activities. Participants across both study settings described many people in their respective communities still refusing VCT due to the fear of being diagnosed with HIV or having an HIV positive status. Similarly, there were still PLHIV who withdrew from ART due to the use of traditional medicines or the influence of anti ART groups who promoted the use herbal medicines instead:

> *"One of the obstacles we experience in carrying out information session activities about HIV and HIV testing service is the refusal of group or community members to take HIV testing due to the fear of getting HIV-positive result" (PM6, XX NGO, Yogyakarta).*
>
> *"There have been several (HIV-positive) people in Yogyakarta who have become victims of a group called Anti-HIV/AIDS and Healthy Society without antiretroviral medicines (MAHA STAR). This group campaigns against the use of antiretroviral medicines which they consider as poison, promotes the idea that HIV is a hoax and encourages the use of herbal medicines to support body immune. There have been patients who withdrew from antiretroviral therapy and use herbal medicines" (PM2, XXX NGO, Yogyakarta).*
>
> *"There are many (PLHIV) in Belu who prefer to use traditional medicines to treat HIV rather than antiretroviral medicines. Some have undergone antiretroviral therapy but decided to stop the therapy and used traditional medicines instead. Therefore, in my opinion, the response to HIV problems, especially HIV treatment, has not been optimal in Belu" (PM2, health department, Belu).*

HIV stigma and discrimination were also reported as external challenges. Policy makers across both study settings noted that fear of stigma and discrimination from other people, including healthcare professionals, was a major factor preventing the participation of community members or PLHIV in HIV-related activities, or testing and treatment:

> *"Lack of community participation is another obstacle to the implementation of HIV programs or activities. The number of community members willing to attend HIV activities is very small. If it is announced that there will be socialisation about HIV then*

> *people will not attend and take HIV testing for the fear that if they are infected with HIV then other people will avoid them. That is why so far those who are HIV-positive were diagnosed when they fell sick and were hospitalised. I was an HIV counsellor at the X community health centre for several years, so I have seen it myself" (PM2, health department, Belu).*
>
> *"Often discrimination towards patients comes from healthcare professionals because of a lack of understanding of HIV or the fear of being infected with HIV when interacting with or serving patients (PLHIV). In the meantime, there are 38 cases of discrimination against them by community members and healthcare professionals, which we have been handling in Yogyakarta. Discrimination is also one of the reasons why they fear or do not want to be involved in HIV activities or access HIV-related health services. I have often been asked by several of them who feel worried if their access to the health services or participation in the activities we carry out could lead to stigma and discrimination against them. This is a challenge to the implementation of HIV programs because what we want is that many people participate in HIV-related activities we deliver" (PM1, XXX NGO, Yogyakarta).*

8.5 Future responses or solutions to halt HIV transmission and address the impact of HIV among PLHIV and their families

For both Belu and Yogyakarta participants reported a need to broaden the coverage of HIV programs or activities, such as HIV information sessions or knowledge dissemination, and the provision of HIV-related training and education for healthcare professionals in healthcare facilities. Participants felt these strategies would prevent or reduce stigma and discrimination towards PLHIV, which were assumed to occur due to lack of knowledge and information:

> *"I think there is a need for massive dissemination of HIV information for all group and community members, and HIV training and education for the healthcare professionals in the healthcare facilities in Belu. I think the more community members and healthcare professionals know about HIV, the less stigma and discrimination against people living with HIV. Stigma and discrimination towards them negatively influence their access to the healthcare services and their social engagement in communities where they live and interact" (PM1, health department, Belu).*
>
> *"I think stigma and discrimination against PLWHA need to be seriously addressed through HIV training or education for first and foremost all the healthcare*

> *professionals in the healthcare facilities and then for general community members. Proper knowledge about HIV can lead to the reduction of stigma and discrimination against them. This is important because stigma and discrimination also lead to a reluctance of PLHIV to access the healthcare services" (PM4, health department, Yogyakarta).*

The participants also described the role of local government is critically important and required for an improved response to HIV. For example, government funding for HIV programs and activities should be increased to broaden the coverage area and reach and involve as many communities and PLHIV as possible:

> *"So far we limit our HIV-related programs or activities because we receive very limited budget from the local government. In order to be able to reach many communities with our HIV programs or activities, such as HIV information sessions and voluntary counselling and testing, the local government of Belu district needs to increase the budget allocated for HIV programs. This will help us carry out all HIV-related programs and activities that we have planned for a year and recruit more HIV workers as we are currently only three persons" (PM3, health department, Belu).*
>
> *"The social and economic impacts of HIV are very much burdensome for many of them (PLHIV), and I think the local government of Yogyakarta municipality should increase its budget for HIV programs in order to better respond to these impacts. The increase of regional income and expenditure budget allocated for HIV programs or activities will enable us to recruit large number of them to participate in training programs and receive start-up business capital. We had run these programs but the number of participants recruited to participate was very small because we had very limited budget" (PM5, social department, Yogyakarta).*

Participants in Belu also outlined several improvements needed to adequately address HIV transmission and its impact among PLHIV. First was the district government needing to consider exempting or covering the healthcare expenses of PLHIV through regional health insurance (Jamkesda) which has been provided for some PLHIV. In addition, there needs to be an increase the number of HIV-trained healthcare professionals or medical doctors to be assigned for providing HIV healthcare services to PLHIV at the community health centres. The local government also needs to provide adequately resourced HIV care services, such as CD4 and viral load testing for PLHIV at the time of diagnosis and throughout treatment. The establishment of inter-sectoral collaboration among local health department and other departments of the district government and social or religious institutions in Belu, is also considered critical in addressing the HIV issue:

> *"The inability of patients (PLHIV) to pay for the healthcare and transportation to the HIV clinic in this town is one of the main reasons why many of them in Belu do not undergo the HIV treatment or do not adhere the treatment. Therefore, I think exempting the healthcare costs for the patients, which can be covered by regional health insurance (Jamkesda), is a solution to get as many patients as possible to access the HIV care services. Besides, another important solution is the role of the government to provide HIV training opportunities for medical doctors at community health centres so that they can deliver HIV care, support and treatment at community health centres. We have proposed these ideas to the head of the local health department to be discussed. These will bring the services closer to the patients and reduce their budget spent for the medical and transportation costs" (PM2, health department, Belu).*
>
> *"The response to HIV problem needs to be improved starting from the improvement of the HIV-related health services. For instance, CD4 and viral load tests need to be provided and we are working on the procurement. This will help the healthcare professionals know about the effectiveness of antiretroviral therapy for each patient. Besides, I think inter-sectoral collaborations among the departments at the local government and between the local government and NGOs and social or religious institutions are needed to better respond to the socio-economic impacts of HIV" (PM1, health department, Belu).*

CHAPTER NINE

DISCUSSION

9.1 Overview

This chapter provides discussion of the study's findings. It begins with the discussion of the cultural and religious factors that supported HIV transmission among women and men living with HIV in Yogyakarta and Belu, Indonesia. Following this, it discusses the stigma and socio-cultural, religious and personal factors that drove stigma and discrimination towards women and men living with HIV. Next, it discusses the practice of traditional treatment for HIV, using traditional medicines from traditional healers and the role of family members, friends and neighbours in determining HIV treatment for PLHIV as being barriers to the access to HIV care services among women and men living with HIV. It also discusses HIV policies and programs in both study settings. These HIV risk factors, the impact of HIV, barriers to the access of HIV care services, and HIV policies and programs were chosen as the main areas for discussion because they identify the findings as new and novel, which show the independent contribution of the study to knowledge. Finally, this chapter provides a critical reflection of the strengths and possible limitations of the study.

9.2 The role of cultural and religious factors in HIV transmission

The findings of this study show that cultural practices and norms, and strict religious beliefs that lead to imbalanced sexual decision powers between men and women, played an important role in HIV transmission among female participants in Yogyakarta and Belu. For example, some women in Belu identified cultural practices such as bride wealth and sanctions for spousal disputes, which obliged them to serve their husband, as factors that influenced their spousal sexual relations and behaviours (see Section 5.2.6.2 for direct quotes). These were affirmed by the views of some men in Belu supporting that such cultural practices in marriage reinforced women's loyalty, obedience and obligation to serve their husbands who had paid bride wealth (see Section 6.2.6.2 for direct quotes). Similarly, these views were echoed by women from Yogyakarta where the Javanese culture of an 'ideal wife', 'good sexual practices' and 'good husband-wife relationships', demand that women have to obey, submit and serve their husbands. Of note were comments from male participants in Yogyakarta who encouraged and acknowledged to be living these cultural norms, values and practices in their spousal relationships (see Section 5.2.6.1 and 6.2.6.1 for direct quotes). Such norms, values and practices were reported as putting men or husbands in a position of power over women, and shaped men's perceptions of their entitlement to be served by their wives, including sexually. These practices meant that married female participants were unable to make decisions, especially in their spousal sexual relationships. As a consequence, women were disempowered, unable to negotiate for protected sex, and consented to their husbands' sexual preferences, even when they suspected their husbands of engaging in extra-marital sexual behaviours with other women, such as FSWs. These cultural norms, values and practices leave married female participants vulnerable to HIV infection. The findings further show an overall male dominance in both urban and rural settings in Yogyakarta and Belu, the leading to the occurrence of predominantly male-led sexual decision making in spousal sexual relations. These findings provide further evidence on the association of male dominance in sexual matters and decision making resulting in the poor use of condoms by men or husbands, as being a supporting factor for husband-to-wife HIV transmission (18, 68, 75). The current findings indicate that these norms and practices imposed the fidelity of women or wives towards their husbands, as is culturally expected, regardless of their knowledge or consent as to their husbands' risky sexual encounters with other women. These conform to the findings of a couple of previous studies conducted elsewhere. For instance, a study in Cambodia reported that in some cultures in the country, women's fidelity to their husband is considered necessary, and women are expected to accept their husband's promiscuity (18). Similarly, a study in Uganda found that in some cultures, husbands are accepted and expected to have multiple sex partners or wives, while women are expected to remain faithful to their husbands (68). Both female and male married participants in Belu also described that culturally, the purpose of marriage was to produce children, and that using condoms was an uncommon practice within marriages. Consequently, these cultural practices reinforce their engagement in unprotected sex in their spousal sexual relations, and enhance women's vulnerability to HIV or the possibility of co-infections for both women and men.

The current findings suggest that Islamic religious beliefs about condom use and husband-wife sexual relationships also influenced the spousal sexual practices of married Muslim participants in Yogyakarta, which led to husband-to-wife HIV transmission. Reports from both married female and male participants in Yogyakarta suggested that their interpretations of their religious beliefs in Islam about prohibitions of condom use in husband-wife sexual relations, were barriers to condom use in their spousal sexual relations (see Section 5.2.6.1 and 6.2.6.1 for direct quotes). It is therefore reasonable to allude that these factors contribute to HIV transmission within marriages, especially in circumstances where husbands engage in risky sexual behaviours with HIV high-risk women, such as FSWs. Some married women in Yogyakarta also talked about the Islamic religious beliefs that sexually serving a husband in marriage is seen a worship by the wife and refusing to do so is a sin, which were also affirmed by some married men in this setting (see Section 5.2.6.1 and 6.2.6.1 for direct quotes) (244, 245). The participants' strong religious beliefs seemed to influence their perceptions about sex and their sexual relations and practices in marriage. Such an influence was reflected in women's inability to refuse their husbands' sexual demands regardless of their desire and women's willingness to oblige their husbands' sexual demands due to the fear of committing a sin. This was also reflected in married men's perceptions of their entitlement to their wives' sexual services. It is therefore plausible to conclude that such religious beliefs favour husbands and support male dominance over Muslim women in Yogyakarta in spousal sexual decision making. In addition, the awareness of some unmarried female and male participants in Yogyakarta about their Islamic religious beliefs that forbid premarital sex seemed to indirectly affect their condom use practices. Even though it was evident that they did not follow these beliefs because they engaged in premarital sex, such an awareness led to the fear of stigma or of being negatively judged by other people who see them accessing condoms. Thus, such fears led to their decision not to access condoms to avoid stigma from others. It should be acknowledged that religious beliefs in Christianity also forbid the use of contraception, including condoms in marriage and premarital sex (246). However, the Christian participants (PLHIV) in Belu did not comment on the religious beliefs in Christianity in relation to these aspects and the influence of such beliefs on their sexual relations and practices, which seemed due to their lack of knowledge.

Thus, this study contributes to knowledge of the risk factors for HIV transmission by presenting an analysis of how cultural norms, values, practices and religious beliefs influenced sexual relations, practices and behaviours of women and men living with HIV in Yogyakarta and Belu, and therefore contributed to HIV transmission among them. All of these cultural and religious differences in terms of how they differently influenced or drove sexual relations and risky behaviours and practices of women and men in Yogyakarta and Belu, identify the findings as new and novel.

9.3 Stigma and discrimination towards PLHIV

The notion of HIV stigma and discrimination as manifested in a range of the discriminatory and stigmatising attitudes and behaviours of family and community members and healthcare providers towards PLHIV, is not a new issue in the literature on the impact of HIV, and has been previously well-documented (80, 214, 219). Our findings show that HIV stigma and discrimination towards both women and men living with HIV, occurred within families in both urban and rural settings in Yogyakarta and Belu. These were manifested in the discriminatory and stigmatising attitudes and behaviours of family members, such as the separation of their personal belongings from those of other family members, being asked to stay away from home, and ostracism within families, which all are consistent with the findings of previous studies (23, 80, 151). Despite the lengthy of period of time since the emergence of HIV in Indonesia, and the current knowledge about how to live safely with it in families, the fear of contracting HIV through physical contact seemed to be one of the significant drivers for such stigma and discrimination towards PLHIV within their families. Similar findings have been reported in earlier studies in other settings, which suggest that a lack of basic knowledge of HIV transmission and prevention contributed to close family members and relatives' discriminatory and stigmatising attitudes and behaviours (219, 247). The current findings also support the HIV stigma framework' concept which suggests that discrimination towards PLHIV is a stigma mechanism which represents the psychological responses of uninfected people to the knowledge about the HIV-positive status of other people living around them who may infect or spread the virus to them (214). These findings further highlight that HIV stigma and discrimination towards PLHIV within families were not merely individual attitudes and behaviours, but also a process of social influence among family members. For example, both women and men across the study settings talked about the social influence among family members through the spread of incorrect information that HIV can be transmitted through personal belongings, eating utensils, as well as physical and social contacts with a person living with HIV. This was acknowledged to lead to family members' fear of contracting HIV, and the stigma and discrimination towards PLHIV within families (see Section 5.3.1.2 and 6.3.1.2 for direct quotes). Close family ties were also identified as a social condition within communities in the study settings, that facilitated the quick spread of such information which influenced family members leading to stigma and discrimination towards PLHIV.

It was evident from these findings that the participants (PLHIV) in both rural and urban settings in Belu and Yogyakarta experienced stigma and discrimination from a wide range of significant people whom they lived with, including friends, neighbours and other community members. The negative social perceptions that associated HIV infection with immoral behaviours and negative moral judgements about PLHIV were perceived as drivers of HIV stigma by community members towards them, which have not been explored in previous literature on HIV-related stigma (151, 219, 247, 248). For example, women from both settings strongly emphasised the negative social perceptions that associated HIV with engagement in sex work and non-marital sexual relations. Such perceptions were described as leading to negative labelling towards them as FSWs, an ashamed self-identity for both themselves and their families, and hence perceived as drivers of stigma towards them (see Section 5.3.1.2 for direct quotes). This is a slight divergence from the stories of male participants (MLHIV) in both settings. Male participants identified the negative social perceptions of HIV that associated

HIV with engagement in sex with multiple female partners, and negative moral judgements of PLHIV as the ones with a low moral standing as the drivers of stigma towards them. However, the men acknowledged that they were not labelled negatively as male sex workers (MSWs) (see Section 6.3.1.2 for direct quotes). Consistent with the HIV stigma framework's concepts, these findings reflect the prejudice, stereotype and discriminatory attitudes imposed by people who are not living with HIV, as the dominant manifestations of stigma towards PLHIV (214). The influence of such negative social perceptions and moral judgements on stigma and discrimination towards PLHIV within communities seemed to further be facilitated by the strong community ties or communal characteristics of societies where people tend to gather and share or exchange information and perceptions through family and social activities or events (249, 250) in the study settings or Indonesia. Because of these close community ties, sensitive and negative information and perceptions about HIV and PLHIV are highly likely to spread quickly among community members, and influence them, as reported by both women and men across the study settings. Thus, the findings suggest that HIV stigma and discrimination towards the participants (PLHIV) reflect a process of social influence linked to the actions of the whole group of people within communities where the participants lived, not simply individual attitudes and behaviours of each community member.

Personal attitudes and behaviours of both women and men living with HIV were also drivers of stigma and discrimination towards themselves within communities. These unique attitudes and behaviours are new findings, as they have not been reported in previous studies (23, 47, 251). To illustrate these novel findings, some healthcare providers noted the attitudes and behaviours of PLHIV that led them to experience some negative outcomes as a result. For example, some healthcare providers from both Yogyakarta and Belu described the behaviours of PLHIV such as covering their face when accessing healthcare services and avoiding social interactions with neighbours and other community members to conceal their self-identity and HIV positive status. As such, even though the public would not have known of the HIV status of individuals who acted as above, such behaviours were described as leading to suspicion and an investigation of information about them by other patients or community members which perpetuated the external stigma and discrimination once their HIV status was discovered (see Section 7.5 for direct quotes). Thus, the findings suggest that the individual responses or reactions of PLHIV towards their own HIV status following the diagnosis could also influence how other people perceive and react towards them. In societies with communal characteristics and strong community ties, such as in Indonesia (151, 252), the acts of covering the face and avoiding social interactions or social disengagement, which are not common behaviours, will definitely raise suspicions and curiosity of other people to investigate information about PLHIV, which could increase the likelihood of them being stigmatised and discriminated against. Such personal reactions of PLHIV towards their HIV status also reflect a stigma mechanism, as explained in the HIV stigma framework, which represents their psychological response to the knowledge that they are infected with HIV and may experience negative treatment from uninfected people (214).

Javanese cultural practices and expectations in spousal relationships were among factors perceived by WLHIV in Yogyakarta, but not in Belu, as drivers of stigma and discrimination towards them by other (non-infected) people within communities. For example, some women in Yogyakarta indicated that the cultural practices and expectations about husband-wife relationships, which suggest the wives' loyalty, submission and obedience towards their husbands, influenced the negative reactions of their family, husband’s family and community members towards their HIV-positive status (see Section 5.3.1.2 for direct quotes). As such, it can be speculated that an HIV diagnosis in married women was associated with being disloyal to their husbands regardless of the husbands’ HIV status, as described by some married female participants in this study. Interestingly, the male participants (MLHIV) in Yogyakarta did not raise such cultural practices and expectations as driving factors for HIV stigma and discrimination against them. This seems to be a reflection of discriminative patriarchal cultural practices towards women within societies in Yogyakarta (245, 253). Similarly, some healthcare providers in Yogyakarta highlighted that socio-cultural norms that do not accept same sex relationships and consider them as deviant or contaminated behaviours, influenced their acceptance, care and treatment towards PLHIV. These were also acknowledged as drivers of their discriminatory and stigmatising attitudes and behaviours towards PLHIV.

It is also noticeable that religiosity played part in augmenting HIV stigma. For example, some religious beliefs in Islam were found to be drivers of HIV stigma and discrimination towards PLHIV (the participants) by non-infected people in Yogyakarta. These factors have not been explored and explained in previous literature, or the HIV stigma conceptual framework applied in this study (214, 254, 255). Examples of these are Islamic religious beliefs that perceive HIV as a sin, disgrace and curse from God, as it is acquired through free sex, sex with multiple partners and IDU which are not allowed in Islam. These beliefs were raised by both women and men (PLHIV) in this setting as drivers of stigma and discrimination by non-infected people towards them and other PLHIV (see Section 5.3.1.2 and 6.3.1.2 for direct quotes). The participants (PLHIV) in Belu did not report the influence of cultural practices and religious beliefs (Catholicism) on non-infected people's attitudes and behaviours towards PLHIV, which seemed to be influenced by their limited understanding about these aspects.

The views of PLHIV in Yogyakarta on the religious drivers of stigma are supported by those of some healthcare providers in Yogyakarta and Belu. These healthcare providers admitted to using religious beliefs (in Islam and Catholicism that forbid the use of illicit drugs, extramarital sexual relations and consider them as sins) as the parameters to judge the behaviours of PLHIV. As a consequence, they were unwilling to provide care, treatment, or interact with PLHIV, and felt disgusted about PLHIV (see Section 7.5 for direct quotes). These findings are in line with the HIV stigma framework's concept of prejudice which refers to the negative emotions or feelings (e.g., disgust, anger) of non-infected people, which is a common manifestation of stigma and discrimination towards PLHIV (214). The current findings add further evidence to the body of knowledge (256), which reports that the inclusion of personal religious beliefs in health delivery to PLHIV leads to clashes between personal religious values and professional expectations. However, some studies have also reported how personal religious beliefs play a role as the motivator or facilitator for some healthcare providers' health service delivery to PLHIV (256, 257). Evidence from the current findings, as explained above, shows a process of influence of social norms, values, perceptions, moral judgements, cultural practices and religious beliefs, which are socially and culturally constructed, on the attitudes and behaviours of non-infected people towards PLHIV. These factors influenced the views and reactions or responses of community members and healthcare providers towards HIV and PLHIV, and played an important role as the driver of HIV stigma and discrimination towards PLHIV, which are identified as new findings that have not been addressed in the previous literature on HIV-related stigma (219, 247, 248).

The current study also reports how the personal values of female healthcare providers across the study settings as being the drivers of their discriminatory and stigmatising attitudes and behaviours towards MLHIV. To the researcher's knowledge, these findings are new in the literature, and have not been reported elsewhere (24, 46, 47, 80, 83, 219). For example, female healthcare providers in both settings spoke about their personal values towards husband-and-wife loyalty and the unacceptability of cheating behaviours in marriage. These personal values led to the projection of what happened in the marriage of PLHIV (e.g., husbands had sex with other women or were unfaithful and contracted HV) to their own situations or marriages, which reinforced their negative attitudes and behaviours towards MLHIV (see Section 7.5 for direct quotes). Interestingly, such personal values were not identified in the interviews with the male healthcare providers in both study settings. These findings may suggest that female healthcare providers had more discriminatory and stigmatising attitudes and behaviours towards PLHIV compared to male healthcare providers. Information about discriminatory behaviours from the female health workers compared to male health workers, has been reported elsewhere including where female doctors and ward staff were cited as having more negative feelings and stigmatising attitudes towards PLHIV compared to their male colleagues (254, 258). However, it should be acknowledged that stigma and discrimination towards PLHIV by health providers who participated in this study were committed prior to or at the beginning of their involvement in HIV healthcare service deliveries to PLHIV. This was a situation before they attended HIV trainings and when they were not equipped with proper knowledge on HIV and how to serve patients living with HIV. Knowledge of HIV and health service delivery to PLHIV, which they acquired through both attending HIV trainings and their experience in treating patients living with HIV, has helped them overcome the fear of contracting HIV from patients, change their perceptions about

PLHIV, and avoid being discriminative towards PLHIV. This supports the previous findings (259-261), which have reported that exposure to HIV-related knowledge or having in-depth HIV knowledge, attending training on stigma and discrimination, gaining more experience in treating patients (PLHIV) and having frequent contact with them, are associated with low levels of stigmatising attitudes or are negative predictors of stigma and discrimination among health professionals.

It was noted that HIV stigma and discrimination experienced by some women and men living with HIV across the study settings caused a further negative impact on themselves and their families. These included family separation, divorce or broken relationships, psychological challenges (e.g., stress, fear, worry, feeling ashamed), and a reluctance to access healthcare services. For example, policy makers from Yogyakarta and Belu identified stigma and discrimination as external challenges to the implementation of HIV programs, as these were perceived to prevent the participation of PLHIV (and also community members) in HIV-related activities, and HIV testing and treatment (see Section 8.4.2 for direct quotes). This can be compared to women and men (PLHIV) from Yogyakarta and Belu who acknowledged hiding their HIV status which was not only to prevent the possibility of stigma towards themselves but also courtesy stigma or stigma by association towards their children and parents (see Section 5.3.1.1 and 6.3.1.1 for direct quotes). Although evidence on courtesy stigma experienced by family members of PLHIV is still limited, a few studies have reported courtesy stigma experienced by healthcare staff, carers of PLHIV and friends of PLHIV due to associating with PLHIV, which led to psychological distress and the thought of leaving HIV work (262-264). Other instances of courtesy stigma are that an HIV diagnosis in a family member caused shame to the family and damaged the family’s reputation, social networks and relationships (153, 154). Family separations, such as the separation of children from HIV-positive mothers by other family members, women being divorced or left by husbands or fiancés or boyfriends due to their HIV status, reflected the impact of HIV stigma and discrimination on individuals and families and the unacceptance of PLHIV, which have also been reported in previous studies (28, 47, 265).

To conclude, previous studies on HIV stigma, discrimination and the HIV stigma framework's concepts used in this study, have mainly focused on exploring and explaining the individual level factors that facilitate or drive discriminatory and stigmatising attitudes and behaviours of non-infected individuals towards PLHIV (214, 219, 247, 248), and have thus ignored the complex socio-cultural and religious factors that influence HIV stigma and discrimination. This study contributes to bridging this gap by presenting the social perceptions, moral judgements, cultural practices and religious beliefs in relation to HIV, PLHIV, sex, and spousal (sexual) relationships as facilitators or drivers of discriminatory and stigmatising attitudes and behaviours of non-infected people towards PLHIV. This study also adds further evidence to the knowledge and understanding of personal factors that support stigma by presenting the personal attitudes and behaviours of PLHIV and the personal values of healthcare providers as drivers of stigma and discrimination towards PLHIV. It also extends our understanding of HIV stigma and discrimination towards PLHIV as a result of the process of social influence among family and community members.

9.4 Traditional treatment of HIV and the role of family members, friends and neighbours in the treatment

This study reports the dimensions of the supply side or healthcare services (availability, approachability, affordability, appropriateness and acceptability of HIV care services), and the corresponding abilities of the demand side or PLHIV (ability to reach, perceive, pay, engage and seek the services) as factors that supported or influenced the access of PLHIV to HIV care services in Yogyakarta and Belu. These are not dissimilar to the previous findings in different settings and the access to healthcare services framework's concepts, which have suggested that accessibility of HIV care services for PLHIV is determined by the interaction between these healthcare service dimensions and the corresponding abilities of PLHIV (164, 165, 220, 266).

The current study also reports new findings on barriers to HIV care access among PLHIV, that have not been explored in previous studies or explained in the access to healthcare framework's concepts (220, 267-270). One of the barriers was the use of traditional treatment for HIV within rural communities in Belu, a well-known cultural practice which has been passed down from one generation to another and was not identified in urban settings in Yogyakarta. The stories of PLHIV and healthcare providers in Belu suggest that access to HIV care services among PLHIV was influenced by the traditional treatment of HIV using traditional medicines provided by traditional healers. Similarly, policy makers in Belu acknowledged the influence of the use of traditional treatment of HIV using traditional medicines as an external challenge to the delivery of HIV programs or activities within communities. These influences were reflected in the stories from all groups of participants in Belu, suggesting that PLHIV in general, and some participants (PLHIV), stopped accessing HIV care services and switched to a traditional treatment after ART initiation, or treated HIV using traditional medicines in the first place (see Section 5.4.5.1, 6.4.5.1, 7.6.1 and 8.4.2 for direct quotes). The availability of, and well-known information about traditional medicines to treat any health issues, were indicated as supporting factors for the use of traditional treatment of

HIV. Previous studies in Africa have reported the use of traditional/herbal medicines or therapies and its influence on ART adherence among PLHIV (271-275), but none of these studies specifically focused on exploring the use of traditional/herbal medicines as a barrier to the access of HIV care services among PLHIV. For example, studies in Ethiopia and Uganda reported a common concomitant use of herbal medicines (e.g., ginger, garlic, moringa) and ART for HIV and its associated factors, such as a lower educational status, the perceived low quality of service at clinics, ART side effects and low social support, as barriers to ART adherence (272-274). Similarly, a study in Tanzania, Uganda and Zambia investigating factors associated with incomplete ART adherence among PLHIV, reported that consulting a traditional healer or herbalist was among other factors (e.g., internalised stigma, depression, alcohol abuse, low level of social support) associated with poor ART adherence (271). However, the study by Lubinga and colleagues in Uganda reported that concomitant use of herbal and antiretroviral medicines for HIV treatment was not associated with poor adherence to ART among PLHIV (274). In addition, a recent study in Ethiopia by Gesesew and colleagues, which explored the access of WLHIV to HIV care services, reported that traditional healers were barriers to the access to HIV care services, as they forbade the women to access and engage in ART (276).

Evidence from the current study suggests that the role of family members in determining HIV treatment using traditional medicines from traditional healers was also a significant barrier to the access to and initiation of ART among the participants (PLHIV) in Belu, which was not raised by the participants in Yogyakarta. Some PLHIV and healthcare providers in Belu reported that the use of traditional medicines by PLHIV for HIV treatment was mainly the decision made by family members, such as parents, siblings and spouses, which hindered or led to the delay of access to HIV care services, ART initiation and non-adherence to ART. The regular use of traditional medicines within families and the positive previous experience of the effectiveness of traditional medicines in treating other health issues, were the underlying reasons for family decisions to use of traditional treatment over ART for their infected family member. Similarly, the findings suggest that a lack of understanding among both participants (PLHIV) and their family members about the function of ART to supress the viral load, led to the 'choice' of traditional medicines over antiretroviral medicines for HIV treatment in the early stage of the participants' HIV diagnosis. This was also reflected in the fact that access to HIV care services or ART was a last choice for participants (PLHIV), and this was made once traditional treatment was felt to be ineffective and their physical and health conditions were getting worse. These are not dissimilar to previous findings which reported insufficient or incorrect knowledge about ART as a barrier to the access and adherence to ART among PLHIV (269), and positive relationships between a lack of ART knowledge and less family support for ART access and adherence (277). In other words, the current study indicates a lack of family support for PLHIV prior to or in the early stages of ART as a barrier to their access to HIV care services and ART initiation or adherence.

The social influence of extended families, neighbours and friends on family decisions for the use of traditional medicines from traditional healers for HIV treatment was another barrier for access to HIV care services and ART initiation among PLHIV in Belu. This was reflected in the comments of some PLHIV in Belu that explained about the encouragement, provision of traditional medicines or information about traditional treatment by extended families, neighbours and friends as factors that influenced their family's decisions for the use of traditional medicines from traditional healers for HIV treatment. The findings add further evidence to a previous study's findings (277) which have reported that social factors, such as gender norms, social status and stigma affected family support for PLHIV and their access to ART. In addition, evidence from the current study also demonstrates that the poor physical and health conditions of PLHIV, and their dependency on family support for their daily needs and healthcare influenced their ability to make decisions about their own health treatment, hence indulging family decisions for traditional treatment, which negatively affected their access to ART.

To conclude, it is apparent that previous studies and the access to healthcare framework's concepts have mainly focused on exploring and addressing barriers to the access to healthcare services based on the dimensions of healthcare services and the characteristics (abilities) of clients or people in need for care (164, 220, 278). Similarly, studies on the use of herbal therapies among PLHIV have not explored the influence of those therapies on the access of PLHIV to HIV care services (271-275). Thus, there is a paucity of evidence on the influence of cultural and social factors on the accessibility to healthcare services. This study contributes to the knowledge of barriers to the access to HIV care services or ART by presenting an analysis about the influence of the cultural practice of traditional treatment for HIV using traditional medicines from traditional healers, and the role of family members, friends and neighbours in determining HIV treatment for PLHIV.

9.5 HIV policies and programs in Yogyakarta and Belu

Findings of the current study suggest that HIV policies and programs existed in government institutions and NGOs from where policy makers were recruited in both study settings. However, the coverage or focus of HIV policies in those institutions and NGOs were limited. For example, policy makers in Yogyakarta reported that HIV policy in their institutions and

NGOs only focused on addressing either HIV-risk factors or its impact (see Section 8.2 for direct quotes). Despite the limited HIV policy focus, the existence of the HIV policy in those government institutions or NGOs in Yogyakarta was an indication of the awareness and commitment of policy makers to addressing HIV problem through policies and practices. The difference in HIV policy coverage or focus in those institutions and NGOs seemed to also provide them with opportunities for intersectoral collaboration to effectively address both HIV-risk factors and its impact in the area. Interviews with policy makers in Belu reveal that HIV policy in the district only focused on addressing HIV- risk factors and treatment, with the local health department as the only sector carrying the responsibility for tackling the problem. Thus, it is plausible to conclude that HIV was not a priority issue for the local government of Belu and its departments to address. This appeared to be the underlying reason for the limited support from the local government of Belu for HIV programs and activities.

The current findings also show that HIV policies in both study settings were derived from the national HIV policy which addresses both HIV-risk factors and its impact (279-281). However, given the limited HIV policy focus or coverage in the two local governments in both study settings, it is plausible to conclude that the response to HIV issue through policies, programs and activities at the district level depends on each local government and their priority programs.

Policy makers from both settings described how HIV policies were translated into various programs and activities to halt the transmission and address the impact facing PLHIV. For example, policy makers in Yogyakarta talked about programs and activities, such as HIV information sessions and VCT for key population groups and the general community members in order to increase their knowledge of HIV-risk factors and acceptance of PLHIV, prevent HIV transmission and diagnose HIV-infected people as early as possible. Training to develop business skills, the provision of business capital and the administration of national or regional health insurance for those who could not afford healthcare service costs, were also delivered to address the economic and health impacts of HIV on PLHIV. These programs and activities show that the response to HIV issue in Yogyakarta have been well established compared to that of Belu. This was also reflected in collaboration between government institutions and NGOs in the implementation of HIV programs and activities, the division of the focus of HIV programs and activities among them, and the networks of support and healthcare service delivery between healthcare facilities and NGOs, which were not found in Belu. The response to HIV issue in Yogyakarta reflects the concept of intersectoral collaboration which provides spaces or opportunities for more than one sector to play different roles in tackling health issues to achieve a common purpose. This concept suggests that the active involvement of other non-health sectors in response to any health issues can lead to the achievement of better health outcomes in a more effective, efficient and sustainable way (282-285).

Compared to Yogyakarta, policy makers in Belu suggested that HIV programs and activities in Belu were limited to HIV information sessions and treatments or ART. These were described to be influenced by the lack of financial support from the local government, limited healthcare devices, a shortage of HIV-trained healthcare professionals, and the lack of involvement of non-health sectors in addressing HIV issue. These factors were also acknowledged by policy makers as challenges for the successful implementation of those existing HIV programs or activities this area. Similarly, policy makers from NGOs in Yogyakarta acknowledged that the low quality of human resources or low level of education of HIV workers (e.g., the companion of PLHIV) and the limited funds to support the implementation of HIV programs or activities, were internal challenges to the implementation of HIV programs or activities in their organisations. These were due to the fact that some NGOs recruited voluntary HIV workers (who were also HIV positive) without educational requirements and relied on donors from international organisations. The current findings are in line with previous findings which reported interventions or implementers' characteristics, such as the lack of funds, the lack of resources (e.g., inadequate number of staff and health equipment), and the lack of knowledge of implementers about interventions being delivered due to their lack of training, as barriers to the implementation of HIV programs or interventions (286-288).

The findings show that HIV policies and programs or activities across the study settings had been implemented to respond to the HIV epidemic. However, it is apparent that HIV policies in both study settings had not fully reflected HIV-related strategies recommended in the HIV policy at the national level (279, 289) (see Section 10.3.1 for detailed explanation of these strategies). This was reflected in a range of factors in one or both study settings, such as limited intersectoral collaboration in the response to HIV issue, limited availability of HIV care services and coverage, limited HIV care facilities and human resources, limited funds to support HIV programs or activities, etc. Similarly, HIV programs or activities implemented across the study settings had not fully addressed or covered aspects or activities recommended in the national HIV policy (279, 289). For example, there was limited or a lack of rehabilitation programs or activities to support PLHIV across the study settings. Rehabilitation programs or activities may include both social and economic aspects, such as improvement of working skills and self-efficacy of PLHIV, so that they can be economically and socially productive, which can lead to the improvement of their quality of life (279, 289). The national HIV policy also suggests that to help PLHIV cope with health, social and economic impacts of HIV, the national and local governments are responsible for ensuring the availability of ART and medical supplies, providing health insurance, eliminating stigma and discrimination, and providing assistance programs for PLHIV (279, 289). They are also responsible to ensure that PLHIV and their families are involved in HIV programs to improve their family income, economic condition and social engagement. These aspects seemed to have not been fully covered in HIV programs and activities across the study settings.

9.6 Critical reflections on the strengths and potential limitations of the study

This study has a number of strengths. To the best of the researcher's knowledge, this is the first qualitative study that covered and explored the influence of, amongst other factors, cultural practices, religious beliefs, social norms and values and moral judgements on HIV transmission, the impact of HIV, and the access to HIV care services among PLHIV in Indonesia, which have not been explored previously (99, 102, 219, 247, 248, 277, 290, 291). This study provides useful insights about the similarities and differences of factors that facilitate or contribute to HIV transmission and the impact of HIV, and influence accessibility of HIV healthcare services among PLHIV, and has resulted in three publications in three high quality international journals (48-50).

Another strength is that the study involved four different types of participants (WLHIV, MLHIV, healthcare providers and policy makers) from two settings with different characteristics. This enabled the researcher to make comprehensive comparisons on HIV-risk factors, the impact of HIV, the accessibility of HIV healthcare services and HIV policies and programs, based on the study settings, sex and type of participant, and draw substantive conclusions. Previous studies involving different groups of PLHIV on these topics have mainly focused on a single setting (38, 130, 151, 160, 292). Thus, the coverage of the two study settings with different characteristics in terms of geographical location, culture, religion and infrastructures, including healthcare system and facilities and transportation systems, provided opportunities for meaningful comparisons of how these different aspects have contributed to HIV transmission and its impact, and influenced accessibility of HIV care services among PLHIV.

In terms of the participants, the initial design of the study focused on WLHIV. The addition of participants: MLHIV, healthcare providers and policy makers, provided valuable insights and understandings of different viewpoints and experiences, especially the comparison between women and men living with HIV. Such comparisons have resulted in valuable insights and understandings of HIV risk-factors, the impact of HIV, and the facilitators of and barriers to the access of HIV care services, that were specifically experienced by WLHIV due to their gender status and by both women and men due to their HIV status. Previous studies on these topics in the context of Indonesia and globally have not attempted to make such comparisons (38, 102, 293, 294). The addition of other groups of participants also enabled a comparison of the views and perspectives of PLHIV with those of healthcare providers and policy makers in order to gain a rich understanding of the facilitators of and barriers to the access to HIV healthcare services, and to identify existing HIV policies. This includes how these policies have been put into programs and activities to address HIV, and where policy and resources are lacking.

The use of a qualitative design (227, 228) is also a strength of this study, as it gave the researcher an in-depth understanding about the views, perspectives, understandings and experiences of the participants regarding the topics being researched. The use of a qualitative approach in this study was guided by the consolidated criteria for reporting qualitative research (COREQ) which is also a strength of this study, as it suggests a checklist of 32 items to represent best-practice in qualitative research and support explicit and comprehensive reporting for this qualitative study (232). These items which are grouped into three domains: (i) the research team and reflexivity, (ii) the study design, and (iii) the analysis and findings, were met or exceeded in this study (see Chapter 4 for a detailed explanation of how each item in the COREQ checklist was addressed in this study). The use of a qualitative data analysis framework (235) to guide the analysis of the findings is also another strength of this study. It helped the researcher manage the collected qualitative data in a coherent and structed way, and enhanced transparency, rigour and validity of the analytic process of the data.

The research's knowledge and several years of work and research experience in the field of HIV in Yogyakarta, Belu, and other settings in Indonesia, are also strengths of this study. They enabled the researcher to access people and organisations, and recruit participants in a timely manner during the data collection process. Such knowledge and experience also assisted the researcher to have conversations with participants during the interviews in a way that enabled them to share their views, stories and experiences in relation to the sensitive topic of HIV risk factors and impacts. The researcher's language skills or ability to speak Bahasa also contributed to the strength of the study as it assisted the researcher to undertake the interviews without an interpreter and interpret the cultural and religious meanings behind particular words used by the participants, which do not have a literal translation into English. Similarly, the researcher's cultural background and familiarity with the study settings helped the researcher to explore and make sense of how cultural practices, religious beliefs, social values, norms and moral perceptions in the study settings contributed to HIV transmission or its impact and influenced access to HIV care services among the participants (PLHIV).

However, the study design has some potential limitations. The use of a snowball sampling technique for the recruitment of PLHIV, and the dissemination of the study information packs through the HIV clinics may have led to the recruitment of participants from the same networks, as the participants would have provided information about the study to only those within their networks, or who had accessed HIV treatment at the clinics. It is therefore possible that the study could have been under-sampled, by potentially not including PLHIV who were outside of the social networks of the current participants. This might have led to an incomplete overview of perceptions, understandings and experiences about HIV-risk factors, the impact of HIV, and the facilitators of and barriers to the access to HIV care services among PLHIV. Due to small number of participants in each group and as is the case of many other qualitative studies, the current study is not meant to claim generalisability of the findings. The findings mainly reflect the views or perspectives and experiences of the current participants, which cannot be generalised to other PLHIV with different characteristics in different settings. Another potential limitation relates to treatments. All participants (PLHIV) were taking ART at the time of the study (by virtue of us recruiting from HIV clinics). PLHIV who are not taking ART may have different HIV-related experiences, including those which may have culminated in them disengaging from ART.

CHAPTER TEN

CONCLUSIONS AND IMPLICATIONS

10.1 Overview

This chapter presents a summary of the methodology used in this study, and how the study has achieved the proposed objectives laid out in 1.3. It also presents the implications of this study for HIV policy and program in Yogyakarta and Belu, and for future research.

10.2 Conclusions

This thesis aims to understand the HIV-risk factors among women and men living with HIV, the impact of HIV on themselves and families, the facilitators of and barriers to the access to HIV care services, and HIV policies and programs in Yogyakarta and Belu. It presents a range of factors that facilitated or contributed to HIV transmission among women and men living with HIV in both study settings. These included poor health literacy about HIV and condoms, behavioural risk factors, IPV against women, economic or financial conditions, social influences, and environmental factors that supported women and men's engagement in risky behaviours such as unprotected sex and IDU. It also presents cultural practices, norms, values, and religious beliefs that influenced participants' perceptions, sexual relations and behaviours, as supporting factors for HIV transmission among women, which were identified as novel findings of this study. A journal article on these novel findings was published in PloS ONE (48) during this thesis. This provides additional evidence as to the rigour and novelty of the research that underpins this thesis, and furthers our knowledge of how cultural and religious factors play a role in HIV transmission among the participants, especially women. These are the key contributions of this study to the knowledge of HIV-risk factors among women and men in the study settings, which the enrich previously reported findings and concepts (115, 191, 295, 296).

This thesis presents a range of the negative impacts of HIV on both women and men living with HIV and their families across the study settings. These impacts included various psychological challenges, family separation, broken relationships or divorce, economic burdens, stigma and discrimination. It also presents social perceptions, norms and values, cultural practices, religious beliefs and moral judgements about HIV, PLHIV, illicit drugs, sex and spousal relationships as drivers of stigma and discrimination towards PLHIV, which were also identified as novel findings of this study. These novel findings were published during the thesis in the International Journal of Environmental Research and Public Health (49). This publication provides additional evidence of the rigour and novelty of the research that underpins this thesis and furthers our knowledge about the drivers of stigma, and stigma and discrimination as a process of social influence among family and community members. Another paper was also published in Frontiers in Medicine (50) during this study, which also extends our knowledge about the perspectives of healthcare providers on how their personal values about marriage, socio-cultural norms that do not accept same sex relations, religious beliefs, and the individual attitudes and behaviours of PLHIV, drive their discriminatory and stigmatising attitudes and behaviours towards PLHIV. These various drivers of stigma are also the key contribution of this study to knowledge which has not been reported in previous studies on HIV stigma (219, 220, 247, 248).

The thesis also presents a number of healthcare services dimensions, including availability, approachability, affordability, appropriateness, and acceptability of HIV care services, and the several corresponding abilities of PLHIV, such as their ability to reach, perceive, pay for, engage in and seek the services, which both acted upon, either as facilitators of or barriers to the access of the participants (PLHIV) to HIV care services. It presents the limited availability of the services, the shortage of HIV-trained healthcare professionals, the limited dissemination of information about the services, the long distant travel to HIV clinic, the poor public transportation system, the unaffordable medical and transport costs more as barriers to HIV care access among participants (PLHIV) in Belu (220, 297-300). These barriers corresponded with other factors from the demand side (PLHIV), including a lack of knowledge of the services, change of residence, the fear of stigma and discrimination, and the poor economic or financial conditions which influenced their ability to perceive their need for HIV care services, and reach, pay for and engage in the services (164, 220, 278). These aspects were not barriers for most participants (PLHIV) in Yogyakarta to accessing the services. The thesis also discusses the traditional treatment of HIV using traditional medicines, and the social influence of families, friends and neighbours in supporting traditional treatment as barriers for participants (PLHIV) in Belu, in accessing HIV care services or ART, which were not the cases for Yogyakarta participants (PLHIV). These were also identified as the novel findings of this study. These novel findings are also the key contributions of this study to the knowledge and understanding about the barriers to HIV care access among PLHIV.

This thesis also reports on the lack of HIV policies and programs in governmental institutions, and the lack of involvement by NGOs and other non-health sectors in Belu in addressing the HIV issue. These were identified as the underlying reasons for the limited support coming from the local government, NGOs, private institutions, limited HIV programs and activities, and the lack of intersectoral collaboration in addressing HIV issue in Belu. These were not the cases in Yogyakarta as HIV policies and programs existed in governmental institutions (health and social departments of the local government of Yogyakarta) and several NGOs, which supported intersectoral collaboration among them.

10.3 Implications

10.3.1 Future HIV policies and programs in Yogyakarta and Belu

The government of Indonesia has launched a national HIV prevention policy in 2013. Its focus is on reducing and eliminating new HIV infections, AIDS-related deaths, discrimination against PLHIV, socio-economic impact of HIV on individuals, families and communities, and improving the quality of life of PLHIV (279, 289). To achieve these outcomes, several strategies have been recommended in this policy: (i) increasing the collaboration among the different sectors in response to HIV; (ii) improving health service facilities and the quality of its human resources: (iii) expanding the coverage of services to reach high-risk community groups, underdeveloped or remote areas, borders, and islands with health problems: (iv) increasing funds for HIV prevention and the equitable distribution of human resources: (v) improving the availability and affordability of HIV treatment; and (vi) ensuring the safety and quality of medicines and health devices used in HIV treatment (279, 289). Several programs and activities have also been recommended in response to HIV problem, including health promotion, the prevention of HIV transmission, HIV diagnosis, and treatment, care, support and rehabilitation for PLHIV, which must be carried out comprehensively and sustainably (279, 289).

However, it appears that the governments at provincial and district level, are independent in their ability to determine their HIV policy focus, and to prioritise HIV programs and activities based on the availability of resources. While this approach could be good as it would address contextual issues locally, this study found a significant divergence at the provincial and district levels, which was not fully in alignment with the national HIV policy that focuses on addressing the important issues of both risk factors and the impact of HIV on individuals, families and communities. As such, the current study findings suggest the need for HIV policies in Yogyakarta and Belu, that continue to address both HIV-risk factors and the impact of HIV on PLHIV and their families, support and expand the provision and coverage of ART and HIV interventions or programs and activities. HIV information or education sessions for population groups, and family and community members would be a vital component of any intervention seeking to raise awareness of HIV/AIDS (301). These are programs or activities that can increase the knowledge and understanding of HIV and the various socio-cultural and religious factors that play a role in supporting HIV transmission. HIV education for family and community members, and healthcare professionals can also be an effective strategy for addressing stigma and discrimination against PLHIV, which often occur due to a lack of knowledge about HIV as reported in the literature on HIV stigma, and which would allow their families and communities to provide social support (301-303). Health system interventions, such as interventions supporting HIV patient self-management, and improving patient engagement in HIV care, can also be a useful strategy in building a positive self-perception and confidentiality of PLHIV, and addressing stigma and discrimination against them (304, 305). These interventions may lead to reducing internalised stigma among PLHIV, which often comes from negative self- perception, worry and fear of other people’s reactions, increasing acceptance of PLHIV within families, communities and healthcare facilities, and supporting their access to HIV care services.

The findings also show that there is a need for the local governments in both settings to increase their financial support for HIV programs and activities designed to address HIV-risk factors and the impact of HIV on PLHIV and their families. Local governments provide the main source of funds for HIV programs and activities of governmental institutions, hence their restricted financial support was the underlying reason for limited HIV programs and activities to address HIV issue in both study settings. Furthermore, there has to be free access to HIV care services for PLHIV (306, 307). It is also important that much more needs to be done, particularly in improving the quality and access of services to ease the burden of healthcare expenses through the provision of free or subsidised health care insurance. Specific to Belu, the current findings show that there is a need for the local government of Belu district to exempt the healthcare expenses of PLHIV through regional health insurance (Jamkesda) which has currently been provided for some PLHIV in the area. In addition, there will need to increase the number HIV-trained healthcare professionals, and provide adequately resourced HIV healthcare services, such as CD4 and viral load testing for PLHIV. These may lead to increasing the number of PLHIV participating in and the successful implementation of HIV programs and activities. The policy of universal access to ART and the expanded coverage of ART for population groups and community members have been reported as effective in reducing HIV infections and AIDS-related deaths globally during the period from 2010 to 2019 (308, 309). However, HIV infections and AIDS cases in the context of Indonesia were reported to significantly increase during the same period (7, 308). This is a reflection of the inequitable distribution or limited coverage of ART, late diagnosis, and poor access and adherence to ART (7, 308). Poor financial conditions seem to be a major problem impacting on PLHIV and their families. Thus, other intervention strategies that can also be used to address the economic impact of HIV, as have started in Yogyakarta, are the provision of both skill training based on

PLHIV’s interests and start-up capital for their own business. These intervention strategies have been reported elsewhere as effective in supporting economic empowerment and reducing HIV vulnerability among PLHIV (310-313). The provision of training and the start-up capital for PLHIV can be done collaboratively between government and other sectors, such as NGOs that can provide continuous support, guidance and supervision (310). Moreover, as was in Yogyakarta, the local government of Belu district needs to consider the establishment of intersectoral collaboration between the local health department and other non-health sectors in Belu, as suggested in the national HIV policy.

10.3.2. Future research

The current findings indicate that there is a need for further largescale quantitative or mixed-methods studies to explore the socio-cultural and religious aspects that contribute to the growing HIV epidemic and its impact facing women in Indonesia. Future studies exploring the cultural, social and family-related barriers to the access to HIV care services or ART among PLHIV in other settings in Indonesia, and studies with PLHIV who have not engaged in HIV care services or ART, are recommended. This would be in order to allow a comparison between their findings and those of the current study. Finally, further research is needed to identify the role of government institutions and NGOs at both policy and practical levels so as to improve health service delivery to PLHIV, halt HIV transmission, and support PLHIV and their families to cope with the impact facing them.

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APPENDICES

Appendix 1 : Publication 1 - Cultural and religious determinants of HIV transmission

PLOSONE

RESEARCH ARTICLE

Cultural and religious determinants of HIV transmission: A qualitative study with peopleliving with HIV in Belu and Yogyakarta, Indonesia

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Citation: Fauk NK, Ward PR, Hawke K, Mwanri L (2021) Cultural and religious determinants of HIV transmission: A qualitative study with people living with HIV in Belu and Yogyakarta, Indonesia. PLoS ONE 16(11): e0257906. https://doi.org/10.1371/journal.pone.0257906

Editor: Joseph Telfair, Georgia Southern University, UNITED STATES

Received: March 30, 2021

Accepted: September 13, 2021

Published: November 15, 2021

Data Availability Statement: Due to privacy restrictions, the underlying data may not be made publicly available. However, interested and qualified researchers who meet the criteria for access to confidential data may send data access requests to the ethics committee (human.researchethics@flinders.edu.au).

Funding: The authors received no specific funding for this work.

Competing interests: The authors have declared that no competing interests exist.

Abstract

As a part of a larger qualitative study to understand HIV-risk factors and impacts on people living with HIV (PLHIV) (52 women and 40 men) in Belu and Yogyakarta, Indonesia, this paper reports the influences of cultural practices and religious beliefs on sexual relationships and behaviours of participants as contributors for HIV transmission. This study was conducted from June to December 2020. Data collection was conducted using one-one-one in-depth interviews. Participants were recruited using the snowball sampling technique. Data analysis was guided by a qualitative data analysis framework. The findings showed that cultural practices in Belu related to the use of bride wealth, managing spousal disputes, marriage, and condom use, influenced spousal relationships and sexual behaviours or practices which contributed to HIV transmission. Javanese cultural practices and expectation of an 'ideal wife', Islamic religious beliefs about expected husband-wife relationships, forbidden premarital sex, and the participants' individual interpretation of their religious beliefs about condom use spousal sexual relations, also influenced spousal sexual relations and behaviours, which supported HIV transmission among the participants. The findings indicate the need for HIV education programs that address cultural practices and religious beliefs for community members and population groups to enhance their understanding about HIV, condom use, and how cultural practices and religious beliefs play a role in HIV transmission.

The findings also indicate the need for involvement of religious leaders in HIV education programs to bring insights to people and help them interpret their religious beliefs in health promoting ways. Future studies that explore different aspects of culture and religion which may contribute to HIV transmission are recommended.

Introduction

The 2020 UNAIDS report [1] showed a global estimation of 38 million people living with HIV (PLHIV) and 1.7 million newly diagnoses in 2019. The same report showed a reduction in new

HIV infections of 12% and 29% less AIDS-related deaths during the period from 2010 to 2019, both of which are associated with the coverage expansion and effectiveness of antiretroviral therapy [1]. However, the UNAIDS report also showed that HIV infection in the context of Indonesia increased by 25.5% during the period from 2010 to 2018, with an estimated 510,000 cases in 2010 to 640,000 in 2018 [2]. Behavioural factors such as unprotected sexual intercourseand injecting drug use (IDU) have been reported as the main routes of HIV transmission in the country [3].

Globally, behavioural factors such as frequent engagement in unprotected sex or sex with- out condoms with multiple partners [4–8] and IDU involving needle sharing [9, 10] have been well-documented as the main contributors for HIV transmission. Low level of education, lackof knowledge of the means of HIV transmission and prevention, unavailability of condoms inthe moment of need [11–14] and lack of clean needles or syringes [9] are reported as the sup- porting factors for people's engagement in such high-risk behaviours. Poor economic or financial conditions is another contributor for HIV transmission as it is reported to often lead to people's involvement in transactional sex or sex with multiple partners in exchange for money and the experience of sexual coercion which often occurs without protection or condom use due to refusal by sex clients or partners [15–17]. Social environmental factors such as availability and ease of accessibility of brothels and peer social influence on casual sex practices and poor condom use have also been as attributable to HIV transmission within population groupsor communities [13, 18–22]. A study in Cambodia also reported an increase in HIV transmission within couples due to cultural practices where a woman or wife has a duty to sexually serve her husband and is expected to accept her husband's promiscuity [23]. This is tied in with cultural practices where men or husbands are perceived to be entitled to sex and accepted to have multiple sex partners, while women are expected to remain faithful, fulfil their duty and submit to their husbands [24–26].

Although many studies globally have explored HIV-risk factors among different population

groups, the majority have focused on individual, structural and socioeconomic-related factors[27–30]. Similarly, studies on HIV-risk factors in the context of Indonesia have mainly coveredindividual level factors (e.g., knowledge of HIV, sexual behaviours, condom use, IDU, environ-mental and socioeconomic factors (e.g., peer influence on risky behaviours, surrounding environment and poor economic condition that facilitate people's engagement risky behaviours) [8, 13, 31–33]. Evidence of cultural and religious factors that contribute to HIV transmission isstill limited, despite 87.18% and 9.87% of the Indonesian population following Islam and Christianity respectively [34]. This paper fills this gap and enriches the existing knowledge of cultural and religious-related determinants of HIV transmission by presenting an analysis of the influence of cultural practices and religious beliefs on sexual relations, condom use practices and sexual behaviours of women and men living with HIV in Belu and Yogyakarta, Indonesia. Indonesia is a country where most people actively follow religion, and hold firmly beliefs and values that are influenced by religious and cultural norms. These have a significant influence on daily life, attitudes, behaviours and relationships [35, 36], so understanding religious and cultural factors is critical for the development of HIV programs and interventions. This understanding can improve knowledge, health promoting attitudes and behaviours of PLHIV and general community members in the study settings and other settings in Indonesiaand globally.

Theoretical framework

The logical model for behavioural and environmental factors diagnosis was used to conceptualise and discuss the findings of the current study [37]. This model suggests that socioenvironmental factors, including social influences, cultural norms, values and practice, determine or contribute to health problem among people within population groups and com- munities [37, 38]. These aspects determine health problem through their influence on people'sbehaviours, such as sexual behaviours and condom use practices. Therefore, health behaviour interpretations should also be based on people's perceptions on behaviours and the influence of socioenvironmental factors that nurture these behaviours [37]. This model also suggests that personal factors can also influence people's sexual behaviours and condom use practices, which are supporting HIV transmission among them [39].

Methods

The report of the methods section was guided by consolidated criteria for reporting qualitative studies (COREQ) checklist (S1 Checklist) (40). The checklist contains 32 items that need to be covered to support the explicit and comprehensive reporting of qualitative studies [40].

Study setting

This study was conducted in Belu and Yogyakarta from June to December 2019. Belu is a part of East Nusa Tenggara (Nusa Tenggara Timor) province, located in the Eastern part of Indonesia, and shares a border with East Timor. Belu district consists of 12 sub-districts and has atotal population of 204,541 people including 100,922 male and 103,619 female [41]. The majority of people in Belu are from several tribes, including Tetun, Marae, Kemak, Atoni dan Rote.There are several local languages, in addition to Bahasa (the Indonesian national language), spoken by people in Belu, such as Tetun, Bunaq, Kemak dan Dawan [41]. In terms of health- care facilities, Belu has a public hospital, and two private hospitals, 17 community health cen-tres, 21 sub-community health centres, 48 village maternity posts, 23 village health posts and 5 private clinics [41]. It only has one HIV clinic providing HIV treatment or antiretroviral therapy (ART) for HIV positive patients. Yogyakarta city is part of the Special Region of Yogya- karta province. This city has a total population of 636,660 people and consists of 14 sub- districts with the coverage area of 32.50 km^2 [42]. The populations in Yogyakarta are from different ethnic groups, such as Java (the majority), Sunda, Melayu, Thionghoa, Batak, Mingkabau, Bali, Madura, Banjar, Bugis, Betawi and Banten [42]. Javanese, in addition to Bahasa, is the language widely spoken in Yogyakarta [43]. In terms of healthcare facilities, it has two government hospitals, 18 private hospitals, 18 public health centres and nine sub-public health centres [44]. Of these healthcare facilities, four hospitals and 10 community health centres pro-vide HIV care services for HIV positive patients [3, 45].

There is no significant difference in the number of HIV cases in the two settings, with Belu

reporting 1,200 HIV cases and Yogyakarta reporting 1,353 cases [46, 47]. Previous studies have reported several factors that have contributed to HIV transmission across both settings [8, 13, 14, 18, 48], but aspects of culture and religion have not been explored before. Belu and Yogyakarta are different in regards to religion perspectives with Belu being a traditionally Christian area where the majority of people hold Timorese culture, while Yogyakarta municipality is a traditionally Muslim area with the majority of people holding Javanese culture. The differences in religion or religious beliefs and cultural practices about sex, condom use, spousal (sexual) relationships, the position of a wife in a marriage, etc, were part of the reasons for the choice for these two study settings. The choice to include these two settings in this study provided opportunities for the researchers to explore and understand whether or not and how these aspects played a role in the transmission of HIV among the participants. To best of ourknowledge, evidence on cultural and religious factors that contribute to HIV transmission is still limited in the context of Indonesia and due to feasibility, familiarity and the potential of undertaking the current study successfully, Yogyakarta and Belu were selected as the studysettings.

Study design and recruitment of the participants

Data reported in this paper are part of a large-scale study that aimed to understand HIV risk factors and impacts on PLHIV and their families in Belu and Yogyakarta, Indonesia. This study useda qualitative methodology exploring perceptions, understandings and interpretations about factors that may have played a role in the transmission of HIV among participants, their experiencesof the challenges of living with HIV, and their access to HIV healthcare services [49].

The recruitment of the participants employed snowball sampling technique. Initially, the researcher solicited the help from the receptionists at the HIV clinics in both study settings to distribute the study information sheets containing the researchers' contact details to patients with HIV who used their services. Patients with HIV who called and stated their intention to be involved in the interview were recruited and asked to recommend a preferred time and place for the interview. After interviews each participant was also asked to distribute the information sheets to their eligible friends and colleagues who might be willing to participate in the study. This process was recursive and took a duration of six months. Only two potential participants withdrew their participations due to personal reasons and finally 92 PLHIV comprising46 from each setting (52 women and 40 men) aged 18 years old or above participated in the study. Recruitment of participants in Yogyakarta ceased after interviewing 46 participants because of data saturation and we then wanted to interview the same number in Belu for consistency, but data saturation was also met in Belu by the 46th participant.

Data collection

Data collection employed in-depth interviews which were conducted in a private room at theHIV clinic in Belu and in a rented house close to the HIV clinic in Yogyakarta, with only the researcher and each participant in the room. The interviews were conducted by the first author(male PhD student), and it should be acknowledged that there were no restrictions on inter- sex interactions among Muslims in Yogyakarta. Interviews were carried out in Bahasa, the national language of Indonesia, which is spoken in both Belu and Yogyakarta and the primary language of the researcher, who also speaks fluent English. The researcher has attended formal training in qualitative methods and regularly conducted research on public health issues, including HIV/AIDS. Interviews were digitally audio recorded and fieldnotes were also under-taken by the researcher once felt necessary. The duration of the interviews varied ranging from35 to 87 minutes, with the total of 4,827 minutes for 92 in-depth interviews. None of the participants were known to the researcher prior to the data collection. An interview guide was pre-pared and used during the interviews (S1 File). The topics on cultural and religious aspects explored in this study focused on several main areas, including practices and beliefs in the participants' culture and religion about husband-and-wife relationships in marriage, extramarital and premarital sex, and how these influenced their sexual relations. Similarly, we explored the participants' cultural practices and religious beliefs about the purpose of marriage, sex and condom use and how these influenced their sexual relations and condom use behaviours. We also explored participants' views and experiences of cultural and religious-related factors that shaped or influenced their sexual relations and practices. Data collection from each group of female and male participants in each setting stopped when the researchers felt that data had been rich enough to address the study objective and data saturation had been reached. Data saturation in each group was indicated in the information or responses provided by the last few participants, which were similar to those of previous participants. Interviews started with the female and male groups in Yogyakarta and continued with the other groups in Belu. We did not offer an opportunity for participants to read and correct the information provided after the transcription due to the sensitivity of the topic and to prevent the possibility of thetranscripts being received and read by their family members, which might divulge the participants' HIV status, in case they had not disclosed it to family members. No repeated interview was conducted.

Data analysis

The first author (NKF) transcribed the recorded interviews manually in Bahasa and then the transcripts were imported to NVivo 12 for analysis. Coding and analysis were performed in Bahasa to retain the cultural, religious and social meanings of the data or information from theparticipants [50]. For the purpose of publication, quotes were translated into English by NKFwho is fluent in both Bahasa and English. The accuracy of translation was maintained through an iterative process of checking and rechecking transcripts against the translated interpretations to examine the meaning in both Bahasa (source) and English (translation) [51]. To maintain reliability and validity of the data, the final themes and interpretation presented in this paper, team-based analysis and discussion was also performed at regular supervision meetings.The team-based analysis and discussion was held throughout the data analysis process. For example, after the identification of the thematic framework and indexing or coding (step 2 and3), data were presented at regular supervision meetings and discussed, and comments were provided for revision and improvement. Similarly, it was performed after the arrangement ofthe themes in a chart and throughout mapping and interpretation process (step 4 and 5), which resulted in the final themes and interpretation as presented in this paper. Data analysis was guided by the five steps of qualitative data analysis framework introduced in Ritchie and Spencer [52]. These steps include (i) *familiarisation* with the data through reading each transcript, breaking down the data into small chunks of data, and making comments or labels to the data; (ii) *identification of a thematic framework* by writing down key issues and concepts that recurrently emerged from the data; (iii) *indexing the data* by listing the open codes that had been made to the data to identify similar or redundant codes and reduce the long list of open codes to a manageable number, and then a closed coding was carried out to group similarcodes under the same themes and sub-themes. The first theme was cultural practices of bride wealth, sanctions for spousal disputes and the purpose of marriage in Belu, which consisted of two sub-themes: (i) cultural practices of bride wealth and sanctions for spousal disputes and

(ii) the purpose of marriage in participants' culture. The second theme was Javanese cultural practices and Islamic religious beliefs about 'ideal wife', husband-wife relationships, sex and condom use, which comprised two sub-themes: (i) cultural practices and religious beliefs about 'ideal wife' or husband-wife relationships, and (ii) religious beliefs about sex and condom use. The themes and sub-themes were derived deductively based on prior knowledge and inductively as they emerged purely from the data; (iv) *charting* data through arranging appropriate thematic references in a summary of chart which enabled comparison across interviews and within each interview; and (v) *mapping and interpretation of the data* through which data were examined and interpreted [52]. These steps were used as they assisted us manage the qualitative data in a coherent and structured way, and guided the analytic process in a rigorous, transparent and valid way.

Ethical consideration

Before commencing the interviews, participants were informed about the purpose of thestudy, the voluntary nature of their participation, their rights to withdraw without any consequences, and the approximate interview duration of 45 to 90 min. They were also advisedthat digital audio recording and notes would be undertaken during the interviews, and data or information they provided will be treated confidentially and anonymously by assigning a specific study identification letter and number for each of them (e.g., FP1, FP2, , or MP1, MP2,

. . .. FP stands for Female Participant and MP stands for Male Participant). They were also informed that that ethics approvals for study were solicited from Social and Behavioural Research Ethics Committee, Flinders University (No. 8286) and the Health Research Ethics Committee, Duta Wacana Christian University (No. 1005/C.16/FK/2019). All participants signed and returned an informed consent form on the interview day. Each participant receivedIDR 100,000 (±USD 7) reimbursement for transport and time after the interview.

Results

Sociodemographic profile of the participants

The participant's age ranged between 18 to 60 years old, with the majority between 30 and 49 years (68 people). Half of them were (re)married and the others were unmarried (divorced, widowed or single). Several reported being diagnosed with any of these sexually transmitted infections: herpes, candidiasis, syphilis and gonorrhoea (13 people), and tuberculosis (28 people) (See Table 1). All (re)married women reported acquiring HIV transmission from their current or ex-husbands and all but four of them reported having HIV-positive current husbands. Similarly, all widowed, divorced and single/never married women but four reported acquiring HIV from their ex- or late husbands, or boyfriends. None of the widowed, divorcedand single women reported engaging in any (sexual) relations following the diagnosis. Eighteen out of 25 (re)married men admitted transmitting the virus to their current or ex-wives and had HIV-positive current wives, while seven had HIV-negative current wives. Of all the widowers, single and divorced men, four reported actively engaging in sexual relations. The majority of participants graduated from senior and junior high school (55 people), and university (21 people), while the rest graduated from elementary school or dropped out of school.

Both female and male participants engaged in different kinds of professions, while several women reported being housewives (21 people). Most participants in Yogyakarta were Muslimand the ones in Belu were Christians (see Table 1).

Cultural practices of bride wealth, sanctions for spousal disputes and thepurpose of marriage in Belu

Cultural practices of bride wealth and sanctions for spousal disputes. Cultural practicesof some tribes in Belu were indicated to play an important role in marriage and spousal relationships of the participants and contributed to HIV transmission among them, which did not exist in Javanese culture in Yogyakarta. For example, the cultural practice of a man and his family paying bride wealth to the bride's family was reported by nearly half of the women and a few men whose tribes applied bride wealth in marriage and influenced their spousal (sexual) relationships. Payment of bride wealth seemed to put men or husbands in a position of power over women. Women were placed in the position where they were culturally obliged to obey and serve their husbands, including sexually, even when they knew of their husbands' promiscuous behaviours. This imbalance of sexual power was a significant factor in HIV transmissionfrom husbands to their wives:

> *"There was bride wealth (from her late husband) because my father is from XXX (name of a tribe in Belu that applies bride wealth). After the bride wealth was received by my family I followed my husband and became a part of my husband's family. Therefore, if my husband*

Table 1. Sociodemographic profile of the participants.

Characteristics	Women Living with HIV		Men Living with HIV	
	Yogyakarta (n = 26)	Belu (N = 26)	Yogyakarta (N = 20)	Belu (N = 20)
Age				
18–19		2		
20–29	6	4		7
30–39	12	12	10	5
40–49	8	6	10	5
50–59		1		2
60–69		1		1
Marital status				
Single	5	3	5	7
Divorced	5	1	2	
Widowed/r	3	12		1
(Re)Married	13	10	13	12
HIV diagnosis				
1–5 years ago	16	18	6	15
6–10 years ago	7	7	7	4
11–15 years ago	3	1	7	1
Other infections				
Herpes	2		2	1
Candidiasis	1	3		
Syphilis			2	
Gonorrhoea			2	1
TB	4	5	10	9
Religion				
Islam	23	1	17	
Catholic	2	25	3	19
Protestant	1			1
Hindu				

Other				
Education				
University graduate/Diploma	6	6	7	2
Senior High school graduate	13	5	11	8
Junior High school graduate	6	6	2	4
Elementary school graduate	1	8		6
Elementary school dropout		1		
Occupation				
Housewife	10	11		
Entrepreneur	3	6	10	1
Tailor	1			
Sex worker	1			
NGO worker	3			
Laundress	1			
Teacher				2
Farmer				3
Police				1
Nurse / health worker	1	2		
Shop keeper	1			

(*Continued*)

Table 1. (Continued)

Characteristics	Women Living with HIV		Men Living with HIV	
	Yogyakarta (n = 26)	**Belu (N = 26)**	**Yogyakarta (N = 20)**	**Belu (N = 20)**
Private employee	2	2	5	1
Banker	1			
Retired civil servant		1		1
Civil servant		1		
University student	1			1
Taxi/truck/Motorbike taxi driver			1	8
Iron welder				2
Mechanic			1	
Unemployed	1	3	3	

https://doi.org/10.1371/journal.pone.0257906.t001

> *wanted anything ...... including sexual demand, I just needed to fulfil it. My husband has already paid the bride wealth, so if we fought then where should I go? If I go to my parents, then they would send me back (to her husband)........I knew that he (her late husband) visited the women (female sex workers) in XX (name of a brothel) but I could not continuously reject every time he asked (for sex)...... " (FP25, widowed, Belu).*

> *"Husband is the one who has the power in a household. So, a wife must listen to her husband as the one who has the power. A wife must serve her husband, including in husband-wife (sexual) relations. In our culture, if the bride wealth has been paid then the wife must submit to her husband, all the decision-making in the household is at the hand of the husband as the head of the household. I have paid the bride wealth, so my wife must submit to me as her husband and the head of the household" (MP11, married, Belu).*

Several women in Belu talked about cultural norms and practices regarding sanctions for spousal dispute, since it is regarded as an embarrassment for a husband and wife and their respective families. Women expressed inability to 'say no' to sexual advances and felt they had no choice, but to oblige to husbands' sexual demands to avoid verbal and physical disputes which could be embarrassing if known to other family members or neighbours and lead to cultural sanctions. The cultural sanctions require them to provide sacrificial animals and a dozen bottles of alcohol, which are used to serve traditional male leaders within a tribe, who gather to teach and provide cultural advice to the couples in disputes. Avoidance of these disputes, feelings of embarrassment and shame, and risk of public cultural sanctions was reported to pre-vent the women from questioning their husband's risky sexual behaviour with other women, including sex workers:

> *"I do not like (spousal) dispute. It is embarrassing if the neighbours hear about it. It is an embarrassment not only for us (the woman and her husband) but more for our parents, uncles and extended families ......If we (the woman and her husband) have a dispute verbally or physically and they know about it, we could get cultural sanction. We once had a cultural sanction: a pig and a dozen bottle of alcohol. So, I try not to get involved in spousal dispute. Thus, sometimes if he (her husband) wants (to have sex) then I just have to serve him even though I do not want to, or I am suspicious that he has had sex with other women or sex workers. It is because I do not want to fight and get cultural sanction" (FP18, married, Yogyakarta).*

However, some married women and men in Belu also talked about respecting and listeningto each other in their spousal (sexual) relationships and family decisions irrespective of their knowledge of the position of a husband as the head of a family. These were also described as a reflection of their understanding and acceptance of each other in spousal relationships:

> *"Indeed, in our culture a husband is the head of the family, but my husband and I respect and listen to each other in our spousal relationship and family. My husband never imposes what he wants, including in terms of husband-and-wife intimate relationship. I think it is because we have been married for a long time and already have children, we understand and accept each other" (FP17, married, Belu).*

> *"In terms of husband-and-wife intimate relationship or decisions in our family, my wife and I listen to each other. We discuss things together, not only myself who makes decisions even though I am the head of the family. We respect each other. In our intimate relationship, we already know each other, if I want (sex) and my wife also wants, we know the signs. There has never been any pressure from me in sexual matter and I also understand the condition of my wife, both of us are (HIV) positive" (MP2, married, Belu)*

The purpose of marriage in participants' culture. The purpose of marriage in the participants' culture, which is to have children, was reported as a barrier to condom use practices among the participants in Belu. This was reflected in the stories of several women and men interviewed who described that they never thought of condom use due to the awareness of such purpose, which also influenced their own and their families' expectations for them to have children:

> *"My (late) husband and I wanted to have children, so (we) did not think of using condoms. In our culture here, getting married is to have children, and our family, especially parents, wanted to have grandchildren. So, it (condom use) was never in my mind even though I was aware (after the HIV diagnosis) that my husband had risky sexual behaviour" (FP9, widowed, Belu).*

> *"My wife and I never used condoms because I think the consequence of using condoms is that we will not have children. We get married to have children. This is our culture, getting married is to have children. The families will continuously ask 'is your wife already pregnant?' If we use condoms then this (pregnancy) will not happen" (MP2, married, Belu).*

In addition, the majority of married men and several women in Belu perceived that condom use was not a common practice in marriage or passed down by their parents or ancestors.Such a perception seemed to also influence their condom use practices or support their consistent engagement in unprotected sex after the HIV diagnosis, a high-risk factor for further HIVtransmission among husbands and wives:

> *"Before I contracted HIV up to now, I never used condoms......... Condom use is not a common*
>
> *practice in spousal relationships, I never heard of other people talking about the necessity of condom use in a husband-and-wife relationship" (FP7, remarried, Yogyakarta).*

> *"Condom use is not a common thing in a husband-and-wife marital relationships, I have never heard of any parents or ancestors talking about condoms. It also feels weird if I have to use a condom every time I have sex with my wife" (MP9, married, Belu).*

Javanese cultural practices and Islamic religious beliefs about 'ideal wife',husband-wife relationships, sex and condom use

Cultural practices and religious beliefs about 'ideal wife' or husband-wife relation- ships. Javanese cultural practices in marriage which have expectations about an 'ideal wife' and husband-wife relationships seemed to have an influence on spousal sexual relations for female and male participants in Yogyakarta, which were not identified from the participants inBelu. Half of the women and several men interviewed in this setting described Javanese cultureof an ideal wife as a woman with characteristics including to serve, obey and listen to the husband, or obliged to respect, submit and does everything the husband wants, including sexually.Serving husbands sexually was described by the participants as part of women's duty and a sign of loyalty to the husbands. Such cultural practices and expectations were lived experiencesin these participants' marriages or spousal sexual relations and seemed to also prevent some women from questioning their husbands' sexual behaviours:

> *"An ideal wife in Javanese culture is the one who serves her husband, submits to her husband, listens to her husband, does whatever her husband says, is not against her husband, and takes care of household chores, children and husband. I live these cultural values in my life as a wife" (FP15, married, Yogyakarta).*

> *"The culture in Yogyakarta or Java dictate for a wife to submit to her husband. A wife must do everything her husband says. It must be like that. A wife who submits to her husband is the one who serves her husband and her husband's needs, including intimate (sexual) need. We live in our culture, so it should be like that" (MP6, remarried, Yogyakarta).*

The Javanese cultural practices were similar to the religious beliefs in Islam about husband-wife sexual relationships. The stories of the majority of Muslim women and several men in Yogyakarta showed that religious beliefs played an important role in their sexual practices.

These religious beliefs were not identified by the Christian participants in Belu. The Islamicreligious beliefs such as 'sexually serving a husband in marriage is a worship of a wife and refusing to do so is a sin and makes the angels angry', seemed to shape their concepts about sex, their spousal sexual relations and practices in marriage, and contribute to HIV transmission among them:

"My experience was that if my husband wanted (to have sex) then I served him. .... Even

though I was not in the mood to have sex,.......I feared being a sinner because the (religious)

thought says so and I obey it. It would be a big sin if I refused. Besides, it (serving husband sexually) is a worship of a wife" (FP11, Muslim woman, widowed, Yogyakarta).

"In Islam, a wife must obey and treat her husband well. She must obey everything her husband said. Whatever a wife wants to do she must firstly get the permission from her husband. She must ask her husband as the head of the family, if her husband does not allow and she insists on doing it, then it is a mistake, a sin for her because she does not obey her husband, she is against her husband. It is also the same in sex matter, as a husband if I want to have sex then my wife must serve me, otherwise it is a sin for her. ...... " (MP3, Muslim man, married,

Yogyakarta).

However, several Muslim women explained that whilst they mostly followed their religious beliefs on husband-wife sexual relations, they adjusted such beliefs to their physical and emotional needs. Similarly, several Muslim men in the setting, who were also aware of these

cultural practices and religious beliefs reported that they adapted such practices and beliefs to their wife's condition and did not force their wife to completely adhere to these practices and beliefs. Good spousal communication and understanding were reported to help them adjustthese practices and beliefs to their situation and lead to positive collaborative decision makingin their spousal relationships:

"In Islam, the one who can bring a wife to heaven is the husband. So, a wife who serves everything requested by a husband will be going to heaven. That is the way for a wife to heaven.

. . .. If my husband asks to have sex but I am tired, then I will tell him kindly to do it tomorrow, do not refuse. So, there is communication" (FP12, Muslim woman, married, Yogyakarta).

"The Javanese culture is very similar to the religious thoughts in Islam, a wife must listen, obey and submit to her husband. I do not do that in my family or my relationship with my wife because we understand each other. My wife and I complement each other. She does not have to do everything I want. We always talk to each other. For example, if I want something from her but she cannot do it because she is tired or not feeling well, she will tell me" (MP1, married, Yogyakarta).

Religious beliefs about sex and condom use. Islamic religious beliefs about sex were alsoreported to influence condom use behaviours of some unmarried Muslim female and male participants in Yogyakarta, which were not identified in the Christian interviewees in Belu.

For example, Islamic religious beliefs that disallow pre-marital or non-marital sex, led their perceptions and fear on the possibility negative judgement and labelling from other people towards their engagement premarital sex practices, if known. Such perceptions and fear pre- vented them from buying and using condoms, which was a supporting their engagement in unprotected sex through which they acquired HIV. Narrative from an unmarried woman whowas diagnosed with HIV several years ago illustrated such perceptions and fear:

> *"It is also the same in religion (Islam) that people have to get married first and they can have sex after they are officially husband and wife.……. That is the reason I feel ashamed to buy condoms because if my neighbours see me buying condoms then I will be labelled negatively. They could label me as a sinner.…….There was not condom use at all in sex with my (ex and current) boyfriends, that is why I get this (HIV). (Her current boyfriend does not know about her HIV status)" (FP23, Muslim woman, single, Yogyakarta).*

A conservative interpretation of Islamic religion regarding prohibition of condom use in marriage was reported by a number of Yogyakarta participants, who said it influenced their sexual behaviours, a factor which was not identified in the Christian participants in Belu. For example, several married Muslim women in this setting described that the lack of condom usein sexual relations with their husband was partly due to such reason, a factor that contributed to HIV transmission among them. The following quote from a 29-years-old Muslim woman who contracted HIV from her ex-husband several years ago illustrated such interpretation:

> *"We (the woman and her ex-husband) did not use condoms because it is not allowed in religion (Islam). I got HIV from him because I know he previously married a female sex worker who is HIV positive (Her current husband is also HIV-positive)" (FP10, Muslim woman, remarried, Yogyakarta).*

However, some Muslim male participants, whose wives were not infected with HIV, reported that religious beliefs in Islam that prohibit the use of condoms in husband-wife sexualrelations did not influence their spousal sexual behaviours. They started using condoms consistently in their sexual relations with their wives following the HIV diagnosis even though they were aware that condom use is prohibited in Islam. Condom use practice was employedto prevent husband-to-wife HIV transmission:

> *"I use condoms after being diagnosed with HIV because I am afraid of transmitting it to my wife.…… We (the man and his wife) know that condom use is not allowed in Islam, but this is for our benefit and health, my wife can get it (HIV) if I do not use condoms" (MP7, married, Yogyakarta).*

> *"In Islam, condoms and other contraception methods are not allowed, my wife and I are aware of that but after the diagnosis I always use condoms in sexual relation with my current wife because I am afraid of transmitting it to her" (MP19, remarried, Yogyakarta).*

Discussions

Despite a global reduction of HIV infections, new diagnoses in Indonesia have increased significantly over the last decade. This paper describes the influence of cultural practices and religious beliefs on sexual relationships, behaviours and practices of women and men living with HIV in Belu and Yogyakarta, as contributing factors for HIV transmission, which have been understudied, both in Indonesia and globally [27–30].

The current study findings suggest that women are vulnerable to HIV transmission due tocultural practices and norms, and strict religious beliefs that lead to power imbalance, including sexually. Cultural practices of bride wealth, and sanctions for spousal disputes in Belu, the expectations of an 'ideal wife' and sexual practices within husband-wife relationships in Javanese culture, all play a part in women being unable to be in control of their own bodies and health. Such norms and practices oblige women to obey, submit and serve their husbands, put men or husbands in a position of power over women, and shape men's perceptions of their entitlement to be served by their wives, including sexually. As a consequence, women are dis- empowered and unable to negotiate and consent to their husbands having access to their bodies. These cultural practices also put married women in a vulnerable position to HIV infection,for example when they had to oblige to sexual demand of and unsafe sex with husbands, even when they suspected them to being engaging in extra-marital sexual behaviours with other women, such as female sex workers. Our findings show overall male dominance in both Beluand Yogyakarta, with occurrence of predominantly male-led sexual decision making in spousal sexual relations. These observations are in conformity with the findings of previous studies [23–25], that have associated male dominance in sexual matters and decision making with the lack of or low condom use by men or husbands, a supporting factor for HIV transmission among spouses or women. These are also in line with the constructs of the logical model for behavioural and environmental factors diagnosis, which suggests that socioenvironmental factors (e.g., in the case of this study, the influence of men, which is underpinned by cultural norms and practices, towards women's sexual decision making and behaviour) determine or contribute to health problem or HIV transmission among women [37]. Similarly, the current findings indicate that these norms and practices imposed the fidelity of women or wives towards husbands as culturally expected, regardless of their knowledge or consent of the husbands' risky sexual encounters with other women, such as female sex workers, another risk factor for HIV transmission among the women and their spouses. This is in line with previous findings of studies in Cambodia and Uganda and the constructs of the logical model [23, 24], suggesting that in some cultures males are accepted and expected to have multiple sex partnersor more than one wife, while women are expected to remain faithful to their husbands.

The current findings show that the purpose of marriage which is to have children and condom use as an uncommon practice within marriage in culture in Belu, and Islamic religious beliefs that prohibit condom use in husband-wife sexual relations [53, 54], were supporting factors for unprotected sex among married participants across the study settings. It is thereforereasonable to allude that these factors contribute to HIV transmission within marriages, especially under circumstances that husbands engage in risky sexual behaviours with HIV high- risk women, such as female sex workers. We also suggest that it is not only the participants' Islamic beliefs of premarital or non-marital sex which is forbidden [55, 56] that impacted their condom use behaviour. Participants also reported fear of stigma and social consequences of engaging in premarital sex as a driving force behind not using condoms. The findings support previous studies conducted elsewhere [57, 58], suggesting that a failure to adhere to religious beliefs leads to unprotected sex or risky sexual behaviours and HIV transmission. On the contrary, other studies [59, 60] have reported that following religious beliefs that emphasise pre- marital virginity or abstinence leads to lower levels of sexual risk among unmarried or youngpeople through the decision to avoid high-risk sexual behaviours. However, the current findings also suggest that some participants adjusted these cultural practices and religious beliefs (e.g., on husband-wife sexual relations and condom use) to their own conditions due to the understanding of the importance of condom use for HIV prevention and for the sake of theirhealth. These findings are consistent with previous suggestions that having a good knowledge of HIV transmission and prevention was a supporting factors for condom use [48, 61]. In addition, it should be acknowledged that Christian beliefs also forbid the use of contraception including condoms in marriage and premarital or extramarital sex [62]. However, the current study indicates that the Belu participants lacked knowledge about specific Christian beliefs around sex and condom use. This seemed to be the underlying reason for them not addressingin their comments the possibility of the influence of such religious thoughts on their sexual relations, practices and possibly HIV transmission among them.

The findings of the current study indicate that conservative Islamic religious beliefs abouthusband-wife sexual relations also influenced spousal sexual relations of married Muslim participants in Yogyakarta and seemed to contribute to husband-to-wife HIV transmission among them. The Islamic religious beliefs that sexually serving a husband in marriage is a worship of a wife and refusing to do so is a sin [63, 64], influenced the perceptions of some marriedwomen and men about sex, and their sexual relations and practices in marriage. Such an influence was reflected in women's inability to refuse husbands' sexual demands regardless of their desire, women's willingness to oblige to husbands' sexual demands due to the fear of commit- ting a sin, and men's perceptions that they are entitled to sexual services by their wives. Such religious beliefs also seemed to be the supporting factors for male dominance over women with regards to spousal sexual decision making. The current findings provide strong evidence that cultural and religious factors did influence the likelihood of the female participants beinginfected with HIV, especially those who reported acquiring the infection from their current, former or late husbands. It is also plausible to suggest that these factors also increase the likelihood of exposure to co-infection and other STI's, by the male participants and indeed, malesin general in these study settings, from their HIV-positive spouses or partners.

Limitations and strengths of the study

The findings should be interpreted with some caution due to several limitations. In general,the study involved a small number of participants in each study setting, thus the study results, including cultural and religious aspects presented in this paper reflected specific situations, views and experiences of the participants. The use of snowball sampling technique may have also led to the recruitment of participants from the same networks, could have under sampled PLHIV who were outside of the social networks of the current participants and led to incomplete overview of the experiences and perceptions of PLHIV about the topics being investigated. Besides, the involvement of widows, single and divorced participants have led to them not being able to provide information on their current experiences of spousal sexual relations due their non-marital status, hence this is also a limitation which should be considered once interpreting the findings of this study. Finally, single coder might also be a limitation in this study since it limited the triangulation during the coding process, although team-based analysis and discussion was conducted. However, to the best of our knowledge, this is first qualitative inquiry that explores cultural and religious factors associated with the transmission of HIV infection in the context of Indonesia. Thus, these findings are useful for the development of HIV programs or interventions that take into consideration cultural and religious aspects toimprove knowledge, understanding and health promoting behaviours of PLHIV and general community members in the study settings and other settings in Indonesia and globally.

Conclusions

Our findings suggest that cultural practices on bride wealth, sanctions towards spousal dispute,purpose of marriage, condom use and cultural expectation of an 'ideal wife' are contributors toHIV transmission among both women and men living with HIV in Belu and Yogyakarta. Similarly, religious beliefs about spousal sexual relationships or women's obligation to serve husbands, forbidden premarital sex and participants' individual of interpretation of their religiousbeliefs about condom use in husband-wife sexual relations, do contribute to HIV transmissionamong them. There is an urgent need for HIV education and policy change, that address andchallenges cultural practices and religious thoughts on sex, condom use and spousal sexual relationships. This change should be tailored for specific population groups, especially women,but also religious groups, and communities, to dispel myths about HIV, enhance understanding about condom use and their protective function, and encourage condom use practices.

Most importantly, a change is needed in the form of female empowerment, and challenging the patriarchal system that these women live in, if HIV transmission is truly going to be impacted. The findings also indicate the need for involvement of religious leaders in HIV education programs to bring insight to people and help them interpret religious beliefs or thoughtsin health promoting ways. Further, large scale studies are needed that deeply explore aspects of culture and religion and how these are contributing to an HIV epidemic among both women and men in Indonesia and elsewhere.

Supporting information

S1 Checklist. COREQ checklist.

(DOCX)

S1 File. Interview guide.

(DOCX)

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Appendix 2 : Publication 2 - Stigma and Discrimination towards People Living with HIV in the Context of Families, Communities, and Healthcare Settings

International Journal of
Environmental Research and Public Health

MDPI

Article

Stigma and Discrimination towards People Living with HIV in the Context of Families, Communities, and Healthcare Settings: A Qualitative Study in Indonesia

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Citation: Fauk, N.K.; Hawke, K.; Mwanri, L.; Ward, P.R. Stigma and Discrimination towards People Living with HIV in the Context of Families, Communities, and Healthcare Settings: A Qualitative Study in Indonesia. *Int. J. Environ. Res. Public Health* **2021**, *18*, 5424. https://doi.org/10.3390/ ijerph18105424

Academic Editor: Erin C. Wilson

Received: 27 April 2021
Accepted: 18 May 2021
Published: 19 May 2021

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Abstract: HIV stigma and discrimination are a major challenge facing people living with HIV (PLHIV) globally. As part of a larger qualitative study with PLHIV in Yogyakarta and Belu, Indonesia, this paper describes the participants' perceptions about drivers of HIV stigma and discrimination towards them within families, communities and healthcare settings, and highlights issues of HIV stigma as a social process. Participants were recruited using a snowball sampling technique. Data analysis was guided by the framework analysis for qualitative data, and conceptualization and discussion of the study findings were guided by the HIV stigma framework. The findings showed that participants experienced stigma and discrimination across settings, including in families and communities by family and community members, and in healthcare settings by healthcare professionals. The lack of knowledge about HIV, fear of contracting HIV, social and

1. Introduction

Human immunodeficiency virus and acquired immune deficiency syndrome (HIV/AIDS) have been reported as a major public health problem for decades, with an estimated 38 million people globally living with the infection [1,2]. It is also well acknowledged that a diagnosis of HIV infection causes a range of detrimental impacts on people living with HIV (PLHIV) [3–6]. Stigma which is often manifested as discrimination or unfair treatment by other (HIV-negative) people is one of the major negative impacts on PLHIV in many settings [3,7,8]. Despite positive achievements in the response to the epidemic globally, increased universal access to antiretroviral therapy (ART) and reduction of infection across the world, HIV stigma and discrimination are still a global problem [2,9].

Previous studies and reports have suggested that HIV stigma and discrimination towards PLHIV occur within families, communities, and in healthcare settings [10–12]. Several studies have reported that stigma and discrimination towards PLHIV often occur within families by parents, siblings, relatives or in-laws [13,14]. These are reflected in a range of discriminatory treatment and behaviors, including refusal by others to share food and rooms with PLHIV, separation of personal belongings and eating utensils of PLHIV moral perceptions about HIV and PLHIV were perceived facilitators or drivers of stigma and discrimination towards PLHIV. HIV stigma and discrimination were also identified as a process linked to

the whole groups of people within families or communities, which occurred within social context in Yogyakarta and Belu. The findings indicate the need for HIV education for family and community members, and healthcare providers to enhance their knowledge of HIV and improve acceptance of PLHIV within families, communities and healthcare settings.

Keywords: HIV stigma and discrimination; people living with HIV; social process; Indonesia

from those of other family members, isolation of PLHIV by their own family, including exclusion from usual family activities such as cooking and family gathering [13–20]. HIV stigma and discrimination towards PLHIV have also been reported to be inflicted by neighbors, friends, and co-workers and these often manifest as rejection, neglect, avoidance, ridicule, verbal abuse, insult and harassment [14–17,19,21,22]. Similar acts of stigma and discrimination towards PLHIV have also reported within healthcare facilities or settings by healthcare professionals in a variety of ways, including criticizing, blaming, shouting at or throwing health records on patients' faces, and neglecting or refusal of care and treatment, and through unnecessary referral to other healthcare facilities [14,18,21,23,24]. The fear of contracting HIV through physical, social and healthcare-related contacts and interactions, and the lack of knowledge about how HIV is transmitted, have been reported as the main drivers of HIV stigma and discrimination in these settings [13,14,25–27]. HIV stigma and discrimination have also been reported to cause negative impacts on psychological state, health outcomes, and social life of PLHIV. They are associated with stress, anxiety, depression and low quality of life for PLHIV [3–6]. They have been reported to negatively influence access and adherence to ART or HIV prevention and treatment efforts and disrupt social relationships of PLHIV with their families, relatives, friends and neighbors [3–6].

Although many other studies have explored HIV stigma and discrimination towards PLHIV in different settings, most of these studies have focused on stigma at individual level, including studying the attitudes and behaviors of HIV non-infected individuals towards PLHIV [8,11,28], leaving the gap in knowledge about how HIV stigma and discrimination are enacted as a social process. Therefore, the aim of this study was to explore HIV stigma and discrimination beyond individuals and to assess how they are enacted as a social process in the context of families, communities, and healthcare settings. The overall aim is to contribute to the understanding of drivers of stigma that arise within social contexts in Indonesia where the influence of strong family and community values, norms, ties, and religious thoughts on stigma and discrimination towards PLHIV have not been addressed in previous studies [8,11,28]. As HIV stigma and discrimination are reported to occur across settings in Indonesia [14,27,29–31] and Indonesian society is influenced strongly by family and community values, norms, ties, influences, and religious [32–34], it is important to unpack this complex societal structure, to further inform how social processes influence and propagate discriminatory and stigmatizing attitudes and behaviors towards PLHIV.

This information is crucial as will provide significant contribution to the current body of knowledge on the topic and inform policies and practices within government and nongovernmental institutions and organizations to address social impacts of HIV and improve health outcomes of PLHIV in Indonesia and globally.

2. Methods

The report of the methods section was guided by consolidated criteria for reporting qualitative studies (COREQ) checklist [35]. The checklist contains 32 items (Figure S1) that need to be covered to support the explicit and comprehensive reporting of qualitative studies [35].

2.1. Conceptual Framework

The HIV stigma framework developed by Earnshaw and Chaudoir [3] was used to guide data collection, conceptualize, and discuss the findings of the current study. This framework suggests that stigma is a devalued attribute which had detrimental effects on PLHIV through various stigma mechanisms [3,27,36]. Stigma mechanisms reflect a psychological response of HIV-negative people towards PLHIV or the devalued attribute, and to the possibility of HIV transmission by PLHIV [27,37]. Such responses are often manifested as prejudice, stereotyping and discrimination towards PLHIV [3,7,27]. Prejudice refers to negative emotions or feelings of uninfected people, such as disgust, anger, and fear towards PLHIV [38]. Stereotype is the negative beliefs (e.g., PLHIV have deviant behaviors or are dangerous) which are often attributed to PLHIV [39]. Discrimination refers to unfair treatment of uninfected people towards PLHIV or the belief of PLHIV about their experience of prejudice and stereotype by HIV-negative people [3,7,8]. This framework suggests that discrimination or unfair treatment, also known as external or enacted stigma, is a mechanism through which PLHIV experience HIV stigma [3,7,8]. It is also a process of influence of social norms and values, and institutional policies on negative attitudes and behaviors of others (e.g., family members, community members and healthcare professionals) towards PLHIV, which negatively impacts behaviors, psychological health outcomes and social life of PLHIV, and constrains their opportunities (e.g., access to healthcare) and wellbeing [40,41].

2.2. Study Design, Recruitment of the Participants, and Data Collection

This paper presents data from a large-scale qualitative study exploring the views or perceptions of PLHIV about HIV risk factors and impacts and their access to HIV healthcare services in Yogyakarta and Belu, Indonesia. The qualitative design was used as it has been found appropriate and effective when exploring participants' perspectives and deep insight of their real-life experiences [42,43]. It facilitated the exploration of the participants' stories, understandings and interpretations about the supporting factors for HIV transmission among them, and drivers of stigma and discrimination against them by other (non-infected) people [44–46].

It also enabled the researchers to explore and understand values and meanings the participants had in relation to HIV stigma and discrimination facing them in their daily lives [42,47].

PLHIV who participated in this study were recruited using the snowball sampling technique. The recruitment process started after a permission letter was solicited from HIV clinics in both study settings. The study information packs were distributed to potential participants who accessed HIV healthcare services in the clinics through the receptionist at each HIV clinic. Potential participants who called and confirmed their willingness to participate in the study were asked to recommend a preferred time and place for an interview. The recruitment process took three months, with 92 PLHIV (52 women and 40 men; 46 in Yogyakarta and 46 in Belu) participating in the study.

Data collection was conducted from June to November 2019 using one-on-one in-depth interviews in a rented house close to the HIV clinic in Yogyakarta and a private room at the HIV clinic in Belu. The interviews were conducted by the first author (NKF) and in Bahasa (the primary language of the researcher, who also speaks fluent English) and audio recorded digitally, and notes were taken during the interviews. The duration of the interviews ranged from 35 to 87 min. Regarding HIV stigma and discrimination, the interview topics explored participants' perceptions and experiences of HIV stigma and discrimination. The researcher probed further about attitudes and behaviors of family and community members and healthcare providers towards them. Moreover, the impacts of unfair treatments and attitudes of other people towards them were explored. Additionally, participants were asked about perspectives regarding drivers or facilitators of and mechanisms or processes through which those facilitators or drivers contributed to stigma and discrimination. Participants' perspectives about how social influence among family and community members which led to stigma and discrimination against them and other PLHIV were also explored. The development of interview questions was informed by the findings of previous studies and the theoretical framework used in this study. Recruitment of the participants and interviews ceased once the research team felt that the collected data were rich enough and data saturation had been reached. This was reflected in the similarities of information provided by the participants in the last few interviews, which justified our decision to cease data collection at that point. No repeated interview was conducted with any of the participants. Two potential participants withdrew their participation due to personal reasons. We did not offer an opportunity for participants to read and correct the information provided after the transcription due to the sensitivity of the topic and to prevent the possibility of the transcripts being received and read by their family members, which might divulge the participants' HIV status, in case they had not disclosed it to family members. There was no established relationship between the researcher and any of the participants prior to the study.

2.3. Data Analysis

The digital recordings of the interviews were manually transcribed verbatim in Bahasa by the first author (NKF). The transcripts were then imported to NVivo 12 where the comprehensive data analysis was performed, which was guided by a framework analysis for qualitative data by Ritchie and Spencer [48]. The framework was used as it helped the management of qualitative data in a coherent and structured way, and guided the analytic process in a rigorous, transparent, and valid way. This framework suggests five steps of qualitative data analysis, which are: (i) Familiarization with the data or transcripts, which was done by repeatedly reading each transcript, breaking down the data into small chunks of data, and making comments or labels to the data extracts of each individual transcript. The transcription of the audio recordings, which was manually performed using a laptop, had been started by the field researcher following each interview during the data collection process. At this stage, emotions or notes undertaken during interviews were added into each individual transcript. Thus, the process of familiarization with the data had been started alongside the data collection process; (ii) identification of a thematic framework by writing down key issues and concepts that recurrently emerged from the data, which was performed after importing each individual transcript with the initial comments, codes, labels into NVivo. Themes that were used to form the thematic framework were derived from both the HIV stigma framework used in this study and the collected data. The identification of the thematic framework was an iterative process that involved changing and refining themes; (iii) indexing the data which was comprehensively performed using NVivo. The process of indexing (coding) was started by making open codes to data extracts of each individual transcript resulting in a long list of open codes or nodes. This was followed by close coding to identify similar or redundant nodes or codes and reduce the long list of open codes to a manageable number, and then, nodes or codes that seemed to fall into the same themes and sub-themes were grouped together; (iv) charting data through arranging appropriate thematic references in a summary of chart which enabled comparison across interviews and within each interview. This was performed by reorganizing and summarizing codes from each individual interview transcript, which had been grouped into separate themes in the previous section, and putting them together under each theme; and (v) mapping and interpretation of the data through which data were examined and interpreted [48,49]. Based on the pieces of data that had been indexed and charted in the previous steps, the researchers systematically pulled together key characteristics of the data, mapped, and interpreted data set as a whole. Transcription, coding and analysis were conducted in Bahasa, and quotations for publication purposes were translated into English by NKF. To maintain the accuracy of the translation and credibility of the findings, checking and rechecking transcripts against the translated interpretations or examination of meaning in both source (Bahasa) and target (English) languages were done during the analysis [50]. Analysis was primarily undertaken by NKF, although team-based analysis was undertaken at regular research team meetings whereby all authors undertook independent analysis and then team decisions were made about the validity of the final themes and interpretation.

2.4. Ethical Consideration

The participants were informed that the study obtained the ethics approvals from Social and Behavioral Research Ethics Committee, Flinders University (No. 8286), and the Health Research Ethics Committee, Duta Wacana Christian University (No. 1005/C.16/FK/2019). They were advised about the purpose of the study and the voluntary nature of their participation prior to the interviews through the study information packs distributed to during the recruitment process and again in person by the field researcher prior to each interview. They were informed about their right to withdraw from the study at any time, without consequence, if they felt uncomfortable with the questions being asked during the interviews. They were also advised about the approximate interview duration of 45 to 90 min and that audio recording and notes would be undertaken during the interviews. The participants were assured about confidentiality and anonymity of the data or information they provided in the interview, which was maintained by assigning a specific study identification letter and number for each participant (e.g., FP1, FP2, ..., or MP1, MP2, ... FP stands for Female Participant and MP stands for Male Participant). Reimbursement of IDR 100,000 (±USD 7) for transport and time of the participants was provided for each of them after the interview. The informed consent form was provided for each participant, signed, and returned to the researcher prior to the interview.

3. Results

3.1. Demographic Profile of the Participants

A total of 52 women and 40 men living with HIV aged between 18 to 60 years old were interviewed. Most of the participants' age was between 30 and 49 years (68 people) and over a half of them were married or remarried (48 people), while the rest were non-married (divorced, widowed or single). Most of the participants had been living with HIV between one to five years (55 people), and a number had been diagnosed with HIV for six to 10 years (25 people) and 11 to 15 years (12 people). Several reported being also diagnosed with other sexually transmitted infections: herpes, candidiasis, syphilis and gonorrhea (13 people). Twenty-eight people had also been infected with tuberculosis. All the participants reported being on ART.

Education backgrounds varied, with 37 of the participants graduating from senior high school, 21 from university, 18 from junior high school and the rest graduating from elementary school or dropping out of school. Twenty-one women reported being housewives, and the others engaged in different kinds of professions: entrepreneur, tailor, NGO worker, sex worker, health worker, shop keeper, private employee, banker, civil servant, and laundress. Eleven men reported being entrepreneurs, nine were drivers (taxi, truck or motorbike taxi) and the rest engaged in a variety of professions as teacher, farmer, police, private employee, and iron welder. Most participants interviewed in Yogyakarta and Belu were Muslim and Christians, respectively.

3.2. Stigma and Discrimination within Families

Participants across both study settings acknowledged the existence of stigma and discrimination towards PLHIV, and some had experienced stigma or discrimination within families or communities or healthcare facilities. For example, relatively similar numbers of both women (*n* = 17) and men (*n* = 12) interviewed in Yogyakarta (*n* = 13) and Belu (*n* = 16) reported having experienced the same HIV stigma and discrimination within families by their parents, siblings, and in-laws at a certain point of time following the HIV diagnosis. Separation of personal belongings such as clothes and eating utensils from those of other family members, separation from children, ostracism, avoidance, negative labelling as sex worker, and being asked to stay away from home or live in other places, were some instances of discriminatory and stigmatizing attitudes and behaviors of family members towards them:

> *"I was separated from my child (by her sister-in-law). My child slept with her aunty. My eating utensils were given a sign. The relatives of my husband also said to my sisters-in-law: 'the spoon she used should be separated, you can be infected'. They were nice in front me but felt disgusted about me at the back. They asked my sisters-in-law to chase me and my husband (her husband was HIV-negative) away from the house (the woman and her husband lived together with her sisters-in-law in the same house)"*. (FP5, married, Yogyakarta)
>
> *"I experienced it (discrimination), it felt painful here (pointing to his chest). I was ostracized by my family: my father, mother, brothers and sisters. At that time, I did not have the spirit to live anymore because I was ostracized like that. It took place for a long period of time till I remarried. . . . . At the first time I told them that I contracted HIV, everybody was shocked and angry at me. I was nearly chased away from home. Finally, my father started to accept me step by step, but my mother was scared of being avoided by other people if my HIV status is known to them (other people within their community). My oldest and youngest brothers and sisters avoided me. My plate was separated, and I washed it myself. I was scolded and asked not to use the toilet, if I used it then I had to clean it up afterwards (The man and his second wife live separated from his family after they got married)"*. (MP19, remarried, Yogyakarta)
>
> *"My father, mother and nephew know about my (HIV) status. My eating utensils, food and water are separated from those of other family members. They separate all of these, I feel so painful and sad, but I cannot do anything and just accept it. I feel like my family members do not really care about me. They do not care whether I eat or not and this makes me cry sometimes"*. (MP5, single, Belu)

Fear of contracting HIV was reported by the participants as a major facilitator of unfair treatment or discrimination by family members towards them. Such fear was reported to be supported by the lack of knowledge of family members about HIV or the means of HIV transmission. The participants also described that their family members were easily influenced by inaccurate HIV information spread by others within their family or dependent on information heard from neighbors or other community members as source of HIV knowledge, which reflected the lack of knowledge of family members about HIV:

> *"We (the woman and her husband who was also HIV-positive and had died from AIDS) were avoided by nearly all the family members of my husband because they were scared of getting HIV, they did not know how it is transmitted. They thought they would get it if they have physical contact with us. A relative of my husband was the one who spread this misleading information to all the family members of my husband, she told all of them this wrong knowledge, hence they were influenced by what she said. Families and neighbors here are very close to each other, so sensitive information like this (about HIV) can quickly spread and they can easily influence each other and believe it"*. (FP4, widowed, Belu)

> *"My food was given to me (by her mom) through the bottom of the door, just like you would do for a dog. It was very painful and if I remember this (how her mom treated her), I sometimes still feel the pain. But she is my mom, she knew very little about HIV. . . . . What she knew about HIV was just based on information she had heard from neighbors and other people around us in the community. Information and perceptions from others influenced her reaction towards me once I told her I have HIV"*. (FP24, divorced, Yogyakarta)

> *"I was discriminated by my parents. My father collected all my clothes and boiled them with hot water. He was asked by his second wife to do so. His second wife does not want to accept me. It is apparent that they are scared of me transmitting the virus to them because they do not know that HIV does not transmit through clothes"*.
>
> (MP4, married, Yogyakarta)

3.3. Stigma and Discrimination within Communities

Several participants in Yogyakarta (*n* = 7) and Belu (*n* = 17) also reported having experienced stigma and discrimination within communities where they lived and interacted. For example, both women (*n* = 13) and men (*n* = 11) described that they were rejected by neighbors, friends, or other community members due to their HIV-positive status, reflected in the acts of refusal of direct physical contact such as shaking hand and eating food they had touched, avoidance or keeping distance, and exclusion from social and community activities. The spread of untrue stories and gossip about their HIV status, were also other instances of discriminatory and stigmatizing attitudes and behaviors of neighbors, friends, and other community members towards them. However, some participants in Yogyakarta who worked for HIV programs also described that although stigma and discrimination towards PLHIV still existed with communities, they seemed to be decreasing due to increased responses (HIV programs) to the issue, which could be the reasons why fewer number of participants in the setting reported the experience of stigma or discrimination within their communities:

> *"I got discrimination in the community where I lived before. If I had touched any foods, then people would not eat those foods. Some (community members) spread information that I am HIV-positive and gossiped about it. I experienced these for about two years"*. (FP17, divorced, Yogyakarta)
>
> *"There are neighbors who keep distance, do not want to close to me (physically) or have physical contact with me such as shaking hand. They do not want to get this disease (infection). Some of my friends who know (about his HIV status) also leave me"*. (MP10, single, Belu)
>
> *"I have been working on HIV programs (with a non-governmental organization (NGO) in Yogyakarta) for many years, and I can say that now HIV stigma and discrimination are still occurring but diminishing a lot compared to 5 years ago. I think it is because there have been many HIV programs and activities carried out by community health centers, hospitals and NGOs here. Dissemination of HIV information especially has reached more communities . . . ."* (MP18, single, Yogyakarta)

The participants across the study settings commented that social perceptions that associated HIV infection with perceived negative behaviors (e.g., sex with multiple sex partners, engagement in non-marital sexual relations or engagement in sex work) were the driving factors for stigma and discrimination towards PLHIV. The stories of some participants in Yogyakarta showed that such social perceptions seemed to be rooted in their religious thoughts in Islam about extra-marital sex and sex with multiple sex partners as sins and HIV infection as a curse for PLHIV due to their engagement in such sexual behaviors, factors which were not identified in the interviews with participants in Belu. Additionally, social perceptions about HIV as a dangerous, deadly, disgusting and embarrassing infection which had no cure, and the lack of knowledge about HIV which led to the fear of contracting it, were reported as the drivers of discriminatory and stigmatizing attitudes and behaviors towards PLHIV by community members:

> *"Social perceptions about HIV are very negative, a disease (infection) of people with negative behaviors, such as women who are sex workers, have multiple sex partners or non-marital sex. . . . . They perceive HIV as a disgrace for family. Such perceptions influence how other people look at or react towards HIV-positive people . . . . To be honest, I feel uncomfortable with these perceptions"*. (FP12, married, Yogyakarta)

> *"It seems that people in the mosque do not like me (due to his HIV status). During the Friday prayer I sit in the middle and the ones who come after me will shake hand with others but not with me. They are scared of getting HIV. I know that they do not know much about HIV. What they know is that HIV is deadly and there is cure for it. This kind of information spreads in the community and influences the way people (community members) see or interact with me"*.
>
> (MP14, divorced, Yogyakarta)

> *"People think that the ones who contract HIV are dirty. They are drug users and female sex workers. HIV is a curse from God to them because their behaviors are not right. That is why many people, including my mom are discriminative towards HIV-positive people like me (her mother was very discriminative to her during the first few months after the HIV diagnosis)"*. (FP24, divorced, Yogyakarta)

> *"Many people do not know about HIV and they think that HIV is a disease (infection) of people who have sex with multiple sex partners. They think people get HIV because they often change sex partners, which is something that many people do not accept. That is why HIV positive people like me look bad, negative to their eyes. Perceptions like this spread from mouth to mouth among community members and people are easily influenced by what they hear"*. (MP8, single, Belu)

Some female and male participants across both study settings also described that moral judgements or perceptions about PLHIV as the ones with low moral standing were also drivers of stigma and discrimination towards PLHIV. Their stories indicated that people had such perceptions about PLHIV because they associated HIV with immoral behaviors such as sex with multiple sex partners or engagement in sex work, which also made them disdain and disrespect PLHIV:

> *"People have in their heads that HIV transmits because of free sex or sex work, hence many do not respect HIV-positive people. They think we (PLHIV) are immoral because we engage in those immoral behaviors. I can feel it if someone who knows about my (HIV) status and disdains or disrespects me"*.
>
> (FP4, single, Yogyakarta)

> *"People associate it (HIV) with bad or immoral behaviors. Such perception is common, and it makes people think that all HIV-positive people have immoral behaviors. That is why many people disdain HIV-positive people like me"*.
>
> (FP7, remarried, Belu)

> *"Many people still look at people living with HIV as the ones who have low moral standing compared to the others (HIV negative people)"*.
>
> (MP11, married, Yogyakarta)

3.4. Stigma and Discrimination within Healthcare Settings

Several participants, both women (*n* = 13) and men (*n* = 14), in Yogyakarta and Belu reported having experienced some similar discriminatory and stigmatizing attitudes and behaviors of healthcare professionals within healthcare settings where they accessed non-HIV related healthcare services. For example, the participants described that they received negative labelling or cynical questions from healthcare professionals, experienced a delay of services or were not served due to their HIV status. They also reported that healthcare professionals spread information about their HIV status to others, showed disgusted feeling towards them and were scared of contracting HIV once their HIV status was known:

> *"I underwent medical check-up, the laboratory staff (a healthcare professional) asked me: 'how did you get it (HIV)?' I got it from my (late) husband, I said. 'Is your husband dead?' Yes, I replied. 'Did your husband like 'jajan' (have sex with female sex workers. It literally means eating snack)?' In their mind, people who contracted HIV must be naughty (sex worker or have sex with multiple sex partners). I have got the same questions before: 'are you 'naughty'?' 'Do you like jajan?'"*. (FP3, remarried, Yogyakarta)

> *"There were nurses who gossiped about my HIV status. They were scared to get close to me or touched me . . . . There was a nurse who told people within the community that I am sick because of this (HIV). She spread information (about his HIV status) within our community that I get HIV"*. (FP21, widowed, Belu)
>
> *"I experienced discrimination in a healthcare facility, but it was in another ward (dental ward), not in HIV ward (clinic). At that time, I wanted to check my teeth. . . . . I was honest, I told the dentist that I am HIV-positive. The dentist was shocked and nervous, perhaps she never had patients with HIV. She said to me: 'please give me a moment, I will talk to my boss (head of the ward)'. She came back and said: 'I cannot take the decision (to serve him) because we have to have a meeting first.' I was told to come back in four days. After four days, I came back and received the same treatment. I was not served, and she said the decision has not been made. . . . ."* (MP10, separated, Yogyakarta)

A few male participants in both study settings (*n* = 5) also reported that they were verbally discriminated by healthcare professionals in non-HIV wards or clinics. Their HIV status was loudly mentioned in front of other patients and healthcare professionals told each other in front of them to use disposal gloves due to their HIV-positive status, were some instances of verbal discrimination by healthcare professionals towards these participants:

> *"I had experienced discrimination. I went to a healthcare facility where I was registered (as indicated in his health insurance) to ask for referral letter (in order to be able to access HIV healthcare services in other healthcare facilities where the services are available), the nurse called out my HIV status. She*

> *mentioned it clearly which made other patients surprised. So, it was like my status was open to other people"*. (MP11, married, Yogyakarta)

> *"Once my child was admitted to hospital, the nurses told each other in front me to use disposal gloves and said: 'this kid's dad has HIV'. What they said made me feel very sad and angry at the same time, but I could not do anything"*.
> (MP9, married, Belu)

As the consequences of HIV stigma and discrimination by healthcare professionals, some participants across the study settings felt disappointed with healthcare professionals, traumatized, and reluctant to access healthcare services at the same healthcare facilities where they experienced stigma and discrimination. Some decided to hide their HIV status from healthcare professionals, access healthcare services in other healthcare facilities or only consult certain healthcare professionals who they expected to have good treatments or non-discriminatory and stigmatizing attitudes and behaviors. The following comments presented the participants' perceptions about these aspects:

> *"I need lots of courage just to come to a hospital. I was traumatized with hospitals, and my body gets cold if I see hospitals. I was treated very badly by the doctor in a previous hospital. My child was not provided with ARV (antiretroviral) medicines with the reason that there should be a healthy (HIV-negative) family member who accompanied her, otherwise ARV would not be provided. Once a healthy family member of mine accompanied her (to access ARV medicines), the doctor said: 'wait until her dad is fully recovered'. My husband was sick (HIV-positive and hospitalized). My child who is HIV-positive was not allowed to pup (use the toilet) in the hospital"*. (FP2, widowed, Yogyakarta)

> *"After I was rejected (he was not served for tooth extraction in a dental clinic due to his HIV status), I decided not to tell my (HIV) status to any healthcare professionals every time I access (non-HIV-related) healthcare services in any healthcare facilities other than HIV clinic and I do not want to go to that (dental) clinic anymore"*. (MP10, separated, Yogyakarta)

> *"I do not want to see her face anymore (a nurse who spread his HIV status to other community members). I do not want to go the community health center either because I might meet her there. So, this (HIV clinic which is a part of a public hospital) is the only place I access healthcare services"*.
> (MP10, single, Belu)

However, most participants in Yogyakarta acknowledged that HIV stigma and discrimination by healthcare professionals had reduced due to improved healthcare services for HIV patients compared to previous years. They described that more community health centers and hospitals were prepared to provide HIV-related healthcare services, and more healthcare professionals became aware of HIV and served HIV patients professionally. Meanwhile, several participants in Belu commented that HIV stigma and discrimination by healthcare professionals still occurred in healthcare facilities other than HIV clinic due to the lack of knowledge of HIV:

> *"Based on my work experience as a companion of HIV-positive people, I would say that now healthcare services for HIV patients have significantly improved compared to 5 or 10 years ago. I experienced that many healthcare professionals were scared to get close to or touch me (physically) back in the early years of the diagnosis (she was diagnosed with HIV in 2007). But now, many of them are aware of HIV and many healthcare facilities are prepared to provide HIV healthcare services to HIV patients. Now HIV patients can mingle with doctors and nurses just like normal without much gap like before, and I think stigma and discrimination by healthcare professionals have reduced"*.
>
> (WP16, divorced, Yogyakarta)

> *"Stigma and discrimination against HIV-positive patients by nurses still happen. I just had an experience of an unpleasant treatment by nurses in XX community health center a few months ago once I collected the referral letter to bring here (HIV clinic). They avoided me, were scared to serve me. I think many of them do not have proper knowledge about HIV. . . . ."*. (MP5, single, Belu)

The interrelation of all identified themes in this study and how different factors that facilitated or drove stigma and discrimination towards PLHIV is presented in the diagram (see Figure 1). The diagram shows that HIV stigma and discrimination were experienced by participants (PLHIV) within families, communities, and healthcare facilities. Lack of knowledge of how HIV is transmitted and fear of contracting HIV, which also led to social influence through dissemination of incorrect information about HIV transmission among family, community members, and healthcare providers, were factors that drove stigma and discrimination towards PLHIV by family and community members and healthcare providers. Negative social perceptions, religious thoughts, and negative moral judgement about HIV, PLHIV, and sexual relations were also drivers of HIV stigma and discrimination towards PLHIV in these settings. Family and community members and healthcare providers in these settings may also influence each other's behaviors and attitudes as they may share the same knowledge, fear, and social, moral and religious thoughts and perceptions.

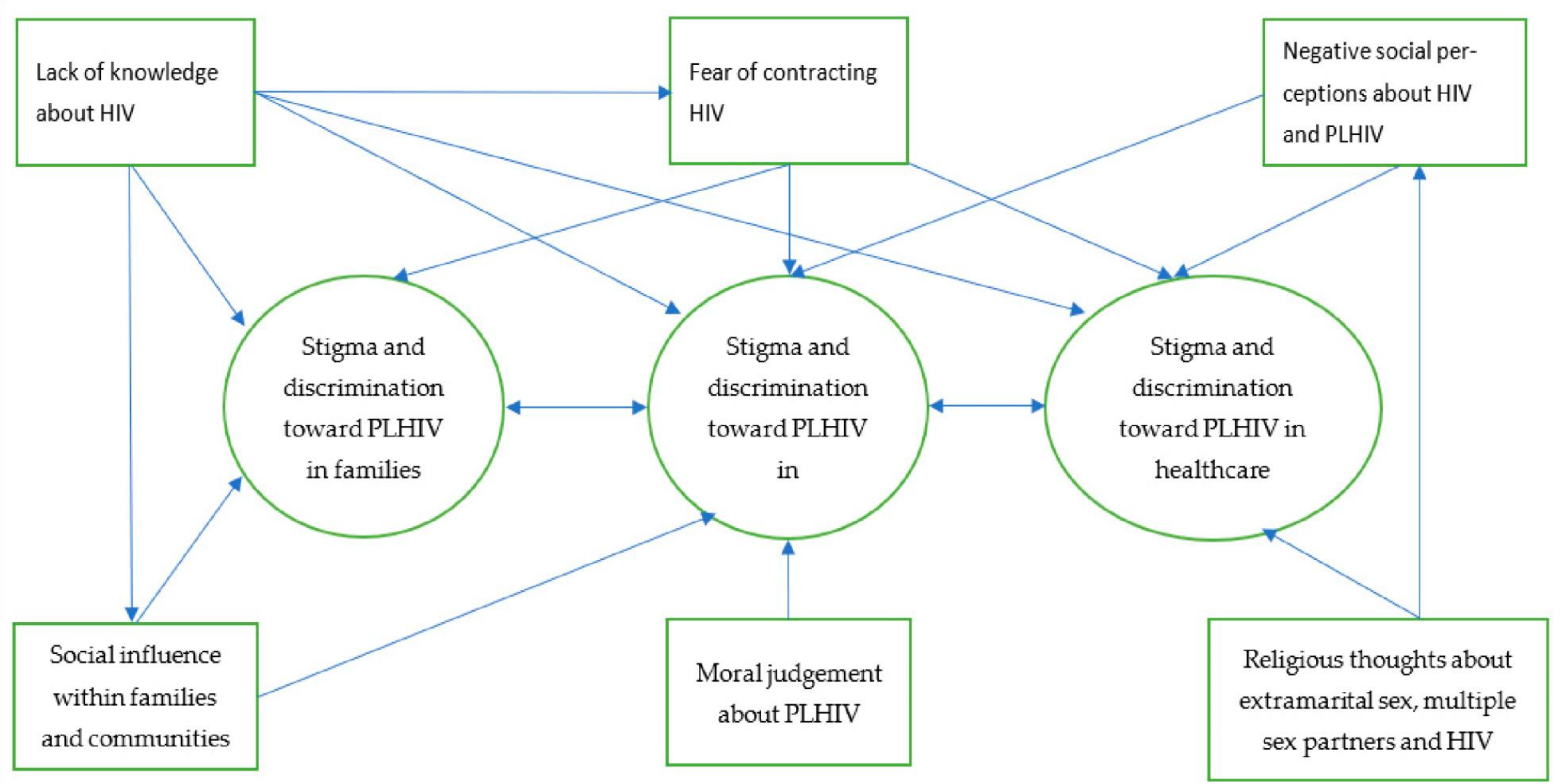

Figure 1. Facilitators or drivers of stigma and discrimination towards PLHIV.

4. Discussion

The paper presents an analysis of the perceptions and experiences of PLHIV about facilitators or drivers of stigma and discrimination towards them within families, communities and healthcare settings in the contexts of Yogyakarta and Belu, Indonesia. It highlights the important role that family and community members played in the participants' experience of HIV stigma and discrimination, which is in line with the notion of stigma as a process that is linked to the actions of whole groups of people, not simply individual behaviors [28].

Findings in the current paper suggest that HIV stigma and discrimination were experienced by the participants across the study settings within their own families. These were reflected in a range of discriminatory and stigmatizing attitudes and behaviors of family members, such as separations of personal belongings such as clothes and eating utensils from those of other family members, separation from children, ostracism, avoidance, negative stereotype or labelling, and eviction from home, which are consistent with previous study's results reported elsewhere [13,27,51]. Supporting the constructs of the HIV stigma framework [3] and the findings of previous studies [13,14,19,20,27,51], the current findings suggest that fear of contracting HIV through physical contacts or interactions, and a lack of knowledge about how HIV is transmitted, were major facilitators of discriminatory and stigmatizing attitudes and behaviors towards participants by their family members. The current findings provide further evidence on the process of stigma and discrimination within families, highlighting that HIV stigma and discrimination towards participants were not merely individual attitudes and behaviors, but also a process of social influence by or among family members through provision of incorrect or misleading information about HIV. The findings also indicate that close family ties, a social condition within communities in the study settings, seemed to facilitate the quick influence and spread of such information among family members, which led to stigma and discrimination towards PLHIV, factor that has not been reported in previous literature of HIV stigma [10–12].

In line with the concepts in the HIV stigma framework and the reports of previous studies in other settings [3,17,19–22,52], the current study confirms that HIV stigma and discrimination also experienced by participants within communities where they lived and worked. These manifested in a range of unfair treatments by other community members, such as refusal of eating food they have touched, avoidance of shaking hands or sitting next to them and keeping a distance from them due to the fear of contracting HIV which seemed to be supported by a lack knowledge of the means of HIV transmission [13,14,25–27,52]. This study also provides new evidence that discriminatory and stigmatizing attitudes and behaviors of neighbors and friends or community members towards the participants were influenced by negative social and moral perceptions or judgements about HIV and PLHIV, which seemed to be rooted in their religious thoughts about extra-marital sex and sex with multiple sex partners as sins and HIV infection as a curse for PLHIV. These perceptions and thoughts played an important role as drivers of HIV stigma and discrimination by community members towards PLHIV, which have not been explored in much of previous literature on HIV-related stigma [8,11,28]. Such influence seemed to be facilitated by the strong community ties or communal characteristics of communities in the study settings or Indonesia, where people tend to gather and share through family and social activities or events [34,53]. Therefore, HIV stigma and discrimination towards participants in this study reflect not simply individual attitudes and behaviors of each community member, but a process linked to the actions of the whole group of people within communities or societies where the participants lived and worked. The findings support the concept asserting that in societies that emphasize collectivism, such as Indonesia, sociocultural thoughts, norms and values have strong influence on attitudes and behaviors of community members [32–34]. In this context, such strong community or social and moral values impacted negatively on participants through discriminatory and stigmatizing attitudes and behaviors of other (non-infected) people.

In line with the previous findings [14,18,21,23,24,51], the current findings suggest that HIV stigma and discrimination also experienced by participants within healthcare facilities where they accessed non-HIV healthcare services. These were reflected in a range of negative attitudes and behaviors of healthcare professionals, such as asking cynical questions to HIV patients, giving negative labelling, spreading information about the HIV status of HIV patients, feeling disgusted towards HIV patients and refusal of care and treatment for HIV patients [14,18,21,23,24,51]. In addition to the fear of contracting HIV, it is plausible to argue that negative social perceptions and moral judgements about HIV and PLHIV could have also been the drivers of such negative attitudes and behaviors of healthcare professionals as they were highly likely to share the same perceptions within communities in the study settings. The current findings also suggest that those HIV stigma and discrimination by healthcare professionals caused traumatized and disappointed feelings for PLHIV, concealment of HIV status, and hindered their access to healthcare services, which are consistent with the previous findings reported elsewhere and HIV stigma concepts applied in this study [3,8,25,27,54,55]. The findings also indicate that health service procedures and policies in healthcare institutions in the study settings, which did not address the needs of HIV patients, constrained the opportunities of PLHIV to access to healthcare services and influenced their health and wellbeing, which are in line with the concept of structural stigma [40,41].

4.1. Reflexivity of the Researchers

The role of researchers in the process of knowledge generation is an important aspect that needs to be acknowledged to account for biases and personal interpretations or experiences the researchers bring into a research, to create a balance between their personal understanding and participants' views, and to improve the trustworthiness of the findings [56]. The researchers in this study have strong educational background in public health and qualitive methods, and many years qualitative research experience in a range of public health issues, including HIV, healthcare services, etc. It is acknowledged that educational background and research experience researchers bring into a research can affect or contribute to the topic under investigation and the interpretations of the research findings [57]. Given the strong educational background and research experience of the researchers in the current study, it is believed that the research questions drove the methodology and methods employed to answer the research questions. For example, prior to designing this study and given the context of the study settings which were in Indonesia where HIV stigma and discrimination towards PLHIV are still common within families, communities, and healthcare settings, the researchers were aware that both women and men living with HIV are highly vulnerable individuals which are difficult to reach. Therefore, the researchers were aware that finding the right channels (e.g., HIV clinics providing HIV services and supports for PLHIV) would be very helpful to disseminate the study information packs to some initial potential participants, who would help disseminate the information further to their eligible friends and colleagues. A qualitative design has been acknowledged to help obtain rich and in-depth personal information or narratives of participants. However, the researchers were aware that the snowball sampling technique used for the recruitment of the participants might be a limitation, but as approaching PLHIV personally would be unethical and was allowed by the ethics committees that approved this study, the snowball sampling technique was considered appropriate for the recruitment of the participants. As is the case for many qualitative studies, the current study's findings cannot be generalized to all PLHIV, but provide rich and detailed information that can be used to inform

HIV-related policies and develop evidence-based programs and interventions to address the needs of PLHIV and stigma and discrimination towards them in Indonesia and other similar settings.

4.2. Limitations and Strengths of the Study

The paper cannot be complete without pointing out its potential limitations. The use of snowball sampling technique for the recruitment of the participants and the dissemination of the study information packs through HIV clinics might have led to the recruitment of participants from the same networks, as the participants would have provided information about the study to only those within their networks or who accessed HIV treatment at the clinics. It is, therefore, possible that the study could have been under sampled by potentially not including PLHIV who were outside of the social networks of the current participants. This might have led to incomplete overview of experiences and perceptions about the drivers of HIV stigma and discrimination towards PLHIV. Indeed, all participants were taking ART at the time of the study (by virtue of us recruiting from HIV clinics), and PLHIV who are not taking ART may have different experiences of stigma and discrimination which may have culminated in them disengaging from ART. Further studies may be undertaken specifically with PLHIV who have disengaged from HIV services, and compare their findings to those presented in this paper. However, the strengths of the study were that the purpose of the study was clearly identified, and the use of qualitative design enabled the researcher to explore in-depth the perceptions and experiences of the participants about HIV stigma and discrimination facing them. The use of a framework analysis to guide this qualitative data analysis was also a strength as it ensured the management of qualitative data in a coherent and structured way, and enhanced transparency, rigor, and validity of the analytic process. Moreover, to our knowledge, this is the first qualitative inquiry to focus on HIV stigma as a social process within social context in Indonesia.

5. Conclusions

The current paper reports HIV stigma and discrimination towards PLHIV by family, community members and healthcare professionals as more of a process that occurs within social context in Yogyakarta and Belu, Indonesia. It shows that discriminatory and stigmatizing attitudes and behaviors of family, community members and healthcare professionals towards PLHIV were influenced by other family or community members, and facilitated or driven by social perceptions, moral judgement, and religious thoughts within communities or societies where PLHIV lived and interacted. Lack of knowledge about HIV transmission and the fear of contracting HIV through physical or social contacts were identified as drivers of stigma and discrimination toward PLHIV within families, communities, and in healthcare settings.

The findings indicate that to respond to HIV stigma and discrimination effectively, targeted interventions are needed, such as specific HIV education at individual, family, healthcare, and societal levels. HIV education for family, community members, and healthcare providers can enhance their knowledge and awareness of HIV and improve acceptance of PLHIV within families, communities, and healthcare settings. Future studies that explore what can be done by government and non-government institutions at policies and practical levels to address HIV stigma and discrimination and improve health service delivery to PLHIV are also recommended.

Supplementary Materials: The following are available online at https://www.mdpi.com/article/10 .3390/ijerph18105424/s1, Figure S1: COREQ checklist.

Author Contributions: N.K.F. was involved in conceptualization, project administration, investigation, and in developing the methodology, conducting formal analysis, writing the original draft of the paper and reviewing and editing the paper critically for important intellectual content. P.R.W., K.H. and L.M. were involved in conceptualization, developing the methodology, supervision and reviewing and editing the paper critically for important intellectual content. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of Flinders University (No. 8286 and 27 March 2019) and Duta Wacana Christian University (No. 1005/C.16/FK/2019, and 26 June 2019).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The data presented in this study are available on request from the corresponding author. The data are not publicly available due to restrictions set by the human research ethics committee.

Acknowledgments: We would like to thank the participants who had spent their time to voluntarily take part in the interview and provided us with valuable information.

Conflicts of Interest: The authors declared no conflict of interest.

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Appendix 3 : Publication 3 - HIV Stigma and Discrimination: Perspectives and Personal Experiences of Healthcare Providers

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Specialty section:
This article was submitted to
Infectious Diseases – Surveillance,
Prevention and Treatment, a section of the journal
Frontiers in Medicine

ORIGINALRESEARC H
published:12 May 2021
doi:10.3389/fmed.2021.625787

Received: 03 November 2020
Accepted: 12 April 2021
Published: 12 May 2021

Citation:
Fauk NK, Ward PR, Hawke K and Mwanri L (2021) HIV Stigma and Discrimination: Perspectives and Personal Experiences of Healthcare Providers in Yogyakarta and Belu, Indonesia. Front. Med. 8:625787. doi: 10.3389/fmed.2021.625787

HIV Stigma and Discrimination: Perspectives and Personal Experiences of Healthcare Providers in Yogyakarta and Belu, Indonesia

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Stigma and discrimination are major challenges facing People Living with HIV/AIDS (PLWHA) globally due to their HIV status. As part of a larger qualitative study in Yogyakarta and Belu, Indonesia, using in-depth interviews with 92 PLWHA (52 women, 40 men) and 20 healthcare providers, this paper describes perspectives and personal experiences of the 20 healthcare providers, relating to HIV stigma and discrimination toward PLWHA in both study settings. The healthcare providers were recruited from healthcare facilities providing HIV-related healthcare services, using a snowball sampling technique. A qualitative framework analysis was used to guide data analysis. Health stigma and discrimination framework guided the conceptualisation and discussion of the findings. The findings presented the views and perspectives of healthcare providers that HIV stigma and discrimination toward PLWHA still occurred within families, communities and healthcare settings. These were reflected in negative labelling, separation of personal belongings, avoidance, denial of treatment and rejection of PLWHA by healthcare providers, family and community members. Some healthcare providers reported that they had personally stigmatised and discriminated against PLWHA. A lack of knowledge about HIV, fear of contracting HIV, personal values, religious thoughts and sociocultural values and norms, were reported as drivers or facilitators behind this HIV-related stigma and discrimination. The findings indicate the importance of continued HIV/AIDS education for families, community members and healthcare providers, to raise awareness and to ensure that healthy and professional support systems are in place for PLWHA. The findings indicate the need to enhance improvement within the healthcare or HIV care system to adequately address the needs of PLWHA, which may facilitate their early initiation of HIV treatment and better treatment adherence and retention to increase Cluster of Differentiation 4 (CD4) count and suppress viral load. Future studies are also needed to explore the role that government and non-government institutions can play in improving health service delivery for people newly diagnosed with HIV and those living with HIV/AIDS.

Keywords: HIV stigma and discrimination, perspectives, experiences, healthcare providers, Indonesia

INTRODUCTION

Stigma and discrimination are major challenges facing People Living with HIV/AIDS (PLWHA) globally due to their HIV status (1, 2). Stigma is defined as a significantly discrediting attribute which serves to devalue people who possess it (3), resulting in status loss and social rejection (4). Attitudes toward the devalued attribute is often manifested as prejudice, stereotyping, and discrimination against PLWHA within families, communities and healthcare facilities (2, 3).

Stigma and discrimination against PLWHA within healthcare facilities or settings by healthcare providers have been well-documented (1, 2, 5, 6). Criticism, blaming, shouting at or throwing health records at patients' faces, and neglect or leaving patients untreated once patients' HIV status is known, are just some of the forms of discriminatory and stigmatising attitudes and behaviours reported (5, 7–10). Denial to treat, rejection and unnecessary referrals by healthcare providers due to a positive HIV status, being coerced to undergo HIV testing and abortion/sterilisation after HIV diagnosis, and loss of private health insurance are challenges PLWHA face on a regular basis (9, 10).

Previous studies have reported a range of drivers or facilitators behind these discriminatory and stigmatising attitudes and behaviours, including lack of knowledge about HIV, a lack of HIV-stigma training, HIV transmission misconceptions, and a fear of getting infected with HIV when interacting with HIV positive individuals (1, 2, 11–17). These characteristics have led to healthcare providers spending less time with PLWHA compared to other patients, and avoiding physical contact during routine medical examinations (14). Less contact with HIV patients increasingly and viciously leads to healthcare providers being less familiar with how to manage and interact with HIV patients, which in turn increases their fear of contracting HIV from patients. Negative perceptions and judgements about people infected with HIV through unprotected sex or injecting drug use (IDU), and general negative portrayals of PLWHA, are also drivers of discriminatory treatment by healthcare providers (12, 14, 18). Other factors such as healthcare providers' gender, race and religion have also been reported to play a role in discriminatory attitudes (1, 13, 14, 16, 19).

There is a paucity of research surrounding personal values, religious thoughts and beliefs and sociocultural values and norms as drivers or facilitators of HIV stigma and discrimination toward PLWHA by healthcare providers. This study aims to bridge these gaps by exploring in-depth perspectives and personal experiences of healthcare providers about HIV stigma and discrimination toward PLWHA in Yogyakarta and Belu, Indonesia. The information will be critical as the number of HIV cases in Indonesia was reported to increase significantly during the last decade, from 55,848 cases in 2010, to 377,565 cases in 2019 (20). While HIV-related stigma and discrimination are known to continue occurring throughout the country (2, 9, 19, 21, 22), an in-depth understanding about the drivers and facilitators of stigma and discrimination by healthcare providers in particular, is still very limited (2, 9, 19, 21, 22). Understanding the perspectives and experiences of healthcare providers related to HIV stigma and discrimination will be an important contribution to the current body of knowledge and useful for the improvement of HIV care systems and delivery, and to improve the health outcomes of PLWHA in Indonesia and globally.

METHODS

The consolidated criteria for reporting qualitative studies (COREQ) checklist was employed to guide the report of the methods section of this study. This checklist contains 32 required items to enhance transparency and comprehensive reporting of interviews and focus groups in qualitative studies (**Supplementary Table 1**) (23).

Theoretical Framework

The Health Stigma and Discrimination Framework (HSDF) was used to conceptualise and discuss the study findings (24). This framework suggests that there are factors that drive or facilitate HIV stigma and discrimination toward PLWHA. These factors may include lack of awareness or knowledge of HIV, fear of contracting HIV infection through contact with PLWHA, fear of social ramification, blame, stereotypes, prejudice, and sociocultural norms (2, 3, 24). Drivers and facilitators determine the occurrence of stigma “marking,” through which stigma is applied to individuals or groups due to their health status or condition (e.g., HIV status) or other factors such as race, class, gender or sexual orientation (24). This framework suggests that stigma that has been applied to individuals or people manifests in discriminatory behaviours or treatments toward PLWHA by HIV negative people (2, 3, 24). It also manifests in stereotypes which reflect the beliefs about the characteristics of PLWHA that are often applied to specific individuals living with HIV, and prejudice which refers to negative emotions of uninfected people toward PLWHA and how they feel (such as disgusted, angry, and afraid) about PLWHA (2, 25, 26). Finally, the framework suggests that stigma manifestations influence PLWHA, including their access to healthcare services and adherence to HIV treatment or antiretroviral therapy (24).

Study Setting

The study was conducted in Yogyakarta and Belu district. Yogyakarta city is a municipality in the Special Region of Yogyakarta province. It covers the area of 46 km^2 and has a total population of 636,660 people (27). This municipality comprises 14 sub-districts and 45 villages and has a number of healthcare facilities, including two government hospitals and 18 private hospitals, 18 public health centres and nine sub-public health centres (27–29). HIV-related healthcare services in this setting were provided for HIV patients at several healthcare facilities, including four hospitals and 10 community health centres (20, 30). HIV counselling and testing, HIV information sessions, antiretroviral (ARV) medicines, cluster of differentiation 4 (CD4) and viral load tests, liver and kidney function tests and other medical tests to support HIV treatment or ARV therapy, were instances of the services provided in these healthcare facilities. Some of the services, such as HIV counselling and testing and information sessions were provided at both the healthcare facilities and through mobile system, through which the services were delivered to people within communities.

Belu district is in East Nusa Tenggara province, the Eastern part of Indonesia, and shares a border with East Timor. It covers the area of 1,284.94 km^2, with the total population of 204,541 people including 100,922 male and 103,619 female, (31, 32). It has 12 sub-districts, 3 hospitals (one public hospital and two private hospitals), 17 community health centres, 21 subcommunity health centres, 48 village maternity posts, 23 village health posts and 5 private clinics (33). It has one HIV clinic, the only healthcare facility where antiretroviral therapy (ART) is available, which is located in the public hospital. HIV-related healthcare services provided in Belu are only HIV counselling and testing and ART. The voluntary counselling and testing (VCT) are provided in the community health centres and the HIV clinic. Mobile VCT is also delivered within communities, which is preceded by HIV information sessions.

Yogyakarta and Belu are different in regards to religious perspectives, with Yogyakarta being a traditionally Muslim area with the majority of people following Javanese culture, while Belu is a traditionally Christian area where the majority of people follow Timorese culture. There is no significant differences in the number of HIV cases in the two settings, with Yogyakarta reporting 1,353 HIV cases and Belu reporting 1,200 cases (34, 35). Most PLWHA in Yogyakarta were reported to have accessed HIV care services, while only 25% in Belu accessed the services when the study was conducted (34, 35). Stigma and discrimination by healthcare providers at healthcare facilities may have been amongst negative impacts facing PLWHA and barriers for them to accessing HIV care services in these settings. However, to the best of our knowledge, there has not been qualitative inquiry which aimed to explore in-depth perspectives and experiences of healthcare providers about HIV stigma, discrimination and drivers and facilitators of stigma and discrimination toward PLWHA in the context of Indonesia, and due to feasibility, familiarity and the potential of undertaking the current study successfully, Yogyakarta and Belu were selected as the study settings.

Study Design and Data Collection

A large-scale qualitative inquiry project using one-on-one in-depth interviews was conducted to understand HIV-risk factors and impacts on HIV positive women and men and their families in Yogyakarta and Belu, Indonesia. A qualitative design was used as it enabled the authors to explore participants' stories, understandings and interpretations about factors associated with HIV transmission among them and the experience of HIV impacts facing them and their families and their access to HIV-related healthcare services (36–38).

This paper focuses on exploring perspectives and experiences of healthcare providers on HIV stigma and discrimination and drivers and facilitators of stigma and discrimination toward PLWHA. The healthcare providers were included in the largescale project to explore their perceptions about HIV-related health service accessibility to PLWHA across the study settings. The topic of stigma was explored as it was frequently raised in the participants' stories. Healthcare providers were recruited using the snowball sampling technique. After soliciting permission letters from the local health departments in the study settings, the study information packs were distributed to healthcare providers through healthcare facilities providing HIV-related health services. Potential participants who called and confirmed their willingness to participate in the study were asked to recommend a preferred time and place for an interview. The recruitment of the participants was an iterative process where the initial participants who had been interviewed were also asked to distribute the information packs to their colleagues or friends who might be willing to participate in this study. The inclusion criteria for the recruitment were one had to be (i) aged 18 years old or above, (ii) a healthcare professional (nurse or medical doctor) working at any healthcare facilities where HIV-related health services are available and (iii) providing HIV services for HIV patients.

One-on-one in-depth interviews were employed to collect the data from the participants. The interviews were conducted in private rooms at the healthcare facilities where the participants worked. These interview locations and times were mutually agreed upon by both the participants and the field researcher (NKF, male) who is a PhD student and had attended formal training in public health and qualitative research. The duration of the interviews with healthcare providers ranged from 35 to 58 min. Only the researcher and participant were present in the interview room and none of the participants were known to the researcher prior to this study. Interviews were conducted in Bahasa, the national language of Indonesia, and audio recorded digitally. No repeated interviews were conducted.

Recruitment of the participants and interviews ceased once the research team felt that the collected data was rich enough and data saturation had been reached. Indeed, the last few interviews provided information similar to that of previous participants, justifying our decision to cease data collection at that point. Finally, 20 healthcare providers were recruited and interviewed in the study (10 from Yogyakarta and 10 from Belu). At the end of the interviews, each participant was offered an opportunity to read and correct the information provided after the transcription, but none requested to do so.

Data Analysis

Interview recordings were transcribed verbatim manually using a laptop and translated into English by the first author (NKF). Analysis was primarily undertaken by NKF, although team-based analysis was undertaken at regular research team meetings (NKF, PRW, KH, LM) whereby all authors undertook independent analysis and then team decisions were made about the validity of the final themes and interpretation. Cross check of the data and discussion among the research team were also conducted to maintain reliability and validity of the collected data. Transcripts were imported into NVivo 12, and data analysis was guided by a framework analysis for qualitative data by Ritchie and Spencer (39). The framework helps to manage qualitative data in a coherent and structured way, and guides the analytic process in a rigorous, transparent and valid way. Five steps of qualitative data analysis are suggested in this framework. (i) *Familiarisation* with the data or transcripts by through reading the data or transcript repeatedly, breaking down the data into small chunks of data, and providing comments or labels to the data, (ii) *identifying a thematic framework* through writing down recurrent key issues and concepts, (iii) *indexing* the *data* by creating a list of open codes through which similar or redundant codes were identified and a long list of codes was reduced to a

manageable number. This was followed by closed coding to group similar codes under the same themes and sub-themes, (iv) *charting* of data by arranging appropriate thematic references in a summary of chart through which data were compared across interviews and within each interview, and (v) *mapping and interpretation of the data* where data examination and interpretations were carried out (39, 40).

RESULTS

Demographic Profile of the Participants

A total of 20 HIV healthcare providers from the two study settings were interviewed for this study. Ten healthcare providers respectively were from Yogyakarta and Belu. The healthcare providers interviewed in Yogyakarta included five medical doctors, two nurses and three counsellors who were also nurses. The healthcare providers interviewed in Belu were two medical doctors and eight nurses who were also counsellors. The medical doctors, nurses and counsellors from both study settings had been involved in HIV-related health service delivery for many years ranging from 1 to 15 years. Characteristics of the healthcare providers are provided in **Table 1**.

Perspectives of Healthcare Providers About HIV Stigma and Discrimination Toward PLWHA

Perceptions of Stigma and Discrimination in Family and Community Settings

HIV stigma and discrimination against PLWHA were reported to occur within families and communities where PLWHA lived and interacted in both Yogyakarta and Belu. Health providers across these study settings described that the fear of contracting HIV was the main factor that led to discriminatory and stigmatising attitudes and behaviours toward PLWHA by family and community members. Avoidance of physical contacts with PLWHA, labelling them as dangerous people and separation of their personal belongings from those of other family members, were some instances of HIV stigma and discrimination which reflected the fear of family and community members in these regions of the possibility of being infected with HIV. Such perceptions were drawn by the participants based on both the stories they heard from HIV patients and HIV stigma and discrimination toward PLWHA they witnessed within communities:

> *"Stigma and discrimination against PLWHA still occur within families and communities even though they are not as bad as before. There are still many people who do not want to be close to PLWHA and avoid them because they are afraid of contracting HIV. They think HIV is a dangerous disease (infection) and people*

TABLE 1 | Sociodemographic profile of healthcare providers.

Characteristics	Healthcare providers	
	Yogyakarta (*N* = 10)	Belu (*N* = 10)
Age		
30–39	2	4
40–49	6	4
50–59	2	2
Sex		
Male	4	3
Female	6	7
Religion		
Islam	5	
Catholic	5	10
Level of Education		
Doctorate	1	
Master's degree	2	
Bachelor/Diploma	7	10
Involvement in HIV service delivery		
1–5 years	4	6
6–10 years		4
11–15 years	6	

who are already infected with HIV are also dangerous, so they avoid PLWHA. .... There are still HIV patients who tell stories of stigma and discrimination that they experience either from their families or from those around them (neighbours and community members). I often ask them about these because I know these can prevent them from accessing the treatment. So, if we (healthcare providers) know about these then we can give them a solution. According to the report from X NGO, currently they are 38 cases of discrimination against PLWHA that they handle" (HCP7, medical doctor, Yogyakarta).

"Stigma and discrimination against PLWHA are still very high here (Belu). If someone's HIV status is known to others, then the person will definitely be stigmatised and discriminated (against). He will definitely be shunned and avoided by many people for fear of being infected with HIV. What people know is that HIV is dangerous and if someone is infected then the person cannot be cured. .... It (discrimination) even happened to the ones (HIV positive people) who died. I have seen several times the discrimination that happened to them in Atambua town. People who went to see the ones (HIV positive people) who died did not want to eat or drink, did not want to stand near the corpses, some even wore masks" (HCP1, medical doctor, Belu).

"People are still very scared of HIV, and stigma and discrimination against PLWHA are still high. If known that someone has HIV, then people will avoid the person. It is very difficult for people to live with HIV here because they are in a state of illness and people avoid them. .... Even family members also commit discriminatory acts. I often hear that clothes, plates, spoons, glasses and soap for PLWHA are separated from those of others because of the fear HIV transmission. There were some PLWHA here who experienced such kinds of discrimination within their families. They told me and I several times personally

> *talked with their family members and gave them knowledge and information about HIV. Now, their family members no longer fear or discriminate against them" (HCP8, nurse and counsellor, Belu).*

Lack of knowledge about HIV was reported as the main supporting factor for the fear of contracting HIV infection through social contact with PLWHA. The participants commented that there were still people within families and communities in in Yogyakarta and Belu who lacked knowledge or information about the means of HIV transmission. This had led to excessive fear about the possibility of contracting HIV if in contact or interacting with PLWHA, and to discriminatory and stigmatising attitudes and behaviours toward them:

> *"Many people within communities do not understand about HIV. They do not know how HIV spreads from one person to another. What they do know is that HIV is dangerous and deadly. These kinds of perceptions seem to be the reasons why there are still people who are very scared of HIV, and stigma and discrimination towards PLWHA still occur within families and communities. Although, HIV stigma and discrimination have reduced a lot compared to 5 to 10 years ago but still exist" (HCP6, nurse and counsellor, Yogyakarta).*

> *"Stigma and discrimination against PLWHA still occur within families and communities because many people do not really know about the means of HIV transmission. They think that physical contact with or being close to someone who is infected with HIV, can transmit them HIV. This frightens them, so if they find out that someone is HIV positive then that person will definitely be avoided. There were HIV patients who told me and cried that their extended family members and neighbours did not want to be close to them for fear of contracting HIV...." (HCP2, medical doctor, Belu).*

Poor participation by community members in HIV-related activities, such as information sessions or awareness raising activities and limited number of HIV-related activities carried out every year were described by the participants in Belu and seemed to be the reasons for limited dissemination of HIV information and the low level of HIV knowledge among family and community members in Belu. Meanwhile, the participants interviewed in Yogyakarta described that even though there were still family and community members who lacked knowledge about HIV, the dissemination of information about HIV among population groups and community members had significantly improved. This was due to collaboration between and different roles undertaken by the health sector and NGOs in the setting, a condition which was not reported by the participants in Belu:

> *"Many community members in Belu do not know much about HIV, what they know is that HIV is dangerous and deadly. It is because not many people want to know more about HIV. Every time we carry out information socialisation about HIV within communities, only a few community members who attend" (HCP10, nurse and counsellor, Belu).*

> *"I see that many community members do not really want to know about HIV. This can be seen from the number of community members who are present when we carry out HIV information sessions, only a few. People are afraid of HIV and do not want to be tested for HIV because they are afraid of stigma and discrimination. In addition, HIV-related activities are carried out only two or three times a year, by community health centres, so if they do not attend then they will know nothing about HIV" (HCP9, nurse and counsellor, Belu).*

> *"It is true that there are still family and community members who do not know about HIV and are afraid of HIV and PLWHA. But to my opinion, information about HIV is quite widespread within groups and communities in Yogyakarta. Here, socialisation about HIV and mobile VCT are often carried out not only by community health centres and hospitals but also NGOs concerned with HIV issue. So, there is collaboration between the health sector: health department, hospitals, community health centres and NGOs. There are HIV-related activities that we implement together and there are HIV-activities that we do separately" (HCP8, medical doctor, Yogyakarta).*

Attitudes and behaviours of HIV positive people were also described by the participants as factors that contributed to stigma and discrimination against them within communities where they lived and healthcare facilities in both Yogyakarta and Belu. Social disengagement or unwillingness to get involved in social activities or interactions with others within communities, was an instance of behaviour that raised suspicion of other community members and led to investigation of information about PLWHA. Similarly, covering the whole face to avoid being identified by other people or patients once accessing health services, was another behaviour of PLWHA that led to discriminatory behaviour toward them by other people or patients in healthcare facilities:

> *"I think their (PLWHA) attitudes or behaviours also contribute to stigma and discrimination against them. There are PLWHA who do not want to socialise with other community members, do not engage in social activities within communities where they live. Of course, such behaviours make their neighbours suspicious and finally find out about their HIV status, and as the consequence, some (PLWHA) were asked to go away or move out from the communities where they lived" (HCP4, medical doctor, Yogyakarta).*
>
> *"There are HIV patients who cover up their entire body when accessing health services at this hospital. They wear mask, hat, jacket and cover their entire faces because they do not want to be recognised by others. I am used to seeing that other patients (HIV negative patients) do not want to sit close to them in the waiting room. Their actions make other people, other patients suspicious. Someone once asked me 'Is the person who covers his entire face an HIV patient?...." (HCP5, nurse and counsellor, Yogyakarta).*
>
> *"There are some HIV patients who always cover up their faces when they come to this clinic to access ARV medicines. This makes other people suspicious about them and want to find out about what disease they have. I always tell them that there is no need to cover up their faces because it will make other people suspicious of their HIV status. Strange thing (covering up face) certainly makes other people wonder" (HCP3, nurse and counsellor, Belu).*

Perceptions of Stigma and Discrimination in Healthcare Setting

HIV stigma and discrimination toward PLWHA were reported to also occur within healthcare facilities in Yogyakarta and Belu by healthcare providers who were not trained in the field of HIV. Participants across the study settings described that HIV patients still experienced stigma and discrimination by healthcare providers once accessing HIV-related health services in healthcare facilities. Avoidance or unwillingness to treat HIV positive patients due to the fear of contracting HIV, divulging the HIV status of PLWHA to other people and proposing offensive questions to PLWHA, were some instances of discriminatory and stigmatising attitudes and behaviours of healthcare providers toward PLWHA in both regions:

> *"Many healthcare providers are still reluctant to treat HIV patients for fear of contracting HIV. Also, some healthcare providers give advice that make HIV patients feel offended, such as asking HIV patients who are gay to stop having sex with the same sex sexual partners" (HCP7, medical doctor, Yogyakarta).*
>
> *"Some healthcare providers propose questions that make PLWHA feel offended, such as: 'How did you get HIV? Why do you have sex with female sex workers or same sex sexual partners?'. I know about these because there were patients who told me" (HSP1, nurse and counsellor, Yogyakarta),*
>
> *"Healthcare providers in this community health centre are often discriminatory against HIV patients. If they know that a patient is HIV positive, then they do not want to treat the patient, they will call me to serve the patient. They are afraid of getting HIV" (HCP9, nurse and counsellor, Belu).*
>
> *"There are healthcare providers in this community health centre who sometimes do not control their mouths. They divulge patients' HIV status to other people, so there are HIV patients who do not want to come to this community health centre for fear of meeting neighbours or people who know them. They are ashamed due to the assumption that other people may have already known about their HIV status through healthcare providers" (HCP4, nurse and counsellor, Belu).*

Lack of knowledge about HIV led to the fear of contracting the infection, stigma and discrimination toward PLWHA by healthcare providers, such as doctors and nurses in both Yogyakarta and Belu. Participants interviewed across the study settings described that many healthcare providers were not trained to provide healthcare services for HIV patients and were reluctant to treat them due to the fear of contracting the infection:

> *"Stigma and discrimination also often come from health workers such as doctors and nurses, especially those who work in nonHIV wards. Due to a lack of knowledge about how to treat HIV patients and fear of getting HIV, there are health workers who avoid handling HIV patients, and do not want to be close to or touch patients to carry out physical examinations" (HCP2, nurse, Yogyakarta).*
> *"There are still healthcare providers who discriminate against HIV patients, such as avoiding, refusing to examine patients physically for fear of contracting HIV. It is because many healthcare providers do not have enough knowledge about HIV (HCP8, nurse and counsellor, Belu).*

Barriers to Accessing Healthcare Services

HIV stigma and discrimination toward PLWHA were also reported to hinder the access to HIV-related health services among PLWHA in both Yogyakarta and Belu. Participants interviewed across the study settings described that discriminatory and stigmatising attitudes and behaviours from family members, community members and healthcare providers toward PLWHA often led to the concealment of HIV status and self-isolation, and hindered the access of PLWHA to healthcare services:

> *"They (PLWHA) fear stigma and discrimination from healthcare providers who do not understand about HIV or from the community if their HIV status is discovered. This is one of the reasons why there are still HIV patients who refuse to seek treatment" (HCP1, male nurse and counsellor, Yogyakarta).*
>
> *"Stigma and discrimination towards PLWHA still occur, so many (PLWHA) are very careful and covering up their HIV status. That is one of the obstacles to their access to health services. This must be overcome so that PLWHA can access health services comfortably and without fear. Stigma and discrimination can come from healthcare providers: doctors and nurses in non-HIV ward, from neighbours or community members, and even from other family members" (HCP2, male nurse, Yogyakarta).*
>
> *"Discriminatory treatments towards PLWHA often occur and these affect their access to health services. For example, recently a patient of mine isolated himself in his house and never accessed HIV services at community health centre or VCT clinic by himself. It was because he received bad reactions neighbours and other people, so he was scared, he told me about that. He passed away last August" (HCP8, nurse and counsellor, Belu).*
>
> *"One of the things that makes them (PLWHA) scared of accessing HIV-related health services is stigma and discrimination from health professionals and community members. They do not come to HIV clinic because they do not want other people to know about their status. Also, the ones who get stigma and discrimination from their family members mostly do not access health services because they are not supported by their family members...." (HCP4, male nurse and counsellor, Belu).*

HIV Stigma and Discrimination Against PLWHA: Personal Stories by Healthcare Providers

Fear of HIV Transmission and Personal Values

A number of healthcare providers interviewed across the study settings (*n* = 11) reported to have committed stigma and discrimination against PLWHA. Avoidance, reluctance and unwillingness to touch or treat patients whose HIV status were known to them were some instances of discriminatory treatment toward PLWHA by these healthcare providers. Fear of HIV transmission due to limited HIV knowledge acquired prior to their involvement HIV-related health service delivery to PLWHA was described by the participants as the main driver of discriminatory and stigmatising attitudes and behaviours they had toward PLWHA:

> *"I previously did not want to meet HIV patients at all. It was before I attended training on HIV and gained basic knowledge about HIV and how to treat HIV patients. So, at that time, if there was a patient who I found out that he or she was HIV positive then I avoided, I did not want to serve because I was very afraid of contracting HIV. HIV training and frequent contact with them help me to overcome the fear. After getting involved in health service delivery to them (PLHWA) for a while, I was not scared anymore and felt normal, just like I serve non-HIV patients" (HCP10, female nurse and counsellor, Belu).*

> *"Initially, I was afraid of interacting with HIV patients because I was afraid of contracting HIV. When I studied medicine, HIV was just one of the many diseases and the knowledge I got from the lecturers about HIV / AIDS was not that much. So, before I attended the special training to serve HIV patients, I still felt afraid to treat them. For example, if an HIV patient has wide wound, that makes me think twice hehehe .... I am afraid of contracting HIV, so I am kind of reluctant to touch or treat their wounds. In addition to knowledge, the experience of treating them and regular contact with them also has helped me overcame my fear. (HCP9, female medical doctor, Yogyakarta).*

Personal values held by female participants, which were raised by male participants, were also drivers of their discriminatory and stigmatising attitudes and behaviours against PLWHA in both regions. The value of loyalty in marriage and unacceptance of cheating behaviour of PLWHA who were married as it was considered painful for their spouse, were some instances of personal values held by several participants in Yogyakarta (*n* = 4) and Belu (*n* = 4), which supported their discriminatory behaviours toward PLWHA:

> *"I myself used to discriminate against HIV patients. That was because I knew what they have done is against the values I hold. For example, in marriage, the value of loyalty is very important to me, so if there is a husband who gets HIV because of having sex with other women, I do not accept it because he is cheating on his wife. As a wife, I do not accept such behaviour. That was why I previously (before attending HIV training) did not really care about male patients who were married and got HIV through sex with other women and I did not want to serve them" (HCP3, female nurse, Yogyakarta).*

> *"In my personal experience, I initially felt angry with those (HIV positive men) who got HIV because they were involved in sex with female sex workers, even though they are married. I am a wife, it certainly hurts if my husband cheats with other women. They are the ones who make mistakes, but the consequences must also be borne by their wives (HCP3, female nurse and counsellor, Belu).*

Personal values held by these female participants also seemed to lead to personal judgement that PLWHA deserved to get the infection as the consequence of their own behaviours. Such judgement seemed to reinforce the participants' discriminatory treatment toward HIV patients:

> *"I used to feel the conflict within myself every time I knew that they (PLWHA) got HIV from having sex with multiple sex partners, even though they were married. It did not feel right to me because that is unacceptable in family life or husband and wife relationship. Who would accept something like that? But as a medical doctor, I had to help them medically. This also made me initially reluctant or unwilling to serve HIV patients and made me think that they deserved to have HIV. But after attending HIV training, I started to change my perception and focus on my job as a health professional" (HCP9, female medical doctor, Yogyakarta).*

> *"In the past (before attending HIV training to be a counsellor), I did not feel empathetic or sympathetic to the male HIV patients here because I knew they got HIV through sex or cheating with FSWs (female sex workers) here or at the time they worked in Kalimantan or Malaysia. Then they passed HIV to their wives too. That is why I once thought that they deserved HIV infection. Infected with HIV was the consequence of their behaviour and it was their responsibility" (HCP10, female nurse and counsellor, Belu).*

Religious Thoughts and Sociocultural Values and Norms

Religious thoughts the participants held were also facilitators of their discriminatory and stigmatising attitudes and behaviours toward PLWHA. For example, religious thoughts in Islam and Christianity that forbid the use of illicit drugs, extramarital sexual relations and consider them as sins were used by both female and male participants in Yogyakarta (*n* = 5) and Belu (*n* = 3) as parameters to judge the behaviours of PLWHA and led to unwillingness to interact with and feeling disgusted about PLWHA:

> *"I admit that initially I discriminated against patients who were husbands and married who got HIV through sex with prostitutes or injecting drug use. One of the reasons was that they violated religious teachings and caused the burden not only on themselves but also on their wives. The sins and mistakes they have committed negatively affect their innocent wives and children. (HCP3, female nurse, Yogyakarta).*
>
> *"When I first started engaging in HIV-related health services, I felt uncomfortable and disgusted by male HIV patients who get HIV because of their engagement in free sex. They have wives but are involved in casual sex with female sex workers and get HIV. I was disgusted because I saw them attend church every Sunday but apparently their behaviours do not reflect what is taught in religion" (HCP7, female nurse and counsellor, Belu).*

The religious thoughts the participants had also seemed to shape their negative views on PLWHA. For example, the views about PLWHA as a group of "trash people" who did not live the thoughts of their religion and the ones who were punished due to their own behaviours which were not accordant with religious thought, were some instances negative views which seemed to stem from their religious beliefs or thoughts:

> *"I still remember that in the past, to me people with HIV were just a group of trash people in society. I was very strict with what is taught in my religion, and to me what they have done is wrong. I was very negative about them. All these views were washed away step by step once I started to involve in the HIV program....." (HCP4, female medical doctor, Yogyakarta).*
>
> *"Before I am assigned to serve HIV patients, I had a very negative view about them (PLWHA), especially those infected with HIV because of free sex. At that time, I had the view that they were punished for their own actions that were not in accordance with religious teachings, wrong and sins (HCP2, male nurse, Yogyakarta).*
>
> *"Before I attended training on HIV and how to serve HIV patients in 2009 or 2010, I had a very negative view about PLWHA. I thought they were punished because they behaved wrongly, were not in accordance with religious teachings and harmed their wives and children (transmitting HIV to wife and children)" (HCP2, female medical doctor, Belu).*

The stories of a few female and male participants in Yogyakarta (*n* = 3), which were not raised by the ones in Belu, also indicated sociocultural values and norms as facilitators to their discriminatory and stigmatising attitudes and behaviours toward PLWHA. Sociocultural values and norms that do not accept sex with same sex sexual partners and considered it as a deviant and contaminated behaviour influenced their acceptance toward HIV positive patients and the way they treated and viewed PLWHA:

> *"Sex with the same sex sexual partners is unacceptable socially and culturally, deviant and wrong. The norm in our social and cultural life is that a man marries a woman, not another man. It was challenging for me when I first got involved in the HIV program because to be honest I was disgusted by their sexual behaviours. I did not accept them because I thought they are infected with HIV due to their own mistakes and they deserved it. But after I attended the training and got knowledge about HIV, I began to change my views about them. ...." (HCP1, male nurse ad counsellor, Yogyakarta).*
>
> *"Same sex sexual behaviour is not accepted in our society and culture. It is against our social and cultural values and norms. So, initially I felt that treating them medically and teaching them to have safe sex or use condoms, are like supporting such behaviour. I quite struggled with this thought at the beginning of my involvement in HIV-related health service delivery to HIV patients. On one side I knew that they have contaminated sexual behaviours and thought that they deserved the consequences (HIV infection) but on the other side, I am a doctor who are supposed to focus on helping patients to get healthy. So, at the beginning I always had the tendency to advise them to stop and have normal relationship with girls. But due to the regular interaction with them almost every day, I also learn to understand them and focus on my task as a medical doctor" (HCP10, female medical doctor, Yogyakarta).*

DISCUSSION

HIV stigma and discrimination toward PLWHA are major challenges facing PLWHA globally due to their HIV status (1, 2, 9). This paper explores in-depth perspectives and experiences of healthcare providers about HIV stigma and discrimination in Yogyakarta and Belu, Indonesia. Supporting the findings of previous studies (2, 6, 9, 41), the current study reports the perceptions of healthcare providers that HIV stigma and discrimination toward PLWHA by family and community members and healthcare providers reflected in avoidance of physical contacts with PLWHA, rejection or unwillingness to treat them, separation of their personal belongings from those of others, and negative labels, still occur within families, communities and healthcare facilities in Yogyakarta and Belu. Fear of contracting HIV through social interactions and healthcare-related contacts and lack of knowledge of HIV, as have been reported in previous findings and HSDF (1, 2, 11, 13, 17, 24, 42), were the drivers of such discriminatory and stigmatising attitudes and behaviours toward PLWHA in the study settings. The current findings suggest that lack of knowledge of the means of HIV transmission not only functions as the driver of stigma and discrimination toward PLWHA, as presented in HSDF (24), but also as the source of fear toward HIV transmission. However, as described by some healthcare providers in this study, HIV stigma and discrimination toward PLWHA in Yogyakarta seemed to have reduced. Such reduction seems to be the positive results of HIV numerous programs and activities, such as HIV information sessions for groups and communities, mobile voluntary counselling and testing, and informational support for PLWHA and family, which are carried out by healthcare providers from healthcare facilities and by several NGOs in Yogyakarta (43, 44). However, such HIV programs or activities seem to be very limited in Belu, with the local health department in the district as the only sector responsible for HIV issue.

Supporting the constructs of HSDF (24), the current study confirms that personal attitudes and behaviours of PLWHA in both study settings also contribute to stigma and discrimination against them. For example, covering face on accessing healthcare services and avoiding social engagement or interaction with neighbours and other community members to conceal self-identity and HIV positive status actually acted as drivers of HIV stigma and discrimination against PLWHA as these led to suspicion and investigation of information about them by other patients or community members. In societies that emphasise collectivism, such as in Indonesia (2, 45), covering face and avoiding social interactions or social disengagement, which are not common behaviours, will definitely raise curiosity and suspicion of other people to find out information about PLWHA, which could increase the likelihood of them being stigmatised and discriminated.

The study findings also suggest facilitators to HIV stigma and discrimination toward PLWHA by healthcare providers which have not been explored in-depth in previous studies (1, 14, 24). For example, personal values of female healthcare provider participants across the study settings, such as husband and wife loyalty and unacceptability of cheating behaviours in marriage, were indicated as the facilitators to their discriminatory and stigmatising attitudes and behaviours toward PLWHA. Such personal values lead to the participants' projection of what happened in the marriage of PLWHA (e.g., husbands had sex with other women or were unfaithful and contracted HV, which were considered unacceptable and painful) to their own situation or marriage, which reinforced their negative attitudes and behaviours toward PLWHA. The current findings also suggest that female healthcare providers had more discriminative and stigmatising attitudes toward PLWHA compared to male healthcare provider participants. These are in line with results of previous studies (14, 46), reporting that female doctors and ward staff had significantly more negative feelings and stigmatising attitudes toward PLWHA compared to their male colleagues.

Religious thoughts in Islam and Catholicism that forbid the use of illicit drugs, extramarital sexual relations and consider them as sins were also facilitators of HIV stigma and discrimination by healthcare providers. The use of such thoughts as the parameters to judge the behaviours of PLWHA leads to the healthcare providers' unwillingness to serve, interact with and feeling disgusted about HIV patients. These support the findings on a previous study (47), reporting that the inclusion of personal religious beliefs in health delivery to PLWHA led to the clash between personal religious values and professional expectations. However, previous studies (47, 48) have also reported personal religious beliefs as motivators or facilitators for some healthcare providers' health service delivery to PLWHA, an aspect which was not diagnosed among the participants in the current study. Although religion as one of the predictors to HIV stigma and discrimination by healthcare providers toward PLWHA has been reported in the findings of several previous studies (1, 13, 14, 16, 19), but the mechanisms through which religion contributes to HIV stigma and discrimination, as explored in the current study, were not explored in-depth in those studies. Sociocultural values and norms that do not accept sex with same sex partners and consider it as a deviant and contaminated behaviour also influenced the participants' acceptance toward HIV positive patients, treatment and perceptions about PLWHA or facilitated HIV stigma and discrimination toward PLWHA by the participants. The findings of previous studies in Indonesia have reported that general perceptions about sex with same sex partner as deviant and contaminated behaviours prevented men who have sex with men and transgender people to openly talk about their health status and to seek healthcare services (49–52).

Personal values, religious thoughts and sociocultural values and norms held by healthcare providers in the current study were also facilitators of their negative judgements toward PLWHA as "trash people" and people who deserved HIV infection as a punishment or consequence of their behaviours (e.g., extramarital sex or sex with multiple sex partners or with same sex partners). It should be acknowledged that stigma and discrimination toward PLWHA by health professionals who participated in this study were committed prior to or at the beginning of their involvement in HIV-related health service delivery to PLWHA, a condition where they had not attended HIV training and were not equipped with proper knowledge on HIV and how to serve HIV patients. Knowledge of HIV and health service delivery to PLWHA acquired through HIV training they attended and the experience of treating

HIV patients, helped them overcome the fear of contracting HIV from patients and supported their non-discriminatory and stigmatising attitudes and behaviours toward PLWHA. These support the findings of previous studies (41, 42, 53), which have reported that exposure to HIV-related knowledge or having in-depth HIV knowledge, attending training of stigma and discrimination, gaining more experience in treating HIV patients and frequent contact with them, are associated with low level of stigmatising attitudes or negative predictors of stigma and discrimination among health professionals. Supporting the constructs of HSDF and the findings of previous studies (1, 2, 24, 42), the current study also suggests that HIV stigma and discrimination are hindering factors for the access to healthcare services among PLWHA and also lead to concealment of HIV status and self-isolation of PLWHA.

STUDY LIMITATIONS AND STRENGTHS

The study cannot be complete without pointing out its limitations. The inclusion criteria for recruitment which required healthcare providers who were involved in HIV healthcare service delivery to PLWHA and the use of snowball sampling technique might have been limitations as these might have resulted in the recruitment of participants from the same networks and the neglection of the perspectives and experiences of healthcare providers who were not directly involved in health service delivery to PLWHA. However, the strengths of the study were that the study purpose was clearly identified, and the use of qualitative design helped the researchers explore in-depth the views, perspectives and experiences of the participants about the topic being studied. The use of a framework analysis to guide this qualitative data analysis was also a strength as it helped the management of these qualitative data in a coherent and structured way, and enhanced transparency, rigour and validity of the analytic process. Besides, to our knowledge, this is the first qualitative inquiry to focus on exploring perspectives and experiences of healthcare providers about HIV stigma and discrimination and drivers and facilitators of stigma and discrimination toward PLWHA by healthcare providers in the context of Indonesia. The current findings are useful for the improvement of healthcare system and delivery that address the needs of PLWHA in the study settings and in Indonesia as whole and other similar settings globally.

CONCLUSIONS

The current study reports on perspectives and experiences of healthcare providers about HIV stigma and discrimination or drivers and facilitators of stigma and discrimination toward PLWHA in Yogyakarta and Belu, Indonesia. It reports that HIV stigma and discrimination toward PLWHA still occurred within families, communities and healthcare settings in both settings. These were reflected in negative labelling by others, separation of their personal belongings from those other family members, avoidance of physical contacts by community members, and rejection or unwillingness to treat and the spread of HIV status of PLWHA by healthcare providers. Lack of knowledge of HIV, fear of contracting HIV from PLWHA, personal values, religious thoughts and sociocultural values and norms, were reported as the drivers or facilitators of HIV stigma and discrimination toward PLWHA. These led to the concealment of HIV status and self-isolation and hindered the access of PLWHA to healthcare services. The findings indicate the importance of HIV/AIDS education for family and community members, and healthcare providers to enhance their knowledge and awareness of HIV/AIDS, and to accept PLWHA. The findings also indicate the need for the improvement of healthcare system and delivery to address the needs of PLWHA. Future studies that explore what can be done by government and non-government institutions to improve health service delivery to PLWHA are recommended.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the dataset is a set of interview transcripts - we cannot (due to restrictions set by the human research ethics committee) provide these transcripts to other researchers. Requests to access the datasets should be directed to paul.ward@flinders.edu.au.

ETHICS STATEMENT

Ethics approvals for this study were obtained from Social and Behavioural Research Ethics Committee, Flinders University, Australia (No. 8286), and the Health Research Ethics Committee, Duta Wacana Christian University, Yogyakarta, Indonesia (No. 1005/C.16/FK/2019). Prior to the interviews, each participant was informed about the purpose of the study and that the study had obtained ethical approvals. Study participants were advised about the voluntary nature of their participation and that they had the right to withdraw their participation at any time, without consequence, if they felt uncomfortable with the questions being asked. They were also advised that the interview would take ∼45– 90 min and would be recorded using a digital recorder. They were assured that the data or information that they provided during the interview was confidential and unidentifiable, as each participant was assigned with a specific study identification letters and number. This was to prevent the possibility of linking back the data or information to any individual in the future. Each participant received reimbursement of IDR 100,000 (±USD 7) for transport and their time. Before commencing the interviews, each participant signed the informed consent form and returned it to the researcher.

AUTHOR CONTRIBUTIONS

NF was involved in the conceptualisation of the study, development of the methodology, data collection and analysis, and in drafting the manuscript, revising it critically for important intellectual content and integrating the comments of the reviewers. PW, KH, and LM were involved in the conceptualisation of the study, development of the methodology, supervision, and in revising the manuscript critically for important intellectual content. All authors approved the final manuscript.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fmed. 2021.625787/full#supplementary-material

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Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Appendix 4: Full searching strategy of the systematic review on HIV risk factors and impacts on WLHIV in LMICs

Database(s): **Ovid Emcare**
Search Strategy:

#	Searches	Results
1	human immunodeficiency virus/	48300
2	acquired immune deficiency syndrome/	31793
3	(HIV* or "Human immunodeficiency virus" or AIDS).tw,kw.	104761
4	1 or 2 or 3	114626
5	female/ or marriage/ or spouse/ or wife/	1666326
6	mother/ or adolescent mother/ or expectant mother/ or mother child relation/	50789
7	female/ or female by marital status/ or girl/	1663936
8	(Wives or Wife or Mothers or female* or girl* or wom?n).tw,kw.	655101
9	5 or 6 or 7 or 8	1734680
10	risk factor/	250614
11	sexual behavior/ or casual sex/ or concurrent sexual partnership/ or contraceptive behavior/ or extramarital sex/ or hiv serosorting/ or premarital sex/ or prostitution/ or sexual practice/ or sexual promiscuity/ or sexual violence/ or transactional sex/ or unsafe sex/	34252
12	condom/	9277
13	social aspect/	25625
14	peer pressure/	1547
15	social norm/	1360
16	cultural factor/	23440
17	socioeconomics/ or economic aspect/ or educational status/ or lowest income group/ or poverty/	101687
18	social interaction/	25491
19	social environment/ or environmental factor/	38774
20	social stigma/ or stigma/	6929
21	social discrimination/ or social problem/ or employment discrimination/ or social distance/	9700
22	psychological aspect/	53200

23	health/ or child health/ or family health/ or mental health/ or sexual health/ or women's health/	277746
24	school attendance/ or absenteeism/	7102
25	health care access/	31015
26	(predictor* or "risk factor*" or determinant* or "sexual behaviour" or "multiple sex partner*" or "sell* sex*" or extramarital* or "transactional sex" or prostitut* or "sex work" or condom* or "unsafe sex" or "unprotected sex" or knowledge or "social influenc*" or "peer influenc*" or "social norm" or cultur* or sociocultural* or socioeconomic* or "social environmental*" or socioenvironment* or Stigma or discriminat* or "psychological impact" or "social impact" or education or "school attendance" or "withdraw* from school" or "psychosocial impact" or stress or distress or depression or employment or "loss of job" or Income or "nutrition security" or "food insecurity" or health or "physical health" or wellbeing or "Healthcare accessibility*" or Absenteeism or religio* or Consequence*).tw,kw.	1730955
27	or/10-26	1943514
28	family/	16587
29	(family* or families).tw,kw.	229914
30	28 or 29	232517
31	developing country/	19941
32	((Developing or Less developed or low resource* or disadvantaged or resource limited or poor or low* income*) adj (countr* or region* or nation? or area*)).tw,kw.	25646
33	31 or 32	32853
34	4 and 9 and 27 and 30 and 33	109

Database(s): **CINAHL**
Search Strategy:

#	Searches	Results
S1	(MH "HIV-Infected Patients") OR (MH "Human Immunodeficiency Virus") OR (MH "HIV-1")	20,187
S2	TI ((HIV* or "Human immunodeficiency virus" or AIDS)) OR AB ((HIV* or "Human immunodeficiency virus" or AIDS))	107,628
S3	(MH "Acquired Immunodeficiency Syndrome") OR (MH "AIDS Patients")	17,180
S4	S1 OR S2 OR S3	114,304
S5	(MH "Female")	1,777,018

S6	(MH "Married Women") OR (MH "Single Women") OR (MH "Women")	18,654
S7	(MH "Mothers") OR (MH "Expectant Mothers") OR (MH "Adolescent Mothers") OR (MH "Surrogate Mothers")	35,360
S8	TI ((Wives or Wife or Mothers or female* or girl* or wom?n)) OR AB ((Wives or Wife or Mothers or female* or girl* or wom?n))	570,492
S9	S5 OR S6 OR S7 OR S8	1,907,528
S10	(MH "Sexual Abuse")	7,326
S11	(MH "Unsafe Sex")	3,049
S12	(MH "Sexual Harassment")	1,805
S13	(MH "Bisexuality")	1,311
S14	(MH "Heterosexuality")	1,745
S15	(MH "Risk Factors")	163,745
S16	(MH "Sexual Partners")	8,215
S17	(MH "Prostitution") OR (MH "Unsafe Sex")	6,244
S18	(MH "Condoms")	7,294
S19	(MH "Socioeconomic Factors") OR (MH "Illiteracy") OR (MH "Poverty") OR (MH "Educational Status") OR (MH "Employment") OR (MH "Unemployment") OR (MH "Social Norms") OR (MH "Social Networks")	158,589
S20	(MH "Stigma")	14,063
S21	(MH "Discrimination")	9,922
S22	(MH "Psychosocial Aspects of Illness") OR (MH "Morals") OR (MH "Social Isolation")	17,871)
S23	(MH "Stress") OR (MH "Stress, Psychological")	54,161
S24	(MH "Depression")	97,772
S25	(MH "Income")	17,714
S26	(MH "Adolescent Nutrition") OR (MH "Child Nutrition") OR (MH "Nutritional Status") OR (MH "Infant Nutrition")	22,876
S27	(MH "Adolescent Health") OR (MH "Child Health") OR (MH "Family Health") OR (MH "Health Status") OR (MH "Mental Health") OR (MH "Wellness")	106,301
S28	(MH "Health Services Accessibility")	77,931
S29	(MH "Absenteeism")	4,275
S30	(MH "Psychological Well-Being")	20,937
S31	TI ((predictor* or "risk factor*" or determinant* or "sexual behaviour" or "multiple sex partner*" or "sell* sex*" or extramarital* or "transactional sex" or prostitut* or "sex work" or condom* or "unsafe sex" or "unprotected sex" or knowledge or "social influenc*" or "peer influenc*" or "social norm" or cultur* or sociocultural* or	1,633,910

	socioeconomic* or "social environmental*" or socioenvironment* or Stigma or discriminat* or "psychological impact" or "social impact" or education or "school attend"))	
S32	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31	1,894,934
S33	(MH "Family")	37,475
S34	TI ((family* or families)) OR AB ((family* or families))	211,816
S35	S33 OR S34	225,608
S36	(MH "Africa") OR (MH "Developing Countries") OR (MH "Indian Ocean Islands") OR (MH "Madagascar") OR (MH "Low and Middle Income Countries") OR (MH "Asia")	30,331
S37	TI (((Developing or Less developed or low resource* or disadvantaged or resource limited or poor or low* income*) N (countr* or region* or nation? or area*))) OR AB (((Developing or Less developed or low resource* or disadvantaged or resource limited or poor or low* income*) N (countr* or region* or nation? or area*)))	61
S38	S36 OR S37	30,371
S39	S4 AND S9 AND S32 AND S35 AND S38	79

Database(s): **PsycINFO**
Search Strategy:

#	Searches	Results
1	hiv/ or "aids (attitudes toward)"/ or aids prevention/ or *HIV Testing/	37411
2	(HIV* or "Human immunodeficiency virus" or AIDS).ti,ab,id.	65147
3	1 or 2	65368
4	wives/ or human females/ or spouses/	101606
5	exp EXPECTANT MOTHERS/ or exp UNWED MOTHERS/ or exp ADOLESCENT MOTHERS/ or exp SINGLE MOTHERS/ or exp MOTHERS/	38975
6	(Wives or Wife or Mothers or female* or girl* or wom?n).ti,ab,id.	647623
7	4 or 5 or 6	659750
8	exp Condoms/ or exp Sexual Risk Taking/ or exp Sexual Partners/	14051
9	exp Sexual Partners/	4753
10	risk factors/ or psychosocial factors/	102177
11	socioeconomic status/ or family socioeconomic level/ or income level/ or lower class/ or social class/ or disadvantaged/ or economic security/ or "income (economic)"/ or poverty/	53714
12	exp Sociocultural Factors/	111645

13	exp Emotional Trauma/ or exp Stress/ or exp Distress/ or exp Psychological Stress/ or exp Well Being/	164364
14	major depression/	111700
15	exp DISCRIMINATION/ or exp SOCIAL DISCRIMINATION/	44976
16	social influences/ or social norms/ or social values/	24912
17	stigma/	10660
18	exp Food Safety/	217
19	*EDUCATION/	24140
20	exp Health/ or exp Health Care Services/ or exp Health Service Needs/	236574
21	exp Employment Status/	18313
22	employment status/ or unemployment/ or employability/	19082
23	exp INCOME LEVEL/ or exp "INCOME (ECONOMIC)"/	14736
24	exp School Attendance/ or exp EMPLOYEE ABSENTEEISM/	4370
25	*religion/	14004
26	(predictor* or "risk factor*" or determinant* or "sexual behaviour" or condom* or "unsafe sex" or "unprotected sex" or "transactional sex" or prostitute* or "social influence" or "social norm" or cultur* or "sociocultural factor*" or socioeconomic* or "social environmental*" or socioenvironment* or Stigma or discrimination or "Psychological impact" or "Social impact" or Education or "Psychosocial impact" or Employment or "Loss of job" or stress or distress or depression or "Nutrition security" or "Food insecurity" or "Healthcare accessibility*" or employment or Income or Absenteeism or health* or religio* or Consequence*).ti,ab,id.	1778260
27	or/8-26	1916047
28	family conflict/ or mother-child relations/ or parenting/	30453
29	*family/	26878
30	(family* or families).ti,ab,id.	351981
31	28 or 29 or 30	372548
32	3 and 7 and 27 and 31	1914
33	exp Developing Countries/	5126
34	((Developing or Less developed or low resource* or disadvantaged or resource limited or poor or low* income*) adj (countr* or region* or nation? or area*)).ti,ab,id.	12025
35	33 or 34	13442
36	32 and 35	80

Database(s): **Ovid MEDLINE(R)**
Search Strategy:

#	Searches	Results
1	exp HIV/ or HIV-1/ or HIV-2/ or HIV INFECTIONS/	220742
2	Acquired Immunodeficiency Syndrome/	75293
3	(HIV* or "Human immunodeficiency virus" or AIDS).tw,kf.	378623
4	or/1-3	411482
5	mothers/ or surrogate mothers/	39205
6	Female/	8032212
7	Women/	14333
8	(Wives or Wife or Mothers or female* or girl* or wom?n).tw,kf.	1969529
9	or/5-8	8363342
10	sexual behavior/ or extramarital relations/ or hiv serosorting/ or sex work/ or safe sex/ or sexual harassment/ or bisexuality/ or heterosexuality/ or homosexuality/ or transsexualism/ or unsafe sex/	77307
11	Condoms/	9576
12	Sexual Partners/	14707
13	culture/ or social environment/ or social isolation/ or social norms/ or socioeconomic factors/ or poverty/ or poverty areas/ or social class/	274849
14	*health/ or educational status/ or employment/ or income/ or "health care facilities, manpower, and services"/ or health facilities/ or health services/	156941
15	health services accessibility/ or health equity/ or healthcare disparities/	76190
16	SOCIAL STIGMA/	5673
17	"Discrimination (Psychology)"/	18682
18	*Religion/	6079
19	STRESS, PSYCHOLOGICAL/	109687
20	DEPRESSION/	103779
21	Nutritional Status/	39191
22	(predictor* or "risk factor*" or determinant* or "sexual behaviour" or "multiple sex partner*" or extramarital* or "sell* sex*" or "transactional sex" or prostitut* or "sex work" or condom* or "unsafe sex" or "unprotected sex" or knowledge or "social influenc*" or "peer influenc*" or "social norm" or cultur* or socioeconomic* or "social environmental*" or socioenvironment* or Stigma or discriminat* or "Psychological impact" or "Social impact" or education or "school attendance" or "withdraw* from school" or Stress or "Psychosocial impact" or Employment or "Loss of job" or stress or	5319673

	depression or distress or "Nutrition security" or "Food insecurity" or health or "physical health" or "Healthcare accessibility*" or well-being or Income or absenteeism or religio* or consequence*).tw,kf.	
23	or/10-22	5588528
24	family/ or family relations/	80246
25	(family* or families).tw,kf.	872815
26	24 or 25	902631
27	4 and 9 and 23 and 26	7252
28	Developing Countries/	70653
29	((Developing or Less developed or low resource* or disadvantaged or resource limited or poor or low* income*) adj (countr* or region* or nation? or area*)).tw,kf.	97251
30	(letter or editorial or comment or note).pt.	1655545
31	28 or 29	128797
32	4 and 9 and 23 and 26 and 31	1361
33	32 not 30	1347
34	limit 33 to english language	1259

Database: SCOPUS

Search strategy:

TITLE-ABS-KEY((HIV* or "Human immunodeficiency virus" or AIDS)) AND TITLE-ABS-KEY((Wives or Wife or Mothers or female* or girl* or women or woman)) AND TITLE-ABS-KEY((predictor* or "risk factor*" or determinant* or "sexual behaviour" or "multiple sex partner*" or extramarital* or "sell* sex*" or "transactional sex" or prostitut* or "sex work" or condom* or "unsafe sex" or "unprotected sex" or knowledge or "social influenc*" or "peer influenc*" or "social norm*" or cultur* or sociocultural* or socioeconomic* or "social environmental*" or socioenvironment* or stigma or discriminat* or "psychological impact" or "social impact" or education or "school attendance" or "withdraw* from school" or stress or distress or depression or "psychosocial impact" or employment or "loss of job" or income or "nutrition security" or "food insecurity" or health or "physical health" or wellbeing or "healthcare accessibility*" or absenteeism or religio* or consequence*)) AND TITLE-ABS-KEY((family* or families)) AND TITLE-ABS-KEY(((Developing or "Less developed" or "low resource*" or disadvantaged or "resource limited" or poor or "low* income*") W/0 (countr* or region* or nation? or area*)))

Results: 1,365

Database(s): ProQuest

Search strategy:

noft((HIV* OR "Human immunodeficiency virus" OR AIDS) AND (Wives OR Wife OR Mothers OR female* OR girl* OR wom?n) AND (predictor* OR "risk factor*" OR determinant* OR "sexual behaviour" OR "multiple sex partner*" OR "sell* sex*" OR "transactional sex" OR prostitut* OR "sex work" OR condom* OR "unsafe sex" OR "unprotected sex" OR knowledge OR "social influenc*" OR "peer influenc*" OR "social norm" OR cultur* OR sociocultural* OR socioeconomic* OR "social environmental*" OR socioenvironment* OR Stigma OR discriminat* OR "Psychological impact" OR "Social impact" OR Education OR "school attendance" OR "withdraw* from school" OR "Psychosocial impact" OR Employment OR "Loss of job" OR income OR distress OR stress OR Depression OR "Nutrition security" OR "Food insecurity" OR health OR "physical health" OR wellbeing OR "Healthcare accessibility*" OR Absenteeism OR religio* OR Consequence*) AND (family* OR families) AND ((Developing OR "Less developed" OR "low resource*" OR disadvantaged OR "resource limited" OR poor OR "low* income*") NEAR/0 (countr* OR region* OR nation? OR area*))) AND PEER(yes)

Results: 479

Appendix 5: JBI Critical Appraisal instruments

Removed due to copyright restriction.
Available online from the Joanna Briggs Institute.

Appendix 6: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Removed due to copyright restriction. Available online from Oxford University Press.

Appendix 7: Interview Guide

1. Interview Guide for women and men living with HIV

Interview guide: women and men living with HIV in Belu and Yogyakarta, Indonesia

Date: ________________________________(Date)
Interviewer: _____________________ (Name)
Interviewee: _________(Code);
Position of the interviewee: ____________ (Position)
Is it OK if I record the interview and take notes during the interview?

Would you like to have someone with you while we talk?

When I write up the results of this study, I will assign a specific study identification letter and number for you (as well as for each participant I interview) to ensure that information or comments you provide in this interview remain anonymous. Is this OK with you? You can withdraw your participation or ask me to stop this interview if you do not want to continue or feel uncomfortable during this interview without any consequences.

As you have known through the study information sheet, introduction letter, and our initial conversation once you confirmed your willingness to participate, the purpose of this study is to gain your insights about factors that have made you contracted HIV infection and the impact of your HIV status on yourself and your family.

1. Demographic information

How old are you? ____________(in years)

Age at first HIV diagnosis ____________(in years)

What is the highest education you received? Not at all/primary/secondary/tertiary

What is your religion? Catholic/Protestant/Muslim/Hindu/other

How many children or family members do you have?____________

In what year were you diagnosed with HIV? _____________

Have you ever been diagnosed with sexually

transmitted infections other than HIV? _____________

Are the any other family members of

yours who are living with HIV? ____________

What is your occupation? ____________

How much income do you earn weekly or monthly? ____________

Is your husband/wife working at the moment

(for the married ones)? ____________

How much does he/she earn weekly or monthly? ____________

Who is the breadwinner in your family? ____________

2. Factors leading to HIV infection among women and men living with HIV in Belu and Yogyakarta, Indonesia

2.1. Knowledge and behavioural factors

What do you know about HIV/AIDS?

- When did you first hear about HIV/AIDS? And how? Who told you?
- How HIV is transmitted and prevented?
- Is HIV or AIDS a serious infection or disease or not? Why? Tell me more about it.
- Before you were diagnosed with HIV, were you aware that you have the possibility to contract HIV infection?

Is it possible for to you to identify how you got HIV infection?

- Is it through engagement in unprotected sex or injecting drug use or blood products? Tell me about it.
- Who do you think may have transmitted the virus to you?
    - Is it your partner or spouse?
    - Or other sex partners? Tell me about it.

What do you know about protected sex (or condoms)?

- What are the functions of condoms or benefits of using condoms?

- Do you know where to access condoms?
    - Have you ever accessed condoms?
    - Was it easy or difficult? Tell me about it
- What are the challenges of accessing condoms?
    - Are condoms available in your place?
        - Pharmacies or supermarkets or healthcare facilities?
    - Are the prices of condoms affordable?
- What do you know about the perceptions or reactions of other people when seeing someone accessing or buying condoms? Tell me about it.
    - Have you ever had any experience about how people reacted to you once you accessed or bought condoms? Tell me more about it.
    - Does it influence you to access condoms?

Have you ever used condoms in your sexual relation with your partner or spouse? (If not at all, why? Tell me about it)

- Who first proposed or communicated about condom use in your sexual relation with your partner or spouse?
- How do you discuss condom use or protected sex with your partner or spouse? Explain about it.
    - Does it lead to any problem or abuse or violence? Tell me about it.
- How regular is condom use in your sexual relation with your partner or spouse?
- Do you and your partner or spouse know how to use condom correctly? Tell me about it
- How do you and your partner or spouse feel about condom use in your sexual relation?
    - Do you feel OK using it or not? Why?
- What do you think about condom use in your sexual relation with your partner or spouse?
    - Is it necessary or not? Explain why?
- Do you know about your partner's or spouse's HIV status?
    - When? How? Was it after your HIV diagnosis or prior to that?

What do you know about your spouse's sexual relation or behaviour?

- Do you know/think he/she has other casual sex partner(s)?
    - Why do you think so? Tell me more about it.
- Who do you think his/her casual sex partners are? (sex workers?)
- How have you talked with him about it?
    - Does it lead to verbal or physical abuse? Tell me about it.
- Do you think he uses condoms in sex with his/her casual sex partner(s)?

Do you have sexual relation with partner(s) other than your current partner or spouse? Or have you ever had sexual relation with partner(s) other than your current partner or spouse?

- Can you describe more on what factors leads you to engage in sexual relation with casual sex partner(s)? Or in what circumstance do you engage in sex with casual male/female sex partner(s)?
- Do you use condom in your sexual relation with your partner(s) other than your current partner or spouse? (If not, why?).
- How regular is condom used?
- Who first proposed or communicated about condom use and why?
    - Does/did it cause any problem or violence or abuse? Tell me about it.
- Do you know about his/their HIV status?
    - How? Tell me about it.
- What do you know/think about their sexual relation or behaviour?
    - Do they have other casual sex partner(s) other than you?
- Do you think he/she uses condoms in sex with his casual sex partner(s) or not? Tell me about it.

Have you ever been involved in injecting drug use? Tell me more about.

2.2. Economic factors

Can you explain to me about your economic or financial condition?

- Do you have your own income? How much is it per month?

- Or do you economically or financially depend on your partner or husbands? Why? Tell me more about it.
- Do you feel it disempowers or hampers you to negotiate or talk about condom use/safe sex with your spouse? Tell me about it.
- Does your economic or financial condition influence your sexual relation or sexual behaviour? How? Please explain about it.
- Have you ever engaged in sex work or transactional sex?
    - Why/for what reasons? Tell me more about it.

Have you ever migrated to other places in Indonesia or to other countries for work or any other purposes?

- Did it influence your sexual relationship?
    - How? Tell me more about it.
- Did you have other sex partner(s) during the work period?
    - What led you to engage in sexual relation with other sex partner(s)? Tell me more about it.

Does your partner or spouse often travel? Or has he ever migrated to other place such as for work purposes?

- How often does he travel? Or how long does he migrate?
- What do you know/think about his sexual behaviour while he is away? Tell me about it.
- Does it influence your sexual relation?
    - How? Tell me more about.

2.3. Socio-environmental factors

Do you feel that your social relationship with friends or colleagues influence your sexual relation or behaviour? How? Tell me more about it.

- Sex with multiple partners
- Engagement on IDU

Would you describe more about the environment or community where you live or work?

- Are brothels or illicit drugs available in the places or communities where you live or work?

- Do they have an influence on you or your partner or spouse? How? Tell me more about it.

Would you describe more about decision making about other aspects in your family? (E.g.: accessing health services and social services, applying for jobs, going out with friends, involving in social activities, etc).

- Who make the decision or have much stronger influence on decision about these aspects? Why?
- How does this has impacted on your life psychologically and socially? Tell me more about it

What do you know about the social perceptions here (Belu/Yogyakarta) about PLHIV?

- How do people within your community look at you or what are their views about PLHIV?
    - Bad woman/man, Unfaithful woman/man, Trouble makers, Stubborn woman/man. Please explain more about these.
- How do you feel about these negative perceptions? Tell me more about it.
- How these perceptions influence your behaviour? Tell me more about it.

2.4. Cultural factors

What do you think about husband-wife relationship in your culture?

- Are there any culture norms that govern husband-wife relationship in your culture? Tell me more about it.
    - Fidelity of wife to husband
    - Women's submission to husbands
    - Who is the decision maker?
    - Women are not allowed to question what husbands do
- Are any cultural values that are highly upheld by women/men in marriage life? Tell me more about it.
    - Concept of an ideal woman/man in marriage life
- Do you feel you have equal rights or power to your spouse in your marriage life? In what matters? Please explain about it.
- Is husband-wife conversation about sex a common cultural practice in the community you live (Belu or Yogyakarta)? Please tell me about your experience related to this.

- When it comes to sex or decision about when and under what condition to have sex, who makes the decision? (Your husband/wife only or you only or both of you). Tell me more about it.
    - Have ever refused sex with your partner of spouse due to some reason?
    - What was the reaction of your partner or spouse?
    - Did it lead to any abuse or violence against you? Tell me about it.
- Do you think it is common in your culture for a husband/wife or male/female partner to have multiple casual sex partners outside his/her steady or marital relationship? Why?
- Do you think it is socially and culturally acceptable and wives should accept that? Why? Please explain more about it.
- Do you think having sexual relation before marriage in acceptable in your culture or not? Why? Please explain more about it.
    - Does it have an influence on your access to condoms? Tell me more about it.

2.5. Religious factors

What do you think about husband-wife relationship in your religion?

- Are there religious thoughts and values that govern husband-wife relationship? Tell me more about it.
    - Fidelity of wife to husband
    - Women's submission to husbands
    - Who is the decision maker?
    - Women are not allowed to question what husbands do
- Are there religious values that are highly upheld by women/men in marriage life? Tell me more about them.
- Based on your religious thoughts, norms and values, do you feel you have equal rights or power to your spouse in your marriage life?
    - In what matters? Please explain about it.
- Based on religious thoughts, norms and values in your religion, when it comes to sex or decision about when and under what condition to have sex, who makes the decision? (Your husband/wife only or you only or both of you). Tell me more about it.

    - Have you ever refused sex with your partner or spouse due to some reason?
    - What was the reaction of your partner or spouse?
    - Did it lead to any abuse or violence against you? Tell me about it.
- What is thoughts about condoms in your religion?
    - Is it allowed for condom use in sexual relation or not? Why? Please explain more about this.
    - Does it hamper you to buy condoms?
- Based on your religious thoughts, norms and values, do you think it is allowed for a husband/wife to have multiple casual sex partners outside or marital relationship? Why?
    - Do you think it is unacceptable, sin, etc.
- Based on your religious thoughts, norms and values, is it acceptable to have sex before marriage or not? Why? Please explain more about this.
    - Is it a kind of hinderance for you to buy condoms? Why?
        - Feeling ashamed if recognised by others

Would you describe more about thoughts and norms in your religion about the position of husbands and wife within a marriage life?

- How do these thoughts and norms influence decision making about other aspects in your family? (E.g.: accessing health services and social services, applying for jobs, going out with friends, involving in social activities, etc).
- Who make the decision or have much stronger influence on decision about these aspects?
- How does this has impacted on your life psychologically and socially? Tell me more about it

What do you know about the perspectives of your religions about women and men with HIV?

- Sinners, bad women/men, unfaithful women/men, trouble makers, stubborn women/men. Please explain more about these.
- How do you feel about these negative perspectives? Tell me more about it.
- How these perspectives influence or impact on your life? Tell me more about it.

Are there any support you get from your religion?

- What are they? Tell me about them.

3. The impact of HIV on themselves and their families:

3.1 Psychological impact on women and men living with HIV and their families

3.1.1 Psychological impact on women and men living with HIV

What did you feel when you were first informed that you are infected with HIV?

- Did you feel scared, stressful, angry, depressed, or ashamed?
    - Would you describe more about the reasons why you had those feelings?
- Now, do you still feel the same or different? (Why? Tell me more about it).
    - Would you describe more about the reasons why you have those feelings?
        - E.g.: Poor physical health, advance stage of HIV infection, family is ashamed of your HIV status, children's health and future, lack of support, social rejection, internalised stigma, etc.
- How do you cope with those feelings?

3.1.2 Psychological impact of HIV on women's and men's family members

Do you feel your status psychologically affects your family members as well (parents, siblings, husband/wife or children?

- Do they feel ashamed, stressful, angry, upset, worried, hurt, etc.? Why? Tell me more about it).
- Have you ever seen any of them showing any kind of psychological distress due to your status? Who? Why do you think that happened to him/her? Tell me more about it.

3.2 Physical impact

What do you think about the influence of HIV infection on your physical health and strength?

- Do you feel physically strong or weak?
- Do you easily get sick or not? Please tell me about your physical health experience since you were diagnosed with the infection
- Does the infection prevent or limit you from doing activities that you used to do? Why? Tell me more about it.

3.3 Social impact

3.3.1 Stigma and discrimination against women and men living with HIV from their family members

Do your family members know about your HIV status?

- What was their reaction or response when they first heard about your status?
- Are there any differences you notice in the way they interact with you or treat you after they know about your status?
    - Please give some examples on how they interact with you or treat you differently.
        - Being blamed, beaten, verbally insulted, avoided, rejected, isolated, threatened to kill, asked to leave or chased away from home, and not allowed to share food or utensils with other family members, etc.
- Do you feel your status affect the relationship between you and your family members? (Tell me more about it).

What have you done or what strategy have you used to cope with negative reactions or treatments, if any, from your family members?

3.3.2 Stigma and discrimination against women and men living with HIV from community members

Do your neighbours, friends and relatives in the community you live know about your HIV status?

- What was their reaction or response once they know about your status?
    - Positive or negative reactions, tell me more about it.
- Are there any changes in their relationship with you?
    - Being rejected, neglected or not visited by neighbours, friends and relatives
- Do you feel they treat you differently after knowing your status or not? Please explain about it.
    - Refused to share foods and drinks, physically assaulted, being labelled or verbally abused with discriminative words, ridiculed, insulted or harassed, excluded from usual activities or social functions, refused to enter or removed from public places.

What do you think about community acceptance towards you?

- Do people within community where you live accept you, involve you in social activities? Tell me about it.

3.3.3 Stigma and discrimination against HIV affected family members from community members

Are there any changes you notice in how your neighbours or friends or relatives relate or interact with your family members after they knew about your status? Tell me more about it.

- Avoidance
- Keeping distance

Do you think your status affects social life or social relation of your family members (parents, siblings, husband, children)? How? Tell me more about it).

- Social exclusion: e.g., excluded from social activities

For women and men with HIV who are married: Do you think your status affects your children's social life and social relation with their friends at home or within community where you live or at school? How? Tell me more about it.

- Avoided by other family members
- Not allowed to share foods and drinks with other family members
- Insulted by neighbours
- Rejected, teased, cursed, abused and isolated by their friends
- Labelled with discriminative words
- Abused by their friends' parents or relatives
- Involved in household chores
- Taking care of you, etc

Do you think your status affects their education? Tell me about it.

- School attendance
- School performance
- Denied from admission into school
- Stigma and discrimination against children at school due to their mothers' HIV status:
    - Placed at separate desk by teachers
    - Other children are told to not play with them, etc.
    - Kicked out from school

Is there any change you notice in the relationship between your children and you and your husband due to your HIV status?

- Disharmony / child-parent conflict
- Child-parent separation
- Blaming
- Avoidance, etc

3.3.4 Stigma and discrimination against women and men living with HIV from colleagues and employers

Do your colleagues and employer know about your HIV status?

- What was their reactions once they knew about your HIV status?
- Are there any changes in how they relate or interact with you? Tell me more about it.
    - Being rejected, neglected, avoided, etc.
- Does your status affect your position or job descriptions assigned to you? How? Tell me more about it.

3.4 Economic impact of HIV on women and men living with HIV and their families

3.4.1 Economic impact of themselves

What do you feel about the influence of your HIV status on your ability to work? (How? Tell me more about it).

- Preventing your involvement in work or reducing your working hours due to poor physical health?
- Are you still actively working or is there any changes compared to the time when you hadn’t got the infection? (Would you describe more on your experience about this?)
    - Does your status affect you financially? (How? Tell me more about it).
        - Reduced / loss of income
    - Does it lead to difficulties in fulfilling your needs? (How? Tell me more about it).

3.4.2 Economic impact on their families

Does your status affect the work of your family members as well? (How? Tell me more about it).

- Reduced working hours due to taking care of you

- Does your HIV status affect your family financially? (How? Tell me more about it).
    - Does it lead to difficulties in fulfilling the needs of your family? (How? Tell me more about it).
        - Basic needs such as foods (food insecurity/hunger), clothes, etc.
        - Children's school fee
        - Children involvement in labour force, household chores, caring for their sick mother, etc. Tell me more about it).
        - Withdrawal of children from school
- Does your HIV status influence in any of your family business?
    - Preventing clients or customers to buy your products or using your services

Does health condition increase your family health expenditure? (Would you describe more about this?)

What strategy do you use to cope with any economic difficulty or financial hardship facing you and your family?

- Spending savings
- Selling family properties (tell me more about this)
- Borrowing money from friends, relatives, etc

4. Access to HIV care services

4.1 Availability and ability to reach:

What do you know about HIV/AIDS-related health services here (in Belu or Yogyakarta)?

- What types of HIV/AIDS-related health services are available?
- At which healthcare facilities are they available/offered?
- Are they such as ART available every time you access or limitedly available?
- Do you think health professionals providing HIV/AIDS-related services are trained in the field? Tell me what you know about them.
- How do you get to any of the health facilities to access HIV/AIDS-related health services?
    - What kind of transport do you use?

        - How far is it from your house to the healthcare facility to access the services? (……in km)
        - How long is it from your house to the healthcare facility to access the services? (……in minutes)
        - Do you think the healthcare facility where the services are available is reachable for you?
        - Do the distance and transport influence your access to the services? Why?
    - Do you think the transportation system here facilitates you or makes it easier for you to access the services or not? Tell me about it.

4.2 Approachability and ability to perceive:

How did you first hear or know about the availability of HIV/AIDS-related health services? Tell me more about it.

- Through television, newspapers, friends, health professionals.

What do you think about dissemination of information about HIV related health services here?

- Is the information well disseminated within communities? How? If not, why?
- Do all/the majority of PLHIV know about the availability of the services?
    - Why do you think yes or no?

How often do you access HIV/AIDS-related health services?

- Rarely/regularly/monthly? Why?
- What kinds of HIV/AIDS-related health services have you accessed?
    - ART, CD4 test, viral load test, etc.
    - Condoms

4.3 Affordability and ability to pay

- Are HIV/AIDS-related services free or not?
- How much money do you spend on HIV/AIDS services and transport every time you access them?
    - What items of the services do you need to pay for?
    - How much is it? Tell me more about it.

        - ……. (in IDR)
    - How much money do you spend for transportation?
        - ……. (in IDR)
    - What do you think about these costs?
        - Do you think you can afford to pay the costs?
        - What sorts of resources do you spend on the costs?
        - Are they burdensome? Why?
    - Do these expenditures hamper you from accessing the services? (Tell me more about it).
    - How do you and your family cope with the health expenditures?

4.4 Appropriateness and ability to engage

Please describe about your experiences related to the access to HIV/AIDS-related health services at any health facility here.

- Do you think the HIV/AIDS-related health services available here are appropriate or the ones that you need? Explain about it.
- Do you think the services are delivered in a good way by qualified health service providers? Please tell me more about this.
- What motivates you to access the services?
    - Are you aware of the benefits of utilising the services? Tell me more about it.

What do you think about the attitudes of health service providers who provide HIV/AIDS-related health services?

- Who often provide the services? (doctors, nurses, men, women?
    - Do you trust the health service providers? Why? Please explain more about this.
        - Keep your status secret or not breach it to other people
- Do you think they treat you differently or the same other patients who do not have the infection? Why?
- How do you feel about the way they interact with you or speak to you every time you access the services?

    - Supportive
    - Do you feel they help you to continue accessing HIV/AIDS-related services? Tell me about it.
    - As a patient, how do you feel about your relationship with them as health professionals?

Have you ever had any negative experience or stigma and discrimination in healthcare settings performed by healthcare professionals or other people accessing healthcare services? Tell me about it.

- Being criticised, blamed, shouted at, neglected or left untreated or unnecessarily referred to other healthcare facilities, coerced to abort or sterilise
- Does it affect your access to healthcare services? Why? Tell me more about.
    - How do you cope with these?

4.5 Acceptability and ability to seek

What are the procedures to access HIV/AIDS-related health services?

- What do you think about the procedures?
    - Do the procedures enable and hamper you from accessing the services? Why? Please explain about it.
    - Do you think the procedures are acceptable? Why? Tell me more about it.
- Who are the HIV-related health service providers that serve you?
    - Men or women
    - If the health service provider is a man/woman: do you think it is socially and culturally acceptable? Why?
        - Do you openly talk with them about your condition? Tell me about it.
    - Does it influence you to seek HIV services?
- Are you the one who makes decision about seeking or choosing HIV-related health services or someone else?
    - Does this influence your access to the services? How? Tell me more about this.

Do you get any support from healthcare professionals or health service providers?

What kind of support do you get? Tell more about it.

  - Emotional support
  - Informational support
  - Instrumental and material support
  - Appraisal support

Do you feel such support helps you? How? Please describe about it.

What sorts of HIV/AIDS-related health services do you need or expect to be provided? Tell more about it.

Is there anything else you wish to add?

Would you like to see a copy of the interview transcript and edit it prior to me analysing the information?

Would you be able to suggest other women or men with HIV who might be willing to participate in this study?

2. Interview Guide for health service providers

Interview guide: Health service providers in Belu and Yogyakarta, Indonesia

Date: ____________________________(Date)
Interviewer: ___________________ (Name)
Interviewee: ________(Code);
Position of the interviewee: ___________ (Position)
Is it OK if I record the interview and take notes during the interview?

Would yu like to have someone with you while we talk?

When I write up the results of this study, I will assign a specific study identification letter and number for you (as well as for each participant I interview) to ensure that information or comments you provide in this interview remain anonymous. Is this OK with you? You can withdraw your participation or ask me to stop this interview if you do not want to continue or feel uncomfortable during this interview without any consequences.

As you have known through the study information sheet, introduction letter and our initial conversation once you called to confirm your participation, the purpose of this study is to gain your views about HIV/AIDS-related health services in the healthcare facilities in Belu district and the access of WLHIV to the services.

1. Demographic information

Institution	Hospital/Com Health Centre/Clinic
How long have you been working for HIV services?	____________(in years)
How old are you?	___________(in years)
What is the highest education you received?	Primary/secondary/tertiary
What is your religion?	Catholic/Protestant/Muslim/Hindu/other
What is your ethnicity	Timorese/Javanese

2. HIV/AIDS-health related services and access of WLHIV to the services

2.1 Availability:

Please tell me about HIV/AIDS-related health services here (in Belu or Yogyakarta)

- What types of HIV/AIDS-related health services are available?
- At which healthcare facilities are they available/offered?
    - What about in your healthcare facility?

- Are the services available all the time or limitedly available/sometime unavailable?
- What is HIV/AIDS-related training or education have you received?
    - How many trained HIV/AIDS staff at healthcare facility you are working for?

  Do you think the number is enough to service PLHIV here? Why?
- Are they living nearby or far away from the healthcare facility you are working at?
    - How do they get to the healthcare facility to access HIV/AIDS-related health services?
    - What kind of transport do they use?
    - Do you think the transportation system here facilitates them or makes it easier for them to access the services or not? Tell me about it.
        - Do you think the healthcare facility where the services are available is reachable for WLHIV? Please explain more about it.
        - Do the distance and transport influence their access to the services? Why?

2.2 Approachability and ability to perceive:

Do you think HIV/AIDS-related health services here are known to people with HIV in this area? Tell me more about it.

- How do you disseminate information about HIV/AIDS-related health services to people with HIV?
    - What kinds of dissemination strategies or activities do you use?
        - Workshops, group discussions, talk show, etc.
        - How often are the activities carried out?
            - What about the participation of WLHIV in the activities? Tell me about it.

Do you think HIV/AIDS-related health services here are approachable to people with HIV?

- Would you describe more about the access of people with HIV HIV to the services at the healthcare facility you are working at?
    - Rarely/regularly/monthly?
    - What kinds of HIV/AIDS-related health services do they access?

        - ART, CD4 test, viral load test, etc.
        - Condoms

2.3 Affordability and ability to pay

Do you think HIV/AIDS-related health services are affordable to people with HIV?

- Do they need to pay for their access to HIV/AIDS-related health?
    - What item do they need to pay for?
    - How much is it?
    - Do you think they can afford to pay the services? Tell me more about it.
    - Do you have any experience where patients (people with HIV) could not afford to pay for medical cost as well as transportation cost? Tell me about it.
    - Do you think medical cost and transportation cost are burdensome and hamper them from accessing the services? Tell me more about it.
        - What have been done to help the ones with these difficulties?

2.4 Appropriateness and ability to engage

Please tell me about HIV/AIDS services provided for people with HIV:

- Do you think the available HIV/AIDS-related health services meet their needs? Why do you think so? Explain about it.
- Who often provides the services? (doctors, nurses, men, women?
    - What kind of HIV/AIDS-related training do you and all other health workers providing HIV/AIDS services at healthcare facilities get?
- Please tell me more about your experience in providing the services for people with HIV
    - How do you deliver the services and interact with them?
        - Are they served differently or in the same way as general populations? Tell me about this.
    - What do you think motivates them to access the services?
        - Are they aware of the benefits of utilising the services? Tell me more about it.
        - Willingness to be healthy

        - Do you think they trust you and feel comfortable talking to you about their HIV status and health condition? Tell me more about it.
            - They openly talk to you about their conditions?
            - They felt scared, shy, not willing to talk, etc? Tell me more about these.
        - What do you think about their adherence to the treatment? Tell me more about your experience related to this.
            - Have you ever got angry or criticised or blame people with HIV because of any reasons such as non-adherence to ART, not attending regular medical check-up, etc. Tell me about it.
                - Do you think it affects their access to the services? Why? Tell me more about.
        - How do you feel about your relationship as a health professional with them as your patients?

2.5 Acceptability and ability to seek

What are the procedures people with HIV need to follow to access HIV/AIDS-related health services?

- What do you think about the procedures?
    - Do the procedures enable and hamper them from accessing the services? Why? Please explain about your experience related to this.
- Do you think the sex of a healthcare professional (male/female) who provides HIV/AIDS-related health services for people with HIV matters? Why?
    - If the health service provider is a man: do you think it is socially and culturally acceptable to talk a woman with HIV? And vice versa. Why?
    - Do you think it influences people with HIV to seek HIV services?

What do you think about their decision to access HIV/AIDS-related services?

- Are they the ones who make the decision or other people in the family? Who?
- Do you think people with HIV have enough courage to access HIV/AIDS-related services at healthcare facility? Why? Tell me more about it.

What do you think about the impact of HIV on the health system here in Belu/Yogyakarta?

- Does it increase burden of disease due to, for example, increased cases of illnesses (TB, malnutrition, diarrhoea, etc.) in any form of opportunistic infections associated with HIV infection? Would you describe more about this?
- Does it increase demand for services or service needs associated with caring for these illnesses and for HIV/AIDS itself? Tell me more about it.
    - The need for medicine/treatment
    - The need for HIV/AIDS-related health facilities
    - The need for human resources, health workers who are trained about the topic
    - Budget/cost for HIV/AIDS-related illnesses treatment
- How do you think these needs have been addressed or dealt with here in Belu/Yogyakarta? Please tell me more about it.

What are the things that you think need to be done to support access to HIV/AIDS-related health services among women and men with HIV in Belu/Yogyakarta?

Is there anything else you wish to add?

Would you like to see a copy of the interview transcript and edit it prior to me analysing the information?

Would you be able to suggest other healthcare workers in healthcare facilities providing HIV services, who might be willing to participate in this study?

3. Interview Guide for policy makers

Interview guide: Policy makers in Belu district and Yogyakarta municipality, Indonesia

Date: ____________________________(Date)
Interviewer: ___________________ (Name)
Interviewee: ________(Code);
Position of the interviewee: ___________ (Position)

Is it OK if I record the interview and take notes during the interview?

When I write up the results of this study, I will assign a specific study identification letter and number for you (as well as for each participant I interview) to ensure that information or comments you provide in this interview remain anonymous. Is this OK with you? You can withdraw your participation or ask me to stop this interview if you do not want to continue or feel uncomfortable during this interview without any consequences.

As you have known through the study information sheet, introduction letter and our initial conversation at the first time I approached and asked for your participation, the purpose of this interview is to gain your views about HIV/AIDS-related policy and program that are in place in Belu/Yogyakarta and what needs to be done in the future to halt HIV transmission among women in Belu and to address HIV impact facing WLHIV and their families in Belu/Yogyakarta.

1. Demographic information

How old are you? _______(in years)

What is the highest education you received? Primary/secondary/tertiary

How long have been involved in policy making _______(in years)

2. HIV/AIDS-related policy

What is the HIV/AIDS-related policy in Belu/Yogyakarta?

- Policy:
- Would you explain more about it?
    - How was the policy made?
    - Who were involved?

What are the focuses or objectives of the policy?

- Objectives:
- Do they address factors leading to HIV infection among women and men HIV?

    - What are the factors addressed? Tell me more about them?
        - Knowledge, attitude, behaviour, socio-environmental
- Do they address the impacts of HIV on WLHIV and their families?
    - What are the impacts addressed in the policy? Tell me more about them?
        - Psycho-social, physical, health, educational and economic

3. HIV/AIDS related programs in Belu/Yogyakarta

How has the policy been translated into HIV/AIDS-related strategies and programs?

- What are the strategies or programs?
    - Who were involved in the development of the strategies and programs?
    - What were the challenges in translating HIV/AIDS-related policy into strategies and programs? Tell me more about these.

How is the implementation of the HIV/AIDS-related strategies and programs?

- So far, are the implementation going well? Tell me more about these.
- What are the challenges faced during the implementation of the programs? Please explain more about them.

Would you describe more about budget or fund for the implementation of HIV/AIDS?

- What is the source of fund?
- How much is the annual amount allocated HIV/AIDS-related activities or programs?
- Who decide the amount and on what basis? Tell me more about it.
- Do you think such amount is enough? Why? Tell me more about it.

What are the things you think need to be considered in the future to halt HIV transmission among women as well as general population in Belu/Yogyakarta? Why? Please explain more about these.

What are the things you think need to be considered to address the impacts of HIV infection among WLHIV and their families in Belu/Yogyakarta? Why? Please, explain more about these.

Is there anything else you wish to add?

Would you like to see a copy of the interview transcript and edit it prior to me analysing the information?

Appendix 8 : Study information sheet

INFORMATION SHEET

(for in-depth interview with women and men living with HIV)

Title: Determinants and impacts of HIV among women living with HIV and their families in Belu district and Yogyakarta, Indonesia

Researcher(s)

Nelsensius Klau Fauk

College of Medicine and Public Health

Flinders University

Tel: 0415370274 / +6281213935433

Supervisor(s)

1. Associate Professor Lillian Mwanri

College of Medicine and Public Health

Flinders University

Tel: 08 7221 8417

2. Prof. Paul Ward

College of Medicine and Public Health

Flinders University

Tel: +61 8 72218415

3. Dr. Karen Hawke

South Australian Health and Medical Research Institute (SAHMRI)

Tel:

Description of the study

This study is part of the project titled “Determinants and impacts of HIV among women living with HIV (WLHIV) and their families in Belu district and Yogyakarta municipality, Indonesia. The number of HIV incidences among women in Indonesia is reported to regularly increase ever year. WLHIV and their family may also suffer from the impact of HIV. However, evidence on determinants and impacts of HIV among women is still scarce in the context of Belu district and Yogyakarta and Indonesia as a whole. Besides, given the fact that WLHIV especially in developing countries or resource limited settings often experience difficulties in accessing HIV/AIDS-related health services due to various reasons, it is also expected that WLHIV in Belu and Yogyakarta may have similar experiences. This study, therefore, aims to understand and compare factors that have facilitated the transmission of HIV infection among WLHIV and the impacts of women’s HIV status on themselves and their families in Belu and Yogyakarta. It will also explore the views of health service providers about HIV/AIDS-related health services available in Belu and Yogyakarta and the access of WLHIV to the services, and the views of policy makers on HIV/AIDS-related policy and program in these settings. This project is supported by Flinders University, College of Medicine and Public.

Purpose of the study

This project aims:

5. To understand and compare behavioural, personal, socio-environmental, economic, cultural and religious factors leading to HIV infection among women aged 18 years old and older living with HIV in Belu and Yogyakarta, Indonesia.
6. To understand and compare psycho-social, physical, health, educational, and economic impacts of HIV on women aged 18 years old and older living with HIV and their families in Belu and Yogyakarta, Indonesia.
7. To understand and compare similarities and differences of the HIV impacts experienced by HIV infected women who are married and those who are not married both at individual and family level.
8. To understand and compare the views of women aged 18 years old and older living with HIV in Belu and Yogyakarta, Indonesia, about HIV/AIDS-related health services and their access to the services.
9. To explore and compare the views of health service providers in Belu and Yogyakarta about HIV-related health services available in these settings and the access of WLHIV to the services.
10. To explore and compare the views of policy makers in Belu and Yogyakarta about HIV/AIDS-related policies and programs that are in place and on what responses or solutions that need to be undertaken in the future to halt HIV transmission among women and to address HIV impact facing WLHIV and their families in Belu and Yogyakarta.

What will I be asked to do?

You are invited to attend a face-to-face in-depth interview with a researcher who will ask you a few questions regarding your views about factors that have made you contracted HIV infection and your experience of the impacts of your HIV status on yourself and your family, and about HIV/AIDS-related health services in Belu/Yogyakarta and your access to the services. Participation is entirely voluntary. The interview will take about 45 to 90 minutes. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by the participant. You will be provided with a hard-copy of the transcript to edit, if you require. An envelope and stamp will be enclosed to enable you send your feedback to the researcher's postal address:

Nelsensius Klau Fauk

Dusun Fatuluka, RT 011 / RW 003, Desa Jenilu,

Kec. Kakuluk Mesak, Kab. Belu, NTT, 85752.

If you are unable to send it, you can contact the researcher at +6281213935433 to pick up.

What benefit will I gain from being involved in this study?

The study may not have direct benefits to you but the sharing of insights and experiences about HIV risk factors and the impacts of your HIV status on you and your family and your access to HIV/AIDS-related health services can be evidence to inform government, healthcare providers, and other institutions concerned with HIV/AIDS problem to develop HIV/AIDS-related strategies and interventions to halt HIV transmission and address the HIV-related impacts among women living with HIV and their families in Belu and Yogyakarta and other similar settings in Indonesia.

Will I be identifiable by being involved in this study?

We do not need your name and you will be anonymous. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced please contact VCT clinic Belu on ……………and HIV clinic in Yogyakarta on…………. for support / counselling that may be accessed free of charge by all participants. If you need a help to contact the clinics please speak to the researcher for support. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is voluntary. You may answer ‘no comment’ or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and return it back to me.

Recognition of contribution / time / travel costs

If you would like to participate, in recognition of your contribution and participation time, you will be provided with IDR 100,000 (±AU $10). This amount will be provided to you face-to-face on completion of the interview.

How will I receive feedback?

On project completion, outcomes of the project will be given to all participants who require to read and edit, in person or via post.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8268). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

INFORMATION SHEET

(for in-depth interview with health service providers)

Title: Determinants and impacts of HIV among women living with HIV and their families in Belu district and Yogyakarta, Indonesia

Researcher(s)

Nelsensius Klau Fauk

College of Medicine and Public Health

Flinders University

Tel: 0415370274 / +6281213935433

Supervisor(s)

1. Associate Professor Lillian Mwanri

College of Medicine and Public Health

Flinders University

Tel: 08 7221 8417

2. Prof. Paul Ward

College of Medicine and Public Health

Flinders University

Tel: +61 8 72218415

3. Dr. Karen Hawke

South Australian Health and Medical Research Institute (SAHMRI)

Tel:

Description of the study

This study is part of the project titled "Determinants and impacts of HIV among women living with HIV (WLHIV) and their families in Belu district and Yogyakarta municipality, Indonesia. The number of HIV incidences among women in Indonesia is reported to regularly increase ever year. WLHIV and their family may also suffer from the impact of HIV. However, evidence on determinants and impacts of HIV among women is still scarce in the context of Belu district and

Yogyakarta and Indonesia as a whole. Besides, given the fact that WLHIV especially in developing countries or resource limited settings often experience difficulties in accessing HIV/AIDS-related health services due to various reasons, it is also expected that WLHIV in Belu and Yogyakarta may have similar experiences. This study, therefore, aims to understand and compare factors that have facilitated the transmission of HIV infection among WLHIV and the impacts of women's HIV status on themselves and their families in Belu and Yogyakarta. This study will also explore the views of health service providers about HIV/AIDS-related health services available in Belu and Yogyakarta and the access of WLHIV to the services, and the views of policy makers on HIV/AIDS-related policy and program in these settings. This project is supported by Flinders University, College of Medicine and Public.

Purpose of the study

This project aims:

1. To understand and compare HIV-risk factors among WLHIV and the impact of HIV on themselves and their families in Yogyakarta and Belu, Indonesia.
2. To understand and compare HIV-risk factors and the impact of HIV on WLHIV and MLHIV in Yogyakarta and Belu.
3. To understand and compare the perspectives and experiences of women/men living with HIV and healthcare providers about the determinants of access to HIV care services in Yogyakarta and Belu.
4. To explore and compare the current and future perspectives of policy makers in Yogyakarta and Belu about policies and programs to address HIV and its impact on WLHIV and their families.

What will I be asked to do?

You are invited to attend a face-to-face in-depth interview with a researcher who will ask you a few questions regarding your views about HIV/AIDS-related health services available in Belu or Yogyakarta and the access of WLHIV to the services. Participation is entirely voluntary. The interview will take about 45 to 90 minutes. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by the participant. You will be provided with a hard-copy of the transcript to edit, if you require. An envelope and stamp will be enclosed to enable you send your feedback to the researcher's postal address:

Nelsensius Klau Fauk

Dusun Fatuluka, RT 011 / RW 003, Desa Jenilu,

Kec. Kakuluk Mesak, Kab. Belu, NTT, 85752.

If you are unable to send it, you can contact the researcher on +6281213936433 to pick up.

What benefit will I gain from being involved in this study?

The study may not have direct benefits to you but the sharing of your views and experiences about HIV/AIDS-related health services and facilitators and barriers to the access of WLHIV to the services can be evidence to inform government, healthcare providers, and other institutions concerned with HIV/AIDS problem to develop HIV/AIDS-related strategies and interventions to halt HIV transmission and address the HIV-related impacts among WLHIV and their families in Belu and Yogyakarta and other similar settings in Indonesia.

Will I be identifiable by being involved in this study?

We do not need your name and you will be anonymous. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?

The investigator anticipates no risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is voluntary. You may answer ‘no comment’ or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and return it back to me.

Recognition of contribution / time / travel costs
If you would like to participate, in recognition of your contribution and participation time, you will be provided with IDR 100,000 (±AU $10). This amount will be provided to you face-to-face on completion of the interview.

How will I receive feedback?

On project completion, outcomes of the project will be given to all participants who require to read and edit, in person or via post.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number:8268). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

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INFORMATION SHEET

(for in-depth interview with policy makers)

Title: Determinants and impacts of HIV among women living with HIV and their families in Belu district and Yogyakarta, Indonesia

Researcher(s)

Nelsensius Klau Fauk

College of Medicine and Public Health

Flinders University

Tel: 0415370274 / +6281213935433

Supervisor(s)

1. Associate Professor Lillian Mwanri
College of Medicine and Public Health
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Tel: 08 7221 8417
2. Prof. Paul Ward
College of Medicine and Public Health
Flinders University
Tel: +61 8 72218415
3. Dr. Karen Hawke
South Australian Health and Medical Research Institute (SAHMRI)
Tel:

Description of the study

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Purpose of the study

This project aims:

1. To understand and compare HIV-risk factors among WLHIV and the impact of HIV on themselves and their families in Yogyakarta and Belu, Indonesia.
2. To understand and compare HIV-risk factors and the impact of HIV on WLHIV and MLHIV in Yogyakarta and Belu.
3. To understand and compare the perspectives and experiences of women/men living with HIV and healthcare providers about the determinants of access to HIV care services in Yogyakarta and Belu.
4. To explore and compare the current and future perspectives of policy makers in Yogyakarta and Belu about policies and programs to address HIV and its impact on WLHIV and their families.

What will I be asked to do?

You are invited to attend a face-to-face in-depth interview with a researcher who will ask you a few questions regarding your views about HIV/AIDS-related health services available in Belu or Yogyakarta and the access of WLHIV to the services. Participation is entirely voluntary. The interview will take about 45 to 90 minutes. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by the participant. You will be provided with a hard-copy of the transcript to edit, if you require. An envelope and stamp will be enclosed to enable you send your feedback to the researcher's postal address:

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Kec. Kakuluk Mesak, Kab. Belu, NTT, 85752.

If you are unable to send it, you can contact the researcher on +6281213936433 to pick up.

What benefit will I gain from being involved in this study?

The study may not have direct benefits to you but the sharing of your views and experiences about HIV/AIDS-related health services and facilitators and barriers to the access of WLHIV to the services can be evidence to inform government, healthcare providers, and other institutions concerned with HIV/AIDS problem to develop HIV/AIDS-related strategies and interventions to halt HIV transmission and address the HIV-related impacts among WLHIV and their families in Belu and Yogyakarta and other similar settings in Indonesia.

Will I be identifiable by being involved in this study?

We do not need your name and you will be anonymous. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?

The investigator anticipates no risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is voluntary. You may answer ‘no comment’ or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and return it back to me.

Recognition of contribution / time / travel costs

If you would like to participate, in recognition of your contribution and participation time, you will be provided with IDR 100,000 (±AU $10). This amount will be provided to you face-to-face on completion of the interview.

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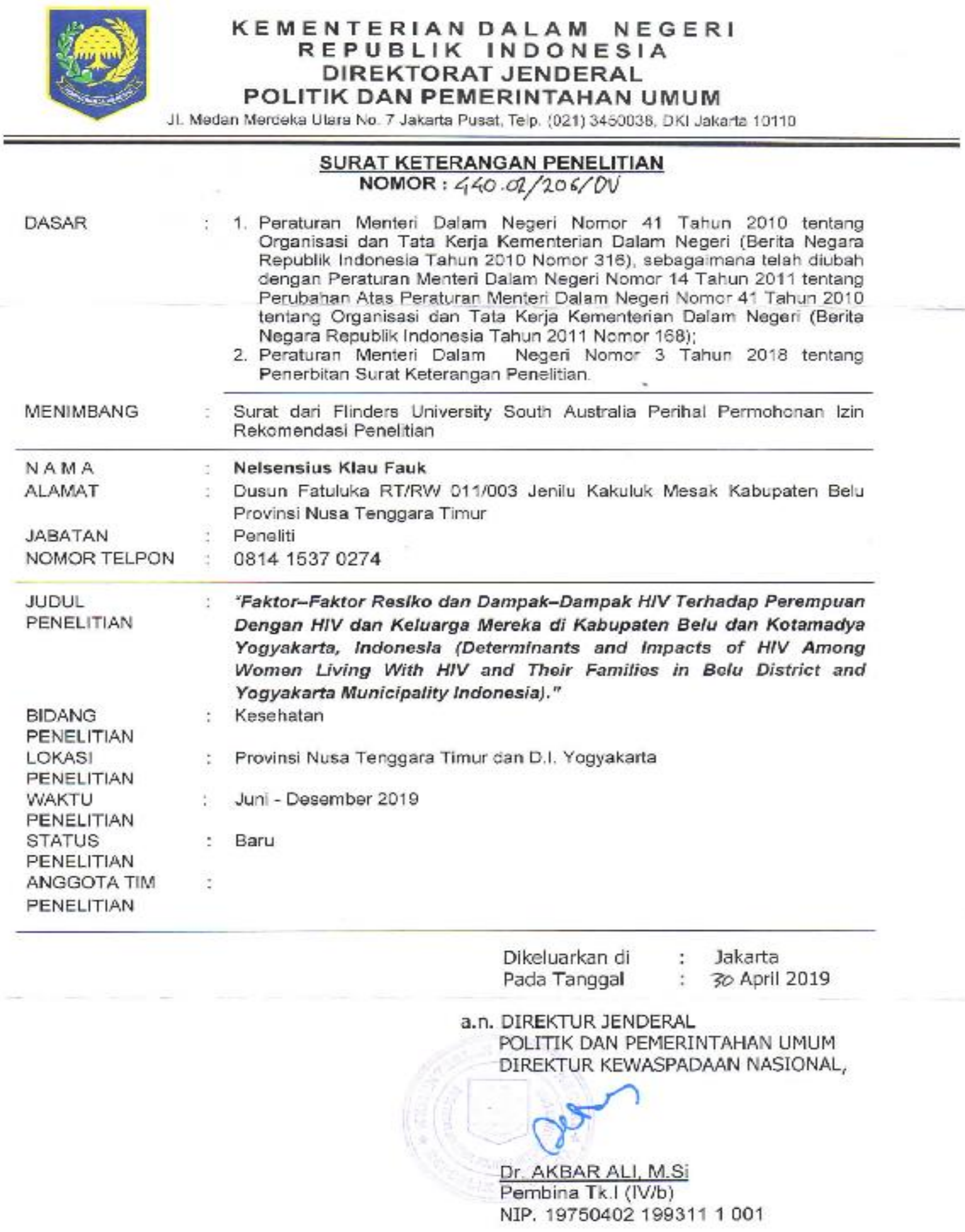
Appendix 9 : Permission letters



KEMENTERIAN DALAM NEGERI
REPUBLIK INDONESIA
DIREKTORAT JENDERAL
POLITIK DAN PEMERINTAHAN UMUM
Jl. Medan Merdeka Utara No. 7 Jakarta Pusat, Telp. (021) 3450038, DKI Jakarta 10110

SURAT KETERANGAN PENELITIAN

NOMOR : 440.02/206/DV

DASAR :
1. Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2010 Nomor 316), sebagaimana telah diubah dengan Peraturan Menteri Dalam Negeri Nomor 14 Tahun 2011 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2011 Nomor 168);
2. Peraturan Menteri Dalam Negeri Nomor 3 Tahun 2018 tentang Penerbitan Surat Keterangan Penelitian.

MENIMBANG : Surat dari Flinders University South Australia Perihal Permohonan Izin Rekomendasi Penelitian

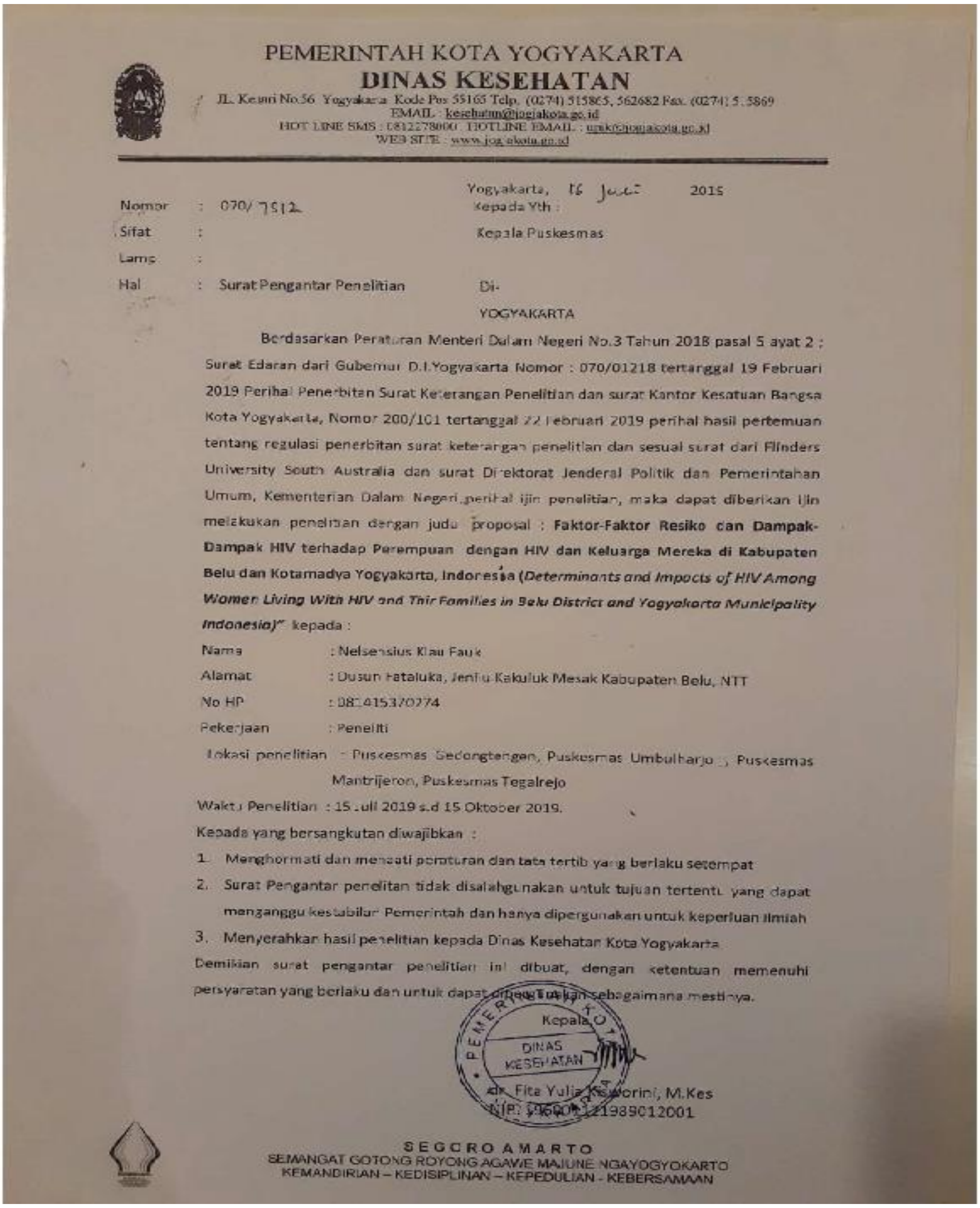
NAMA : **Nelsensius Klau Fauk**
ALAMAT : Dusun Fatuluka RT/RW 011/003 Jenilu Kakuluk Mesak Kabupaten Belu Provinsi Nusa Tenggara Timur
JABATAN : Peneliti
NOMOR TELPON : 0814 1537 0274

JUDUL PENELITIAN : ***"Faktor–Faktor Resiko dan Dampak–Dampak HIV Terhadap Perempuan Dengan HIV dan Keluarga Mereka di Kabupaten Belu dan Kotamadya Yogyakarta, Indonesia (Determinants and Impacts of HIV Among Women Living With HIV and Their Families in Belu District and Yogyakarta Municipality Indonesia)."***
BIDANG PENELITIAN : Kesehatan
LOKASI PENELITIAN : Provinsi Nusa Tenggara Timur dan D.I. Yogyakarta
WAKTU PENELITIAN : Juni - Desember 2019
STATUS PENELITIAN : Baru
ANGGOTA TIM PENELITIAN :

Dikeluarkan di : Jakarta
Pada Tanggal : 30 April 2019

a.n. DIREKTUR JENDERAL
POLITIK DAN PEMERINTAHAN UMUM
DIREKTUR KEWASPADAAN NASIONAL,

Dr. AKBAR ALI, M.Si
Pembina Tk.I (IV/b)
NIP. 19750402 199311 1 001



PEMERINTAH KOTA YOGYAKARTA
DINAS KESEHATAN
Jl. Kenari No.56 Yogyakarta Kode Pos 55165 Telp. (0274) 515865, 562682 Fax. (0274) 515869
EMAIL : kesehatan@jogjakota.go.id
HOT LINE SMS : 08122780001 HOTLINE EMAIL : upik@jogjakota.go.id
WEB SITE : www.jogjakota.go.id

Yogyakarta, 16 Juli 2019

Nomor : 070/ 7512
Sifat :
Lamp :
Hal : Surat Pengantar Penelitian

Kepada Yth :
Kepala Puskesmas
Di-
YOGYAKARTA

Berdasarkan Peraturan Menteri Dalam Negeri No.3 Tahun 2018 pasal 5 ayat 2 ; Surat Edaran dari Gubernur D.I.Yogyakarta Nomor : 070/01218 tertanggal 19 Februari 2019 Perihal Penerbitan Surat Keterangan Penelitian dan surat Kantor Kesatuan Bangsa Kota Yogyakarta, Nomor 200/101 tertanggal 22 Februari 2019 perihal hasil pertemuan tentang regulasi penerbitan surat keterangan penelitian dan sesuai surat dari Flinders University South Australia dan surat Direktorat Jenderal Politik dan Pemerintahan Umum, Kementerian Dalam Negeri perihal ijin penelitian, maka dapat diberikan ijin melakukan penelitian dengan judul proposal : **Faktor-Faktor Resiko dan Dampak-Dampak HIV terhadap Perempuan dengan HIV dan Keluarga Mereka di Kabupaten Belu dan Kotamadya Yogyakarta, Indonesia (*Determinants and Impacts of HIV Among Women Living With HIV and Thir Families in Belu District and Yogyakarta Municipality Indonesia)*"** kepada :

Nama : Nelsensius Klau Fauk
Alamat : Dusun Fataluka, Jenilu Kakuluk Mesak Kabupaten Belu, NTT
No HP : 081415370274
Pekerjaan : Peneliti
Lokasi penelitian : Puskesmas Gedongtengen, Puskesmas Umbulharjo I, Puskesmas Mantrijeron, Puskesmas Tegalrejo
Waktu Penelitian : 15 Juli 2019 s.d 15 Oktober 2019.

Kepada yang bersangkutan diwajibkan :

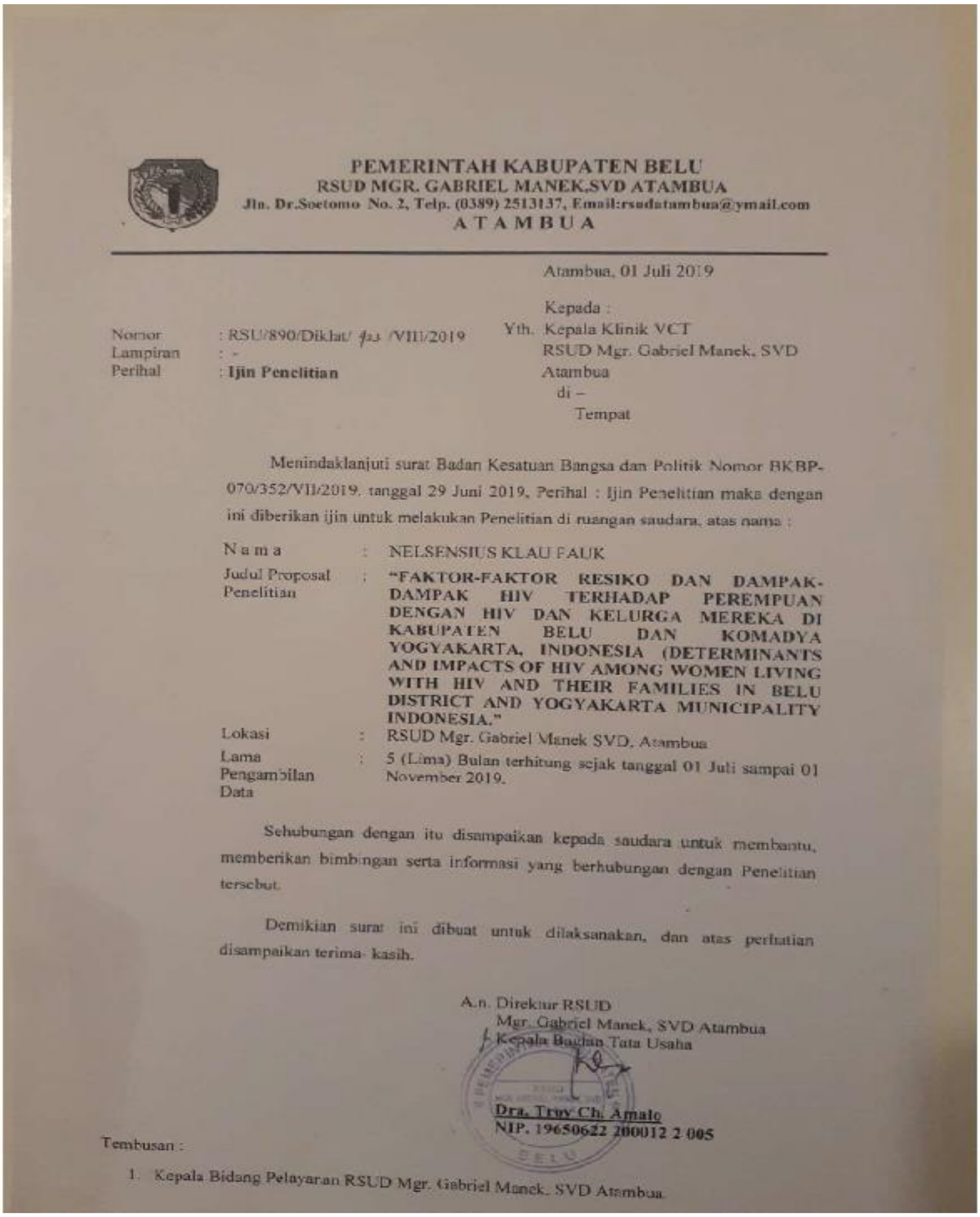
1. Menghormati dan mentaati peraturan dan tata tertib yang berlaku setempat
2. Surat Pengantar penelitan tidak disalahgunakan untuk tujuan tertentu yang dapat menganggu kestabilan Pemerintah dan hanya dipergunakan untuk keperluan ilmiah
3. Menyerahkan hasil penelitian kepada Dinas Kesehatan Kota Yogyakarta.

Demikian surat pengantar penelitian ini dibuat, dengan ketentuan memenuhi persyaratan yang berlaku dan untuk dapat dipergunakan sebagaimana mestinya.

Kepala
DINAS KESEHATAN

dr. Fita Yulia Kisworini, M.Kes
NIP: 19600[illegible]1989012001

S E G O R O A M A R T O
SEMANGAT GOTONG ROYONG AGAWE MAJUNE NGAYOGYOKARTO
KEMANDIRIAN – KEDISIPLINAN – KEPEDULIAN - KEBERSAMAAN



PEMERINTAH KABUPATEN BELU
RSUD MGR. GABRIEL MANEK,SVD ATAMBUA
Jln. Dr.Soetomo No. 2, Telp. (0389) 2513137, Email:rsudatambua@ymail.com
ATAMBUA

Atambua, 01 Juli 2019

Nomor : RSU/890/Diklat/ 423 /VIII/2019
Lampiran : -
Perihal : **Ijin Penelitian**

Kepada :
Yth. Kepala Klinik VCT
RSUD Mgr. Gabriel Manek, SVD
Atambua
di –
Tempat

Menindaklanjuti surat Badan Kesatuan Bangsa dan Politik Nomor BKBP-070/352/VII/2019, tanggal 29 Juni 2019, Perihal : Ijin Penelitian maka dengan ini diberikan ijin untuk melakukan Penelitian di ruangan saudara, atas nama :

Nama	:	NELSENSIUS KLAU FAUK
Judul Proposal Penelitian	:	**"FAKTOR-FAKTOR RESIKO DAN DAMPAK-DAMPAK HIV TERHADAP PEREMPUAN DENGAN HIV DAN KELURGA MEREKA DI KABUPATEN BELU DAN KOMADYA YOGYAKARTA, INDONESIA (DETERMINANTS AND IMPACTS OF HIV AMONG WOMEN LIVING WITH HIV AND THEIR FAMILIES IN BELU DISTRICT AND YOGYAKARTA MUNICIPALITY INDONESIA."**
Lokasi	:	RSUD Mgr. Gabriel Manek SVD, Atambua
Lama Pengambilan Data	:	5 (Lima) Bulan terhitung sejak tanggal 01 Juli sampai 01 November 2019.

Sehubungan dengan itu disampaikan kepada saudara untuk membantu, memberikan bimbingan serta informasi yang berhubungan dengan Penelitian tersebut.

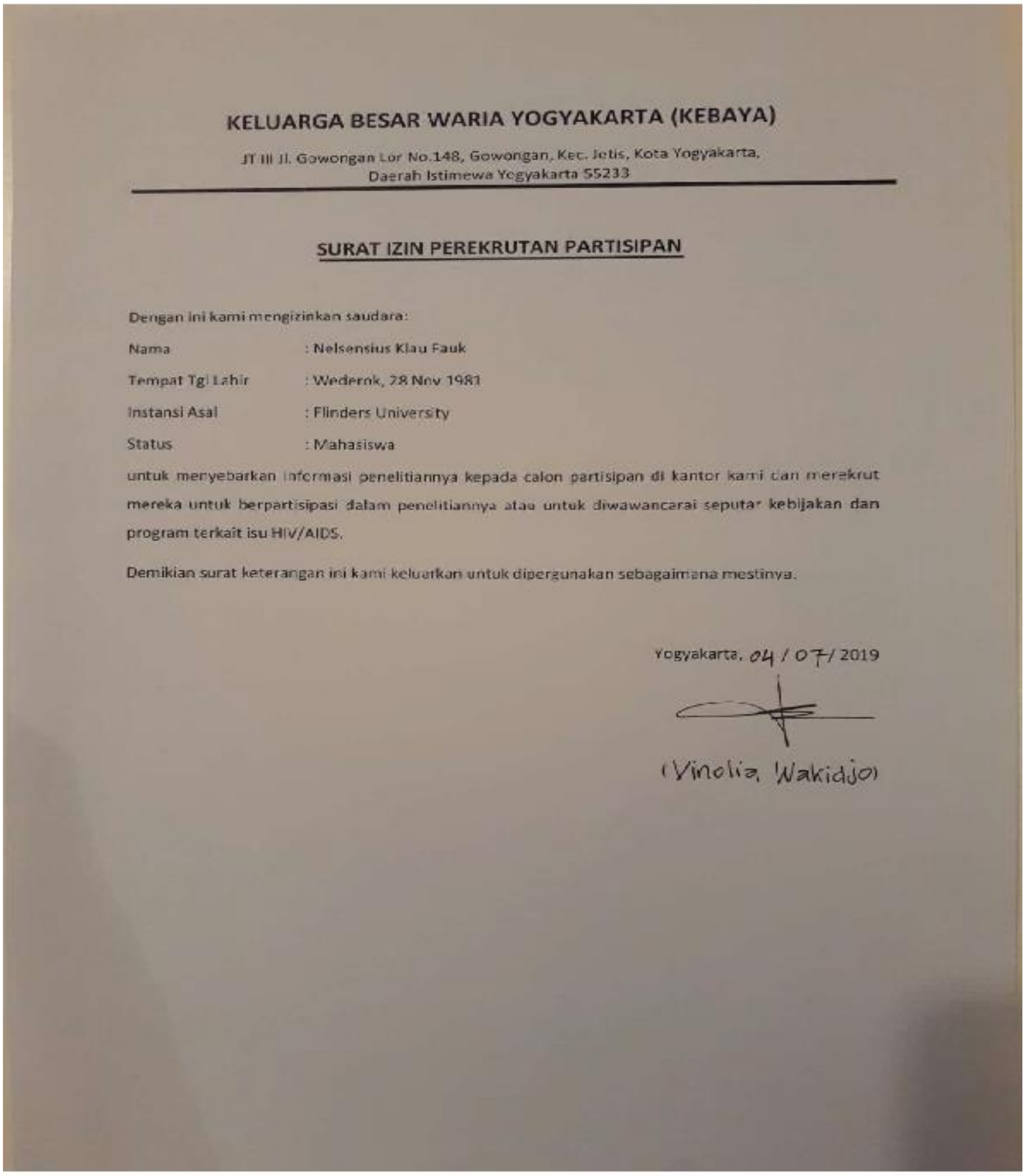
Demikian surat ini dibuat untuk dilaksanakan, dan atas perhatian disampaikan terima kasih.

A.n. Direktur RSUD
Mgr. Gabriel Manek, SVD Atambua
Kepala Bagian Tata Usaha

Dra. Troy Ch. Amalo
NIP. 19650622 200012 2 005

Tembusan :

1. Kepala Bidang Pelayaran RSUD Mgr. Gabriel Manek, SVD Atambua



KELUARGA BESAR WARIA YOGYAKARTA (KEBAYA)

JT III Jl. Gowongan Lor No.148, Gowongan, Kec. Jetis, Kota Yogyakarta,
Daerah Istimewa Yogyakarta 55233

SURAT IZIN PEREKRUTAN PARTISIPAN

Dengan ini kami mengizinkan saudara:

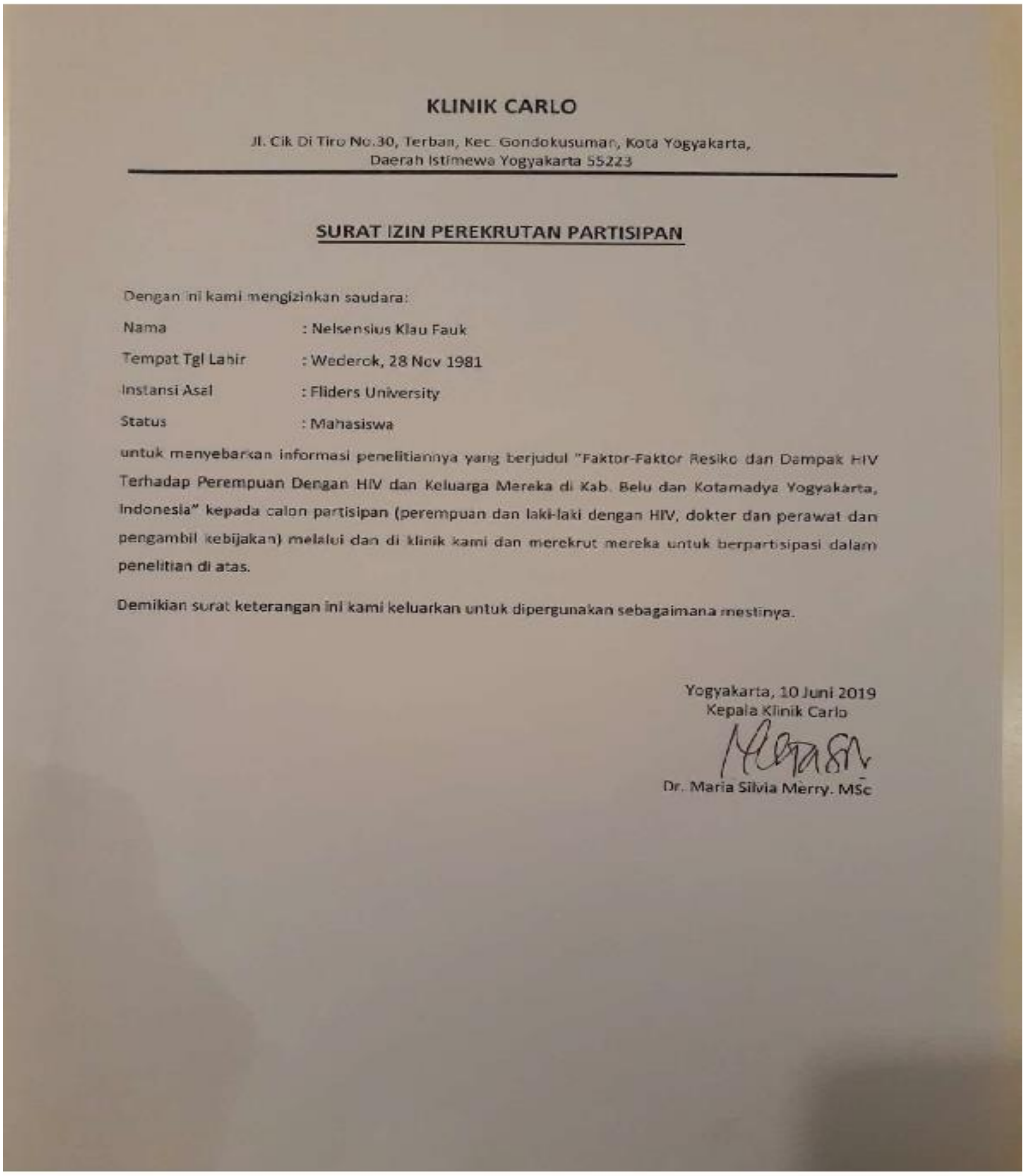
Nama : Nelsensius Klau Fauk
Tempat Tgl Lahir : Wederok, 28 Nov 1981
Instansi Asal : Flinders University
Status : Mahasiswa

untuk menyebarkan informasi penelitiannya kepada calon partisipan di kantor kami dan merekrut mereka untuk berpartisipasi dalam penelitiannya atau untuk diwawancarai seputar kebijakan dan program terkait isu HIV/AIDS.

Demikian surat keterangan ini kami keluarkan untuk dipergunakan sebagaimana mestinya.

Yogyakarta, 04 / 07 / 2019

(Vinolia Wakidjo)



KLINIK CARLO

Jl. Cik Di Tiro No.30, Terban, Kec. Gondokusuman, Kota Yogyakarta,
Daerah Istimewa Yogyakarta 55223

SURAT IZIN PEREKRUTAN PARTISIPAN

Dengan ini kami mengizinkan saudara:

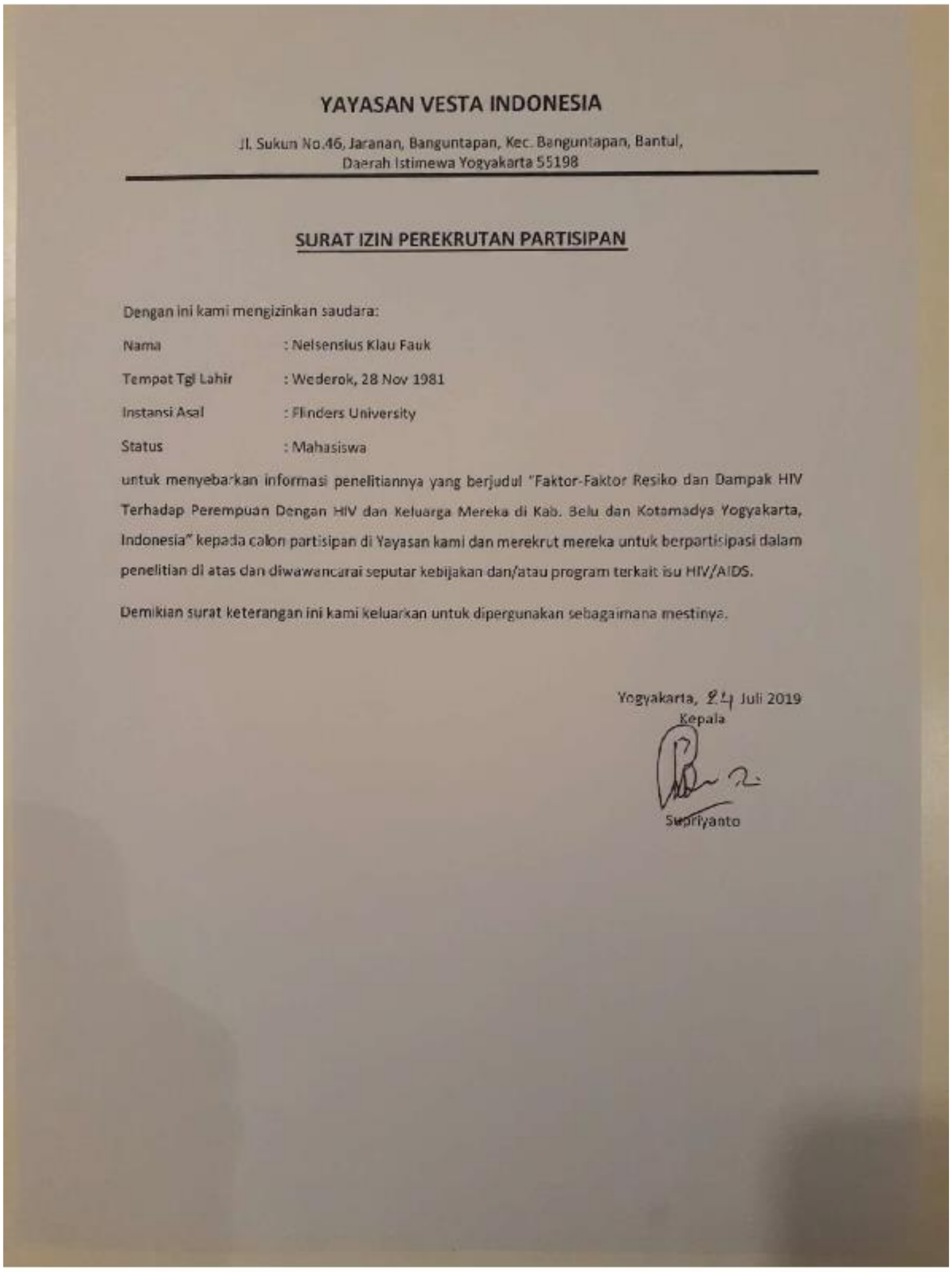
Nama : Nelsensius Klau Fauk
Tempat Tgl Lahir : Wederok, 28 Nov 1981
Instansi Asal : Fliders University
Status : Mahasiswa

untuk menyebarkan informasi penelitiannya yang berjudul "Faktor-Faktor Resiko dan Dampak HIV Terhadap Perempuan Dengan HIV dan Keluarga Mereka di Kab. Belu dan Kotamadya Yogyakarta, Indonesia" kepada calon partisipan (perempuan dan laki-laki dengan HIV, dokter dan perawat dan pengambil kebijakan) melalui dan di klinik kami dan merekrut mereka untuk berpartisipasi dalam penelitian di atas.

Demikian surat keterangan ini kami keluarkan untuk dipergunakan sebagaimana mestinya.

Yogyakarta, 10 Juni 2019
Kepala Klinik Carlo

Dr. Maria Silvia Merry. MSc



YAYASAN VESTA INDONESIA

Jl. Sukun No.46, Jaranan, Banguntapan, Kec. Banguntapan, Bantul,
Daerah Istimewa Yogyakarta 55198

SURAT IZIN PEREKRUTAN PARTISIPAN

Dengan ini kami mengizinkan saudara:

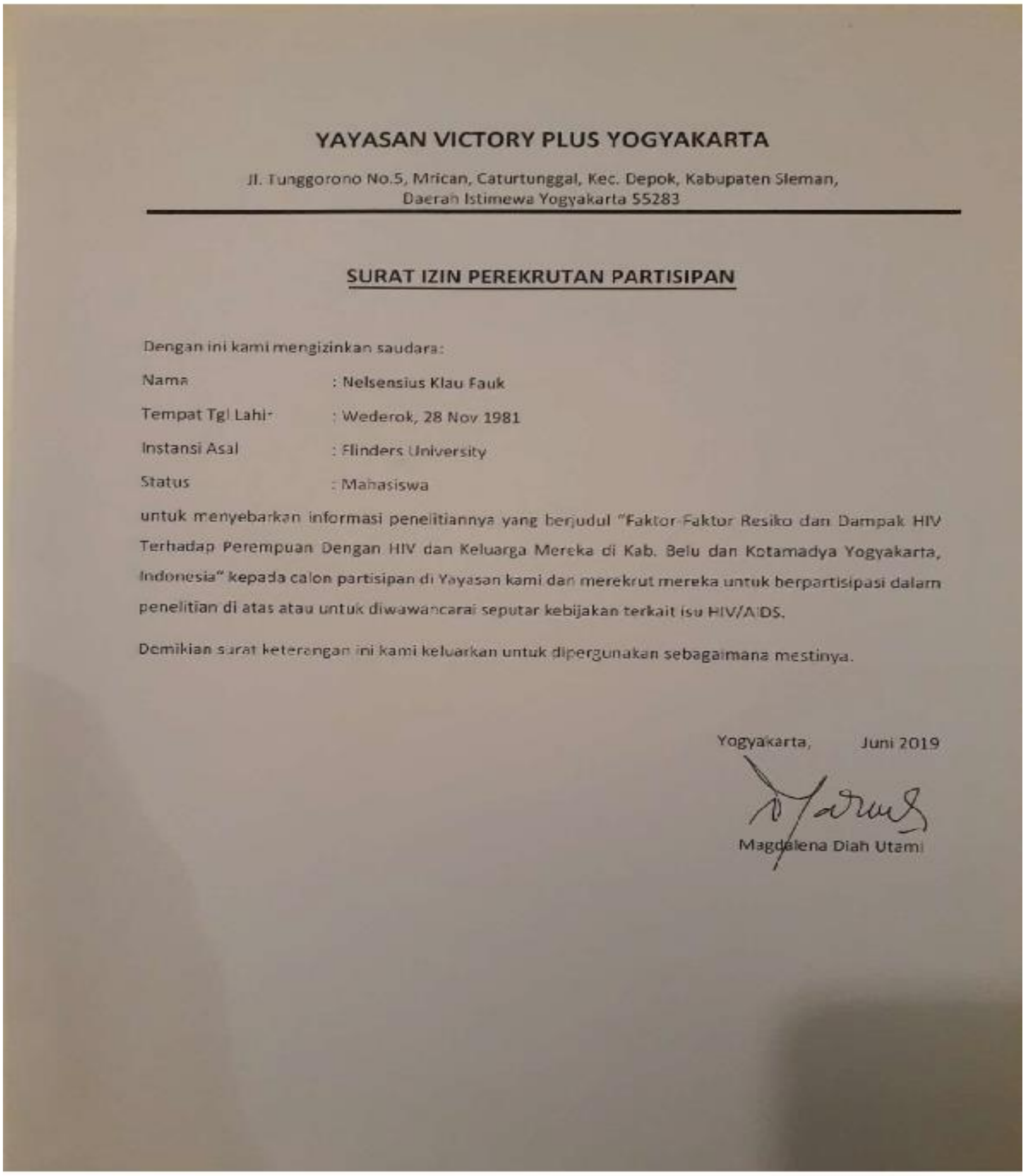
Nama : Nelsensius Klau Fauk
Tempat Tgl Lahir : Wederok, 28 Nov 1981
Instansi Asal : Flinders University
Status : Mahasiswa

untuk menyebarkan informasi penelitiannya yang berjudul "Faktor-Faktor Resiko dan Dampak HIV Terhadap Perempuan Dengan HIV dan Keluarga Mereka di Kab. Belu dan Kotamadya Yogyakarta, Indonesia" kepada calon partisipan di Yayasan kami dan merekrut mereka untuk berpartisipasi dalam penelitian di atas dan diwawancarai seputar kebijakan dan/atau program terkait isu HIV/AIDS.

Demikian surat keterangan ini kami keluarkan untuk dipergunakan sebagaimana mestinya.

Yogyakarta, 24 Juli 2019
Kepala

Supriyanto



YAYASAN VICTORY PLUS YOGYAKARTA

Jl. Tunggorono No.5, Mrican, Caturtunggal, Kec. Depok, Kabupaten Sleman,
Daerah Istimewa Yogyakarta 55283

SURAT IZIN PEREKRUTAN PARTISIPAN

Dengan ini kami mengizinkan saudara:

Nama	: Nelsensius Klau Fauk
Tempat Tgl Lahir	: Wederok, 28 Nov 1981
Instansi Asal	: Flinders University
Status	: Mahasiswa

untuk menyebarkan informasi penelitiannya yang berjudul "Faktor-Faktor Resiko dan Dampak HIV Terhadap Perempuan Dengan HIV dan Keluarga Mereka di Kab. Belu dan Kotamadya Yogyakarta, Indonesia" kepada calon partisipan di Yayasan kami dan merekrut mereka untuk berpartisipasi dalam penelitian di atas atau untuk diwawancarai seputar kebijakan terkait isu HIV/AIDS.

Demikian surat keterangan ini kami keluarkan untuk dipergunakan sebagaimana mestinya.

Yogyakarta, Juni 2019

Magdalena Diah Utami

Appendix 10 : Ethics approvals

8268 ETHICS approval notice (27 March 2019)

HE

Human Research Ethics

Reply all

Yesterday, 2:07 PM

Nelsensius Fauk;

Lillian Mwanri <lillian.mwanri@flinders.edu.au>;

+2 more

Dear Nelsensius,

Your conditional approval response for project 8268 was reviewed by the Chairperson of the Social and Behavioural Research Ethics Committee (SBREC) and was **approved.** The ethics approval notice can be found below.

APPROVAL NOTICE

Project No.: **8268**

Project Title: Determinants and impacts of HIV among women living with HIV and their families in Belu district and Yogyakarta municipality, Indonesia

Principal Researcher: Mr Nelsensius Klau Fauk

Email: fauk0001@flinders.edu.au

Approval Date: 27 March 2019 Ethics Approval Expiry Date: **31 May 2023**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comments.

Additional comments:

1. Please ensure that copies of the correspondence granting permission to conduct the research from (a) Administration Service Unit, Ministry of Internal Affairs at the National Government of Indonesia in Jakarta; (b) Voluntary Counselling and Testing (VCT) in the Belu district; (c) HIV clinic

in Yogyakarta; and (d) Every institution and NGO from which participants will be recruited; are submitted to the Committee *on receipt.* Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – number 5).

2. Provision of a copy of the ethics approval notice from the Health Research Ethics Committee, Duta Wacana Christian University, Yogyakarta, Indonesia *on receipt*. Please note that data collection should not commence until the researcher has received the relevant ethics committee approvals (item E3 and G1 and Conditional approval response – number 6).

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (2007-Updated 2018)* an annual progress report must be submitted each year on the **27 March** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **27 March 2020** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 orhuman.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Wendy Green

On behalf of Andrea Mather

KOMİSİ ETİK PENELITIAN KESEHATAN FAKULTAS KEDOKTERAN
UNİVERSITAS KRİSTEN DUTA WACANA
GEDUNG KOINOMA

Jl. Dr. Wahidin Sudirohusodo 5 — 25 Yogyakarta Indonesia 55224 Telp: 0274-563929 Ext. 124
Fax: 0274 —8509590 Email: kedokteranukdw@yqhoo.com Website: http://www.ukdw.ac.id

KETERANGAN KELAIKAN ETİK

(Ethical Clearance)

Nomor : 1005/C.16/FK/2019

Komisi Etik Penelitian Kedokteran Fakültas Kedokteran Universitas Kristen Duta Wacana, setelah mempelajari dengan seksama rancangan penelitian yang diusulkan, dengan İni menyatakan bahwa penelitian dengan:

Judul	. FAKTOR-FAKTOR RISIKO DAN DAMPAK-DAMPAK HIV Dl KALANGAN PEREMPUAN DENGAN HIV DAN KELUARGA MEREKA Dl KABUPATEN BELU DAN KOTAMADYA YOGYAKARTA, INDONESIA
Peneliti	. Nelsensius Klau Fauk
NİM	
Pembimbing	
Lembaga/tempat penelitian	Kabupaten Belu dan Kota Yogyakarta

Dinyatakan memenuhi persyaratan etik untuk dilaksanakan, dengan catatan sewaktu-waktu komisi dapat melakukan pemantauan. Kelaikan etik ini berlaku I (satu) tahun sejak tanggal di tetapkan.

Yogyakarta, 26 Juni 2019

dr. Arum Krismi, M.S

Dr. dr. Rizaldy Taslim Pinzon, Pinzon, Sp.S., M Kes •sıni, M.sc., sp.KK

(Ketua) (Sekretaris)

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(In-depth interview with women and men living with HIV)

Determinants and impacts of HIV among women living with HIV and their family in Belu district and Yogyakarta, Indonesia

I ……………………………………………………………., being over the age of 18 years hereby consent to participate as requested in the Introduction Letter for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - Participation is entirely voluntary and I am free to withdraw from the project at any time; and can decline to answer particular questions.
    - The information gained in this study will be published as explained, and my participation <u>will be</u> anonymous and confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Participant's name………………………………………………………………………………

Participant's signature……………………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she understands what is involved and freely consents to participation.

Researcher's name…………………………………………………………………………...

Researcher's signature…………………………………………....Date……………………

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Item 8 as appropriate.

6. I, the participant whose signature appears below, have read a transcript of my interview participation and agree to its use by the researcher as explained.

Participant's signature……………………………………………Date…………………...

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8268). For more information regarding ethical approval of the project please contact the Executive Officer on (08) 8201-3116 or human.researchethics@flinders.edu.au

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(In-depth interview with health service providers)

Determinants and impacts of HIV among women living with HIV and their family in Belu district and Yogyakarta, Indonesia

I …..., being over the age of 18 years hereby consent to participate as requested in the Introduction Letter for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - Participation is entirely voluntary and I am free to withdraw from the project at any time; and can decline to answer particular questions.
    - The information gained in this study will be published as explained, and my participation will be anonymous and confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Participant's name………………………………..……………………..........................

Participant's signature…………………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she understands what is involved and freely consents to participation.

Researcher's name……………………………….……………………….................

Researcher's signature………………………………………....Date……………………

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Item 8 as appropriate.

6. I, the participant whose signature appears below, have read a transcript of my interview participation and agree to its use by the researcher as explained.

Participant's signature…………………………………………Date…………………...

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8268). For more information regarding ethical approval of the project please contact the Executive Officer on (08) 8201-3116 or human.researchethics@flinders.edu.au

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(In-depth interview with policy makers)

Determinants and impacts of HIV among women living with HIV and their family in Belu district and Yogyakarta, Indonesia

I …..., being over the age of 18 years hereby consent to participate as requested in the Introduction Letter for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - Participation is entirely voluntary and I am free to withdraw from the project at any time; and can decline to answer particular questions.
    - The information gained in this study will be published as explained, and my participation will be anonymous and confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Participant's name……………………………….…………………….........................

Participant's signature……………………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she understands what is involved and freely consents to participation.

Researcher's name……………………………….…………………….................

Researcher's signature………………………………………....Date……………………

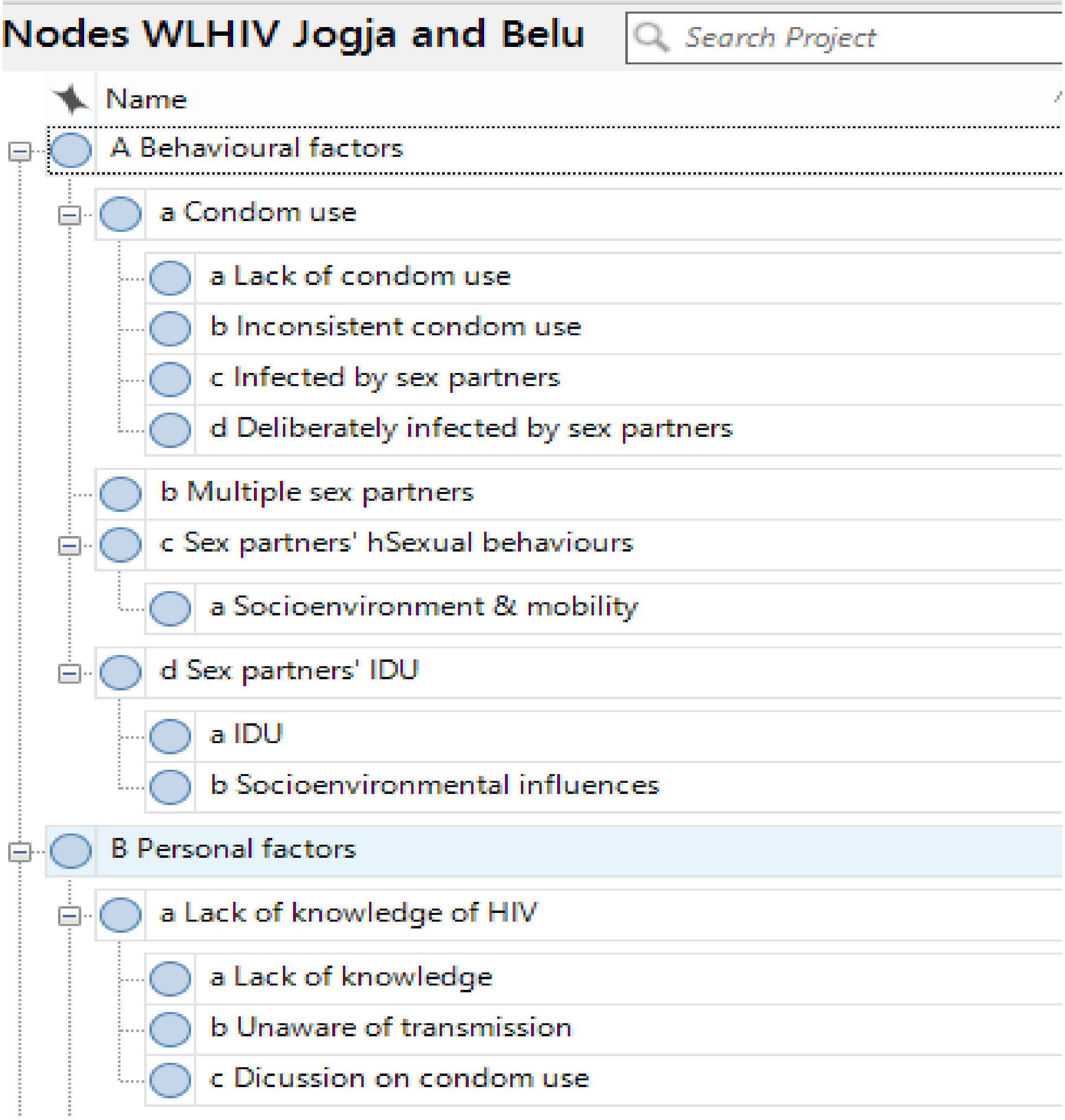
NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Item 8 as appropriate.

6. I, the participant whose signature appears below, have read a transcript of my interview participation and agree to its use by the researcher as explained.

Participant's signature………………………………………….Date…………………...

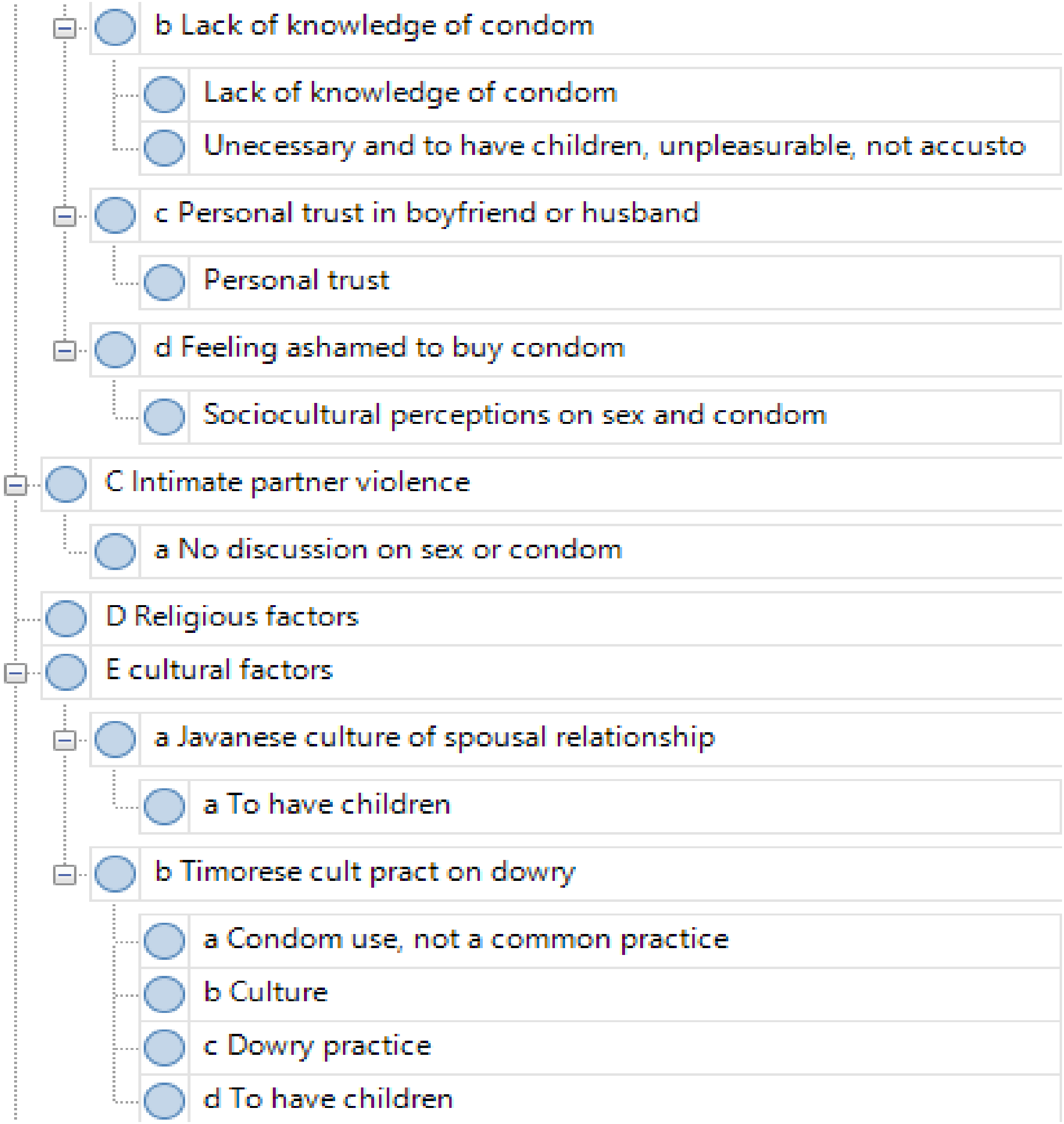
This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8268). For more information regarding ethical approval of the project please contact the Executive Officer on (08) 8201-3116 or human.researchethics@flinders.edu.au

Appendix 12 : Thematic framework of data analysis

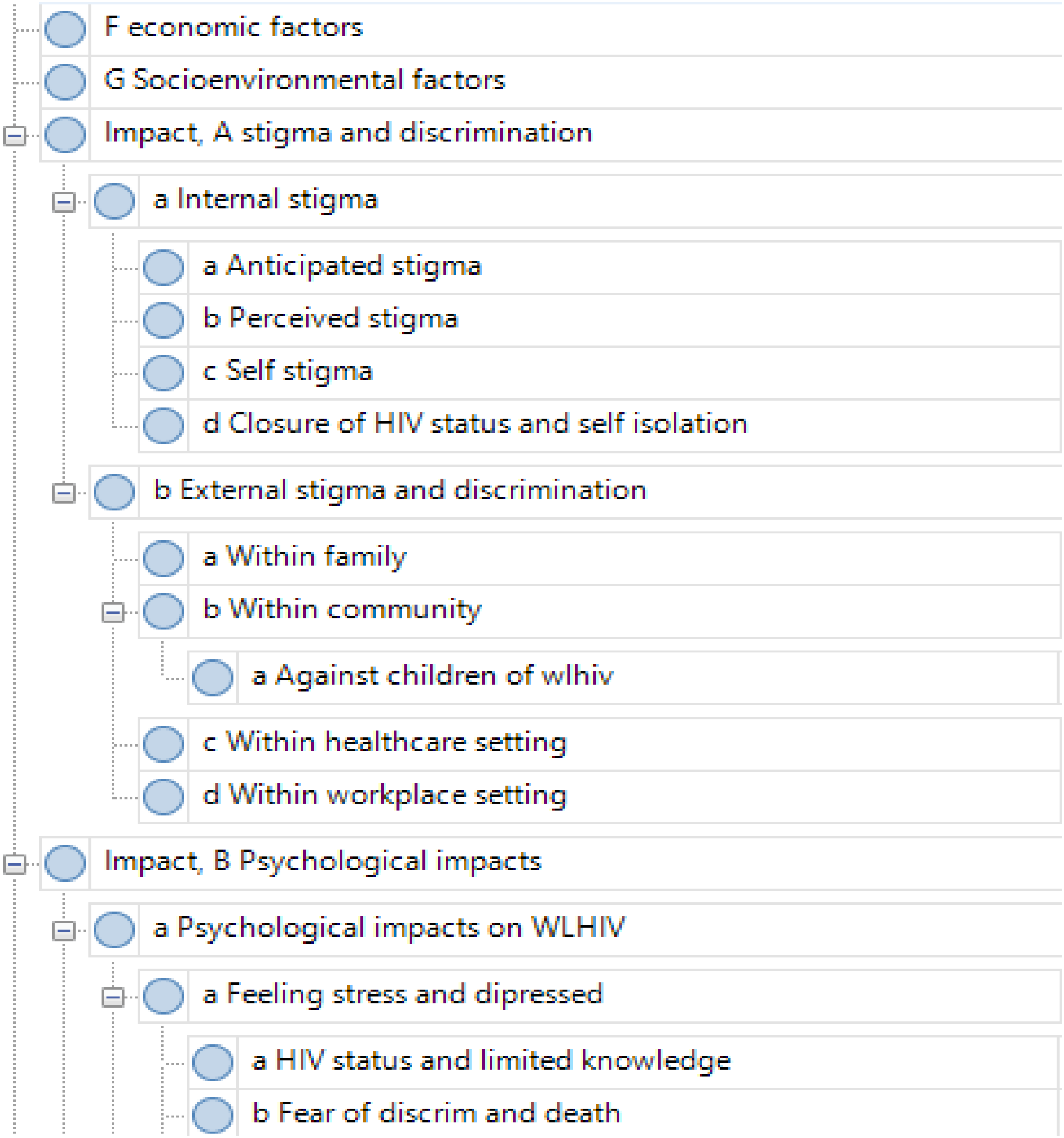


Nodes WLHIV Jogja and Belu

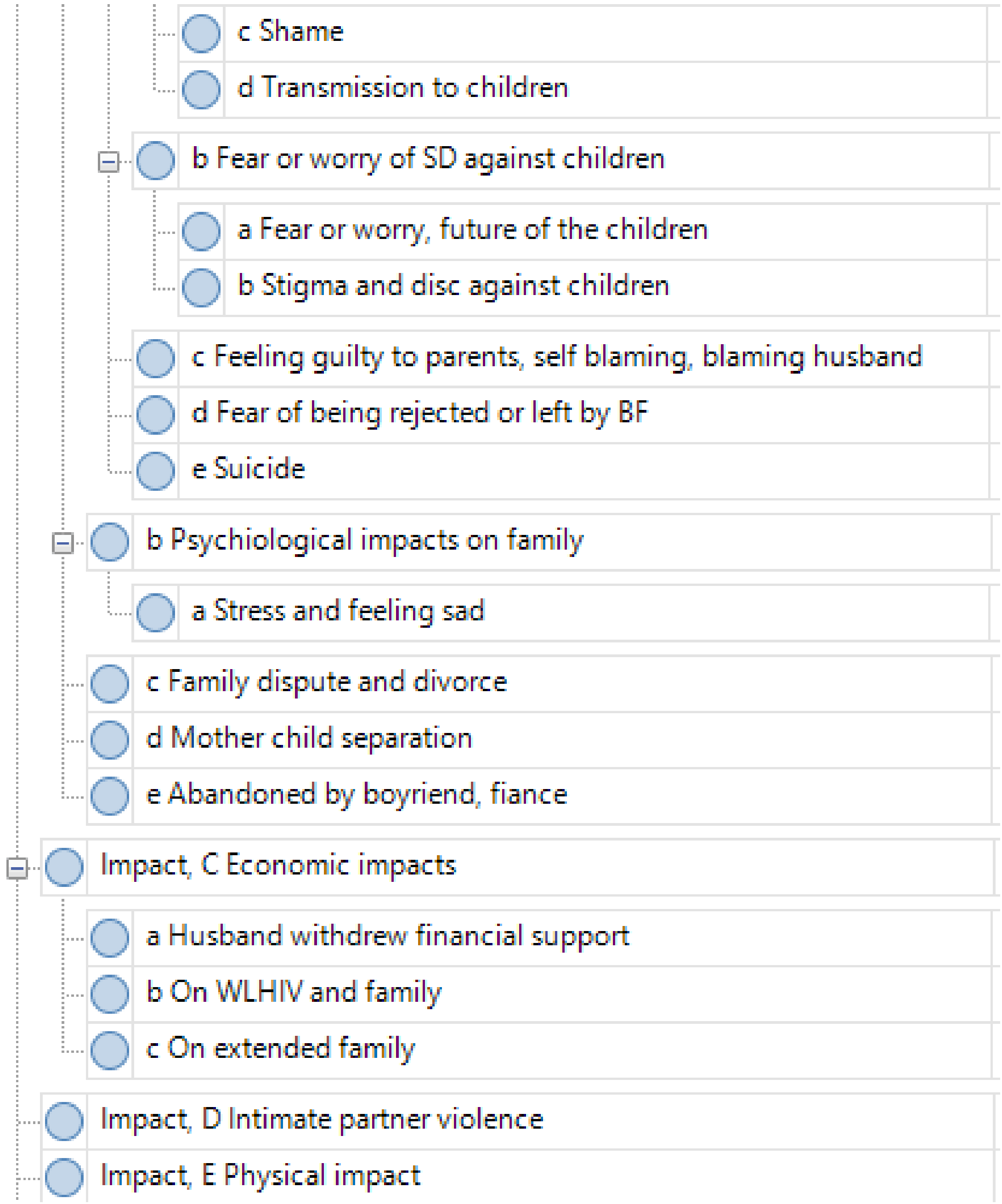
- A Behavioural factors
  - a Condom use
    - a Lack of condom use
    - b Inconsistent condom use
    - c Infected by sex partners
    - d Deliberately infected by sex partners
  - b Multiple sex partners
  - c Sex partners' hSexual behaviours
    - a Socioenvironment & mobility
  - d Sex partners' IDU
    - a IDU
    - b Socioenvironmental influences
- B Personal factors
  - a Lack of knowledge of HIV
    - a Lack of knowledge
    - b Unaware of transmission
    - c Dicussion on condom use



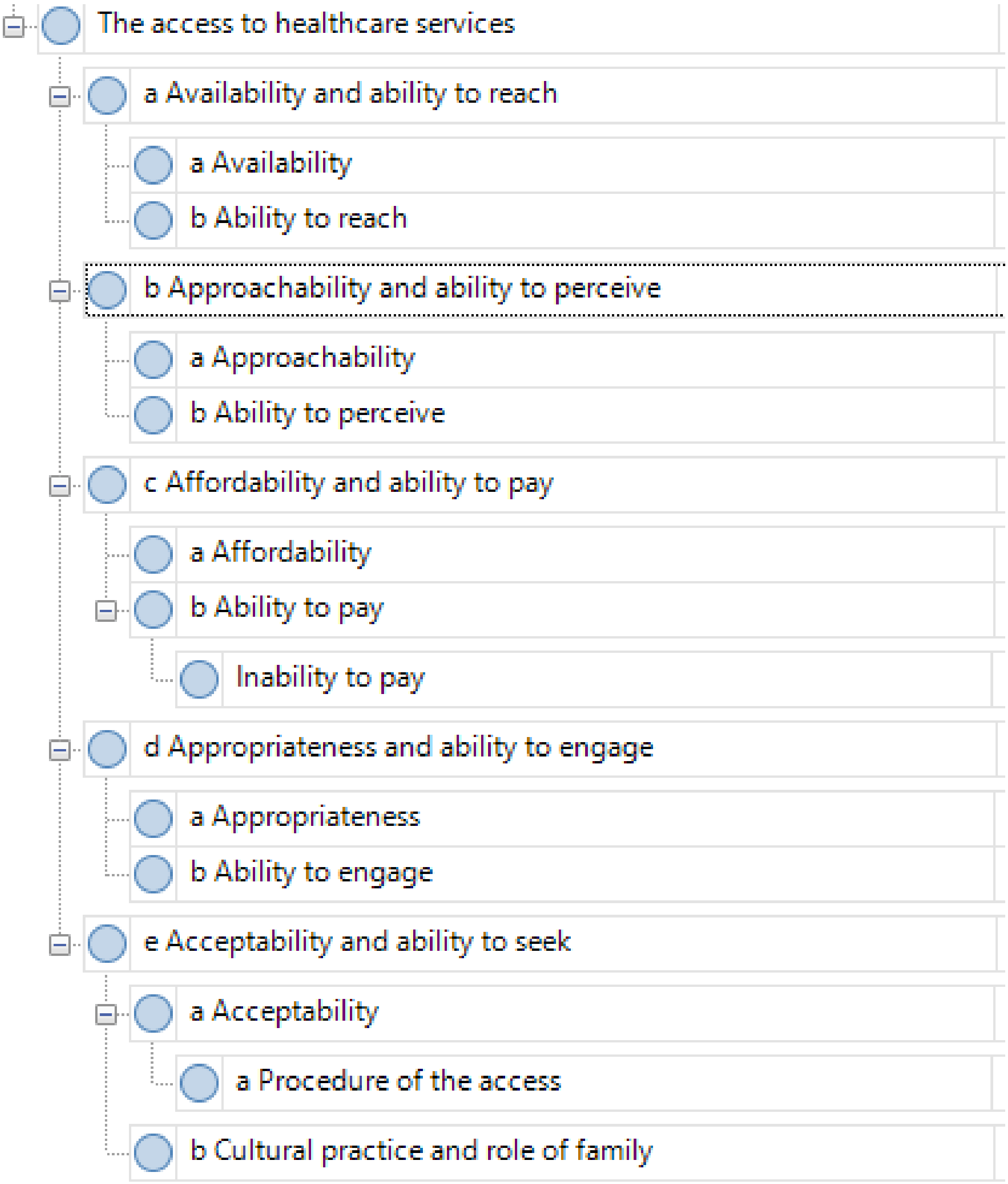
- b Lack of knowledge of condom
  - Lack of knowledge of condom
  - Unecessary and to have children, unpleasurable, not accusto
- c Personal trust in boyfriend or husband
  - Personal trust
- d Feeling ashamed to buy condom
  - Sociocultural perceptions on sex and condom
- C Intimate partner violence
  - a No discussion on sex or condom
- D Religious factors
- E cultural factors
  - a Javanese culture of spousal relationship
    - a To have children
  - b Timorese cult pract on dowry
    - a Condom use, not a common practice
    - b Culture
    - c Dowry practice
    - d To have children



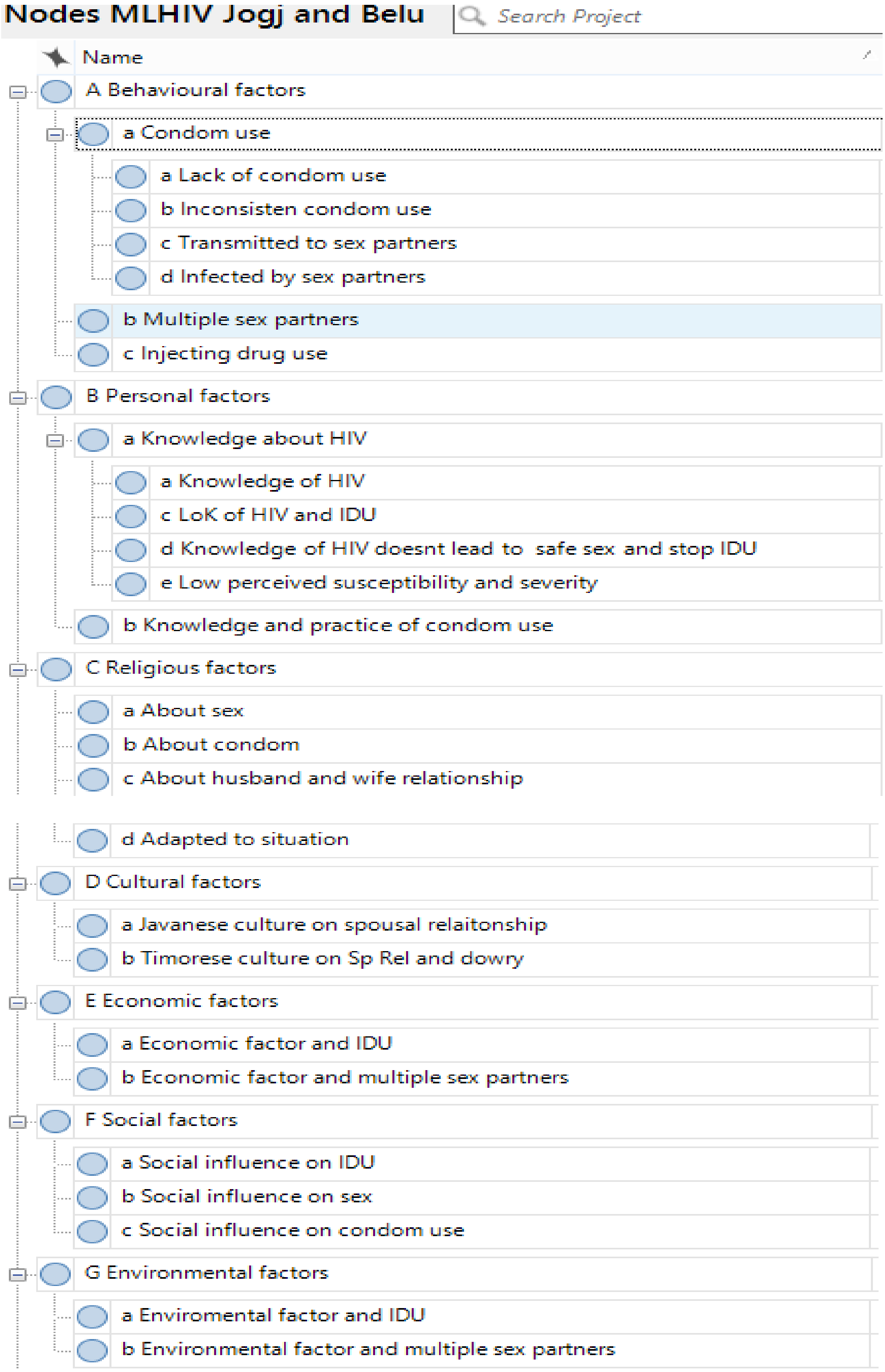
- F economic factors
- G Socioenvironmental factors
- Impact, A stigma and discrimination
  - a Internal stigma
    - a Anticipated stigma
    - b Perceived stigma
    - c Self stigma
    - d Closure of HIV status and self isolation
  - b External stigma and discrimination
    - a Within family
    - b Within community
      - a Against children of wlhiv
    - c Within healthcare setting
    - d Within workplace setting
- Impact, B Psychological impacts
  - a Psychological impacts on WLHIV
    - a Feeling stress and dipressed
      - a HIV status and limited knowledge
      - b Fear of discrim and death



      - c Shame
      - d Transmission to children
    - b Fear or worry of SD against children
      - a Fear or worry, future of the children
      - b Stigma and disc against children
    - c Feeling guilty to parents, self blaming, blaming husband
    - d Fear of being rejected or left by BF
    - e Suicide
  - b Psychiological impacts on family
    - a Stress and feeling sad
  - c Family dispute and divorce
  - d Mother child separation
  - e Abandoned by boyriend, fiance
- Impact, C Economic impacts
  - a Husband withdrew financial support
  - b On WLHIV and family
  - c On extended family
- Impact, D Intimate partner violence
- Impact, E Physical impact

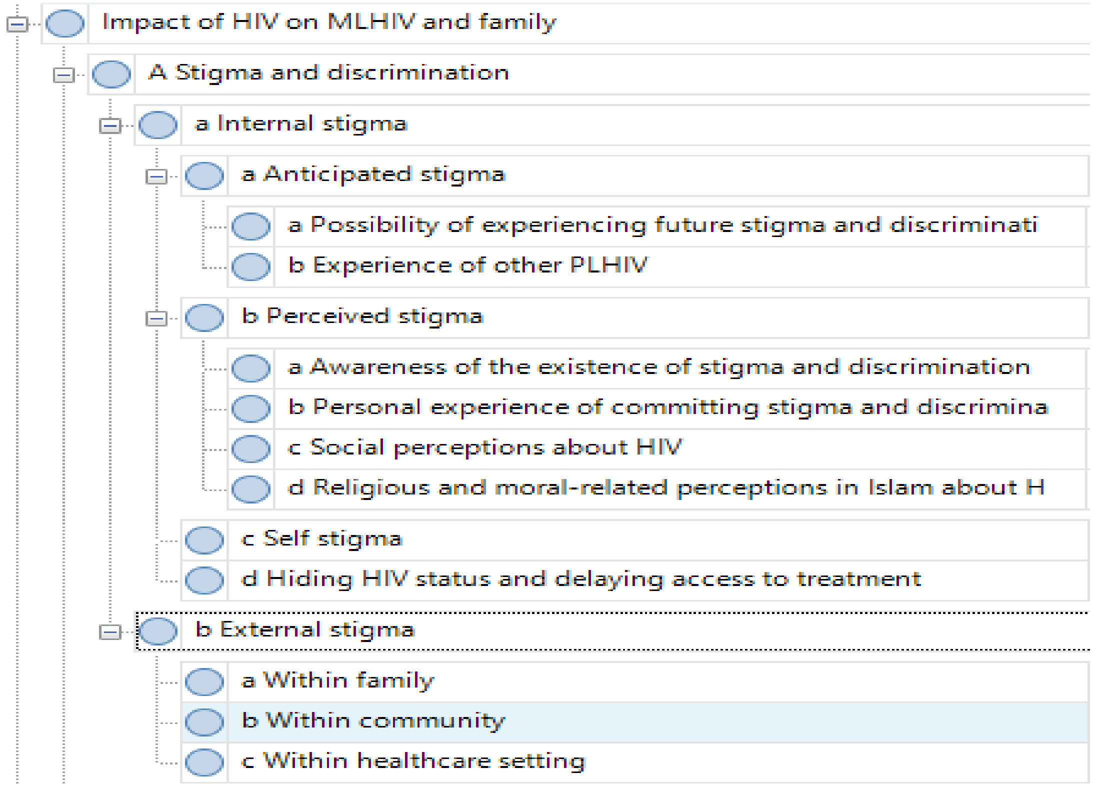


- The access to healthcare services
  - a Availability and ability to reach
    - a Availability
    - b Ability to reach
  - b Approachability and ability to perceive
    - a Approachability
    - b Ability to perceive
  - c Affordability and ability to pay
    - a Affordability
    - b Ability to pay
      - Inability to pay
  - d Appropriateness and ability to engage
    - a Appropriateness
    - b Ability to engage
  - e Acceptability and ability to seek
    - a Acceptability
      - a Procedure of the access
    - b Cultural practice and role of family

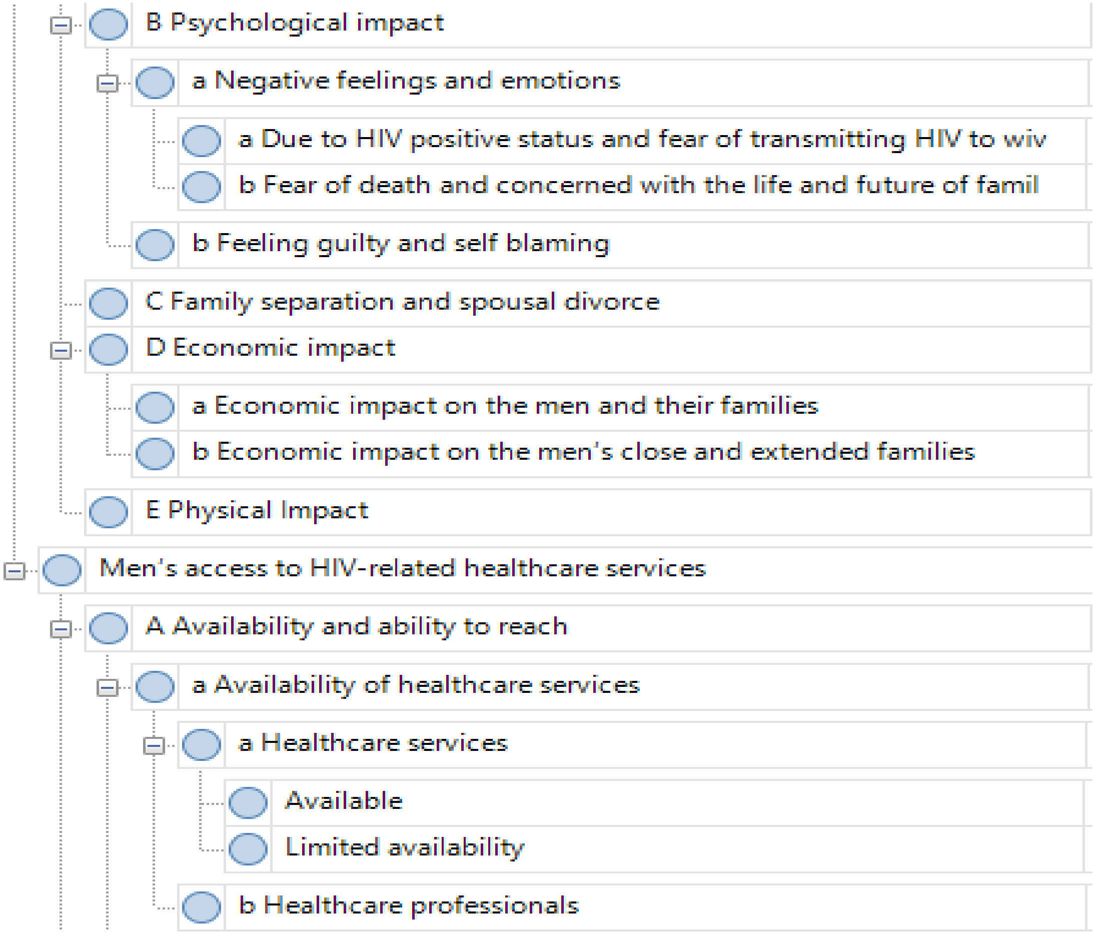


Nodes MLHIV Jogj and Belu

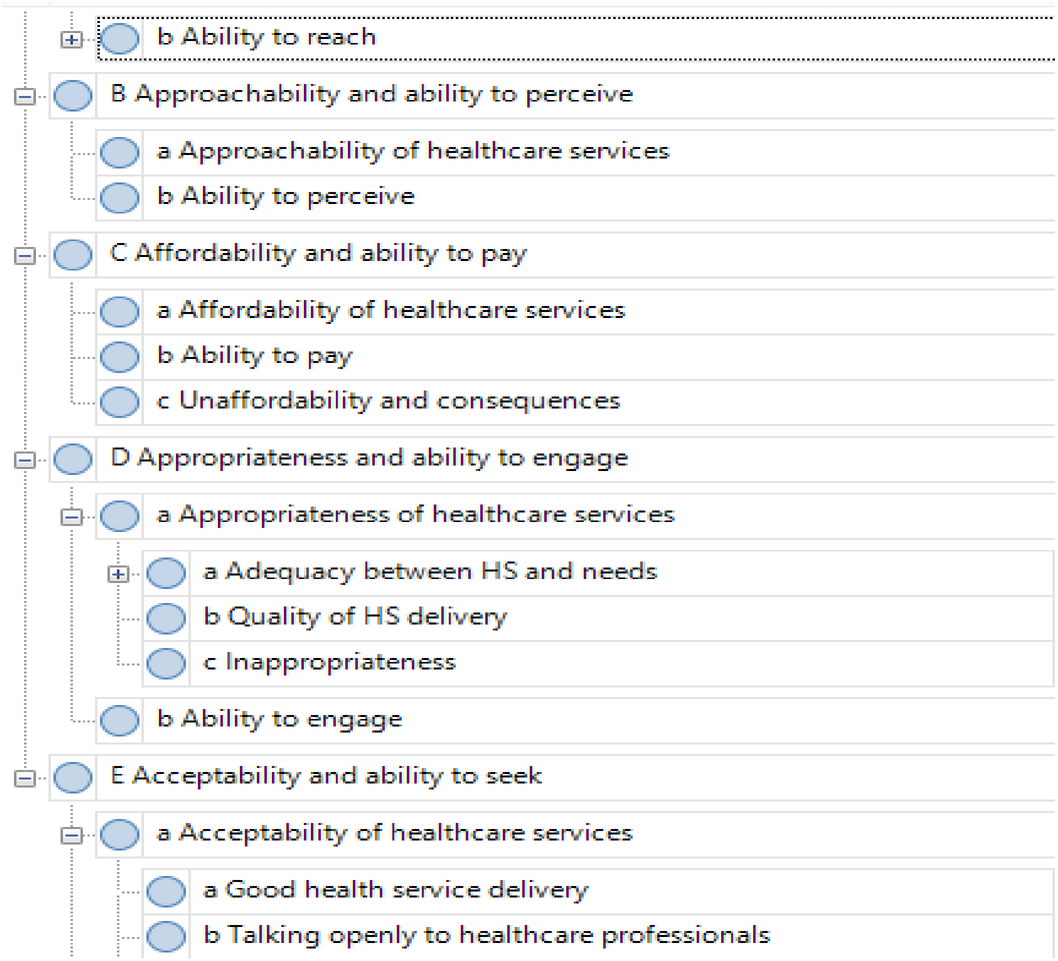
- A Behavioural factors
  - a Condom use
    - a Lack of condom use
    - b Inconsisten condom use
    - c Transmitted to sex partners
    - d Infected by sex partners
  - b Multiple sex partners
  - c Injecting drug use
- B Personal factors
  - a Knowledge about HIV
    - a Knowledge of HIV
    - c LoK of HIV and IDU
    - d Knowledge of HIV doesnt lead to safe sex and stop IDU
    - e Low perceived susceptibility and severity
  - b Knowledge and practice of condom use
- C Religious factors
  - a About sex
  - b About condom
  - c About husband and wife relationship
  - d Adapted to situation
- D Cultural factors
  - a Javanese culture on spousal relaitonship
  - b Timorese culture on Sp Rel and dowry
- E Economic factors
  - a Economic factor and IDU
  - b Economic factor and multiple sex partners
- F Social factors
  - a Social influence on IDU
  - b Social influence on sex
  - c Social influence on condom use
- G Environmental factors
  - a Enviromental factor and IDU
  - b Environmental factor and multiple sex partners



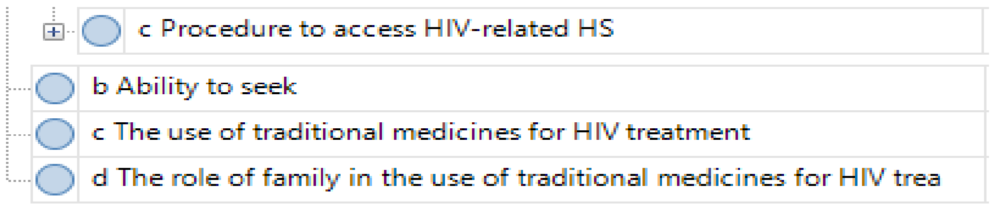
- Impact of HIV on MLHIV and family
  - A Stigma and discrimination
    - a Internal stigma
      - a Anticipated stigma
        - a Possibility of experiencing future stigma and discriminati
        - b Experience of other PLHIV
      - b Perceived stigma
        - a Awareness of the existence of stigma and discrimination
        - b Personal experience of committing stigma and discrimina
        - c Social perceptions about HIV
        - d Religious and moral-related perceptions in Islam about H
      - c Self stigma
      - d Hiding HIV status and delaying access to treatment
    - b External stigma
      - a Within family
      - b Within community
      - c Within healthcare setting



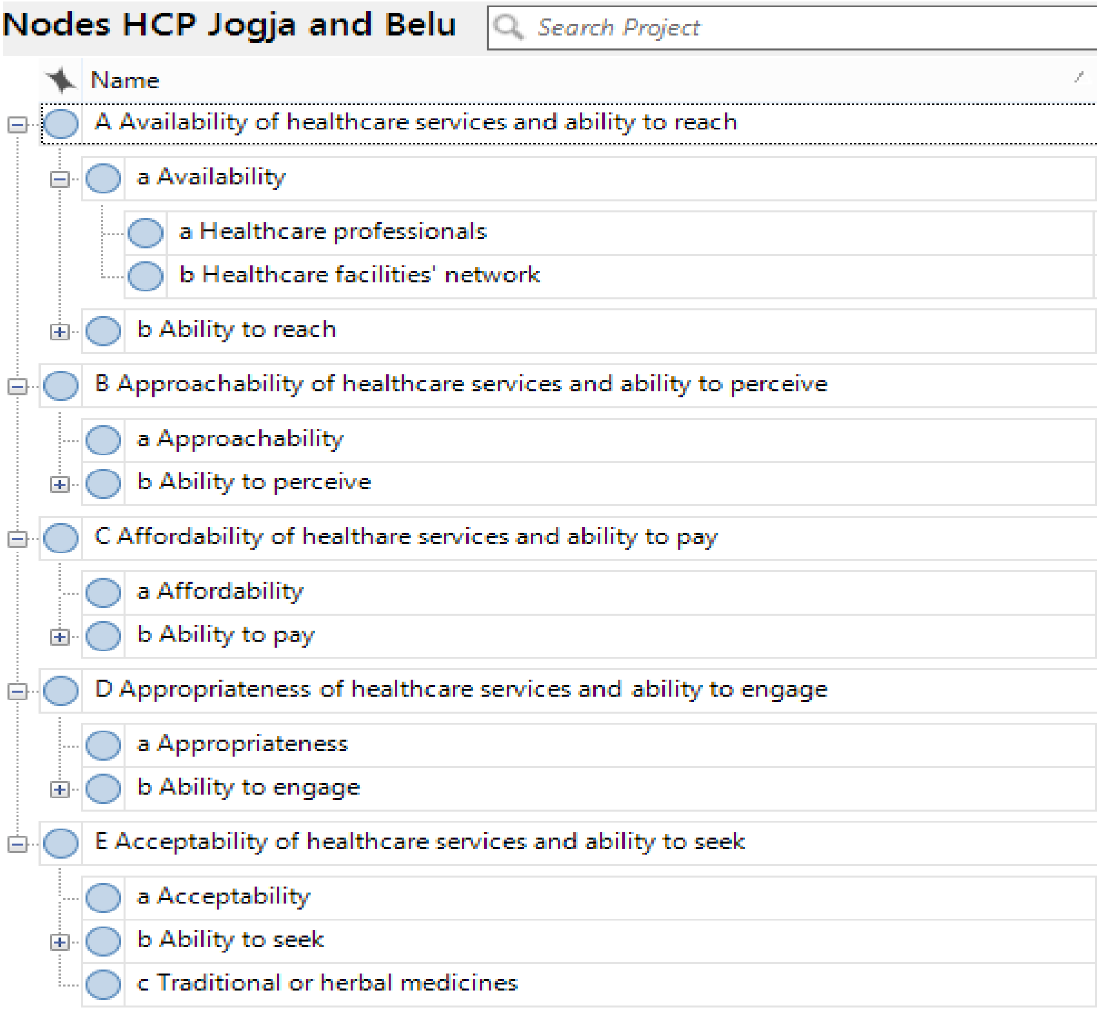
  - B Psychological impact
    - a Negative feelings and emotions
      - a Due to HIV positive status and fear of transmitting HIV to wiv
      - b Fear of death and concerned with the life and future of famil
    - b Feeling guilty and self blaming
  - C Family separation and spousal divorce
  - D Economic impact
    - a Economic impact on the men and their families
    - b Economic impact on the men's close and extended families
  - E Physical Impact
- Men's access to HIV-related healthcare services
  - A Availability and ability to reach
    - a Availability of healthcare services
      - a Healthcare services
        - Available
        - Limited availability
      - b Healthcare professionals



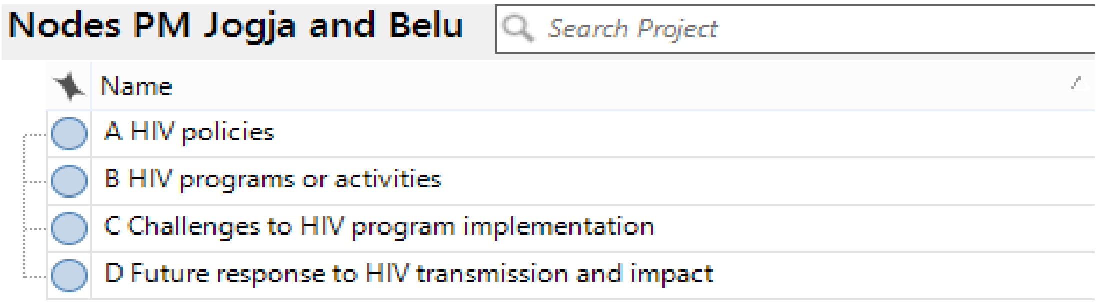
- b Ability to reach
- B Approachability and ability to perceive
  - a Approachability of healthcare services
  - b Ability to perceive
- C Affordability and ability to pay
  - a Affordability of healthcare services
  - b Ability to pay
  - c Unaffordability and consequences
- D Appropriateness and ability to engage
  - a Appropriateness of healthcare services
    - a Adequacy between HS and needs
    - b Quality of HS delivery
    - c Inappropriateness
  - b Ability to engage
- E Acceptability and ability to seek
  - a Acceptability of healthcare services
    - a Good health service delivery
    - b Talking openly to healthcare professionals



- c Procedure to access HIV-related HS
- b Ability to seek
- c The use of traditional medicines for HIV treatment
- d The role of family in the use of traditional medicines for HIV trea


Nodes HCP Jogja and Belu

- A Availability of healthcare services and ability to reach
  - a Availability
    - a Healthcare professionals
    - b Healthcare facilities' network
  - b Ability to reach
- B Approachability of healthcare services and ability to perceive
  - a Approachability
  - b Ability to perceive
- C Affordability of healthare services and ability to pay
  - a Affordability
  - b Ability to pay
- D Appropriateness of healthcare services and ability to engage
  - a Appropriateness
  - b Ability to engage
- E Acceptability of healthcare services and ability to seek
  - a Acceptability
  - b Ability to seek
  - c Traditional or herbal medicines


Nodes PM Jogja and Belu

- A HIV policies
- B HIV programs or activities
- C Challenges to HIV program implementation
- D Future response to HIV transmission and impact