Indonesian Children with Human Immunodeficiency Virus (HIV) and Their Families' Experiences of Care across the Continuum

By

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List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CD4	Cluster of Differentiation 4
CNS	Central nervous system
CST	Care support and treatment
DFAT	Department of Foreign Affairs and Trade
DLHO	District Level Health Office
FDC	Fixed-dose combination
FSWs	Female sex workers
GPs	General Practitioners
HIV	Human Immunodeficiency Virus
HPs	Health professionals
IMCI	Integrated Management of Childhood Illness
LGBT	Lesbian, gay, bisexual, and transgender
LKB	*Layanan Komprehensif Berkesinambungan* services or the framework of a decentralised continuum of prevention and care services
LMICs	Low Middle-Income Countries
MSM	Men who have sex with men
NGOs	Non-government organisations
NUMs	Nurse Unit Managers
PHCs	Primary Health Centres
PITC	Provider Initiated Testing and Counselling
PMTCT	Prevention of mother to child transmission
POI	Proof of identity
RCT	Randomised Controlled Trial
RIC	Resident Identity Card

SES	Socioeconomic status
SIHA	*Sistem Informasi HIV/AIDS*
SMS	Short Message System
STD	Sexually transmitted diseases
STI	Sexually transmitted infection
SUFA	The strategic use of antiretrovirals
UNAIDS	The Joint United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and testing

Glossary

A number of Indonesian terms are used in this thesis. The following are the terms translated into English:

1. JKN *(Jaminan Kesehatan Nasional)* is the Indonesian National Health Insurance system for Indonesian citizens who choose to pay a premium in a three-tiered system. The government of Indonesia established the Jaminan Kesehatan Nasional (JKN) scheme to implement Universal Health Coverage from 2014, and this was officially administered by the social security agency, Badan Penyelenggara Jaminan Sosial Kesehatan (BPJS). This scheme covered a range of treatments via health services from either public or private providers that had joined the scheme. BPJS Kesehatan premiums are paid at least every month, depending on the number of family members and the level of cover and benefits they have.
2. *Kade*r (Cadre) is a person or a group of people who have received health training and who act as associate health workers in the community.
3. *Kartu Tanda Penduduk* (*KTP*, a resident identity card) is an official card issued by the government, showing that a person is permanently living in a specified region.
4. *Puskesmas* (*Pusat Kesehatan Masyarakat*, Public Health Centre), is a government-mandated first-level healthcare service for the population at the sub-district level, located across Indonesia and monitored by the Ministry of Health.

Abstract

Indonesia is ranked third highest in the world for the number of children living with HIV, following only India and China. Although the government of Indonesia has responded with a policy package for HIV management, the focus is on adults with HIV, while children with HIV receive little attention. The aim of this thesis is to explore the subjective experiences and perspectives of children with HIV, their families, and healthcare professionals; and to generate a substantive grounded theory on HIV care for children and their families across the continuum in the Indonesian context.

A qualitative constructivist grounded theory design was used to guide the research. Semi-structured interviews were conducted with children with HIV aged 8-18 years and their family carers, and health professionals across eight different healthcare settings, including five Public Health Centres (PHCs) and three hospitals in Surabaya, in the East Java Province of Indonesia. The participants were recruited using purposive sampling, and the data were analysed according to grounded theory methods. This study purposively sampled 12 children with HIV, 8 parents or family members, and 23 health professionals.

The coding analysis constructed three major categories, namely maintaining the health of the child, living with fear and stigma, and predisposing factors for ineffective healthcare. Children with HIV and their families experience financial and other challenges, such as discrimination and marginalisation that negatively affect their care. However, families are motivated to maintain their children's health through developing family caregiving responsibilities to sustain the uptake of Antiretroviral (ARV) treatment while continuing to promote the child's growth and development. Children with HIV and their families experience fragmentation of care due to the absence of child-centred care, inadequate healthcare system support, and their social determinants of health. In this study, the integration of the categories constructed the core category, 'The need for comprehensive care'. The resulting model was structured on child-centred care and social support to address the fragmentation of care.

Exploring the perspectives of children with HIV, their families, and health professionals has revealed the need to enhance the delivery of comprehensive care. These perspectives will inform policy-makers, health professionals, nursing educators, and researchers to improve care across the continuum for these children and their families in Indonesia.

Declaration

I, Nuzul Qur’aniati, certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that 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.

Signed Date November 2020

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CHAPTER 1
INTRODUCTION AND BACKGROUND

The number of children with Human Immunodeficiency Virus (HIV) has increased annually in Indonesia, with the Ministry of Health reporting that children with HIV aged below 19 years have cumulatively increased over the past five years (2013-2017) from 2,133 to 3,055 thousand cases (Kementerian Kesehatan Republik Indonesia, 2018). HIV infection is caused by a persistent retrovirus which continually replicates, duplicates, and destroys helper T cells, otherwise known as the coordinators of the entire immune system (Hoy & Lewin, 2004; Kementerian Kesehatan Republik Indonesia, 2014a). HIV infection increases susceptibility to physical infection and disease, through immunodeficiency, which attacks the internal organs, such as the lungs, the digestive tract, and other internal organs (World Health Organization, 2019b). The increasing number of children with HIV infection may thus have an impact on child-aged population groups and the household structure of the affected population.

The government of Indonesia has established a national HIV programme, although it does not focus on children (Limardi et al., 2019). Constructing an understanding of the experience of care for children with HIV and their families across the continuum will provide a rich explanation of the phenomenon, one that is currently little known. This, in turn, may contribute to the formation of evidence-based recommendations concerning current practice and future healthcare to meet the needs of these children and their families.

This chapter introduces the study and sets out the research context through the provision of background information about the situation of children in Indonesia and an overview of the Indonesian health system. The research problem and research question are stated, followed by the aim and objectives, and the anticipated contribution of the study, finishing with an overview of this chapter.

Background

Being diagnosed with HIV has a negative impact not only for children, but also for their families. Children with HIV and their families face complex problems due to financial and social issues which may lead to inadequate HIV treatment (Limardi et al., 2019; Sayegh et al., 2018; Shaluhiyah et al., 2016). These problems affect the morbidity levels of children and their families (Limardi et al., 2019; Sayegh et al., 2018; Shaluhiyah et al., 2016). For example, a study in Jayapura, Indonesia, found that the majority of children with HIV live with their grandparents due to their parents having died of HIV/AIDS (Oyaitou, Dedi & R, 2019). Therefore, HIV infection does not only have an impact on the physical health of children, but also results in socioeconomic hardship, psychosocial stress on families, and emotional problems which directly have an impact on children with HIV and their families leading to sub-optimal treatment and care for the children.

Children with HIV taking antiretroviral (ARV[1]) treatment are highly vulnerable. Children with HIV depend on their parents or caregivers for adequate care to support optimal health outcomes. For example, children with HIV need daily care in relation to their nutrition and education for their growth and development. Children also rely on caregivers to gain access to healthcare services or to administer ARV drug admissions. Being dependent on parents or caregivers for care and treatment poses a number of challenges. For example, grandmothers who took responsibility for providing care of their orphaned grandchildren with HIV influenced the quality of the caring role (Ntuli & Madiba, 2019; Rutakumwa et al., 2015). Grandmothers may be weak with low levels of physical strength and have their own health problems with physical illness (Ntuli & Madiba, 2019; Rutakumwa et al., 2015). A heavy burden on the caregiver often causes adverse outcomes for children, such as being more likely to fail in follow-up HIV treatment, as well as non-adherence to ARV therapy.

Care for children with HIV is most often supported by caregivers in the family. However, due to dependence on their caregivers, children with HIV rely on caregivers to provide them with care. If a family has problems, a child would likely be at risk of sub-optimal care and development. Families influence all aspects of caring for children with HIV and it is essential for them to have an understanding of the child’s illness (Achema & Ncama, 2016b). The provision of care for children with HIV requires the help of the entire family, and thus, children with HIV should be in their care. Families play an integral role in the delivery of healthcare services for the sick child, so the relationship between the family and health professionals is essential to promote optimal health outcomes for these children (Achema & Ncama, 2016b).

The nature of the illness results in patients living with HIV often being treated in hospital when they suffer from a severe illness or become physically ill (Akib, 2004). When patients do not require hospitalisation, they take ARV therapy in an outpatient clinic or a Primary Health Centre (PHC). ARV therapy consists of a set of antiretroviral drugs that are used to

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[1] ARV is antiretroviral drugs that are used for the suppression of HIV virus and stop the progression of HIV disease.

suppress the HIV virus and to stop the progression of HIV disease. HIV care and treatment services have moved from acute hospital treatment to community-based services. Due to the nature of HIV, children need continuous care management that requires the implementation of integrated practise among health professionals (HPs) in hospitals and in the community to promote optimal quality of life across the continuum (Bauer et al., 2014).

The government of Indonesia has established HIV programmes in response to the growing number of HIV cases. These programmes include the *"Layanan Komprehensive Berkesinambungan (LKB*, the framework of a decentralised continuum of prevention and care services)*"*, HIV counselling and testing, ARV treatment, and social support (Kementerian Kesehatan Republik Indonesia, 2012b). However, HIV care programmes for children have not been prioritised in the national HIV/AIDS programme in Indonesia (Limardi et al., 2019). These programmes only focus on adults with HIV, such as female sex workers (FSWs) and men who have sex with men (MSM) (Ibrahim et al., 2010; Limardi et al., 2019; Pusat Kebijakan dan Manajemen Kesehatan Fakultas Kedokteran Universitas Gadjah Mada, 2015; World Health Organization, 2019a). The topic of HIV care for children across the continuum remains unacknowledged in Indonesia. Limited attention to children with HIV highlights that this population is vulnerable and needs particular attention in research, with added importance on including their perspectives in the Indonesian context.

Exploring the experiences of care across the continuum from the perspective of children with HIV and their families may warrant further investigation. It would be of considerable benefit to construct knowledge about HIV care for children across the continuum. This, in turn, would improve the quality of care and enhance health outcomes for children across the continuum. Uijen et al. (2012) asserted that a continuum of care focusing on patient-centred care, communication, and cooperation between HPs and families enhances the quality of care for people with HIV.

HIV in Indonesia

The actual number of patients living with HIV reached 280,623 people in 2017, increasing every year from 2015 to 2017 (Kementerian Kesehatan Republik Indonesia, 2018). In concordance with new HIV infections per 1,000 uninfected population, the number of new HIV infections among the uninfected population of all people of all ages was 0.17 per cent over one year, with the majority of the HIV reported spread through sexual activities with an estimated 48,000 new HIV infections in 2016 (The Global Fund, 2019; The Joint United

Nations Programme on HIV and AIDS, 2020). In Indonesia in 2018, 640,000 people were diagnosed as HIV-positive, and 46,000 people were newly infected with HIV (The Joint United Nations Programme on HIV and AIDS, 2020). The percentage of people with HIV among adults 15-49 years was 0.4%, while 35.48 per cent of adults with HIV were women. In the case of children with HIV, an estimated 3,200 were reported to be newly infected with HIV, acquired by mother to child transmission in 2016 (The Global Fund, 2019). Figure 1 shows that the number of Indonesian children with HIV aged below 19 years cumulatively increased during the five years, 2013-2017 (Kementerian Kesehatan Republik Indonesia, 2018).

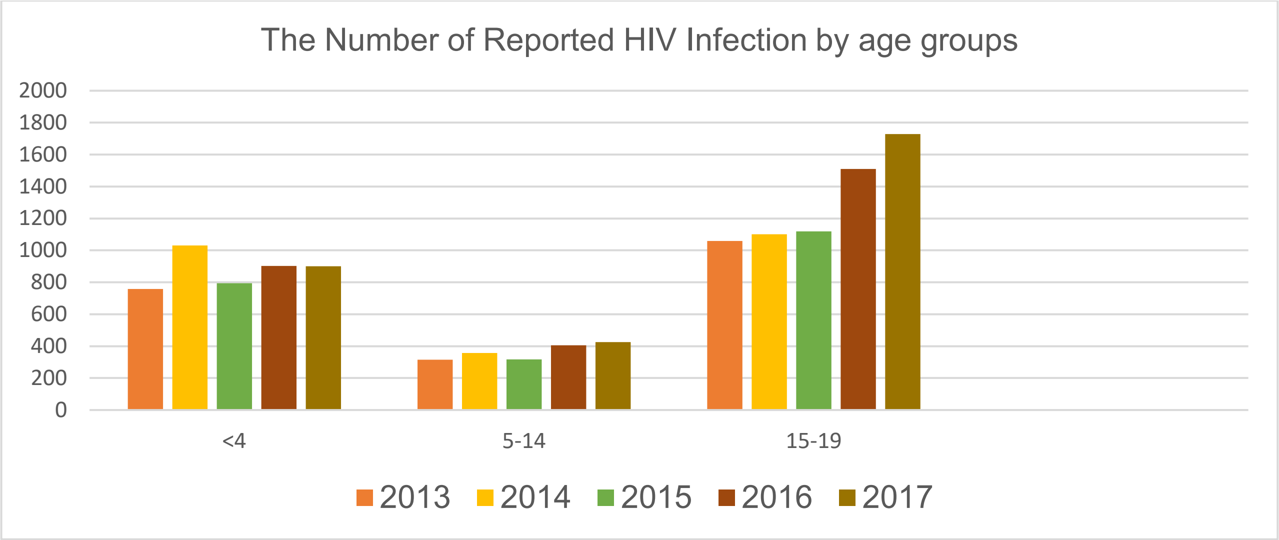

Figure 1: Trend number of reported HIV infections by age group

Furthermore, the Country Programme Action Plan 2016-2020 reported that Indonesia has had a rapid increase in the number of prevalent cases among adolescents and adults aged 15-49 years at 0.5 per cent (The Government of Indonesia & UNICEF, 2015). Adolescents have a high prevalence of HIV and sexually transmitted infections and have limited knowledge and access to HIV-related information and services (The Government of Indonesia & UNICEF, 2015).

In terms of all people living with HIV, reaching the 90-90-90 targets envision that, by 2020, 90% people living with HIV will know their HIV status, 90% of people knowing their status will be accessing ARV treatment and 90% of people on ARV treatment will have supressed viral loads. Meanwhile 51 per cent of people with HIV knew their status and 17 per cent were on ARV treatment, while 22 per cent of children 0-14 years with HIV were on ARV treatment (The Joint United Nations Programme on HIV and AIDS, 2020). Only 17 per cent of adolescents with HIV aged 15 years and over were on ARV treatment (The Joint United Nations Programme on HIV and AIDS, 2020).

An Overview of the Indonesian Health System

Indonesian Presidential Regulation number 72, 2012 regulates the national health system. The main goal of the national health system is to plan and implement the highest quality of public health (Kementerian Kesehatan Republik Indonesia, 2012c). The implementation of the national health system is guided by the Ministry of Health, representing the central government.

One focus of the national health system is on communicable diseases. HIV/AIDS is an issue of national security in Indonesia. HIV prevalence is still rising in Indonesia, and the growing HIV/AIDS epidemic will have significant human, economic and health security impacts if left unchecked. HIV can cause problems against humanity leading to infringements of the abuse of human rights, and discrimination contributing to adverse consequences for human security (Emmers & Anthony, 2017). If the government failed to maintain a minimum level of security, the security of all individuals would be threatened (Emmers & Anthony, 2017). Due to the fact that individual security and national security are interrelated HIV may pose a risk to human security and national stability. In this regard, several stakeholders, such as the national government, and local and non-governmental organisations (NGOs) play an important role to formulate, implement new policy to manage the HIV/AIDS epidemic (Emmers & Anthony, 2017). The implementation of national HIV/ AIDS programmes must be rapid and adaptable (Emmers & Anthony, 2017). The Ministry of Health set the goal of improving disease control and designed the implementation of the national HIV/AIDS plan through development activities to achieve the goal. This plan drives policy direction into three essential components: (1) strengthening primary healthcare through improving health insurance and the provision of the *Indonesia Sehat Card* in addition to increasing access to, and quality of, primary health services and referrals; (2) implementing a continuum of care; and (3) developing risk-based health interventions (Kementerian Perencanaan Pembangunan Nasional/ Badan Perencanaan Pembangunan Nasional, 2014).

Even though health development has made significant progress, health inequities remain a major concern (Gani & Budiharsana, 2019). Public Health Centres (PHCs) are the frontline healthcare facilities and are supported by other healthcare facilities at the district and provincial levels through referrals (Agustina et al., 2019). The Indonesian Ministry of Health introduced a new regulation, Number 43, 2019 in relation to Public Health Centres. In this new regulation, the *Puskesmas* was defined as a healthcare facility that provides community health services and primary care for individuals, with an emphasis on health promotion and prevention activities (Kementerian Kesehatan Republik Indonesia, 2019). The *Puskesmas* must perform the first level of integrated community healthcare services and individual primary care to enhance the health status of individuals and the community, and uses the family approach as a method of service delivery (Kementerian Kesehatan Republik Indonesia, 2019). Besides providing services at the primary level, the *Puskesmas* provides appropriate referral services in improving access to healthcare for the community. However, there are still gaps in the referral system which affect levels of care (Gani & Budiharsana, 2019). The quality of the health services in the PHCs is inadequate due to shortages of physicians and limited numbers of skilled health professionals (Gani & Budiharsana, 2019).

The Ministry of Health has rolled out a continuum of HIV care through the initiation of ARV therapy to patients once they have been diagnosed with HIV, regardless of their CD4[2] count. This intervention is in line with the Joint United Nations Programme of HIV and AIDS (UNAIDS) 90-90-90 goal targets by 2020. The UNAIDS 90-90-90 targets aim for 90 per cent of people living with HIV, including children and adolescents, knowing their status; 90% of all people diagnosed with HIV receiving ARV; and 90% of people receiving ARV having viral suppression (Gani & Budiharsana, 2019; Lee & Hazra, 2015). However, a wide gap exists because only 58.7 per cent of patients living with HIV knew their status in 2019, 33 per cent of patients diagnosed with HIV were receiving ARV therapy in 2018, and 0.6 per cent of those patients receiving ARV achieved suppression of the viral load in 2017 (Tuasikal, 2019). Meanwhile, in the child population, 22 per cent of children aged below 14 years diagnosed with HIV were on ARV therapy, and 17 per cent of all adolescents aged above 15 years diagnosed with HIV were on ARV therapy (The Joint United Nations Programme on HIV and AIDS, 2020). These showed that the healthcare system at the PHC and hospital levels was suboptimal, and this in turn resulted in inadequate care for children with HIV in Indonesia.

Indonesia’s Decentralisation

The implementation of HIV management programmes in the local region has been influential not only within the central government, but also in local government due to the implementation of decentralised governance. The government of Indonesia follows a

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[2] CD4 stands for Cluster of Differentiation 4 laboratory testing to check the immune system

decentralised system which has been in place since 1986 and which was redefined in 2001 (World Health Organization, 2017a). According to Law No. 32/2004, decentralisation is:

> *A transfer of power by the central government to the autonomous regional government to regulate and manage the responsibilities of government (World Health Organization, 2017a, p. 60)*

The Indonesian healthcare delivery system is separated into central government and local government responsibilities, including at the provincial and district/city levels, and in the community. Each level of government has its mandates, areas of authority, and is not subordinate to the central government (World Health Organization, 2017a). The central government produces policies, regulations, and guidance documents for all healthcare services (Limardi et al., 2019). These policies or regulations are ‘vertical’ and directly function at the local government level (World Health Organization, 2017a). In terms of programmes to combat HIV/AIDS, the central government has overall responsibility for organisation and management. Services are delivered by a network of public healthcare facilities at the district and community levels, such as in the hospitals, and in PHCs and their networks. The regulations and guidance related to HIV are intended to assign authority to local government to formally allocate budgets to conduct HIV programmes and activities, particularly in surveillance, prevention, care, treatment, and support following national standards (World Health Organization, 2017b).

In the case of the health sector, local governments, including provincial and district governments, have a responsibility to provide physical and social healthcare services and to ensure the availability of health resources for the community (Limardi et al., 2019). The provincial government owns the provincial hospitals and organises healthcare services through the provincial health offices. The provincial government provides management of provincial level hospitals and coordinates cross-district problems across the province (World Health Organization, 2017a). The provincial government acts on behalf of the national government in coordination and supervisory functions. However, provincial governments do not have direct authority over the districts (World Health Organization, 2017b). On the other hand, the district healthcare system is structured in the same way as the provincial healthcare system. The district government owns district/city hospitals and operates healthcare services through public healthcare centres and their associated networks.

The Indonesian health system is financed by both the public and private sectors (World Health Organization, 2017a). For example, the Ministry of Health engages with various non-government organisations (NGOs) and private sector actors to support HIV prevention and promotion programmes. The Global Fund has supported most HIV programme funding since 2002 (World Health Organization, 2017a).

Both the public and private sectors deliver healthcare services. The provision of public health is mostly undertaken through the public sector, which follows the Indonesian government's administrative decentralisation, and the budget for public healthcare institutions, such as hospitals and PHCs, comes from both the central and local governments (World Health Organization, 2017a). In the private sector, private networks of hospitals and clinics are owned by religious-affiliated organisations, companies, and individual or groups, and are managed by either for-profit, not-for-profit, or charitable organisations (World Health Organization, 2017a).

National Programmes and Policies Relevant to Access to HIV Services

The Indonesian government has taken action in the national HIV/AIDS programmes through the implementation of services carried out by a decentralised network of public facilities (De Bresser et al., 2019; Demartoto, Gerilyawati & Sudibyo, 2014; Demartoto, Gerilyawati Ies & Priyo Sudibyo, 2014; Departemen Kesehatan RI, 2007; Direktorat Jenderal Pencegahan dan Pengendalian Penyakit, 2017; Gamell et al., 2016; Ibrahim et al., 2010; Kementerian Kesehatan Republik Indonesia, 2012a, 2012b, 2014b, 2018; Limardi et al., 2019; World Health Organization, 2017b). These healthcare facilities include district health offices, hospitals, and PHCs and their networks. The broad range of policies and programmes include the following:

- Several sets of guidelines for stigma and discrimination strategies for HPs and cadres, national guidelines for ARV treatment, national guidelines for the prevention of mother-to-child transmission (PMTCT), management of ARV in children, and guidelines for the prevention of sexual transmission of HIV.
- Guidelines have been developed for a national continuous comprehensive care framework known as the *"Layanan Komprehensive Berkesinambungan (LKB)* for HIV and sexually transmitted infection (STI). This *"Layanan Komprehensive Berkesinambungan (LKB)* framework focused on promotion, prevention, curative, and rehabilitative activities. These LKB activities include Voluntary counselling and testing (VCT), testing and treatment for STIs, psychosocial and spiritual support, post-exposure prophylaxis for HIV, PMTCT, ARV therapy, provision of care support and treatment (CST), home-based care, and palliative care.

- PMTCT is a programme that provides a range of interventions to prevent the transmission of HIV from an HIV-positive mother to her infant during pregnancy, labour, delivery, or breastfeeding.
- VCT including pre and post counselling. A client is seeking HIV counselling and testing services to understand his or her status.
- An ARV initiation programme irrespective of the CD4 count for specific populations.
- Implementation of the strategic use of antiretrovirals (SUFA) in the revised/ consolidated guidelines on ARV for adults, children, and PMTCT.
- TB/HIV collaborative activities
- Harm reduction programmes through the provision of needle syringe, and harm reduction community meetings and education for injecting drug users.
- Behavioural change counselling including outreach and guidance, communication, information and education, and peer education specifically targeted towards men who have sex with men and transgender people.
- Provision of methadone substitution therapy in the hospitals, and PHC ‘satellite’ services and rehabilitation for drug addiction, and ARV treatment.
- Electronic medical records for patients with HIV called ‘Sistem Informasi HIV/AIDS’ (SIHA).
- The HIV surveillance program aims to estimate the total number of HIV infections among key HIV populations. Indonesia has discovered HIV cases through healthcare institutions which provide HIV testing and counselling services for several groups of the population, such as pregnant women, TB patients, babies or children born to mothers with HIV, and key HIV populations. However, the real number of HIV cases found and reported is still far below the estimated number (De Bresser et al., 2019; Demartoto, Gerilyawati & Sudibyo, 2014; Demartoto, Gerilyawati Ies & Priyo Sudibyo, 2014; Departemen Kesehatan RI, 2007; Direktorat Jenderal Pencegahan dan Pengendalian Penyakit, 2017; Gamell et al., 2016; Ibrahim et al., 2010; Kementerian Kesehatan Republik Indonesia, 2012a, 2012b, 2014b, 2018; Limardi et al., 2019; World Health Organization, 2017b).

As part of governance, the Ministry of Health has developed national HIV policies and programmes and acts as a technical adviser to local governments (World Health Organization, 2017b). The involvement of two ministries in the decentralised implementation of the HIV programmes hampers the coordination of the HIV programme (World Health Organization, 2017b). Therefore, the government of Indonesia has established a national healthcare system concerning HIV programmes and the epidemic. These programmes, on the other hand, are not specifically targeted at children, and in turn, might influence the delivery and quality of healthcare.

Statement of Problem and Research Question

Children with HIV have to deal with a number of medical and psychosocial problems. Children with HIV have also been orphaned due to their parents dying of HIV/AIDS. Previous studies conducted in Low Middle-Income Countries (LMICs) and/or developing countries have highlighted that the issue of caring for children with HIV is fragmented, and contributes to a lack of continuity (Haskins et al., 2016; Horwood et al., 2010a; Koerich et al., 2015). The government of Indonesia has implemented the national HIV programme, but children have received little attention compared to adults. The possibility that the experience of children with HIV, their families, and HPs may have a considerable impact on HIV care practices warrants further investigation to explore care across the children's continuum and the factors influencing their care.

The research question for the study is: '**How do Indonesian children with HIV and their families experience their care across the continuum?'**

Aim and Objectives

Aim

The aim of this study is to generate substantive grounded theory to understand HIV care for children across the continuum in the Indonesian context from the perspective of children with HIV, their families, and the HPs that look after them.

Objectives

The objectives of this study are to:

1. Explore the experience of children with HIV and their families of HIV care across the continuum in the Indonesian context.
2. Generate a substantive grounded theory on HIV care for children and their families across the continuum in the Indonesian context.

Definition of Key Terms

The following definitions are used to describe meanings and key people in relation to the HIV care for children across the continuum throughout this study.

- Continuity of care or HIV care for children across the continuum – the delivery of comprehensive care delivered by the coordinated health professionals across different healthcare settings throughout the illness trajectory from pre-diagnosis and diagnosis through to post-diagnosis, varying over period of time related to the age of the children (i.e., infant, toddler, preschool, school age children, and teenagers), and across the range of healthcare services (i.e., hospital and PHC).
- Care coordination – the delivery of a patient's health care from multiple health professionals, designed to meet the needs and preferences of children and their families.
- Fragmentation of care – the process or the act of fragmenting; lack of continuity or an interruption in care as a result of many different factors (i.e., lack of social support, inadequate referral system and care coordination), which negatively impacts health quality and outcomes.

Anticipated Contribution of the Study

The constructivist paradigm and grounded theory method will assist with constructing knowledge to inform the experience of care for children with HIV and their families. Exploring information from three different viewpoints will provide a diverse set of meanings and insights regarding the experience of care and the care needs of Indonesian children with HIV and their families. Insights from Indonesian children with HIV and their families will enhance the reader's understanding of the care, and the relationships between the healthcare practices that they experience across their continuum. Furthermore, insights from HPs provide the meanings behind the current practices of care provision for children with HIV and their families in Indonesia. The findings will contribute to the formation of evidence-based recommendations, which will help to inform current practice and to serve the ongoing healthcare needs of these children and their families.

Understanding the experience of care for children across the continuum will provide a comprehensive understanding of continuity of care for Indonesian children with HIV, which is currently unknown. It is critically important to build an understanding of how children with HIV and their families experience care in the healthcare setting, and how the HIV care delivery system is implemented across the nation's hospitals, in the community, and in the home. These understandings will help to build knowledge about patients' unique perspectives in relation to their experiences of care concerning comprehensiveness and continuity of care.

An Outline of the Study

This thesis consists of eight chapters. Chapter 1 has provided an introduction and the background context for this study, the problem statement, the research questions, the aim and objectives, and the anticipated contributions of the study. The second chapter presents a literature review on the provision of care of children with HIV in developing countries. The key findings of the related research and discussion are also presented. Chapter 3 discusses the research methodology for the constructivist philosophical paradigm. The assumptions behind the ontological, epistemological, and theoretical perspectives will be discussed. This chapter also explains the research methodology and provides a justification for the use of constructivist grounded theory. Chapter 4 presents the research methods and explains how grounded theory methods are employed in this thesis. The chapter details the study's inquiry process, including the process of recruiting participants, ethical considerations followed by data generation, data analysis, and developing the core categories in the grounded theory. The elements of grounded theory methods, such as comparative analysis, theoretical sensitivity, and theoretical sampling, are detailed, and the rigour of the grounded theory method is also discussed in this chapter. Chapter 5 presents Part A of the findings. The findings were constructed into three major categories, namely (1) maintaining the health of the children, (2) living with fear and stigma, and (3) predisposing factors leading to ineffective care. This chapter explains the first two major categories, starting with a description of the participants' profiles. Chapter 6 presents Part B of the findings. This chapter presents the third category of predisposing factors leading to ineffective care, followed by an overview of the core category 'needing comprehensive care'. Chapter 7 provides a theoretical explanation of the core category 'needing comprehensive care', incorporating the literature to support the core category. Finally, Chapter 8 provides the conclusions of, and the recommendations arising from, the study.

Chapter Summary

In Indonesia, the number of children with HIV infection has been increasing year upon year. However, government policies and programmes only prioritise adults. Children with HIV and their families face complex medical, social, emotional, and financial problems. Investigating the experience of care for children with HIV and their families across the continuum is essential to achieving optimal health outcomes.

The following chapter will present a literature review examining the provision of care for children with HIV. The review will help to build knowledge on the provision of care for children with HIV, provide an indication of what is known on the topic, assist with identifying the key questions, and provide a rationale for the need for further research.

CHAPTER 2
LITERATURE REVIEW

Chapter One established the need for an understanding of the experience of care for children with HIV and their families across the continuum in the Indonesian context. Overall, the chapter provided the background, and described the research question and the aim of the study.

Chapter Two reviews the literature relevant to the provision of care for children with HIV. The literature review will identify the relevance of the research questions and establish the rationale or justification for the methodology used in the study. This chapter begins with a justification for undertaking a literature review whilst using grounded theory, followed by the process of review, the review findings, and discussion. In the review process, general concepts on the provision of care for children with HIV in developing countries/Low Middle-Income Countries (LMICs) will be provided. This review will also provide a critique of the methodological gaps and limitations and will propose a suitable method for the current study. This chapter presents the synthesised review findings on understanding the barriers to, and the facilitators of, the implementation of HIV care among children with HIV. The chapter concludes with a discussion followed by recommendations for further research linked to the reviewed literature.

Justification for Undertaking this Literature Review

Two broad perspectives inform the timing of a literature review in grounded theory (Charmaz, 2006; Strauss & Corbin, 1990; Timonen, Foley & Conlon, 2018). For classical grounded theory, it has been suggested that a review be postponed until the data collection and analysis emerge (Strauss & Corbin, 1990; Timonen, Foley & Conlon, 2018). The reason for postponing the literature review is that preconceived ideas about what is already known about the phenomenon can inhibit the discovery process (Bluff, 2005; Glaser, 1992).

For Straussian and constructivist grounded theory, the review must be conducted before the study starts in order to construct an understanding of the phenomenon. Strauss and Corbin (1990) suggested that the literature, both technical (i.e., reports on research studies, theoretical or philosophical papers) and non-technical (i.e., biographies, manuscripts, documents), provides many benefits at the beginning of the research process. For constructivist grounded theorists, Birks and Mills (2011) and Charmaz (2014a) argued that a literature review provides an indication of the existing studies and prevents entering the research field with a blank state. A literature review identifies the focus of the study and justifies the research questions, and also uncovers areas in which further research is needed (Snyder, 2019; Timonen, Foley & Conlon, 2018). For these reasons, the literature review was conducted prior to the refinement of the research process.

Review Process of Care Provision for Children with HIV

This review has used an integrative method developed by Whittemore and Knafl (2005) to answer the question: "What is the provision of care among children with HIV in developing countries settings/LMICs?". This literature review has aimed to build evidence, to review methodological issues, and to inform potential research and practice. Integrative reviews allow for the inclusion of varied research methods, such as quantitative and qualitative studies, which support the understanding of the phenomenon under investigation (Souza, Silva & Carvalho, 2010; Torraco, 2005; Whittemore & Knafl, 2005).

This review uses a structured approach, starting with problem identification, after which followed the literature search, the critical appraisal, and presentation of the findings (Morgan, Pullon & McKinlay, 2015; Whittemore & Knafl, 2005). The PRISMA flow process assisted with an overview of the selected articles, the construction of a summary table of the reviewed articles, a quality appraisal table, and a summary table of the strengths and weaknesses of each article. The details of this review process are presented in Appendix 1, pp. 225-267.

The initial stage of this review aimed to identify a clear problem in the literature (Whittemore & Knafl, 2005). For the literature search, this review followed four stages, namely identification, screening, eligibility, and inclusion of articles and documentation (the PRISMA flow diagram) (Liberati et al., 2009; Moher et al., 2009). The researcher assessed the retrieved articles for relevance based on the inclusion criteria. The inclusion criteria for this review were: primary articles, nurses who provided care for children with HIV between 0-19 years old, and conducted in developing countries and/or LMIC settings. Studies that included data on knowledge, beliefs, perceptions, implementation, strategies, documentation, and communication were included to understand the provision of care for children living with HIV. Studies which included families, caregivers, and nurses in the care of children with HIV were also included. If an article did not meet the included criteria, it was excluded.

All included articles were placed into a summary table, specifying the title of the study, the author and year of publication, the aims and/or objectives, research design, data collection, sampling, participant characteristics and setting, data analysis, and key findings (please refer to Appendix 1.2, pp. 227-258). A critical appraisal of all included articles was then undertaken using the critical review guidelines for quantitative and qualitative studies adapted from Schneider and Whitehead (2016) to evaluate the research process (please refer to Appendix 1.3, pp. 259-264.). Evaluating the quality of the included articles helped to meet the standards of rigour required for a review (Whittemore & Knafl, 2005).

This review used a wide range of electronic databases, such as PubMed, CINAHL, Scopus, Ovid Gateway: Ovid MEDLINE (R), and PsycINFO. Table 1 presents the related concepts and keywords/search terms used in this review to retrieve articles related to the provision of care for children with HIV. A total of 2,047 articles were retrieved.

Table 1: Related concepts and keywords for the provision of care for children with HIV

Concepts	Keywords or terms
Nurse	*Nurses, nursing staff*
The provision of care	*Care, caring, support, the provision of care*
Child	*Child, children, childhood, pediatric*
HIV	*HIV, children with HIV infection*
Experience and practice	*Knowledge, beliefs, perceptions, experience*
	Implementation, strategies, practice
	Communication, documentation
Low middle-income country	*A developing country, low-income country*
Filter by: - Publication year: January 2006 to December 2016 - English language - Combine queries: OR, AND, smart text searching	

The researcher manually identified the country of origin of each article using the list of LMICs from the World Bank (2015). All articles were compiled and checked for duplication with 1,907 articles being retrieved. The articles were then screened based on title and abstract using the inclusion and exclusion criteria, with 112 remaining. Once screened, only 12 articles met the inclusion criteria for this literature review. The 12 articles included 9 qualitative and 3 quantitative studies.

Summary of Outcomes of the Critical Appraisal

Location and Study Participants

The articles came from a range of countries, including South Africa (n=6), Zimbabwe (n=2), Nigeria (n=2), Malawi (n=1) and Brazil (n=1). Most studies were conducted in hospitals (n=8), while 4 were conducted in the community. Most used different perspectives to explore the provision of care for children with HIV, including from the perspective of nurses (n=4), nurses and other health professionals (n=2), nurses and caregivers (n=4), and children (n=2) (Achema & Ncama, 2016a, 2016b). There were no studies across multiple settings, which demonstrates a gap in the available body of evidence. This gap has been addressed in the current study.

Methodological Review

This review used two critical appraisal checklists developed by Schneider and Whitehead (2016) to critically appraise all the included articles specific to quantitative and qualitative study design. As described earlier, this review involved 9 qualitative studies in which 6 used a descriptive design, while 3 adopted a grounded theory method using Strauss and Corbin's approach. The 3 quantitative studies included a cross-sectional descriptive survey (n=1), a pre and post intervention design (n=1), and an operational research method (n=1) (Haskins et al., 2016; Richter et al., 2012; Weigel et al., 2012). All the studies gained ethics permissions, but three did not explain how the confidentiality and anonymity of the participants was assured (Govender et al., 2006; Olaleye et al., 2016; Richter, Chandan & Rochat, 2009). Maintaining confidentiality and anonymity is essential to ethical research as these principles protect the privacy of participants who voluntarily agree to participate in the research (Polit & Beck, 2008).

All the qualitative studies collected data via interviews, focus group discussions, or observations, or a combination of these techniques. Almost all the qualitative studies presented their findings as being part of a 'descriptive qualitative' study. Three quantitative studies used questionnaires (n=2) and a paper assessment form (n=1) to evaluate the practice on ARV adherence between nurses and other HPs, the impact of nursing interventions on caregivers' psychological well-being, the perception of caregivers on the support provided by nurses during hospitalisation, and to measure the provision of maternal, child, and HIV services, as well as to describe the service delivery at the PHC (Haskins et al., 2016; Richter et al., 2012; Weigel et al., 2012). Among the three studies, operational research conducted in Malawi used a small sample size and was not able to generalise the findings (Weigel et al., 2012). A pre-post intervention study conducted in South Africa did not present a hypothesis which was essential to test the analysis of the data and to draw a conclusion based on a representative sample (Haskins et al., 2016).

Review Findings

This review presents a synthesis of the findings from the selected articles using the thematic analysis process developed by Braun and Clarke (2006). Through this process, the review identified common themes, analysed them, and then compiled the findings into a coherent body of evidence.

The review findings are presented under two themes and related sub-themes, with gaps in the literature being identified as recommendations for future research. Figure 2 presents a summary of the literature.

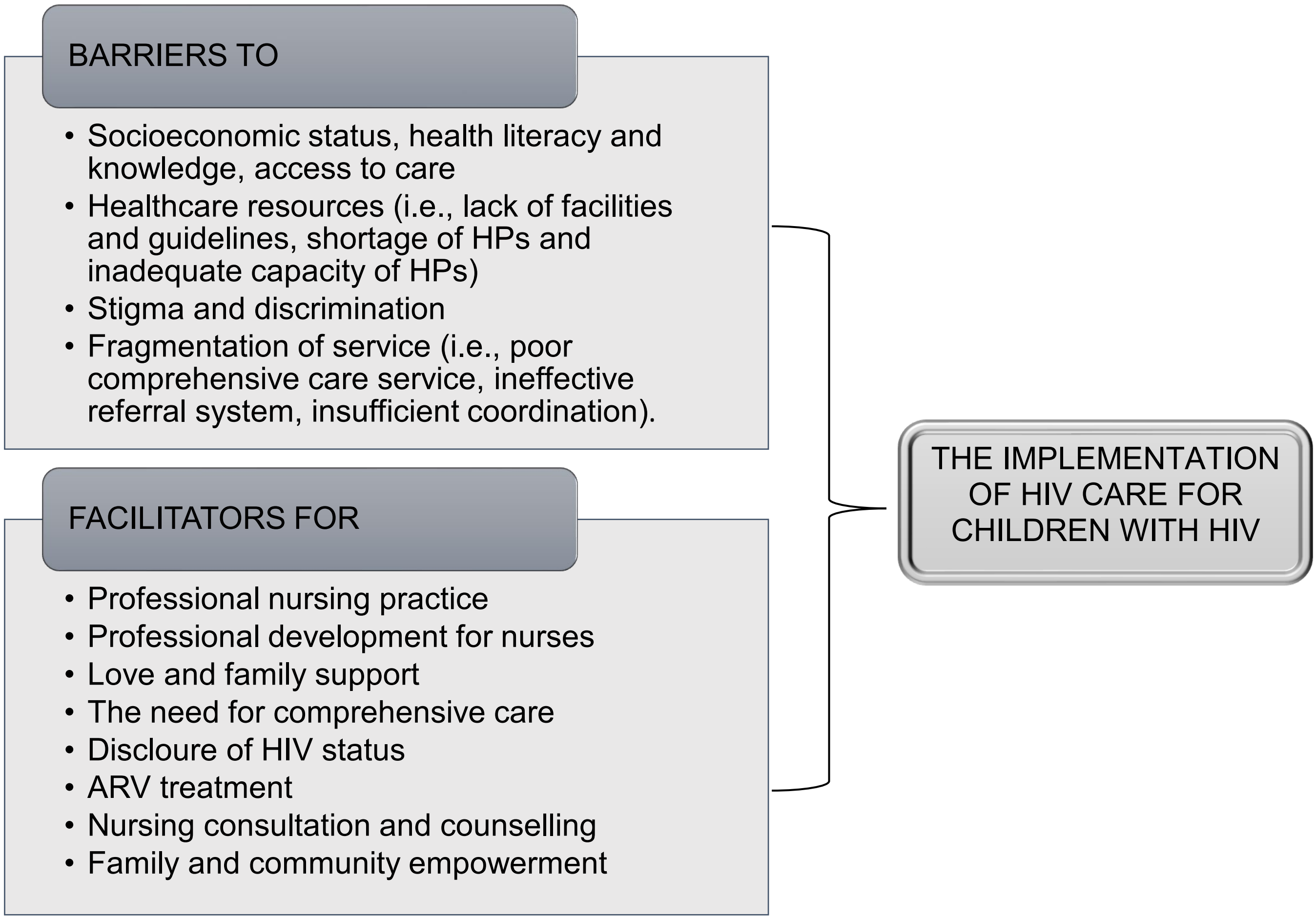


Figure 2: Representation of barriers to, and facilitators for, the implementation of HIV care for children

The review findings describe the barriers to, and facilitators of, care among children with HIV. The results of this review identified a wide range of barriers, including the familial context (socioeconomic status, health literacy, access to healthcare), the healthcare system (resources, fragmentation of service), and stigma and discrimination. Each of these barriers lead to reductions in optimal care for children with HIV. Although barriers existed in implementing care for children with HIV, several facilitators of children's care were also identified. Facilitating factors related to the care of children with HIV included good quality nursing practice, the capacity of health providers, and supportive care. The following section presents these barriers to, and facilitators of, care for children with HIV from developing country and/or LMIC perspectives.

Barriers to Care

Socio-economic status, health literacy and knowledge, and access to care

Low socioeconomic status, lack of parental knowledge of HIV, and family distance from health facilities are barriers to care-seeking behaviour. Two studies conducted in Nigeria aimed to analyse the nature of care given to children with HIV (Achema & Ncama, 2016a, 2016b). These studies interviewed caregivers of children with HIV and nurses, reporting that due to poverty, families were unable to provide good nutrition for their children with HIV (Achema & Ncama, 2016a, 2016b). Both of these studies analysed the role of family members in the provision of care for children with HIV (Achema & Ncama, 2016b). Data were collected through a combination of focus group discussions and interviews with children, caregivers, nurses, and two stakeholders from two agencies for the control of HIV. The nurses and caregivers expressed the view that children with HIV needed good nutrition to boost their immunity (Achema & Ncama, 2016a). Achema and Ncama (2016b) claimed that a family's level of poverty was a barrier to healthcare-seeking behaviour. The clinical nurse reported that during home visits, they often found orphaned children with HIV living with extended family and suffering from a lack of basic needs, such as adequate clothing, nutrition, schooling, and medical treatment (Achema & Ncama, 2016a, 2016b). However, these stakeholders also claimed that they had developed supportive care policies for children with HIV consisting of nutritional, educational, psychosocial, and emotional supports (Achema & Ncama, 2016a, 2016b).

Qualitative studies conducted in rural Zimbabwe Campbell et al. (2012), using interviews and focus groups with nurses and guardians of children taking antiretroviral therapy, found that a lack of food and the distance to health facilities hindered adequate levels of care and treatment for Zimbabwean children with HIV. Many guardians reported borrowing money from relatives, neighbours, and fellow church members to cover the medical expenses of the children in their care (Campbell et al., 2012). Another qualitative study by the same author explored the perceptions of patients and HPs in relation to HIV treatment. This study agreed with the negative impact of financial hardship on treatment (Campbell et al., 2011).

Lack of money has also been shown to influence care, as families are often unable to cover the cost of transport to attend appointments or pay the cost of required drugs, and the nurses in the study felt frustrated by this situation (Campbell et al., 2011). The participants explained that if they did not have money to pay the consultation fee, the nurses would say there were no drugs available. Money influences healthcare because it allows families to meet their children’s daily needs, such as nutrition and education, and to pay for healthcare such as the consultation fees and ARV treatment.

Campbell et al. (2011) explored the perceptions of patients on ARV care, finding that caregivers wanted several months’ supply at one time, as they believed the need to attend a regular monthly clinic was a significant cost imposition (Campbell et al., 2011). As a result of not having the money to afford the cost of transport, living far away from a healthcare centre, and the lengthy queues during visits, patients had been prompted to acquire several months’ supply of ARV drugs at one time (Campbell et al., 2011). In terms of ARV refills, the nurses and the patients had different perceptions about the usefulness of monthly visits (Campbell et al., 2011). The nurses stated that monthly visits were important for antiretroviral therapy (ART) refilling and to monitor the effects of therapy and opportunistic infection. The nurses believed that the opportunity for monthly monitoring and surveillance was part of good clinical care. However, the purpose of the surveillance provided was not well described (Campbell et al., 2011). Families believed they were punished by nurses when they did not have enough money to pay for their child’s medication by only receiving a small amount of drugs at each visit (Campbell et al., 2011).

As well as families experiencing financial hardship, and not being able to purchase ART, the health literacy of families has been shown to affect their care-seeking behaviour for children with HIV. Using focus group discussions, it was found that Zimbabwean parents often did not take their children to hospital for antiretroviral therapy refills (Campbell et al., 2011). Two reasons were given for this; the first being that the child felt better, and therefore, their carer did not perceive the further need for the drugs; and the second was avoiding the long queues for services (Campbell et al., 2011). Additionally, due to their lack of knowledge, parents often could not make decisions that allowed their children to have HIV testing; however, their children were often suspected of having a HIV infection as their parents had already tested positive (Olaleye et al., 2016).

Campbell et al. (2012) claimed that according to the perspectives of the nurses, caregivers needed knowledge about ARV, specifically giving medication in a timely fashion and the importance of seeking professional help for their children who may have experienced side-effects from ART. For example, from the nurses' perspectives, ART needs to be given once a month to keep the child healthy (Campbell et al., 2011), but for the parents, going to the hospital once a month was seen as an interruption in their lives as it was too expensive to travel so often (Campbell et al., 2011; Campbell et al., 2012). However, Achema and Ncama (2016b) found that according to the perspective of the nurses, family members were able to provide ART at the right time to assist protection from opportunistic infection. Hence, financial hardship and levels of knowledge influenced the daily care of children with HIV which, in turn, caused negative consequences for the children, leading to discontinuity in their care and treatment.

Healthcare Resources

In this review, healthcare resources included all the facilities and guidelines and health personnel contributing to the provision of HIV care. Healthcare resources are institutional factors that contribute to the quality of care for children with HIV (Haskins et al., 2016; Horwood et al., 2010b; Koerich et al., 2015). This review has identified inadequate healthcare resources as a significant issue due to insufficient clinical equipment, and poor clinical standards and guidance for HPs in the healthcare setting, as well as the inadequate capacity of HPs. In addition, the shortage of health professionals causes burn-out and has contributed to high levels of stress among health professionals. This, in turn, affects the quality of a professional’s performance in the healthcare setting. This lack of healthcare resources results in a decline in the quality of care for children with HIV.

Lack of facilities and guidelines

Two studies have shown that inadequate resources negatively affected the care of children with HIV (Achema & Ncama, 2016b; Govender et al., 2006). According to Govender et al. (2006), the lack of facilities and equipment within South African hospitals caused frustration and feelings of helplessness for nurses. Similarly, a cross-sectional descriptive survey conducted in South Africa observed that while resources were often available in the community, they were scattered throughout the clinic and not available in the rooms where the nurses provided their services, thus influencing the effectiveness of healthcare delivery for children with HIV (Haskins et al., 2016).

In addition, inadequate equipment, and a lack of clear guidelines regarding access to medical services and medical payments, caused stress and resulted in negative interactions between health providers and caregivers of children with HIV and their families (Campbell et al., 2011). Due to a lack of clear ART procedures, there was a conflicting perception between health professionals and clients on how, and when, to access ART which caused stress for clients (Campbell et al., 2011).

Shortages of HPs and Inadequate Capacity of HPs

Human resources, including HPs, are crucial to the delivery of healthcare. This review found that the capacity of HPs was impacted by a shortage of nurses, heavy workloads, and inadequate knowledge and skills, which negatively affected the quality of care for children with HIV. Six articles discussed how a shortage of nurses required them to undertake many jobs in their work setting, which again, had a negative impact on the quality of their care for children with HIV (Campbell et al., 2011; Govender et al., 2006; Koerich et al., 2015; Olaleye et al., 2016; Richter, Chandan & Rochat, 2009; Richter et al., 2012). Campbell et al. (2011) reported that in government hospitals, children with HIV and their families had to wait a long time to see a doctor due to the poor availability of physicians. Due to these staff shortages, nurses were very busy with daily routine activities and did not have enough time to interact effectively with their clients (Govender et al., 2006; Richter, Chandan & Rochat, 2009). For example, nurses felt stressed due to the busy nature of the ward, which limited them when they fed children, as this is a time-consuming activity (Govender et al., 2006). A heavy nursing workload resulted in a lack of balance, and a range of stressors, including emotional distress, burnout, and exhaustion, which negatively influenced the quality of care (Govender et al., 2006; Olaleye et al., 2016; Richter, Chandan & Rochat, 2009). This work stress not only resulted in poor quality care, but also in detrimental errors, such as nurses often documenting incorrect client records or not correctly filling in a child’s documentation record (Koerich et al., 2015; Olaleye et al., 2016). Moreover, nurses stated that if a hospital had enough nurses, they could allocate tasks for every nurse to participate, contributing to the provision of optimal management and care of children with HIV (Koerich et al., 2015).

Apart from the shortage of nurses, emotions also affected the capacity of care delivery in HIV care settings. Nurses expressed emotional distress related to their caring for children with HIV, worrying about the risk of infection from the children’s visitors (Govender et al., 2006; Horwood et al., 2010b). According to Govender et al. (2006), nurses are conflicted between infectious disease protocols and being empathetic to their patients. Nurses recognise that visitors are good for children with HIV, but are also concerned for their safety, as the more people who visit the HIV-positive child, the more likely they are to expose them to high-risk infections. Furthermore, nurses who were also mothers felt guilty when they left their own children at home to come to work and care for HIV-infected children. Finally, nurses stated that working with children with HIV increased their own negative feelings of sorrow, frustration, and stress (Govender et al., 2006; Richter, Chandan & Rochat, 2009).

Inadequate knowledge and skills directly affect nursing performance in the delivery of HIV care for children. Nurses feel frustrated and helpless, feeling emotionally distressed as they lack the necessary knowledge and skills to deal with the distress of caring for children with HIV (Govender et al., 2006). Nurses reported that they often did not understand how to reduce pain for children with HIV, even though they were able to conduct other nursing interventions (Govender et al., 2006).

Empirical evidence from this review found that nurses are conflicted about when and why to test children and adolescents for HIV, which was related to their inadequate knowledge and skill levels. Nurses who provided Integrated Management of Childhood Illness (IMCI) in primary health clinics in South Africa reported that their limited knowledge and training resulted in being unable to answer mothers' questions about HIV (Horwood et al., 2010b). Integrated Management of Childhood Illness was a strategy developed by WHO/UNICEF to improve child survival in resource-poor settings to identify and manage children with symptomatic HIV infection in high HIV-prevalence settings. The IMCI programme encouraged mothers to bring their sick children to an HIV clinic to get them checked for common signs and symptoms of HIV infection (Horwood et al., 2010b). Nurses expressed that implementing the Integrated Management of Childhood Illness HIV guidelines was time-consuming. Nurses often did not feel confident when using the guidelines, as they did not provide clear instruction for the provision of care for a child attending the clinic without his/her mother (Horwood et al., 2010b).

Qualitative studies conducted in two provinces of South Africa found that nurses did not routinely test children without visible signs of HIV in the belief that it was not essential and was time-consuming, despite HIV testing guidelines recommending testing (Horwood et al., 2010b; Olaleye et al., 2016). Similarly, nurses in the Olaleye et al. (2016) study believed that children under eight years of age should not be counselled about, and tested for, HIV due to their limited cognitive understanding. They also suggested that the need for informed consent from parents should be simplified or removed, with a process similar to that used for HIV testing for pregnant women being adopted, as reported:

> *I think we must do away with consent. It must be done continually, as in pregnancy now. If you can do it like that also, I think it will be better (Olaleye et al., 2016 p. 25).*

Inadequate healthcare resources, including lack of facilities, inadequate clinical guidelines, inadequate knowledge and skills of HPs, professional shortages, workload demands, and lack of time caused emotional distress and work stress for nurses, often resulting in poor professional performance and quality of patient care for children with HIV. The emotional state of the individual nurse also adversely affects care. All these factors reduce nurses' capacity to provide adequate care for children with HIV. Olaleye et al. (2016) suggested that enhancing the nursing workforce and increasing the numbers of trained staff will improve competencies for nurses working with HIV.

Stigma and Discrimination

The results of this review show that children with HIV and their families often felt judged, which in turn, lead to discrimination from families and the community. As a consequence, this stigma and discrimination had a negative impact on care for children with HIV and their families. For example, Nigerian families were afraid to see the doctor and so often chose not to bring their children into the hospital, thus preventing disclosure of the child's HIV status to others (Achema & Ncama, 2016b). South African mothers explained that they would often be judged by community members if they accessed HIV services (Horwood et al., 2010b), which subsequently, contributed to isolation and rejection from their families and the community.

The findings from different studies supported the notion that adolescents with HIV experienced stigmatisation from the community, which also caused them difficulties in accessing HIV care (Koerich et al., 2015). A qualitative study exploring family-centred care for children with HIV and AIDS in Nigeria found that some families could not accept their child having HIV due to the stigma of being HIV-positive which lead to isolation and withdrawal (Achema & Ncama, 2016b). Families would often leave their community because their family would disown the child when he/she was identified as HIV-positive. In a different study, the same author claimed that Nigerian parents said that the community often did not accept HIV-positive children as being healthy:

> *So many people discriminate against us. They even speak to our faces that we are carrying HIV. Uko chuu (derogatory remark) (Caregiver Participant 1; Hospital B) (Achema & Ncama, 2016a p. 6).*

Moreover, nurses in both studies explained that families needed counselling to understand the problems faced by a child with HIV. They also worked with families to outline activities they could use to minimise stigma and discrimination for their children (Achema & Ncama, 2016a, 2016b). As well as being stigmatised by the community, caregivers claimed that as the HIV clinic was separate from other clinic services, this also created stigma for them (Horwood et al., 2010b).

In this review, children with HIV and their families were found to have experienced social stigma from their families and from the community, which caused them to be judged, and which often resulted in social rejection or isolation. From the caregivers' perspective, a spatially separated HIV service created social stigma. Stigma also lead to the discontinuity of treatment and care, which affected the health outcomes of children with HIV.

Fragmentation of services

This review identified issues in the healthcare system that cause service fragmentation, such as poor comprehensive care services and an ineffective referral system for children with HIV. Koerich et al. (2015) explored the perceptions of HPs on the characteristics of managed care for adolescents with HIV and the proposed strategies for the transition to this service. The health professionals interviewed were nurses, psychologists, social workers, doctors, and nurse technicians. This study found that HIV care for children was centralised around the physician and did not include multidisciplinary care. According to the nurses in this study, due to the centralisation of care in hierarchial multidisciplinary teams, they felt as if they were an inferior profession and felt undervalued by other health professionals, causing them to feel dissatisfied with their work, which resulted in difficulties in building professional relationships (Koerich et al., 2015). Nurses stated that they were not involved in the transition of adolescents with HIV because physicians or medical professionals conducted planning and implementation in both the child and the adult services, even though HPs believed that nurses were the most proficient services across both disciplines. As a result, transitioning adolescents with HIV was poorly organised, as nurses stated that there was a lack of preparation to welcome adolescents with HIV into the adult care setting. This study also showed that referral services for adults were better than children's services as the childhood clinic did not provide multidisciplinary care (Koerich et al., 2015).

A cross-sectional survey of 12 public health clinics in South Africa showed that not all these clinics provided an integrated healthcare service. While a variety of services had been provided for HIV mothers and their babies, there was also considerable fragmentation of care (Haskins et al., 2016). Mothers and their children often left the clinic without seeing a nurse to screen the child's growth and development (Haskins et al., 2016). In other studies, nurses reported that HIV care for children in South Africa was fragmented because children and their families needed to see different health professionals to receive the services they needed (Horwood et al., 2010b). For example, South Africa established a PMTCT programme in primary healthcare clinics to provide HIV care services for mothers and children on Fridays. The problem was that if those children were sick, health professionals would send them to and fro to receive their care services according to their ailments. This, in turn, caused sub-optimal compliance (Horwood et al., 2010b).

The provision of care for children with HIV in developing countries and LMICs involved an inadequate referral system and coordination, insufficient transition care for adolescents, and being sent to see different physicians. The delivery of HIV care for children was also centred around the doctor. These factors acted as barriers to the delivery of HIV care for children, leading to fragmentation in care and services.

Facilitators for Care

This review also identified the factors that contributed to improved HIV care and health outcomes for children with HIV. The sub-theme of facilitators for care included professional nursing practice, professional development for nurses, love and family support, disclosure of HIV status, ARV treatment, home-based care, nursing consultation and counselling, and family and community empowerment as facilitators for supporting optimum HIV care for children.

Professional Nursing Practice

The sub-theme of professional nursing practice relates to nurses' professional attitudes towards children with HIV, and their provision of respectful care. Five articles highlighted how professional attitudes and practices of nurses, including empathy, respect, and communication influence the care given to children with HIV (Achema & Ncama, 2016a, 2016b; Campbell et al., 2011; Koerich et al., 2015). Being empathetic improves the positive interactions between nurses and children with HIV, and helps the children to be more relaxed and cooperative (Achema & Ncama, 2016a; Campbell et al., 2011; Richter et al., 2012). Examples of providing empathy reported by nurses in both qualitative studies conducted in South Africa and Zimbabwe included sensitive touch, kindness, normalising the child's care, and being tolerant and encouraging (Achema & Ncama, 2016a; Campbell et al., 2011). Zimbabwean nurses recognised that being friendly and developing responsive care for children contributed to building a trusting relationship between nurses and clients (Campbell et al., 2011).

Respect is a foundational element of professional nursing practice. Despite having a diagnosis of HIV, these children deserve respect. Nurses stated that they should provide care for children with HIV in the same manner as they provide care for children without HIV (Campbell et al., 2011). Respect is evident when nurses treat the HIV-positive child as a normal child providing supportive care (Achema & Ncama, 2016a; Campbell et al., 2011). Respect for HIV-positive children assists in establishing good relationships between nurses and clients, which improves patient satisfaction (Campbell et al., 2011).

Good communication and listening skills can assist nurses to improve their care for HIV-positive children and their families. Four articles reported that communication and listening skills promoted comfort for clients and encouraged HIV-positive children and their parents to engage in their care (Achema & Ncama, 2016a; Campbell et al., 2011; Koerich et al., 2015; Richter, Chandan & Rochat, 2009). Koerich et al. (2015) undertook a qualitative study to describe the characteristics of management for adolescents with HIV. Koerich et al. (2015) stated that effective communication between nurses, adolescents, and the multidisciplinary team should be ensured to support the humane transition of the adolescent to adulthood. This, in turn, helps to strengthen continuity of care, and also promotes adherence of the adolescent to their recommended therapy (Koerich et al., 2015).

Furthermore, Campbell et al. (2011) reported that being friendly and shaking hands with patients builds the relationship between nurses and children, supporting positive clinical interaction. However, in another study, caregivers reported that nurses often did not listen to what the patients were trying to tell them. Due to the demands of the hospital-based nurses, they did not have time to effectively communicate with the children in their care (Govender et al., 2006). Poor communication has been shown to impair adherence to therapy for children with HIV in a rural health facility in Zimbabwe (Campbell et al., 2012). Families of children with HIV also expressed dissatisfaction when the nurses failed to listen to them. For example,

> *The nurse might just tell the patients to go on bed rest without listening to what the patient has to say (Patients, a government hospital, FG) (Campbell et al., 2011 p.179).*

As shown, empathy, respect, friendliness, kindness, and responsiveness to care are professional attributes of nursing which enhance professional nursing practice and positively influence the quality of care for children with HIV. An important professional nursing skill is good communication which relates to active listening, being friendly and shaking hands, and establishing friendly communication with the child, which promotes effective communication and the building of a trusting relationship between the nurse and the child.

Professional Development for Nurses

Professional development of nurses incorporates the updating of knowledge and skills, working in interdisciplinary teams, and supervising nursing care to support a better quality of care for children with HIV. Three studies recommended that updating knowledge and training courses may assist in improving nursing competencies to positively support nurses in the care of children with HIV (Horwood et al., 2010b; Olaleye et al., 2016; Richter, Chandan & Rochat, 2009). A focus group discussion among South African nurses recommended that training in taking blood samples from children would improve nurses' skills, enabling them to collect specimens and perform HIV testing of children to obtain accurate results (Olaleye et al., 2016). Similarly, Horwood et al. (2010b) recommended that nurses need to update their knowledge on HIV and attend training on HIV-AIDS counselling to improve their care and their supervision of others. Koerich et al. (2015) stated that nurses must update their knowledge in this area and enhance their professional performance and nursing duties to support the care of adolescents with HIV. Therefore, knowledge and skills development, collaboration with the interdisciplinary team, the implementation of continuity of care, and an increase in professional support for nurses can lead to improvements in the care of children with HIV.

Love and Family Support

Love and support from family can provide a positive contribution to the care for children with HIV. According to Achema and Ncama (2016a), the family should accept and treat children with HIV as a normal child in the home. Family members should provide love and support for children with HIV to reduce stigma because the family unit is what helps children to identify and fulfil their needs in the home setting (Achema & Ncama, 2016b; Campbell et al., 2012). As part of family support, Campbell et al. (2012) reported that children, who have a responsible adult who lives in the same house and understands the child's progress, can understand the progress of HIV, and can work collaboratively with a nurse to establish continuity of care (Campbell et al., 2012). Furthermore, families believed that if they looked after their children with HIV, they would be rewarded by God (Campbell et al., 2012). However, the tasks or responsibilities of the adult as a treatment partner of the child with HIV has not been well-defined (Campbell et al., 2012).

The need for comprehensive care

This review has shown that inadequate multidisciplinary collaboration in healthcare causes fragmented provision of care for children with HIV. Due to fragmentation of care, the findings of this review have also identified that the delivery of comprehensive care for children with HIV positively supports optimal health outcomes. According to Koerich et al. (2015), nurses described that seeing adolescents with HIV as a whole being was the best way to support comprehensive care. Furthermore, nurses described that working collaboratively with other health professionals supported their comprehensive care for adolescents with HIV (Koerich et al., 2015). For instance, nurses stated:

> *… continuity of care should be implemented for adolescents with HIV before they are discharged. I think we should implement continuity, a contact before these people leave the child service and come to us […] teamwork means to me that each professional can contribute, then we exchange about the case. So you do not see it only in parts. For me, nowadays, it is the best way to work, it is to work in an interdisciplinary team [...] performing comprehensive care, looking at the human being as a whole being (Koerich et al., 2015 p. 120).*

In most studies, nurses identified a variety of interventions to tackle the problem of care fragmentation among children and adolescents with HIV in the healthcare setting. These interventions included family counselling and education, providing a supportive environment, palliative care, psychosocial support for children and caregivers, transition care for adolescents with HIV, enhancing communication skills with children, nursing consultations, and supporting optimal ARV adherence and health outcomes (Achema & Ncama, 2016b; Campbell et al., 2011; Campbell et al., 2012; Govender et al., 2006; Koerich et al., 2015; Richter, Chandan & Rochat, 2009).

Furthermore, HPs stated that adolescents with HIV need privacy and friendly services to discuss sexual health and condom use. They stated that nurses play an essential role in providing this service (Koerich et al., 2015). A qualitative study in a paediatric ward with the use of observation and video documentation suggested that good home-based care through discharge planning would reduce the need for repeat hospitalisation for children with HIV (Richter, Chandan & Rochat, 2009). Discharge information for caregivers of children with HIV should include information on monitoring their children, how to promote healthy nutrition, and how to administer medication. Home-based care may support the care for children with HIV from the healthcare facility through to the home level.

Caregivers stated that despite the need for antiretroviral therapy, children with HIV also needed supportive care. Such care should cover nutrition, education, psychosocial support, and family and community support because many children with HIV were orphaned and did not have enough money to provide for their care at home (Achema & Ncama, 2016a, 2016b).

Disclosure of HIV status

This review earlier identified that stigma was related to not disclosing the child's HIV status to them. However, disclosure of HIV status within families increased the uptake of HIV treatment. Two studies indicated that children who understood their HIV status actively took part in HIV care (Campbell et al., 2011; Campbell et al., 2012). Snowball sampling was used to enrol 40 Zimbabwean guardians of children taking ARV and found that well-informed children with HIV reminded their caregivers of review dates. This study also found that disclosure improves the awareness of children to pay attention to the advice offered by healthcare providers during consultations (Campbell et al., 2012). Disclosure of HIV status allowed the children to pay attention to their ARV adherence and to attend the monthly consultations (Campbell et al., 2012). According to Koerich et al. (2015), adolescents with HIV have a right to know their diagnosis, so health providers should encourage families to disclose the HIV diagnosis to motivate and have open relationships with family members.

ARV treatment

ARV therapy is an effective treatment for keeping children with HIV healthy (Achema & Ncama, 2016a; Campbell et al., 2012). Using interviews and focus group discussions with 25 nurses and 40 guardians of children on ARV treatment, Campbell et al. (2012) found that children with HIV could access free ARV in Zimbabwe and most of the caregivers rarely experienced stock-outs of ARV drugs and related supplies. NGOs have participated in supporting ARV adherence among children with HIV through providing health education about HIV-AIDS and stigma reduction, child-centred and community-based counselling and HIV testing programmes, and distributing nutritional support for children with HIV aimed specifically at children living in poverty (Campbell et al., 2012). CD4 machines were also available in the district health facilities to monitor the effectiveness of treatment and to determine the stage of HIV progression, which contributed to the monitoring of the side-effects of ARV therapy (Campbell et al., 2012). Regular ARV availability benefitted not only children with HIV, but also motivated nurses to play an effective role in prolonging the child's health (Campbell et al., 2012).

However, nurses stated that caregivers often had challenges in maintaining adherence to ARV treatments due to distance and financial difficulties, as described under the sub-heading: socioeconomic status, health literacy and knowledge, access to care, and social norms. Social norms that contributed to child adherence included commitment and support among children, their families and/or caregivers, the community, NGOs, and HPs to improve care, and a recognition that children with HIV have a right to health and need to be treated as normal children (Campbell et al., 2012).

Moreover, nurses discussed the strategies which enhanced adherence to the therapy, including establishing a ‘treatment partner’ who would be an adult living in the same house as the child to assist with their care and to collaborate with nursing staff for monitoring treatment, support groups, counselling, and education on paediatric ARV and adherence, and enhancing the interaction between the family and the nurse (Campbell et al., 2012). Health professionals, therefore, suggested that strategies such as guardian support and support groups facilitate adherence to therapy for the children while strengthening the trust of guardians in the healthcare service (Campbell et al., 2012).

Nursing consultation and counselling

This review identified that nurses provided consultations and counselling for children and adolescents with HIV in the healthcare setting. This review also highlighted that the terms “consultation” and “counselling” had slightly different meanings. Referring to examples of the interventions discussed in these articles, a “consultation” referred to a formal discussion between a nurse and a child with HIV about a particular health problem. Meanwhile, “counselling” referred to a collaborative activity between nurses and children and adolescents with HIV and their families. Three articles reported that nursing consultations positively assisted care for children with HIV (Campbell et al., 2011; Campbell et al., 2012; Koerich et al., 2015). Campbell et al. (2011) found that nursing consultations were implemented every month in Zimbabwe to review the progress of children with ART. An exploratory study using semi-structured interviews and participant observation among nurses and other HPs conducted by Koerich et al. (2015), stated that nursing consultations supported the HIV care management of adolescents, by enabling discussions of medication regimes, sexual and reproductive health, and condom use. Furthermore, Koerich et al. (2015) described that discussions about medication therapy management and sexual health were part of the post-consultation process, which the adolescents with HIV preferred. However, in a subsequent study, they found that parents often did not attend the monthly consultations due to economic barriers, even though the price of the consultations was considered affordable at one to two dollars for each visit (Campbell et al., 2012).

Four articles identified the importance of counselling (Campbell et al., 2011; Campbell et al., 2012; Koerich et al., 2015; Olaleye et al., 2016). Achema and Ncama (2016a) found that counselling cooperatively enhanced the care of children with HIV. A qualitative study conducted in government-operated and Christian hospitals in Zimbabwe found that spiritual counselling along with praying together was applied in the Christian hospital before children with HIV received their treatment (Campbell et al., 2011). Additionally, as part of the informed consent process, Campbell et al. (2011) found that maintaining the confidentiality of the positive status of children with HIV was fundamental to ethical nursing practice. Nurses, therefore, played a significant role in discussing the importance of HIV testing for clients and their families. However, South African nurses reported that testing healthy children wasted resources unless they were suffering from pneumonia, diarrhea, or loss of body weight (Olaleye et al., 2016).

As well as HIV counselling and testing, the findings of this review highlighted the importance of informed consent and maintaining confidentiality. Two articles identified informed consent as the first step before HIV counselling and testing (Horwood et al., 2010b; Olaleye et al., 2016). Olaleye et al. (2016) claimed that the need for informed consent from a parent or guardian was a significant barrier to the uptake of HIV counselling and testing in children up to 8 years of age. A qualitative study describing attitudes about, and experiences of, the implementation of a routine check for children in South Africa, by Horwood et al. (2010b), identified that South African mothers had conflicting perceptions of HIV testing for children. Some South African mothers were keen for their children to be tested for HIV to understand their status and to support their treatment, and could give informed consent as the mothers were also HIV-positive (Horwood et al., 2010b). However, other South African mothers often could not decide on HIV testing for their children until they had permission from other family members. Some even disagreed with getting their children tested even though the children had HIV-related signs and symptoms (Horwood et al., 2010b).

Family and community empowerment

Empowering families and communities has been shown to be beneficial for the care of children with HIV. Five studies reported that involving families, caregivers, and the community can result in supportive care for children with HIV (Achema & Ncama, 2016a, 2016b; Campbell et al., 2012; Olaleye et al., 2016; Richter, Chandan & Rochat, 2009). For example, nurses should involve caregivers in the care of their children, particularly in relation to bathing, feeding, dressing, and comforting children while they are in hospital (Richter, Chandan & Rochat, 2009).

Furthermore, the knowledge of caregivers on how to sustain adequate nutrition, how to administer medication, how to identify the side-effects of treatment, and how to provide follow-up care needs to be developed to support better outcomes for children with HIV (Richter, Chandan & Rochat, 2009). If these things could be achieved, they would promote continuity of care for children at home, and reduce recurrent hospitalisations (Richter, Chandan & Rochat, 2009). However, Govender et al. (2006) claimed that empowering mothers in the care of their children is not easy. They found that mothers of children with HIV are severely stressed, and often spend their time sitting by themselves, not communicating with nurses, and not participating in the care of their children in the hospital (Govender et al., 2006).

Two qualitative studies found that community activities for children with HIV and their families positively supported the care of the children (Campbell et al., 2012; Olaleye et al., 2016). According to Campbell et al. (2012), private organisations in Zimbabwe implemented HIV counselling and testing programs in the community to support the identification and care of HIV-positive children. They reported that an education campaign on HIV-AIDS could minimise stigma in the community (Campbell et al., 2012). Most people were well-informed through educational campaigns about how HIV is spread; however, stigmatisations still occurred. Similarly, Olaleye et al. (2016) reported that health education in the community using mass media could reduce stigma and improve the obtaining of consent for HIV counselling and testing for older children. However, people in the community still did not accept patients with HIV, and disclosure was still a problem. For example, mothers did not want to tell their child about their own HIV status or reveal the child’s HIV status to them (Olaleye et al., 2016).

Discussion

The findings from the reviewed studies found barriers to, and facilitators for, care. These findings were derived mainly from descriptive studies based on the perspectives and insights of individual nurses, caregivers, and other HPs, rather than from the perspectives of children. The existing body of evidence has informed the barriers to, and facilitators for, linkage care, leading to discontinuities or fragmentation of care for children with HIV.

Barriers to care included low socioeconomic status, family health literacy and knowledge, and stigma and discrimination. Economic and social conditions are social determinants of health which contribute to health outcome inequalities (LaBrec, Butterfield & Corporation, 2017). Furthermore, poor referral systems and coordination, and lack of resources including insufficient facilities, lack of human resources and guidelines, and the limited knowledge and skills of HPs, caused sub-optimal healthcare delivery. The findings also revealed that adolescents with HIV did not receive transition care and sexual reproductive health education, caused by a lack of continuity of care. Poorly coordinated and fragmented care resulted in poor outcomes for patients with complex bio-psychosocial needs, such as people with HIV (Lloyd et al., 2017). Barriers to care in this review could be grouped into individual, health professional, and healthcare system levels, which in turn, influence discontinuous HIV care for children.

As well as barriers to care, the review findings also suggested care interventions to support optimal care for children with HIV and their caregivers, such as a need for supportive care and enhancing professional nursing practice and development. Comprehensive care is an essential step for HIV control and disease outcomes. This care requires interventions and programmes to ensure that patients with HIV access medical care, psychological and social services (Sanga et al., 2019).

Most of the reviewed studies explored HIV care from HP's perspectives, while few studies have explored the issue from the viewpoint of caregivers, with a far smaller number exploring the perspectives of children with HIV. The studies on the provision of care for children with HIV in this review were also primarily conducted in hospitals, so the review findings may not be able to be generalised. However, exploring children’s experiences as the main subject of the research would provide them with an opportunity to speak about their experiences and needs (Harcourt & Sargeant, 2016). Children’s involvement conveys the notion of children’s right to express themselves (The United Nations International Children's Emergency Fund, 2019a). Input from children's perspectives will provide benefit by being considered in the care planning process, ensuring that children will receive care based on their needs. Future research needs to focus on evaluating HIV care for children across the continuum.

In the context of Indonesia, most of the studies on children with HIV have focused on the experience of living with HIV, stigma and discrimination, and ARV treatment (Oyaitou, Dedi & R, 2019). Published articles on continuity-of-care for children with HIV is limited. These review findings warrant further investigation to explore the child’s voice or perspectives combined with those of families and health professionals across a wide range of healthcare settings to determine the provision of care for children with HIV across the continuum in Indonesia. It is important to explore the different perspectives and experiences across various healthcare settings to gain the whole picture of HIV care across the continuum of healthcare services. Therefore, the current study aims to address these gaps in knowledge.

Chapter Summary

Children with HIV face considerable challenges to their care due to low socioeconomic status, inadequate resources, stigma and discrimination, and the fragmentation of services. Additionally, shortages of nurses and high workloads cause burnout, emotional distress, and errors leading to ineffective care, such as erroneous documentation, and less interaction with children.

Besides barriers to comprehensive care, facilitators of effective care include positive attributes of professional nursing practice, such as empathy, respect, good communication skills, and professional development for nurses, to support the optimal care of children with HIV. Providing family support and love to the children by accepting children who are HIV-positive as a healthy child and providing comprehensive care can improve children’s health outcomes. HPs, in this review, suggested the provision of supportive care and the importance of professional nursing practice and development, supporting optimal care delivery.

This chapter has also identified the limitations of the reviewed articles in relation to the perspectives of children and their families as well as a lack of recognition in the area of HIV care service provision across multiple care settings, such as in the hospitals and in the community, which help to understand continuity in healthcare. However, it is interesting to note that no studies from Indonesia were identified in the search results. As well, a gap in knowledge was identified from the review, warranting further research to investigate continuity of care for children with HIV and their families.

The following chapter presents the research methodology, including an overview of the constructivist paradigm complete with its underlying ontological and epistemological assumptions, and the theoretical perspective and methods used to meet the aim of the study.

CHAPTER 3
RESEARCH METHODOLOGY

This study aims to explore the subjective experiences and perspectives of children with HIV, their families, and healthcare professionals; and to generate a substantive grounded theory on HIV care for children and their families across the continuum in the Indonesian context. The literature reviewed in Chapter Two identified that the majority of studies focusing on the provision of care for children in developing countries and/or LMICs indicated that the provision of HIV care for children was inadequate, leading to the fragmentation of care. The reviewed literature did not explain the experience of care from the perspective of children with HIV and their families across multiple healthcare settings. In Indonesia, existing studies discussed stigma, discrimination, and ARV treatment. There are minimal published studies available on how children with HIV experience care across the continuum. This current study sets out to address this knowledge gap and the limitations identified in the reviewed literature, which leads to an exploration of the experiences of care for children with HIV and their families across the continuum in the Indonesian context.

Chapter Three presents a description of the research design related to the constructivist philosophical paradigm and the grounded theory method used to construct a theory to explain the experience of care for Indonesian children with HIV and their families across the continuum. This constructivist paradigm is underpinned by the philosophical assumptions of a relativist ontology and an interpretivist epistemology. This chapter also discusses symbolic interaction as the theoretical perspective upon which grounded theory is based (Charmaz, 2014a). The chapter concludes with an explanation of the decision to use the constructivist paradigm and the grounded theory method to meet the aim of the study.

The Constructivist Paradigm

The study employs qualitative research in order to explain the phenomena under examination, the situation for people, and social life in a natural setting by revealing the meanings behind people's subjective experiences (Yilmaz, 2013) by exploring the ‘insider view’ of the participants (Guba & Lincoln, 1994). This study aims to explore the subjective experiences and perspectives of children with HIV and their families; and to generate a substantive grounded theory on HIV care across the continuum for children and their families in the Indonesian context. Exploring views from participants constructed meanings that included experiences and behaviour, thereby increasing the understanding of the HIV care for children in Indonesia. Qualitative research was chosen for this study because it helps the researcher and the reader to understand the participants' beliefs in depth, rather than the concrete realities of objects which rely on numerical data (Streubert & Carpenter, 2011). Qualitative researchers adopt a person-centred perspective and view the individual participant's perspective holistically and naturally (Holloway & Wheeler, 2010; Yilmaz, 2013). Qualitative research operates:

> *… within a naturalistic, interpretive domain, guided by standards and principles of a relativist orientation, constructivist ontology, and an interpretive epistemology (Sarantokos, 2013, p. 36).*

The researcher positioned this qualitative study within a constructivist philosophical paradigm to guide the research process. A paradigm is crucial as it guides the research direction and outcomes (Creswell, Poth & Cheraghi, 2017; Francis, Chapman & Whitehead, 2016; Guba & Lincoln, 1994). The paradigm consists of beliefs about the nature of reality (ontology), how the relationship is between the researcher and the participants (epistemology), and how knowledge is constructed (methodology) (Davies & Fisher, 2018; Khanal, 2019). Numerous studies have recognised a variety of research paradigms, and the conceptualisation of each paradigm often overlaps with others (Adom, Yeboah & Ankrah, 2016; Davies & Fisher, 2018; Denzin & Lincoln, 2005; Kelly, Dowling & Millar, 2018). However, the four basic paradigms offered by Guba and Lincoln (1994) are the most frequently cited and discussed among qualitative researchers (Annells, 1996). These paradigms are positivism, post-positivism, critical theory, and constructivism (Guba & Lincoln, 1994). This study follows Guba and Lincoln (1994) process of generating inquiry through a constructivist paradigm to achieve the aim of this study.

Adopting Constructivism Paradigm to Constructivist Grounded Theory

This study used constructivist grounded theory to underpin the research, guided by a relativist ontology and an interpretivist epistemology (Charmaz, 2014a; Jeon, 2004). A relativist ontology accepts the subjective reality of the individual (Annells, 1996; Guba & Lincoln, 1994). An interpretivist epistemology underpinned by symbolic interactionism was used to understand the subjectivity of the participants' perspectives, and the participants' actions and interactions in their everyday lives (Charmaz, 2014a; Jeon, 2004). The following section discusses each of these philosophical tenets and a justification for the use of constructivist grounded theory is embedded within.

Ontological Perspectives and Rationale for this Study

The ontological position of this study is relativism which interprets reality as being subjective, and this differs for every person (Guba & Lincoln, 1994; Scotland, 2012). Constructivist grounded theory accepts multiple individual realities (Gardner, Fedoruk & McCutcheon, 2013; Mills, Bonner & Francis, 2006b) and appreciates the subjective experience of reality and the process of co-constructing meanings (Charmaz, 2014a; Mills, Bonner & Francis, 2006b). From a qualitative perspective, there are multiple subjective realities in understanding HIV care for children across the continuum from various perspectives. This study interviewed people who had three individual subjective perspectives to determine meanings about the experience of children with HIV and their families on HIV care across the continuum in the Indonesian context. These three different sets of participants included children with HIV, their families, and HPs. Subjective data collected through interviews with the three cohorts helped to construct the realities and knowledge of HIV care for children across the continuum. These multiple realities were constructed through the interactions between the participants and their world in the social context (Burr, 1995; Crotty, 1998; Scotland, 2012) and are based on social and cultural perspectives (Achora & Matua, 2016; Mead, 1934). These constructions helped to develop an insight into how children with HIV and their families experienced and participated in their care and their interactions with health professionals across the continuum. The rationale behind the use of a relativist ontology will be explained from the perspective of caring in nursing.

The rationale from the perspective of caring in nursing

The experience of patients is widely recognised as a component of a quality healthcare system and is directly related to the caring process (Edvardsson, Watt & Pearce, 2017). The caring process involves patients as the recipients of care, nurses, and the attributes and outcomes of care. The attributes of caring were associated with nursing practice and interpersonal and intimate relationships (Edvardsson, Watt & Pearce, 2017). The outcomes of caring for the recipient of care include physical and mental well-being.

Understanding the nature of caring in nursing, HIV care for children across the continuum is a reciprocal social process that involves the inter-relationship between the children with HIV, the families, the nurses, and other healthcare professionals within the healthcare setting. This social process influences the relationship that the individual patient and their family have with nurses and other healthcare professionals. This study assumed that there would be multiple realities from which one child with HIV and their family's experiences would be different from another. Through the subjective experiences of children with HIV, their families, and health professionals, it was expected that these would co-create an understanding by providing enough thick description to inform meaning and desired actions.

Constructivist grounded theory was considered to be appropriate to meet the aim of this study. This study did not follow Strauss and Corbin's grounded theory approach because they accepted a combination of objectivism and reflexivity (Timonen, Foley & Conlon, 2018). Similarly, this study did not follow classical Glaserian grounded theory. On the other hand, constructivist grounded theory contradicts classical grounded theory, denying the existence of objective reality (Khanal, 2019; Mills, Bonner & Francis, 2006b) and the positivist assumptions of (Glaser & Strauss, 1967). Ontologically, classical Glaserian grounded theory is founded on the premise of critical realism and post-positivism (Mills, Bonner & Francis, 2006a). Classical grounded theory has its roots in both positivism and pragmatism (Gardner, Fedoruk & McCutcheon, 2013), or pragmatism view leaning toward critical realism (Annells, 1996). Critical realism assumes that the nature of reality is a 'real' reality and so searches for 'true meaning' (Annells, 1996), also recognising that reality is objective and measurable (Siti Soraya Lin Binti Abdullah Kamal, 2019). Positivism refers to an ontology in which one reality can be studied in its individual parts and independent of our minds (Lincoln & Guba, 2013). The reality is what the researcher collects, codes, and analyses exactly what it is to be used for (Glaser, 2002). Classical grounded theory gives little attention to the relationship with the participants and views participants' words and actions in an objective manner (Mills, Bonner & Francis, 2006a). On the other hand, constructivist grounded theory refutes an objective analysis of subjective experience and positions the researcher as a partner in the research alongside the participant (Mills, Bonner & Francis, 2006a). For these reasons, constructivist grounded theory is best suited for this study.

Epistemological Perspectives

The epistemological position of this study is interpretive. Interpretivism embraces two dimensions that include the complex process by which all of us in daily life interpret the meanings of our actions and those of others with whom we interact (Schwandt, 2000). Individuals generate knowledge based on individual perspectives relating to lived experiences, behaviours, and activities (Jennieffer, 2013), while Lincoln and Guba (2013) stated that interpretivism seeks out a relativism between multiple realities that are co-created by the mind(s) of the researcher and the participants. Reality is the result of the participants' perspectives, which is co-constructed in social interaction between social agents (Schwandt, 1998).

The interpretivist epistemology is used in this study because the researcher and the participants engaged in meaningful dialogue using interpretation to construct a detailed understanding or knowledge of HIV care for children across the continuum. The epistemology of this constructivist grounded theory recognises the subjective inter-relationships between the researcher and the participants in the process of co-constructing meaning (Charmaz, 2014a; Mills, Bonner & Francis, 2006b; Siti Soraya Lin Binti Abdullah Kamal, 2019).

This study set up interaction between the researcher and the participants during the interview process to reconstruct the self-understandings of the participants engaged in particular actions (Schwandt, 2000), and to understand meanings and actions and how people construct them (Charmaz, 2014a). The researcher explored the subjective experiences of the participants, including their feelings, beliefs, language, desires, their institutional context, practices on HIV care across the continuum which was contextually situated in an Indonesian healthcare setting. Schwandt (2000, p. 193) explained that there are three ways of conceiving the notion of interpretive understanding, including viewing human action as meaningful, evincing an ethical commitment in the form of respect for and fidelity to the life world, and emphasising the contribution of human subjectivity. In order to understand this, the researcher needs to grasp the complexity of beliefs, forms of life, language, desires, institutional context, practices, and language (Schwandt, 2000).

As part of the interview process, the researcher developed a position of equity within the relationship. The researcher and the participants developed mutual meaning-making by answering questions during the interviews and afterwards. When children with HIV, their families, and HPs were involved together, deep meanings were constructed. This study understood that meanings and information about a situation aligned with social interaction, including participants' experiences, behaviours, and actions in HIV care. For example, when children with HIV and their families attended the physician's consultation service, they may have had different experiences within the healthcare context of professional and patient interaction. Collective meanings shared by all the participants in the experience of HIV care for children across the continuum in this study informed different perspectives from others which aligned with their values, beliefs, and actions in different situations and circumstances. Therefore, constructivist grounded theory recognises the mutual creation of knowledge by the researcher and the participants, which focuses on interpretive understandings of subjective meaning (Charmaz, 2000; Siti Soraya Lin Binti Abdullah Kamal, 2019).

Besides the mutual interaction during the interview process, this study acknowledges the interaction between the researcher and the participants' data or narratives for constructing meaning and interpretations. The researcher interprets, analyses, and seeks an understanding according to the subjective experiences of the participants (Gardner, Fedoruk & McCutcheon, 2013). These constructions help the researcher to inform the development of a substantive grounded theory, or a detailed understanding, through sharing subjective experiences of reality, which is socially constructed and modified through meaning and interpretation. The researcher gains knowledge about the meaning of human interaction through an intellectual process (Schwandt, 2000).

The following section briefly presents the philosophical perspectives embedded within interpretive paradigm in constructivist grounded theory. Understanding that varying perspectives exist, the researcher gains a comprehensive understanding of these perspectives and confirms the most appropriate theoretical framework for a grounded theory study.

The Philosophical Perspectives Embedded within Interpretivism in the Grounded Theory Method

Interpretive threads in the social sciences encompasses a range of perspectives, such as social constructionism and symbolic interactionism (Charmaz, 2014a). Social constructionism and symbolic interactionism are embedded in the interpretive paradigm (Crotty, 1998). These perspectives then inform other research approaches, including constructivist grounded theory (Charmaz, 2014a).

Grounded theory deals with the conceptualisation of the nature of reality and epistemology (Achora & Matua, 2016). There are three primary approaches to grounded theory: Glaser and Strauss; Strauss and Corbin; and Charmaz. Grounded theory was initially developed by sociologists Glaser and Strauss in 1967 in *The Discovery of Grounded Theory* (Glaser & Strauss, 1967). Since then, grounded theory has diverged into two streams, those who follow Glaser and Strauss's approach, known as Glaserian or classical grounded theory, and those who follow Strauss and Corbin's approach, known as Straussian grounded theory (Charmaz, 2014a; Stern, 2013; Streubert & Carpenter, 2011). More recently, through the 1990s and early in the 21st century (Gardner, Fedoruk & McCutcheon, 2013), Charmaz, a student of Strauss, continued the development of grounded theory and has been central in articulating constructivist grounded theory (Birks & Mills, 2011; Schreiber & Martin, 2013).

The three versions of grounded theory have different philosophical roots. Classical or Glaserian grounded theory did not specifically discuss theory or theoretical perspectives (Stern, 2013); however, Glaser and Strauss (1967) stated that other grounded theory researchers published their methods for generating theory. Glaser and Strauss (1967) conveyed the dominance of positivistic quantitative research in their studies (Charmaz, 2014a). Post-positivists believe in multiple perspectives, and present their studies through the structure of quantitative research (Creswell, Poth & Cheraghi, 2017). Straussian grounded theory is informed by the philosophies of pragmatism and symbolic interactionism (Corbin, 2013). Strauss used Blumer's (1967) symbolic interactionism as his theoretical perspective (Corbin, 2013). Strauss stated that:

> *Blumer talked about concepts, theory, and interaction, but he never developed a method for putting these together in research (Corbin, 2013, p.170).*

In Strauss's philosophy, people are active recipients of events and situations, and have to solve the problems in their life (Corbin, 2013). Strauss believed that action not only focused on physical activities but also covered thought and action (Corbin, 2013). Action or interaction leads to change in the situation that needs further self- or other interaction. It will continue to develop until resolution of the problem (Corbin, 2013). Charmaz (2014a) agreed with Strauss and Corbin who were more nuanced than Glaser by incorporating the experiences of participants into the research (Kenny & Fourie, 2015) and acknowledging the researchers. Grounded theory used symbolic interactionism and Marxist and phenomenological perspectives to reveal that people derive meaning from shared interactions (Charmaz, 1990). There are three dominant grounded theory methods, and symbolic interactionism is the philosophical root of grounded theory.

Many constructivist grounded theorists have conducted constructivist grounded theory studies. Various philosophical perspectives have influenced numerous constructivist grounded theory studies. These philosophies have included social constructionism, symbolic interaction, and pragmatism (Charmaz, 2014a; Giles, 2015; Lee et al., 2018; Mills, Bonner & Francis, 2006a; Robbins, 2016; Trisyani, 2016). All these philosophies have their roots in the interpretivist philosophy (Charmaz, 2014a). For example, Charmaz developed the pragmatist underpinnings of grounded theory to include interpretive analysis (Charmaz, 2014a; Mills et al., 2007). Annells (1996) stated that pragmatism is based on symbolic interactionism, with an emphasis on action and process (McCann & Polacsek, 2018) and the concept of 'the self' (Annells, 1996; Mead, 1962). Furthermore, symbolic interactionism is based on the notion that human action constructs the self, the situation, and society through social interaction (Annells, 1996; Charmaz, 2014a; Chenitz & Swanson, 1986). Showing that pragmatism is compatible with symbolic interactionism. Symbolic interactionism is compatible with the philosophical assumption of interpretivism as both philosophies focus on how people act and interact in natural settings (Annells, 1996; Oliver, 2012).

Charmaz's constructivist grounded theory studies are also in line with social constructivists such as Lev Vygotsky (1962) and Yvonna Lincoln (2013) (Charmaz, 2014a). Through her study, "Discovering Chronic Illness", Charmaz used social constructionism in four stages: (1) reshaping and refining of the data and the research; (2) raising terms of concepts; (3) asking more conceptual questions on a generic level; (4) making further discoveries and clarifying concepts through writing and rewriting (Charmaz, 1990, p. 1162). Hence, Charmaz positioned herself as a critical interpretivist (Mills, Bonner & Francis, 2006b). Chen, Shek and Bu (2011) described the term social constructionism as being associated with the publication of 'The Social Construction of Reality' by Berger and Luckmann (1966), who asserted that people create and sustain phenomena together through social practices by focusing on how people act and create a practice in their social life. Social constructionism refers to all knowledge and meaningful reality being contingent upon human practices and being constructed in and out of the interaction between human beings within their social context (Crotty, 1998). Guba and Lincoln labelled constructionism as naturalistic, hermeneutic, and interpretive (Broido & Manning, 2002; Guba & Lincoln, 1989). Showing that constructionism and interpretivism are centred on subjectivism, which is based on subjective experience .

Burr (1995, 2003); Crotty (1998) distinguish between social constructionism and social constructivism. Social constructionism is the development of phenomena relative to social context and accepts both realism and relativism (Burr, 2003; Crotty, 1998). Realism recognises independent reality without interpretation, while relativism recognises multiple realities; there are multiple interpretation of those realities and language is seen to generate reality (Burr, 2003). Meanwhile, social constructivism is the process of how individual make meaning of their experiences within a social context (Burr, 1995, 2003; Crotty, 1998).

Moreover, Schwandt (2000) explained that social constructionism is constructivists, who believed that the mind is active in the construction of knowledge. In this sense, a social constructionist constructs concepts, models, and schemes to make sense of experience through shared understandings, practices, language, and so forth (Schwandt, 2000). Schwandt (2000) classified constructionism into 'weak' and 'strong' constructionist perspectives. 'Weak' constructionism argues for a social epistemology in which ideology and values are tied to social practices, which avoids the relativist view that any interpretation is as good as another (Schwandt, 2000). Meanwhile, 'strong' or radical constructionism such as that put forward by Denzin, endorses the idea that social constructionism leads to an improvement in the human condition (Schwandt, 2000). In Denzin's epistemology, knowledge is the study of world experiences by the historically and culturally situated individual (Schwandt, 2000). Furthermore, Schwandt (2000) labelled social constructionism as constructivists who believe that shared understandings of meaning, language, and experience construct knowledge. Burr (2003), a social constructionist, agreed that knowledge is constructed based on collective meanings between people and their social world to understand experiences.

In summary, the philosophies of symbolic interactionism, pragmatism, constructionism, and constructivism recognise subjectivity. These philosophies are embedded in interpretive philosophy. Therefore, constructivist grounded theory is part of the broader interpretive tradition (Charmaz, 2014a), focusing on the process through which people make sense of their realities (McCann & Polacsek, 2018). The philosophy of symbolic interactionism is used in this constructivist grounded theory study and is described in the following section. Birks and Mills (2011) claimed that subscribing to one version of grounded theory is not necessary. Grounded theory researchers can adopt alternative perspectives rather than following a previously developed idea (Holloway & Wheeler, 2010).

Symbolic Interactionism in Constructivist Grounded Theory Studies

This constructivist grounded theory study applies the principles of symbolic interactionism which helps to construct interpretive insights into the experience of care for children with HIV and their families across the continuum. This study uses symbolic interactionism as a theoretical perspective. This theoretical perspective is not a theory that specifies variables and predicts outcomes (Charmaz, 2014a). However, it is an abstract theoretical perspective of human behaviour that helps the researcher to understand the participants' actions and interactions (Annells, 1996), within a context in which society is created and maintained through repeated meaning-making and interaction among individuals (Carter & Fuller, 2016).

This study is interpretive because reality arises from the interactive process between ‘the self’ (of the participants in this case) and the subjective experiences, actions, and interactions of the participants in their social context (Gardner, Fedoruk & McCutcheon, 2013). Symbolic interactionism will direct the researcher in understanding the participants’ views, experiences, meanings, and actions, and their social interactions during the study (Blumer, 1969; Charmaz, 2014a; Jeon, 2004). This theoretical perspective produces a dynamic understanding of actions and events (Charmaz, 2014a, p. 263), because symbolic interactionism encourages learning about people, places, actions, and problems, and sees people as active human beings engaged in social activities (Charmaz, 2014a; Jeon, 2004).

George Herbert Mead was the ‘founding father’ of symbolic interactionism (1863-1931) (Oliver, 2012). In 1960, Hubert Blumer, a student of Mead, refined and extended the notion of symbolic interactionism (Annells, 1996). Blumer established symbolic interactionism as a research approach that emphasises the concept of the self (Annells, 1996; Mead, 1962), and took the view that social interaction constructs the self, the situation, and society (Annells, 1996; Charmaz, 2014a; Chenitz & Swanson, 1986). Following Blumer, symbolic interactionism is the study of people which is formed through the activities and interactions between them and is an ongoing process of social interaction (Blumer, 1969; Charmaz, 2014a). Blumer’s perspective on symbolic interactionism relies on three core premises (Blumer, 1969):

1) People will act toward things based on the meanings the things have. Things include persons, objects, situations, activities, and a combination of these things;
2) The meaning of things arises from the social interaction between people;
3) Meanings will change through social interaction, and the process of interpretation is used to direct and modify the meanings when individuals deal with the things that they encounter.

Charmaz (2006) endorsed the principles of symbolic interactionism by emphasising meaning, language, interpretation, and interaction. Charmaz (2016) believed that meaning and action are dynamic and inter-related, in which actions shape meaning and meaning evokes action. Furthermore, Charmaz (2014a, pp. 270-271) clarified and extended the premises of Blumer’s symbolic interactionism through three additional premises:

1) ‘Meanings are interpreted through shared language and communication’ (Charmaz, 1980, p. 25);
2) ‘The mediation of meaning in social interaction is distinguished by a continually emerging processual nature’ (Charmaz, 1980, p. 25);
3) ‘The interpretive process becomes explicit when people’s meanings and/or actions become problematic or their situation changes’ (Charmaz 1980; Snow, 2002).

Symbolic interactionism and the grounded theory method complement each other well (Charmaz, 2014a). Symbolic interactionism can inform an analysis of everyday experience and practice, while grounded theory provides the tools to make theoretical sense of these experiences and practices (Charmaz, 2014a).

This makes it appropriate to use symbolic interactionism in guiding the implementation of constructivist grounded theory in a study of HIV care for children and their families across the continuum in the Indonesian context. Symbolic interactionism will allow the researcher to uncover knowledge, grounded in symbolic meaning as a direct result of interactions with others, where the individual participant is continuously interacting with others and evolving through a social process (Straughair, 2019). Stemming from the symbolic interactionist approach, understanding the experience of HIV care for children across the continuum requires an understanding of an individual participant's experiences and how they construct their actions with other people during social interactions. These involve the salient concepts of symbolic interactionism, namely the self, the object and meaning, and social interaction (Aldiabat & Le Navenec, 2011; Blumer, 1969).

Understanding the concepts of self, the object, and meaning helped the researcher to explore the past, present, and future experiences and perspectives of the participants on HIV care for children across the continuum. An individual participant uses ‘self’ to think about the care they have received across the continuum in Indonesian healthcare services. The self is the result of the reflective interaction process (Carlson, 2013), and involves continuous communication between the “I” and the “Me” (Aldiabat & Le Navenec, 2011). Understanding the individual’s “Me” provides insight into how an individual participant engages with the care of children, evaluates the care, and plans for future HIV care for their children, promoting continuity of care for Indonesian children with HIV and their families.

The researcher built meaning from the individual participants by looking for abstract objects, namely the participants’ views, values, beliefs, and situations within the data (Annells, 1996;

Blumer, 1969; Charmaz, 2000; Guba & Lincoln, 1994). The researcher explored the participants' norms, roles, language, and symbols that linked to their actions and interactions in the social process (Annells, 1996; Blumer, 1969; Charmaz, 2000; Guba & Lincoln, 1994). For example, when children with HIV and their families engaged with the new situation of living with HIV for the first time, they had little understanding of their disease. There was a range of beliefs and values which had to be dealt with. The feeling of shock and hopelessness accompanied each situation. An individual participant responds to others based on their understanding of the meaning of behaviours derived from past interactions and anticipated future interactions.

Understanding the participants' language, gestures, and symbolic objects facilitates the shaping of a better understanding of meaning (Carlson, 2013). The researcher interpreted the data through language for analysis and then uses this to present the participants' stories. The participants used different words to share their experiences of their child's care needs and preferences; for example, how the participants perceived living with HIV and how they experienced HIV care and treatment for their children, including their interaction with HPs in the healthcare setting, and how the participants in this study coped with the caregiving process in different circumstances. Furthermore, the researcher used memo writing as the process of internal communication or dialogue to develop thinking, record the conceptualisation of the study, and raise these concepts to theoretical abstraction (Milliken & Schreiber, 2012). Meaning and language helped the researcher to understand the participants' experiences of HIV care across the continuum, supporting continuity of care for children with HIV and their families in the Indonesian context. The researcher then interpreted this knowledge in relation to how and why the participants constructed meaning and action through their ongoing social interaction (Charmaz, 2014a).

In this way, the philosophy of symbolic interactionism is relevant to constructivist grounded theory. Symbolic interactionism provides a perspective through which to study the experience of care for children with HIV and their families across the continuum. By using symbolic interactionism, the researcher can learn about the participants' behaviours through which they construct and engage with the social environment in their daily lives (Milliken & Schreiber, 2012). Symbolic interactionism helped the researcher to understand the participants' actions and interactions in a social process which allowed the researcher to develop an understanding (Straughair, 2019) grounded in symbolic meaning regarding HIV care for children across the continuum. This, in turn, constructed a fully grounded and contextualised theory which explained children with HIV and their families' experiences of HIV care across the continuum.

Research Methodology

Methodology is a strategy for conducting research based on ontological and epistemological foundations (Guba & Lincoln, 1994; Lincoln & Guba, 2013). Guided by an ontological relativism and an epistemological interpretivism, this study used constructivist grounded theory to conduct the research (Achora & Matua, 2016; Birks & Mills, 2011; Charmaz, 2014a; Schwandt, 1998). Charmaz (2000) wrote extensively about constructivist grounded theory. "Constructivism assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and viewed, and aims toward interpretive understanding of the subject's meanings" (Charmaz, 2000, p. 510). Constructivist grounded theory is the most appropriate methodology for this study given its compatibility with the constructivist paradigm. The fundamental contribution of constructivist grounded theory is the creation of a substantive theory, explaining the experience of care for children with HIV and their families across the continuum in the Indonesian context. Grounded theory provides the conceptual overview of phenomenon understudy with grounded interpretation, explanation impacts, underlying causes and effect, focusing on the participant's perspective and gives them the opportunity to articulate their thoughts about issues with understanding ('<CHOOSING-GROUNDED-THEORY-2014.pdf>,'). Therefore, the explicit goal of theory development makes grounded theory unique and is well-suited to the aim of this study among other qualitative methods.

Charmaz (2000) was the first researcher to explicitly coin the term constructivist grounded theory. She used the term "constructivist" to acknowledge the involvement of the subjectivity of the researcher in the construction and interpretation of data (Charmaz, 2014a). Constructivist grounded theory is part of the broader interpretive tradition and is based on four principles: (a) reality is made up of multiple interpretations; (b) reality is constructed through the use of language in social interaction; (c) understanding of the interpretive process in which people act and interact with their realities through social interaction, and develop dialectical relationships between what they do, think, and feel; (d) knowledge is constructed together between the researcher, the participants, and the research-practice during the study process, and the development of explanations of concepts is derived from the empirical data (Achora & Matua, 2016; Birks & Mills, 2011; Charmaz, 2006, 2014a; Giles, de Lacey & Muir-Cochrane, 2016b; Holloway & Wheeler, 2010; Keane, 2014). Each of these principles presents the ways in which constructivist grounded theory can provide philosophical assumptions for a study of care experiences for children with HIV and their families across the continuum (see Table 2).

Table 2: Philosophical assumptions of constructivist grounded theory for this study

Philosophical assumptions of constructivist grounded theory for this study are:

a. HIV care for children in Indonesia is a reciprocal caring process that involves the inter-relationship between children with HIV, their families, nurses, and other healthcare professionals within healthcare settings, such as hospitals and PHCs. This study proposes to use constructivist grounded theory to explore HIV care for children across the continuum based on their individual subjective experiences from multiple perspectives to gain rich and diverse data.

b. Individuals' thoughts and experiences can be understood by exploring their subjective worlds in living with HIV, and in their interactions in the healthcare setting. These subjective worlds include individual's feelings, perspectives, beliefs, values, preferences, attitudes, and capacities. These, in turn, can shape the individual behaviours and experiences of participants on HIV care across the continuum. The use of language and communication reflects individual perspectives and points of view. The researcher pays particular attention to language in this process.

c. Individuals are constantly involved in social interaction. They understand and respond to others in the process of communication and interpretation. These interactions reflect the human interpretive process.

d. Knowledge is not 'out there', but is available through the 'construction process'. In doing qualitative research, the researcher deals with words. The construction of knowledge occurs throughout the study process, from the process of interviewing and analysis of the narrative or the written language. The active role of the researcher is crucial in exploring the experiences of the participants. The researcher should facilitate an interactive dialogue between themself and the participants during the interview process. Furthermore, the researcher is involved in the interpretation to uncover hidden meanings through the interaction between the researcher and the written or narrative language of the participants. The researcher again places attention on language in this process.

Constructivist grounded theory is appropriate for this study, because there is little previous research or knowledge of HIV care for children across the continuum in Indonesia. The findings from this constructivist grounded theory may provide a detailed understanding through data of subjective experiences collected through interviews, with the interpretation constructing the realities and knowledge about HIV care for children across the continuum. Constructivist grounded theory helps the researcher to conceptualise participants' experiences of HIV care across the continuum to understand and resolve the problems of care for children with HIV and their families.

Constructivist Grounded Theory as Research Design

Constructivist grounded theory provides both a way to learn about the phenomenon of the study and a research method for developing a theory to understand the experiences (Rand, 2013). Therefore, constructivist grounded theory can also be conceptualised as a strategy of enquiry due to its methodological design (Lincoln & Guba, 2013).

Constructivist grounded theory is an iterative research approach (Groen, Simmons & McNair, 2017) that provides a set of flexible strategies (Charmaz, 2000) and is not an objective process (Chamberlain-Salaun, Mills & Usher, 2013). A series of strategies in the research process include the principles and procedures to collect, analyse, and construct the theory in a systematic and flexible manner (Charmaz, 2014a; Groen, Simmons & McNair, 2017; McCann & Polacsek, 2018; Ratnapalan, 2019). The methodological aspects of constructivist grounded theory in supporting the scientific results of this study include: (a) coding analysis; (b) constant comparative analysis: (c) theoretical sampling; (d) theoretical data saturation; (e) theoretical sensitivity; (f) memo writing; (g) diagramming and the development of the core category of the theoretical model (Barreto, Garcia-Vivar & Marcon, 2018; Charmaz, 2014a). In addition to following the analysis of the coding process and the construction of the core category, this study also articulated a rigorous standard for the research (Achora & Matua, 2016). This study followed the process of constructivist grounded theory based on Charmaz (2014a), and is presented in Chapter 4: Methods.

Constructivist grounded theory offers a number of strengths, enabling a mutual process with the participants who help the researcher to uncover hidden meanings, contributing to insightful theoretical interpretation (Rieger, 2019). Symbolic interactionism was used to help the researcher to learn about the participants as active human beings engaged in social activities (Charmaz, 2014a; Jeon, 2004). The symbolic interactionist perspective inspired the analytical and interpretive work of this constructivist grounded theory. These include, meanings, the concepts of action and interaction, and the self are associated with grounded theory (Chamberlain-Salaun, Mills & Usher, 2013; Salvini, 2019). Meaning arises in the process of social interaction and is not fixed. The process of ascribing meaning demonstrates the tenets of the grounded theory methods of coding and constant comparative analysis. Through the interviews, the researcher explored the subjective experience of the participants, and then interpreted how they acted towards persons, objects, situations, activities, and a combination of these based on meaning which is socially constructed and modified in relation to their experience of HIV care for children across the continuum. Symbolic interactionism encourages the participants way of knowing through their experience and connected meanings which are formed in, and through, their social interactions with other people (Blumer, 1969); for example, how children with HIV and their families experience their interactions with health professionals in the healthcare setting.

Constructivist grounded theory offers a way to think about critical qualitative inquiry through the analytic process before, and during, the research process in a flexible way (Charmaz, 2016). The researcher interacted with the data and continually reassessed meaning, which led to the development of codes, categories, and sub-categories, which then advanced the development of the theory (Chamberlain-Salaun, Mills & Usher, 2013). From this analysis the researcher constructed an abstract representation of a range of meanings. From here both the participants and the researcher ascribed meaning to the data to explain the experience of HIV care for children across the continuum. Using symbolic interactionism helped the researcher to think about expanding the breadth of the theoretical coding to improve the quality of the study (Milliken & Schreiber, 2012). The data were analysed with initial and then focused codes, as suggested by Charmaz (2014a).

Action and interaction, and the concept of ‘self’ are the philosophical assumptions that underpin symbolic interactionism. The processes of interaction and action are key activities within a grounded theory study, such as the iterative process of data generation, analysis, and theoretical sampling throughout the research process leading to the development of theory. Symbolic interactionism fosters the development of reflexivity in this study to which the constructivist grounded theorist aspires (Salvini, 2019). An example of reflexivity in grounded theory is demonstrated in Hall and Callery (2001). Similar to the self, memo writing is developed throughout the grounded theory research process, supporting the development of theoretical sensitivity. Here, the researcher is enabled to adopt a more flexible approach to data analysis by creating memos to form an abstract interpretive understanding of the data (Charmaz, 2006, p. 9). This study used reflexivity and memo writing throughout the study process, and these are presented in Chapter 4.

Other strengths of constructivist grounded theory are voices of participants are emphasised and are involved in the development of theory. This form of analysis offers deeper insight into the participants' lives thereby achieving rigour in the study (Charmaz, 2014a). This, in turn, reflected the style of writing that was evocative of the experience of the participants (Mills, Bonner & Francis, 2006a; Mills, Bonner & Francis, 2006b).

In summary, the philosophical foundations of relativist ontology and the theoretical perspective of symbolic interactionism guides the constructivist grounded theory in this study. In addition, constructivist grounded theory is also a method to collect, analyse, and construct the theory to meet the aim of the study. Constructivist grounded theory design consists of flexible procedures, including interviews, constructing meaning and interpretations through language, coding analysis, the constant comparative method, theoretical sensitivity, memo writing, reflexivity, and the development of a core category. The procedures of constructivist grounded theory will help the researcher to construct a theoretical understanding of the experience of care for children with HIV and their families across the continuum in the Indonesian setting.

Chapter Summary

Chapter Three has described the constructivist paradigm. The paradigm comprises an overview of the ontological perspective, the epistemology, and the theoretical perspective of symbolic interactionism used to conduct the study. The constructivist paradigm suggests that reality is subjective, differs from person to person, and is constructed through interaction between humans and their world in the social context. Epistemologically, the researcher and the participant are involved together in the process of co-constructing meaning. The philosophies of relativism and interpretivism guide the methodological design. This study has used constructivist grounded theory to construct an understanding of the experience of care for children with HIV and their families across the continuum in the Indonesian setting. This chapter has also justified the chosen constructivist grounded theory method.

The following chapter will present the research methods, detailing the application of constructivist grounded theory developed by Charmaz (2014a) to generate a substantive grounded theory about the experience of HIV care for children across the continuum in the context of Indonesia. The chapter will explain the constructivist grounded theory process, starting with obtaining ethics approval, recruiting research participants, and generating and then analysing the data. The components of the constant comparative method, theoretical sampling, and the criteria for evaluating the rigour are also explained.

CHAPTER 4
METHODS

Chapter Three described the constructivist paradigm, which guided the research process. Chapter Four describes the methods used to conduct this constructivist grounded theory and to generate the substantive theory. This chapter addresses the grounded theory method, the setting of the study, the recruitment of the participants, the process of data generation and analysis, along with the rigour and ethics considerations.

Grounded Theory Method

The study employed a constructivist grounded theory method to explore the experience of care for children with HIV and their families across the continuum in Indonesia. The constructivist grounded theory method provided a systematic way of researching with a set of flexible guidelines in the process of data generation and analysis (Birks & Mills, 2011; Charmaz, 2014a; Giles, de Lacey & Muir-Cochrane, 2016b). Through in-depth interviews from three different viewpoints, those of children with HIV, their families, and HPs, the researcher constructed meaning, actions, and interpretations (Birks & Mills, 2011; Strauss & Corbin, 1990; Whitehead, Dilworth & Higgins, 2016). Following the constructivist grounded theory research process helped the researcher to manage the study, to analyse the data (Birks & Mills, 2011; Charmaz, 2014a), and to build knowledge on care for children with HIV and their families across the continuum in Indonesia (Charmaz, 2000).

Figure 3 presents the process of the constructivist grounded theory method used in this study as well as the relationship between the various stages of the study. The researcher began with a literature review to develop a research question, then gained ethics clearance, generated the data, undertook transcription and translation of the raw data, and then analysed the data simultaneously using the constant comparative method. Data analysis continued with moving through each step of the analytical process towards the development, refinement, and inter-relationship of the concepts to build an explanatory framework that specified the relationships between the concepts (Charmaz, 2000). The researcher engaged in memo-writing, theoretical sampling, and ensured theoretical sensitivity, before continuing the process of theory development by sorting, diagramming, and integrating the data. The stages of the constructivist grounded theory method process are presented in detail in the following sections.

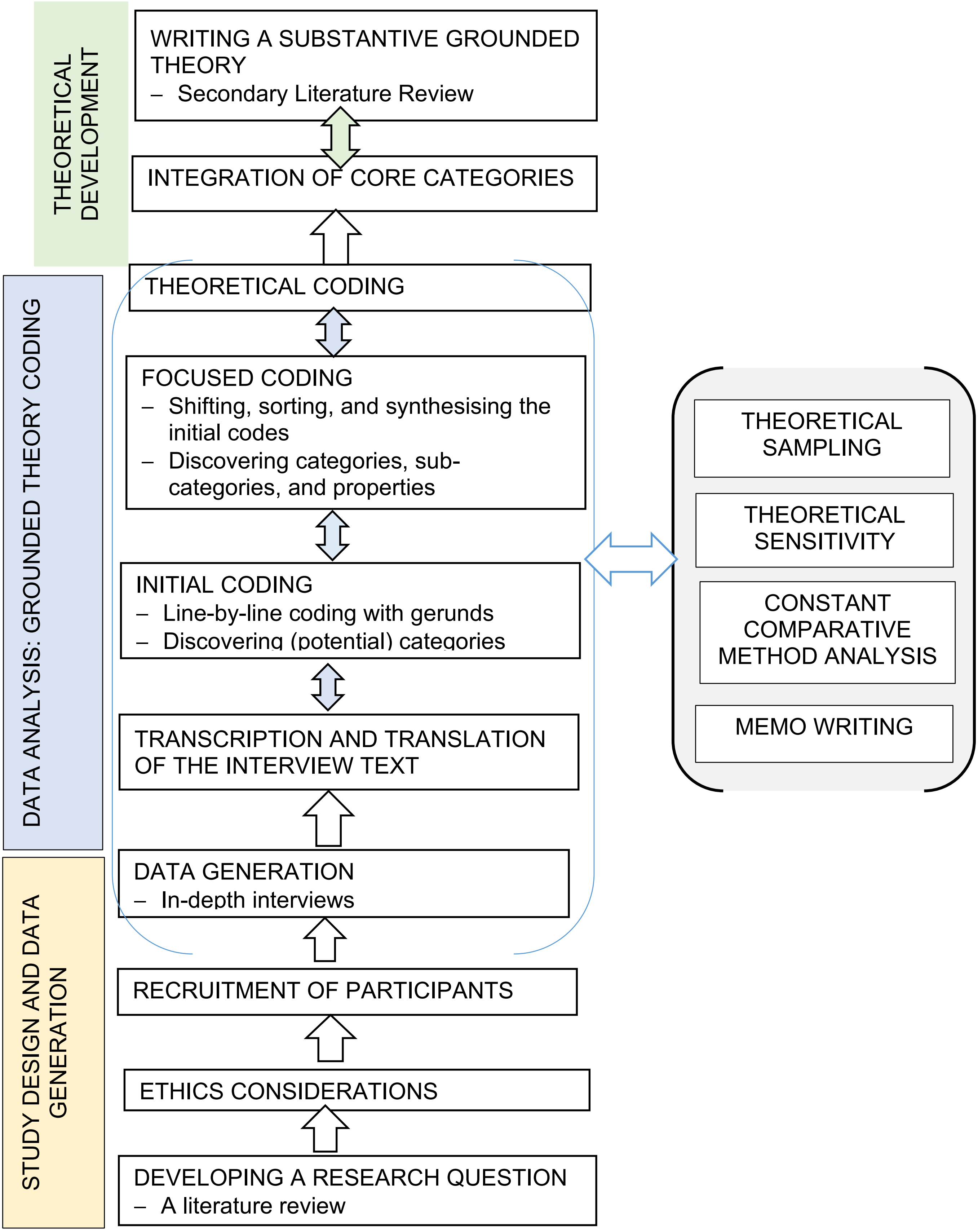


Figure 3: A representative diagram for the grounded theory process of this study

Developing a Research Question

The formulation of a good research question is the first critical step in the research process because it guides the area of study and the methodology (Ratan, Anand & Ratan, 2019). The researcher chose HIV as a broad topic of interest before limiting the topic to HIV among children as a specific issue.

The researcher conducted a literature review to develop the research question, initially identifying potential issues related to HIV among children by comparing and contrasting the researcher's experience and the Indonesian national policy documents concerning HIV/AIDS. The research followed the constructivist view that conducting a literature review helps to understand what research has been done and what still needs to be understood in the area of study. The first step was undertaking a review of the literature. Constructivist grounded theorists refuse the classical grounded theory suggestion of postponing the literature review until the analysis has been completed (Charmaz, 2006; Keane, 2014; Strauss & Corbin, 1990). Following the review of the literature, it is evident there is limited knowledge on how children with HIV and their families experience care across the continuum in Indonesia.

Ethics Considerations

Procedural Ethics

Ethics approval is necessary before entering the research setting and gathering the data, to ensure that the study meets the rigorous ethics and health and safety requirements. Ethics approval for this study was initially obtained from the Social and Behavioural Research Ethics Committee (SBREC) of Flinders University, approval number 7818. To satisfy the East Java Provincial Government procedures before conducting research, a further three ethics approvals were required from the Ethics Committee(s) of the involved provincial hospitals and the faculty of Nursing, *Universitas Airlangga*. These applications required the delivery of a presentation to the ethics panel. The three ethics approvals included Ethical Clearance No.34/Panke.KKE/I/2018, Ethical Clearance No.10/EC/KERS/2018, Ethical Approval No.506-KEPK (see Appendix 2 for the Ethics Approval forms, pp 268-278).

This study adheres to The National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2018), which links to the ethical principles of respect and protection for the participants, justice, and beneficence. The following section explains the three fundamental principles of research ethics: respect, confidentiality and anonymity, and procedural justice.

Respect: Informed Consent, Voluntary, and Not Harmful

Respect for participants in human research means that every individual has the autonomy to make a decision about their participation, with any potential participant with diminished capacity being protected, helped, and empowered (National Health and Medical Research Council, 2018). To satisfy the principle of respect, the potential participants were informed that consent was voluntary. The participants were informed about their choice to withdraw from the research at any time and were asked to sign a consent form to this effect (Holloway & Wheeler, 2010; Streubert & Carpenter, 2011). The participants were assured that their healthcare or employment would not be affected in any way if they did not wish to continue with the interview. If they were willing to participate in the project by signing and returning the consent form, they were recruited as participants. For children with HIV below 16 years of age, the researcher sought parental consent from the parents or family carers of the children. Furthermore, children aged 16 years or over with HIV were able to provide consent for themselves.

The participants were given a project package consisting of a letter of introduction from the principal supervisor, an information sheet concerning the project, and a consent form for the participants (see Appendix 3 for the research information package for children with HIV, their families, and HPs in English and Indonesian languages, pp. 279-297). The information sheet consisted of the title of the research, the purpose of the study, and information about the voluntary nature of participation, the benefits or risks of participating in the study, and confidentiality and anonymity isues.

Participants should be protected from the potential harm that may occur throughout their participation in a research study (Streubert & Carpenter, 2011). This study had minimal risk of harm to the participants or the institutions involved. However, as the topic of HIV is sensitive, the risks potentially may relate to psychological distress due to the disclosure of sensitive information. The participants, who primarily were asked about their experiences of HIV care for children across the continuum, may have felt some discomfort during the interviews, particularly if they had past and/or current negative experiences related to HIV care delivery. If the participants became distressed due to the study, the researcher planned to respond by stopping the interview immediately and offering details of an appropriate counselling service. The researcher initially coordinated with a HIV counselling service from a HIV outpatient clinic service in a provincial hospital, so that the participants would have immediate access to support and counselling from a professional HIV counsellor that they were already familiar with.

Confidentiality and Anonymity

The researcher protected the privacy, confidentiality, and anonymity of the participants (National Health and Medical Research Council, 2018). Any information that could potentially have identified the participants was not disclosed to others or their institutions, and were kept confidential (Holloway & Wheeler, 2010; Streubert & Carpenter, 2011) thus assuring their confidentiality.

The researcher protected the anonymity of the participants, by using fictional names for the participants in a variety of data formats, such as the written demographic data, the digital voice interviews, and the transcriptions (Streubert & Carpenter, 2011). The researcher used “wayang” names as the pseudonyms of the participants (e.g., Sita/Arjuna). Furthermore, as well as providing a confidentiality agreement for the translation service, the researcher provided pseudonyms in the transcribed text to the translation service (Holloway & Wheeler, 2010). Therefore, all the information collected was kept and preserved using pseudonyms so that the participants could not be identified. All the collected information was also protected, so the anonymity and confidentiality of the participants was ensured.

Procedural Justice for Participant Recruitment

As well as recognising respect and protection for the participants, the process of recruiting them was also fair as there was no exploitation or unfair burden on participation in the study, thus meeting the principle of justice (National Health and Medical Research Council, 2018). For example, the researcher distributed information research packs and flyers to recruit participants, thereby ensuring that it was not a coercive process. For children living with HIV and their families, the researcher provided flyers, and left information packs for potential participants with health providers in hospitals and PHCs. For health professionals, the researcher provided flyers in staff tea rooms and a physical examination room alongside the information packs. All participants contacted the principal researcher if they wished to participate. The researcher made an appointment with them to explain further details about the project and gave them a decision to participate or not by signing a consent form.

Data Storage and Information

The researcher kept all the data and information protected for the duration of the research on a password-protected university computer. Data refers to information in its raw form, whereas information refers to data that has been interpreted, analysed, and/or contextualised (National Health and Medical Research Council, 2018). Any identifying data and information that could identify the participants were removed, protecting their privacy. De-identified interview transcripts were saved on a secure shared drive on a password-protected university network drive in the College of Nursing and Health Sciences at Flinders University. These files will be stored for five years on completion of the project. Data storage was managed in accordance with Flinders policy and guidelines for Research Data Management (Flinders University, 2015). Only the research team have access to the data. At the end of the data storage period, the computer files will be deleted.

Setting of the Study

The researcher conducted this study in Surabaya, in the East Java Province of Indonesia. East Java had the second-highest prevalence of HIV in Indonesia after Jakarta in the period 2009-2015 (Kementerian Kesehatan Republik Indonesia, 2016). Surabaya is the capital city of East Java and is ranked as having the highest recorded number of HIV-positive people in 2015 in Indonesia (Kementerian Kesehatan Republik Indonesia, 2016). Therefore, Surabaya was a suitable setting for this study.

The health care services and facilities in Surabaya include 47 hospitals in both public and private sectors at the district and provincial levels, 63 public PHC institutions, and a number of private practitioner practices. However, only 9 hospitals (19.1 %) and 9 PHCs (14.3 %) have been able to provide HIV care and treatment services (Perhimpunan Rumah Sakit Seluruh Indonesia, 2019).

Entry into Settings

To satisfy the East Java Government procedures, the researcher sought permission from the East Java Provincial Government and the East Java District Government before entering PHCs and/or hospitals (see Appendix 4 letters of permission, pp. 298-302). After letters of permission were sought, the researcher sent a proposal written in Bahasa Indonesian attached to letters of approval from both the provincial and district government to the Head of PHCs and the Hospital Directors at the research sites that provided HIV service and treatment delivery. The translated proposal provided background information, as well as details of the literature review, methodology, methods, and appendices (e.g., the letter of introduction, information sheet, consent form, interview guidelines, institutional letter of permissions, and ethics clearance). The researcher was solely responsible for the translation of the documents from English to Indonesian. Five PHCs and three hospitals confirmed their willingness to participate in the study.

Recruitment of Participants

Consistent with grounded theory, this study employed two sampling strategies: initial sampling and theoretical sampling (Charmaz, 2006). Purposive sampling was used first to recruit targeted participants.

Purposive Sampling

Purposive sampling was the method used for participant recruitment based on a set of predetermined inclusion criteria. This study involved three different groups of participants: children with HIV, their families, and HPs working across five PHCs and three provincial hospitals. The inclusion criteria for children with HIV and their family members were:

- a child diagnosed with HIV aged 8-18 years and their family members
- the family of a child living with HIV aged 8-18 years, having experience dealing with the HIV-positive child
- able to speak Indonesian
- having a willingness to participate in the study and willing to sign an informed consent or parental consent form.

The inclusion criteria for health professionals were:

- Health professionals (e.g. registered nurses, doctors, or from other health professions)
- Have a minimum of one year of experience dealing with people with HIV or providing care for children with HIV
- Able to speak Indonesian
- Having a willingness to participate in the study and willing to sign an informed consent form.

At the practical level, this study conducted purposive sampling simultaneously with the data analysis. This study purposively sampled 12 children with HIV, 8 parents or family members together, and 23 health professionals.

Theoretical Sampling

Theoretical sampling underpinned the second phase of data generation to identify, develop, and refine the provisional categories and the emerging substantive grounded theory (Charmaz, 2000, 2006). Theoretical sampling was conducted to recruit further participants, or re-interview earlier participants to ask further questions that had not been covered to saturate the categories (Birks & Mills, 2011; Charmaz, 2006). The researcher engaged theoretical sampling to develop and refine the properties of the categories under development (Charmaz, 2014a). Theoretical sampling helps the researcher to saturate the categories to develop the emergent theory (Glaser & Strauss, 1967). Theoretical sampling fosters data saturation, and reaching data saturation determines when recruiting of participants should stop (Aldiabat & Le Navenec, 2018). Theoretical sampling and data saturation is a reciprocal process which is reached when there are no new theoretical insights being identified in the data analysis (Charmaz, 2006), and the categories and their properties have been developed and integrated (Strauss & Corbin, 1990).

To engage in theoretical sampling, the researcher also used the constant comparison method and was able to reach data saturation. Reaching data saturation was subjective because there are no specific rules to achieve this (Aldiabat & Le Navenec, 2018). As the data were being analysed, other participants were willing to be interviewed, and an interview time and place was agreed upon. The second phase of the recruitment process resulted in a further 23 participants. After completing 35 in-depth semi-structured interviews, 9 categories were constructed, after which no new information was being yielded.

Following the advice of Charmaz (2006) and Charmaz (2014a), this study achieved theoretical saturation when there were new theoretical insights identified in the data analysis. The researcher analysed the two datasets with the use of Indonesian and English transcripts. The coding process, together with the constant comparative method, theoretical sensitivity, and memo writing, are described in the following section. The researcher used her memo writing to support her decision to stop collecting further data. For example, during the coding process, information such as the disclosure of HIV status, and ARV therapy, required further exploration in subsequent interviews and was recorded in the memos.

Data Generation

The researcher collected data through two data-generating activities, in-depth semi-structured interviews and memos.

Semi-Structured Interviews

Consistent with a constructivist paradigm, semi-structured interviews were used to explore the subjective experience of the participants in this study (Charmaz, 2006). Individual semi-structured interviews allowed for rich data from the participants.

The researcher began with a pilot interview with the first participant and sent the transcribed interview text to her thesis supervisors for feedback. Following the feedback, the opening section was changed to “could you tell me about …”, while prompt questions were added to enhance the richness of the collected data. When interviewing children with HIV and their families, the researcher tried to create a relaxed situation by asking about the child’s hobbies and activities, avoiding jargon, and by using simple language.

The researcher used a list of predetermined questions to elicit information (Longhurst, 2016), but did not strictly follow this. The researcher started the interviews with a general question “could you tell me about yourself” and continued in a more focused manner to gather specific data. The researcher explored the participants’ experiences and perceptions with non-judgemental questions by listening to, and having a willingness to understand, the participants’ responses and facilitating all communications interactively (Mills, Bonner & Francis, 2006a). If the participants raised questions, the researcher answered them during the interview and afterwards, respecting the principle of co-constructed interviews between the researcher and the participants in relation to their experiences about the continuity of care for children with HIV and their families.

The researcher allowed the participants to choose the time and the venue to increase their feelings of comfort and to maximise their convenience. During the interviews, the researcher allowed the participants to have additional time to share their experiences. The duration of the interviews varied. The length of the interview with the children with HIV and their families took 45 to 90 minutes. One teenager and mother shared their experiences for almost two hours. All the interviews with the children and their families took place in restaurants or cafeterias. The interviews with HPs took about one to one and a half hours. The HPs selected their offices for the interviews, usually in their lunch break or in the afternoon before their shift started. To develop rapport and trust, the researcher arrived on time, allowed the participants to tell their stories without imposing, and listened actively to their stories.

The researcher recorded the interviews with a digital audio recorder. Digital audio recording helped the researcher to retain a permanent record of the voice, intonation, pauses, and emphasis of each interviewee, and enabled the researcher to focus on and understand what the interviewees said (Arksey & Knight, 1999). As well as recording the in-depth interviews, the researcher also considered the physiological condition of the participants. A few participants started to cry during the interviews. The researcher paused the interview and offered them time to consider whether they wished to continue or not. The interviews could have been terminated immediately upon request. The researcher reminded the participants of the counselling and support services available to them. For the interviews with the children under 16 years of age, the researcher first asked the parent or family member whether the child knew about their HIV diagnosis to avoid unintentional or accidental disclosure. The researcher kept the child's HIV diagnosis secret from those children who did not know their diagnosis during the interview. The researcher thanked the participants for their participation at the end of the interview.

The Interview Process, Constructivism and Symbolic Interaction

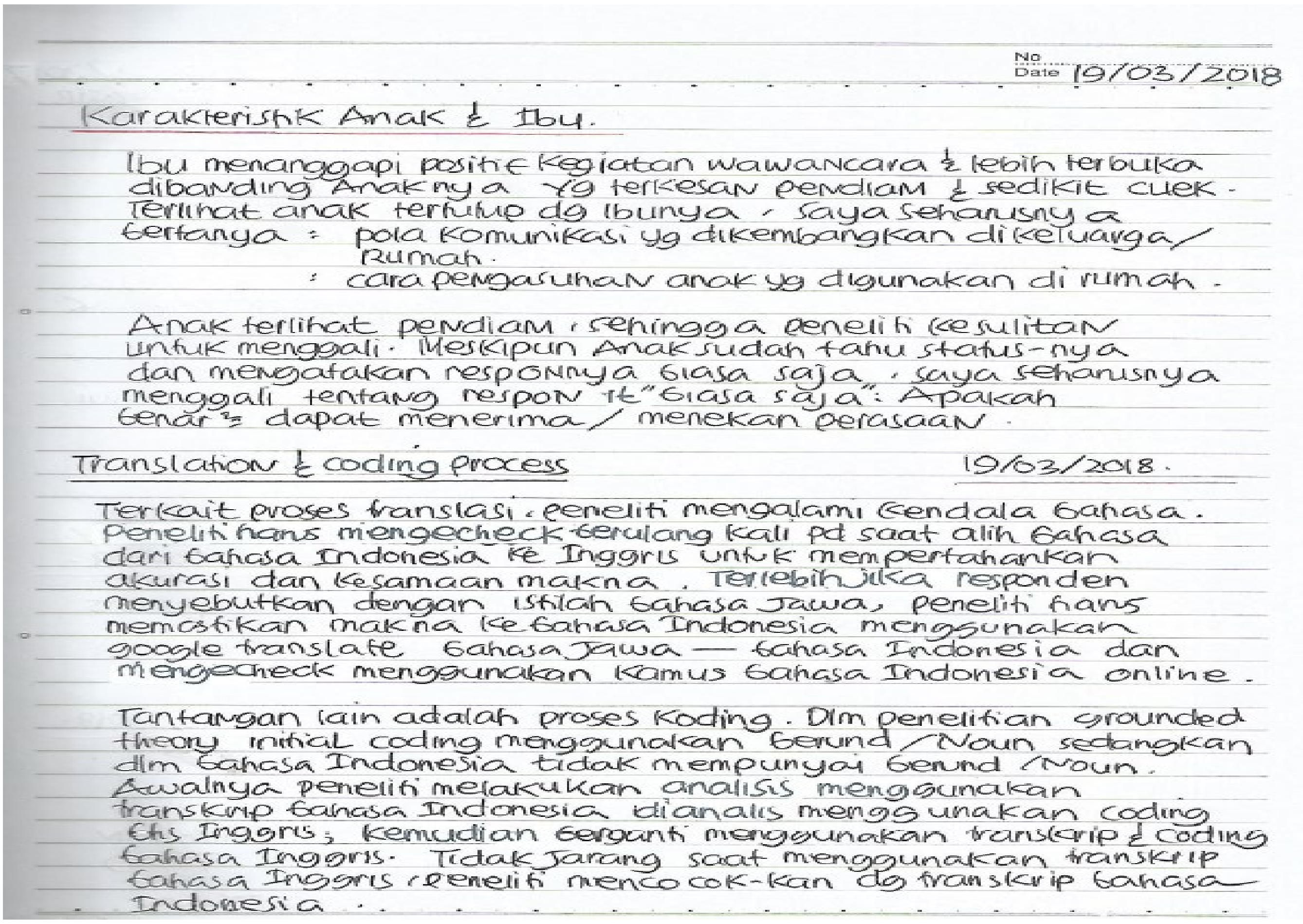
The researcher acknowledged the personal relationship between herself and the participants. The researcher developed a reciprocal relationship between the participants and the researcher consistent with the constructivist paradigm (Birks & Mills, 2011; Charmaz, 2006). This process was also in line with symbolic interactionism, focusing on meaning-making through the ongoing process of social interaction (Blumer, 1969; Charmaz, 2014a; Jeon, 2004).

Consistent with symbolic interactionism, the researcher listened to the participants actively and clarified any of the more vague detail (Charmaz, 2014a; Jeon, 2004). The researcher was aware of maintaining a sense of comfort during the interview process and was open with the participants during the interview process to build trust and create a safe emotional environment with them. The researcher avoided moral judgement by being respectful and open and facilitating therapeutic relations, so that the communication and co-construction of knowledge could proceed naturally between the researcher and the participants. Following the advice of Charmaz (2006) and Hallberg (2009), the researcher listened attentively during the in-depth interviews and encouraged the participants to talk by saying 'could you tell me more about it?", responding to each patient's experiences. This approach reassured the participants during the interviews.

Memo Writing

During data generation, memo writing was used to help the researcher to describe her thoughts during the interviews and the process of transcription. Furthermore, the application of memo writing continued throughout the entire process of data generation, analysis, and theory development.

Memo-writing is one element of analysis in grounded theory (Charmaz, 2006; Strauss & Corbin, 1990). Seminal works describe various types of memo writing (Birks & Mills, 2011; Charmaz, 2014a; Ryan & Bernard, 2000; Strauss & Corbin, 1990). The researcher adopted the styles of Birks and Mills and Charmaz, in which the researcher writes descriptive memos spontaneously, naturally, and flexibly to reflect the development of the researcher's thinking about elements of the project (Birks & Mills, 2011; Charmaz, 2006). The researcher used a few techniques for memo writing, such as handwriting in *Bahasa* and typing in English with the use of NVivo Pro.



No
Date 19/03/2018

Karakteristik Anak & Ibu.

Ibu menanggapi positif kegiatan wawancara & lebih terbuka dibanding anaknya yg terkesan pendiam & sedikit cuek. Terlihat anak tertutup dg ibunya. Saya seharusnya bertanya : pola komunikasi yg dikembangkan di keluarga/ rumah.
: cara pengasuhan anak yg digunakan di rumah.

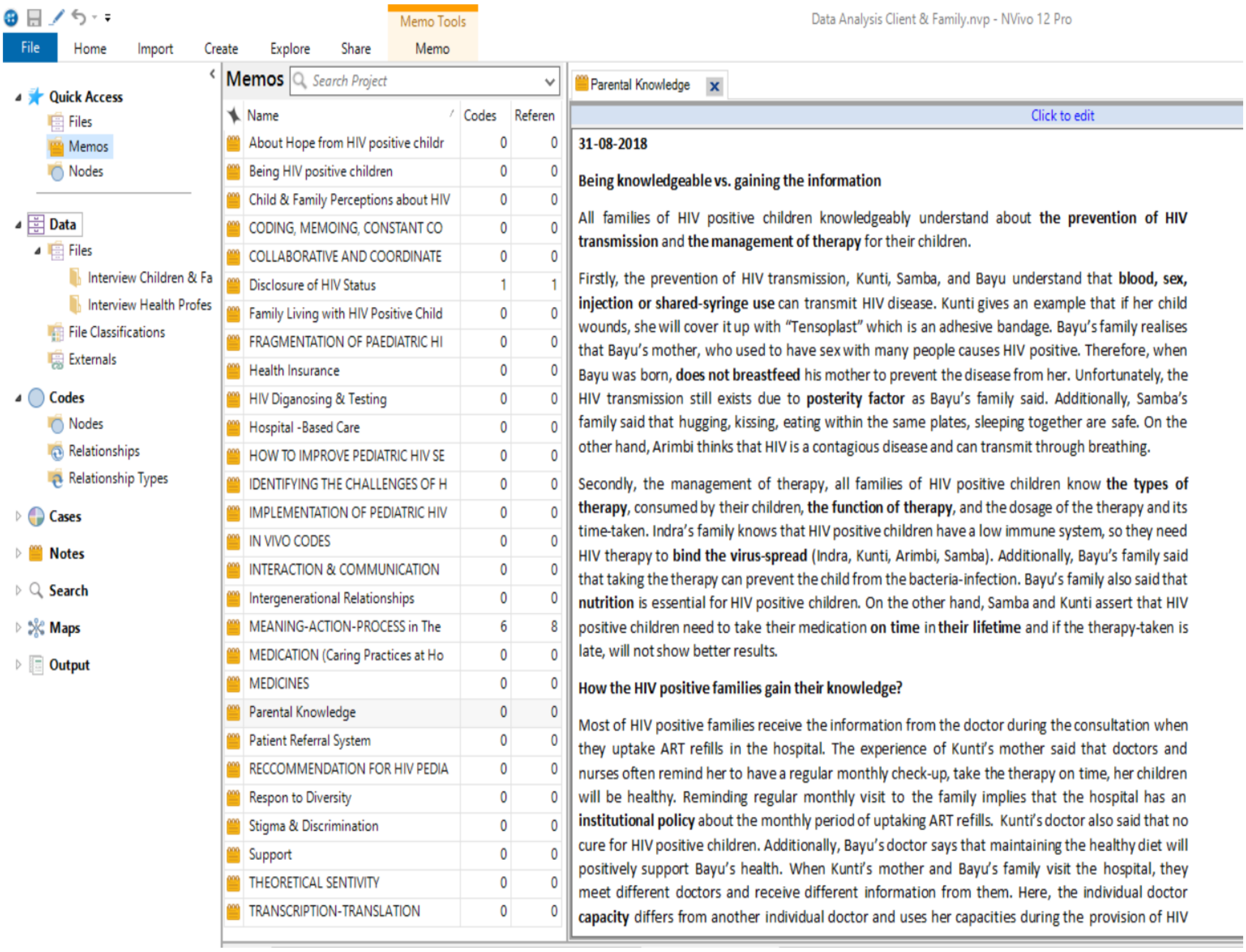
Anak terlihat pendiam, sehingga peneliti kesulitan untuk menggali. Meskipun anak sudah tahu status-nya dan mengatakan responnya biasa saja. Saya seharusnya menggali tentang respon tt "biasa saja": Apakah benar² dapat menerima/ menekan perasaan.

Translation & coding process 19/03/2018.

Terkait proses translasi, peneliti mengalami kendala bahasa. Peneliti harus mengecheck berulang kali pd saat alih bahasa dari bahasa Indonesia ke Inggris untuk mempertahankan akurasi dan kesamaan makna. Terlebih jika responden menyebutkan dengan istilah bahasa Jawa, peneliti harus memastikan makna ke bahasa Indonesia menggunakan google translate bahasa Jawa — bahasa Indonesia dan mengecheck menggunakan kamus bahasa Indonesia online.

Tantangan lain adalah proses koding. Dlm penelitian grounded theory initial coding menggunakan Gerund/Noun sedangkan dlm bahasa Indonesia tidak mempunyai Gerund/Noun. Awalnya peneliti melakukan analisis menggunakan transkrip bahasa Indonesia dianalis menggunakan coding bhs Inggris; kemudian berganti menggunakan transkrip & coding bahasa Inggris. Tidak jarang saat menggunakan transkrip bahasa Inggris, peneliti mencocok-kan dg transkrip bahasa Indonesia.

Figure 4: Example of memo writing in *Bahasa Indonesia*



Name	Codes	Referen
About Hope from HIV positive childr	0	0
Being HIV positive children	0	0
Child & Family Perceptions about HIV	0	0
CODING, MEMOING, CONSTANT CO	0	0
COLLABORATIVE AND COORDINATE	0	0
Disclosure of HIV Status	1	1
Family Living with HIV Positive Child	0	0
FRAGMENTATION OF PAEDIATRIC HI	0	0
Health Insurance	0	0
HIV Diganosing & Testing	0	0
Hospital -Based Care	0	0
HOW TO IMPROVE PEDIATRIC HIV SE	0	0
IDENTIFYING THE CHALLENGES OF H	0	0
IMPLEMENTATION OF PEDIATRIC HIV	0	0
IN VIVO CODES	0	0
INTERACTION & COMMUNICATION	0	0
Intergenerational Relationships	0	0
MEANING-ACTION-PROCESS in The	6	8
MEDICATION (Caring Practices at Ho	0	0
MEDICINES	0	0
Parental Knowledge	0	0
Patient Referral System	0	0
RECCOMMENDATION FOR HIV PEDIA	0	0
Respon to Diversity	0	0
Stigma & Discrimination	0	0
Support	0	0
THEORETICAL SENTIVITY	0	0
TRANSCRIPTION-TRANSLATION	0	0

31-08-2018

Being knowledgeable vs. gaining the information

All families of HIV positive children knowledgeably understand about **the prevention of HIV transmission** and **the management of therapy** for their children.

Firstly, the prevention of HIV transmission, Kunti, Samba, and Bayu understand that **blood, sex, injection or shared-syringe use** can transmit HIV disease. Kunti gives an example that if her child wounds, she will cover it up with "Tensoplast" which is an adhesive bandage. Bayu's family realises that Bayu's mother, who used to have sex with many people causes HIV positive. Therefore, when Bayu was born, **does not breastfeed** his mother to prevent the disease from her. Unfortunately, the HIV transmission still exists due to **posterity factor** as Bayu's family said. Additionally, Samba's family said that hugging, kissing, eating within the same plates, sleeping together are safe. On the other hand, Arimbi thinks that HIV is a contagious disease and can transmit through breathing.

Secondly, the management of therapy, all families of HIV positive children know **the types of therapy**, consumed by their children, **the function of therapy**, and the dosage of the therapy and its time-taken. Indra's family knows that HIV positive children have a low immune system, so they need HIV therapy to **bind the virus-spread** (Indra, Kunti, Arimbi, Samba). Additionally, Bayu's family said that taking the therapy can prevent the child from the bacteria-infection. Bayu's family also said that **nutrition** is essential for HIV positive children. On the other hand, Samba and Kunti assert that HIV positive children need to take their medication **on time** in **their lifetime** and if the therapy-taken is late, will not show better results.

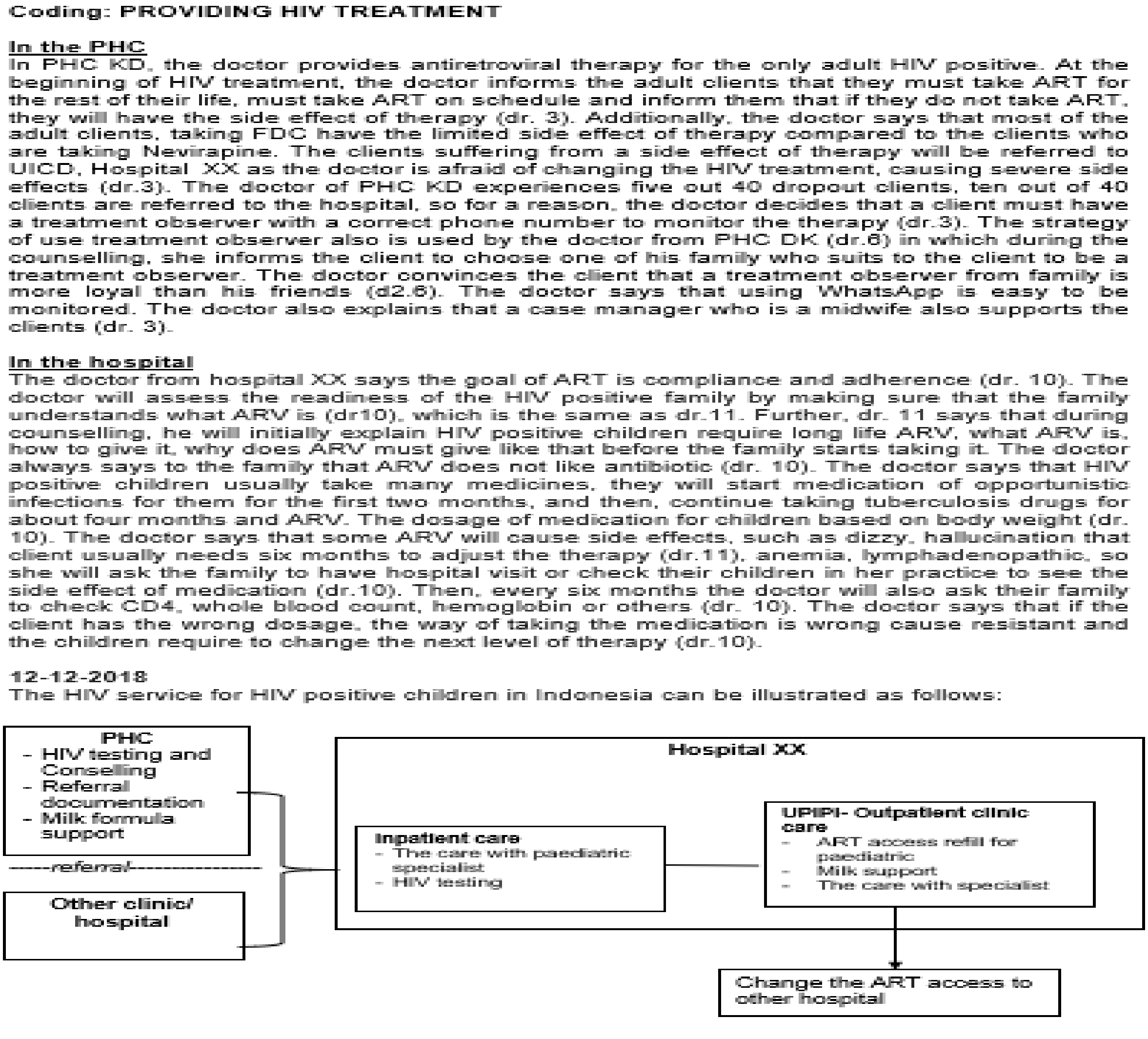
How the HIV positive families gain their knowledge?

Most of HIV positive families receive the information from the doctor during the consultation when they uptake ART refills in the hospital. The experience of Kunti's mother said that doctors and nurses often remind her to have a regular monthly check-up, take the therapy on time, her children will be healthy. Reminding regular monthly visit to the family implies that the hospital has an **institutional policy** about the monthly period of uptaking ART refills. Kunti's doctor also said that no cure for HIV positive children. Additionally, Bayu's doctor says that maintaining the healthy diet will positively support Bayu's health. When Kunti's mother and Bayu's family visit the hospital, they meet different doctors and receive different information from them. Here, the individual doctor **capacity** differs from another individual doctor and uses her capacities during the provision of HIV

Figure 5: Examples of descriptive memo writing with the use of NVivo Pro 12

The researcher wrote memos to map the research activities, to record the ideas, to interrogate the data to develop a theory, and to record potential issues that influenced the quality of the study (Birks & Mills, 2011; Charmaz, 2006). Writing memos in this study functioned as a reflective diary that helped to construct the researcher's thoughts. Memo writing kept the researcher focused on the analysis as the memos helped to make comparisons between the data, the data and codes, codes and categories, and categories and the main concept (Charmaz, 2006). The researcher continued writing memos to elaborate the processes and to tease out the assumptions under each code, leading her to explore the codes, to expand upon the process, and to create a structure for sorting the data (Charmaz, 2000). The researcher laid out the memos in different ways and sorted them by category, comparing categories with categories to produce a logical schema (Birks & Mills, 2011; Charmaz, 2006).

In addition to memo writing, the researcher summarised the relevant data with dimensions and properties, and sometimes combined them with diagramming. Diagramming helped the researcher to remember, question, and analyse, and to record all thoughts, feelings, insights, and ideas related to the study (Birks & Mills, 2011; Strauss & Corbin, 1990). Memo writing combined with diagramming, provides an immediate illustration of an idea and helps to develop reflection, ideas, and codes (Glaser & Strauss, 1967; Kenny & Fourie, 2015). The researcher included illustrations or diagrams to clarify her thinking and to visualise the data relationships that enhanced the conceptualisation of the theory (Birks & Mills, 2011). For example:



Coding: PROVIDING HIV TREATMENT

In the PHC

In PHC KD, the doctor provides antiretroviral therapy for the only adult HIV positive. At the beginning of HIV treatment, the doctor informs the adult clients that they must take ART for the rest of their life, must take ART on schedule and inform them that if they do not take ART, they will have the side effect of therapy (dr. 3). Additionally, the doctor says that most of the adult clients, taking FDC have the limited side effect of therapy compared to the clients who are taking Nevirapine. The clients suffering from a side effect of therapy will be referred to UICD, Hospital XX as the doctor is afraid of changing the HIV treatment, causing severe side effects (dr.3). The doctor of PHC KD experiences five out 40 dropout clients, ten out of 40 clients are referred to the hospital, so for a reason, the doctor decides that a client must have a treatment observer with a correct phone number to monitor the therapy (dr.3). The strategy of use treatment observer also is used by the doctor from PHC DK (dr.6) in which during the counselling, she informs the client to choose one of his family who suits to the client to be a treatment observer. The doctor convinces the client that a treatment observer from family is more loyal than his friends (d2.6). The doctor says that using WhatsApp is easy to be monitored. The doctor also explains that a case manager who is a midwife also supports the clients (dr. 3).

In the hospital

The doctor from hospital XX says the goal of ART is compliance and adherence (dr. 10). The doctor will assess the readiness of the HIV positive family by making sure that the family understands what ARV is (dr10), which is the same as dr.11. Further, dr. 11 says that during counselling, he will initially explain HIV positive children require long life ARV, what ARV is, how to give it, why does ARV must give like that before the family starts taking it. The doctor always says to the family that ARV does not like antibiotic (dr. 10). The doctor says that HIV positive children usually take many medicines, they will start medication of opportunistic infections for them for the first two months, and then, continue taking tuberculosis drugs for about four months and ARV. The dosage of medication for children based on body weight (dr. 10). The doctor says that some ARV will cause side effects, such as dizzy, hallucination that client usually needs six months to adjust the therapy (dr.11), anemia, lymphadenopathic, so she will ask the family to have hospital visit or check their children in her practice to see the side effect of medication (dr.10). Then, every six months the doctor will also ask their family to check CD4, whole blood count, hemoglobin or others (dr. 10). The doctor says that if the client has the wrong dosage, the way of taking the medication is wrong cause resistant and the children require to change the next level of therapy (dr.10).

12-12-2018

The HIV service for HIV positive children in Indonesia can be illustrated as follows:

Figure 6: Example of descriptive memo combined with diagramming

The Challenges of Simultaneous Data Generation and Analysis

The researcher used simultaneous data generation and analysis, and was aware that in grounded theory, this was crucial and required time. The researcher managed the time constraints in a range of ways. If there was no interview scheduled on a particular day, the researcher transcribed previous interview recordings and coded some of the previous data using the constant comparative method and the memos. If the researcher had an interview scheduled, she would, while waiting, spend her free time coding, reading the interview transcripts, listening to the interviews, recording, or memo-writing, depending on the situation. Using text-based paper coding enabled continued engagement with the data analysis process.

Initially, the researcher found it difficult to reach children with HIV and their family members because the topic of HIV was sensitive. The researcher initiated contact with the adults' networks who she already knew. The researcher regularly attended an HIV outpatient clinic at least two times a week, specifically on the day of ARV access for children, which facilitated the building of rapport between the researcher and the children and their families. In addition, the researcher used flyers to recruit further participants. Being present at the HIV outpatient clinic facilitated recruitment of children with HIV and their families. The researcher conducted interviews in different locations and took at least 90 hours of driving time in total to get to the various interview destinations. Accommodating the participants' time and location preferences challenged the researcher to analyse all the data in tandem with the data generation (Timonen, Foley & Conlon, 2018). As a doctoral student, the researcher, a novice grounded theory analyst, needed to conduct her research within a defined timeline, and identified early on that the time aspect was a challenging factor in undertaking grounded theory. Apart from the time constraints, the sensitive topic of HIV among children in this study, and the differing interview locations challenged the process of concurrent data generation and analysis. According to Timonen, Foley and Conlon (2018), ideal grounded theory practice consists of simultaneous data generation and analysis in order to support emergent theory. However, in practice, this was not practicable because of the scope of the study, the varying locations, and the time constraints.

The researcher also identified another challenge when using grounded theory for the novice researcher. Grounded theory requires brain activities for at least four overlapping processes of analysis (i.e., coding, the constant comparison method, theoretical sensitivity, and theoretical sampling). As a result, the researcher found this difficult to explain in writing. Besides these challenges, the researcher found that applying grounded theory facilitates the effective learning of the principles of grounded theory. Many grounded theorists have argued that doing grounded theory is the best method of learning grounded theory (Charmaz, 2006; Giles, de Lacey & Muir-Cochrane, 2016a).

Data Organisation and Management

Organising the Data with NVivo 12 Pro

The researcher used NVivo 12 Pro to organise the data, including the interview texts, the line-by-line coding, and the memo writing (Bringer, 2006). The researcher interpreted the data and decided what to code. Before doing so, the researcher attended a series of NVivo workshops. NVivo is a program that facilitates text searches, ideas to be linked, and accesses the original data behind the code and allows the researcher to write memos that relate to the material (Bringer, 2006). The researcher used NVivo 12 Pro to describe and share the coding with her research supervisors.

The reasons for using NVivo 12 Pro was to show the transparency of the data and to produce an audit trail. Bringer, Johnston and Brackenridge (2004) asserted that the use of NVivo is essential in providing enough evidence for the examiners to evaluate a study. NVivo facilitates an electronic audit trail that helps to trace the progress of the project (Bringer, Johnston & Brackenridge, 2004), assisting in the maintenance of the contextual richness of the data.

Transcription of Audio-Recorded Data

The researcher transcribed the recorded interviews into a written document to allow the data to be read and organised. The transcription was undertaken mostly in ‘Bahasa Indonesian’. For several of the interviews conducted in a local “Javanese” language, the researcher translated the data into Indonesian Bahasa. The researcher maintained the written document as an exact copy of what was in the recorded interviews. The researcher engaged several activities to ensure the transcription was not taken out of context, including listening to the recorded interviews several times, transcribing them, re-reading the transcribed interview text while listening to the recorded interviews, and making corrections as necessary. Each transcription took four to six hours to complete depending on the length of the interview. The transcripts were typed into a Microsoft Word© document using two columns, one containing the Indonesian transcription, and the other for coding.

Translation of Interview Text Transcriptions

The researcher employed an English translation service to translate the interview data. The researcher was aware of the issues associated with the translation of interview text, as the accuracy of the interpretation of meaning could change the context of the message, contributing to a loss of meaning in the translation process. The researcher employed a rigorous approach in anticipating the potential problems in the translation, namely maintaining confidentiality by signing a translation service confidentiality agreement and ensuring that the meanings in the translations were the same as the original meanings in the interviews.

The researcher used a professional translator to translate the interview data. Consistent with grounded theory analysis, the analysis of the data had to be coded using gerunds, but Bahasa does not have gerunds. The researcher looked for a professional translator due to the timeline needs for completion and facilitated this with a modification to the original ethics application. The researcher used the translation service to translate the transcribed interview text from Bahasa to English after the translator had agreed to sign The Translation Service Confidentiality Agreement (please see appendix 5 confidentiality agreement translation service, p. 303). The researcher maintained the anonymity of the participants by using pseudonyms during the transcription process.

The researcher maintained the meanings within the translation by constantly checking the text during the translation process. Constructivist grounded theory does not provide clear guidelines on the translation process (Nurjannah et al., 2014). The researcher was aware that the translation service provided accurate translations, but may have potentially lost the meanings in the data. The researcher maintained the meanings within the data by comparing the translated English interview text with the transcribed Indonesian interview text. The researcher engaged in effective communication with the translator via WhatsApp and email to explain the words or the meanings behind what the participants had said, thus preventing misconceptions about the meanings. The researcher initially checked the translated documents. After checking the documents, they were sent back to the English translator for revising and proofreading. Figure 7 demonstrates the process involved in the translation of the transcribed interviews.

TRANSCRIPTION	TRANSLATION
• The researcher transcribed the recorded interviews into a text format • The translator signed a Translation Service Confidentiality Agreement • The researcher sent the transcribed interviews with pseudonyms	• The translator translated the transcribed interview text from Bahasa into English • The researcher communicated with the English translation service and constantly checked the text to maintain the intended meanings of the participants • The researcher compared the translated English interview text with the Indonesian transcribed text to ensure validity

Figure 7: Translation of transcribed interview text

Data Analysis

The researcher used several data analysis techniques to answer the research questions. She used coding, the constant comparative method, theoretical sensitivity, and memo writing to facilitate the emergence of the substantive theory. The researcher used the software program NVivo 12 Pro © Qualitative Research Solutions International (QSR) to organise the data, memo-writing, and analysis.

Two data analysis processes were undertaken, the first involving two languages, Indonesian and English. The researcher initially began with the transcribed texts of the recorded interviews in Indonesian. After the Indonesian transcription had been produced, the researcher coded the words in English. The researcher ensured the simultaneous integration of the data generation and analysis. Therefore, a partial data analysis in English was undertaken in the field.

The study also included a secondary coding analysis using the full English translation of the interview text. The English language translation enabled the supervisors to follow the coding process and analysis as the study progressed. The researcher was aware of the importance of language in grounded theory. Language is crucial in a qualitative study due to the search for meaning in subjective experiences (Van Nes et al., 2010). The data in this study were collected in languages other than English, and language differences have consequences. Meanings and interpretation in one language might be understood differently in another language. The researcher used a range of ways to preserve the meaning of the translation of the transcriptions across the two languages. Once the translation of the transcripts was finalised, a secondary analysis was conducted by re-analysing the data available using

English coding. Conducting the secondary analysis was useful for the researcher, who was a novice grounded theorist, and this process provided the experience of doing grounded theory in a different language.

Coding in Grounded Theory

Coding is the first step in data analysis (Corbin & Strauss, 2008). The researcher coded the data manually, defining what was happening in the data and labelling segments to be coded (Charmaz, 2000). The codes arose from the participants' language, meanings, and perspectives. With coding, language plays a vital role in how and what the researcher codes (Charmaz, 2006). In this project, the researcher continually checked the data in the original language during the coding, ensuring that the interpretation would fit in both languages. The researcher coded all the text of the translated English interviews to gain a deep understanding of the data, to generate initial categories, and to reveal the relationships among the categories (Charmaz, 2014a).

The researcher employed the two-step coding process outlined by Charmaz (2006, 2014a), as follows:

1) Initial coding: the researcher fragmented the data into lines, paragraphs, or incidents and then named them with a short label (code). The researcher then continued to develop provisional categories.
2) Focused coding: the researcher assessed the initial codes (provisional categories) by sorting, synthesising, integrating, and organising them to make connections between them, and then constructed tentative categories and sub-categories.

Figure 8 presents the steps of a grounded theory analysis until the development of the core category, including initial and focused coding, the constant comparison method, and memo writing, all the while being mindful of theoretical sensitivity. The next section explains each phase of the coding analysis process.

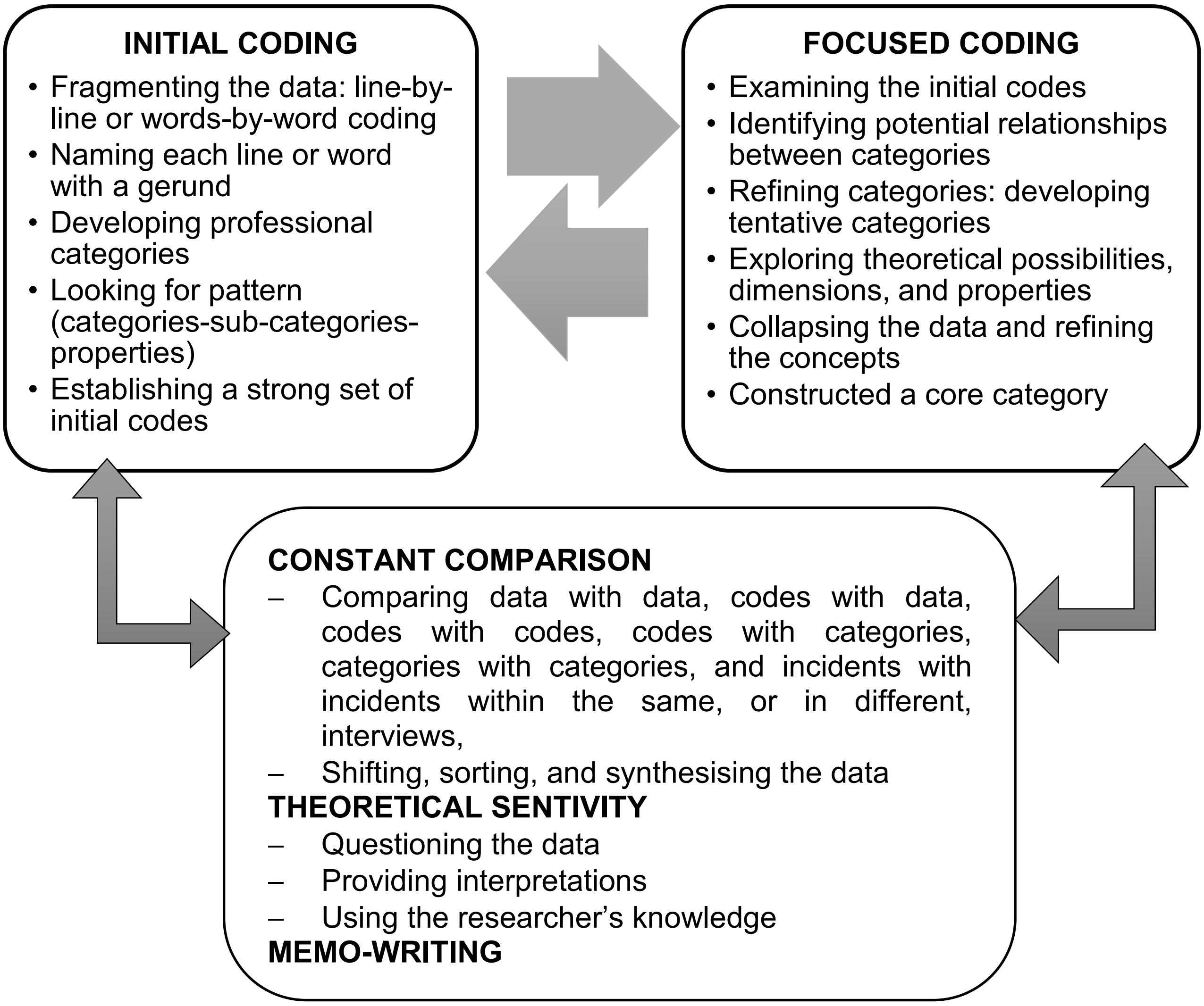
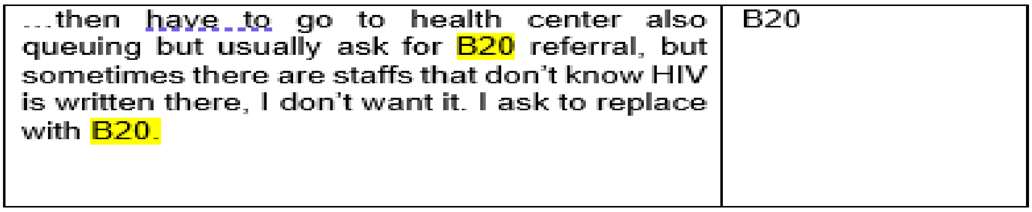


Figure 8: The grounded theory analysis process

The Initial Coding Process

The first step in the coding process was initial coding which aimed to categorise and then label the data. In the initial coding process, the researcher interpreted the meaning from each participant's perspective and remained open to what they said or what their views were (Charmaz, 2006). The researcher interpreted the data and examined the interview text to understand the participants' points of view, beliefs, and actions, and the significant issues or situations embedded in the text (Annells, 1996; Charmaz, 2000; Guba & Lincoln, 1994). During the initial coding phase, the researcher separated the data into fragments and labelled or coded the data using line-by-line, word-by-word, or incident-by-incident coding of the interview data (Charmaz, 2006, 2014a). Line-by-line coding helped the researcher to understand the meanings and actions of the participants, thereby informing the overall research problem (Charmaz, 2000, 2014a). The researcher coded quickly and spontaneously with gerunds to generate a fresh view of the data (Charmaz, 2006), and to avoid forcing the data into preconceived codes (Giles, de Lacey & Muir-Cochrane, 2016a). The researcher kept the initial codes short and simple, ensuring that they fit the data. The researcher went through the coding process for every sentence of each interview transcript.

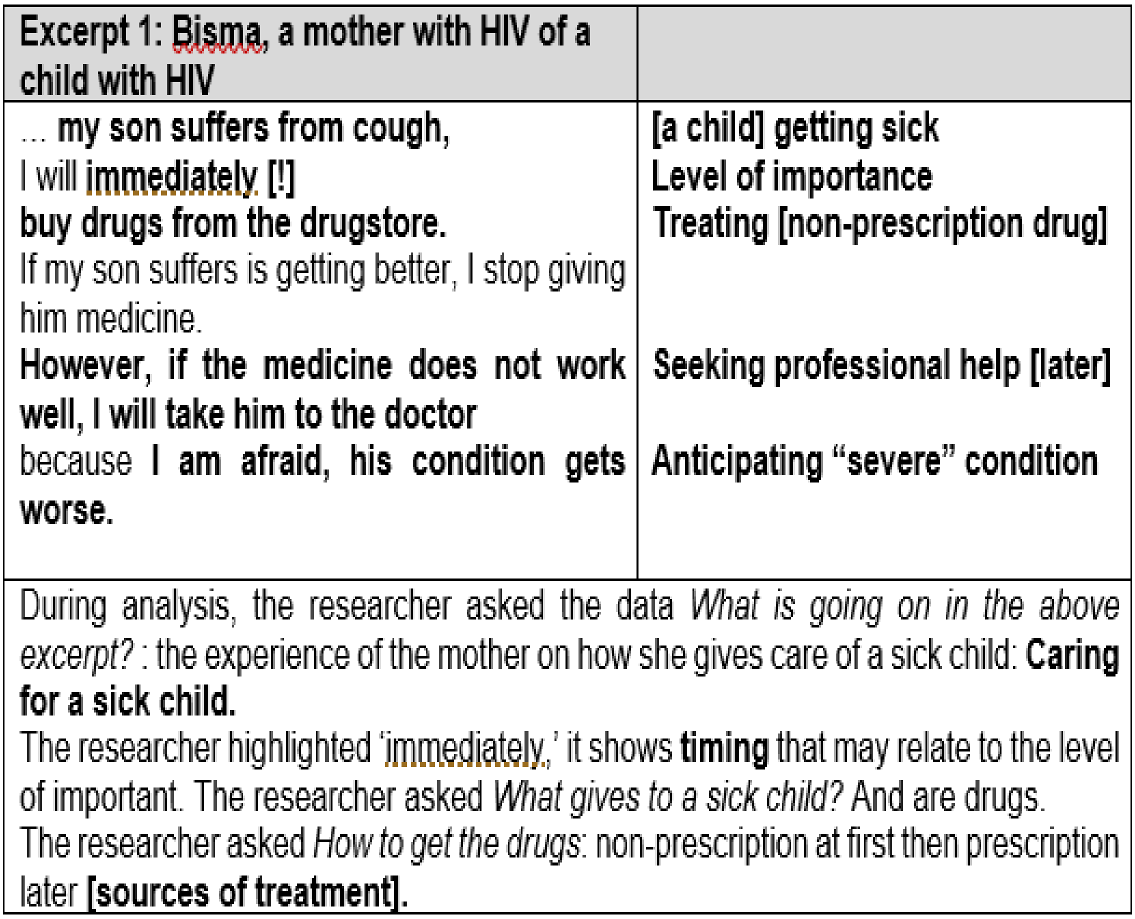
The initial coding process helped the researcher to separate the data into provisional categories. These codes were grouped under related categories. In other words, a category represented several codes (Khanal, 2019). A category explains the data, ideas, events, and processes at the conceptual level, which connects and enables the construction of an explanation of the phenomenon under investigation (Charmaz, 2006). The researcher organised the codes through the NVivo software programme and generated descriptive memos which helped to filter the data for the analysis. The researcher also used the words of the participants to accurately represent their speech and meanings in the initial coding process (Charmaz, 2006). Identifying the categories and terms used by participants is known as in-vivo coding (Charmaz, 2006; Ryan & Bernard, 2000). The most common terms used by the participants were 'B20', 'CD4', and 'VCT'.



...then have to go to health center also queuing but usually ask for B20 referral, but sometimes there are staffs that don't know HIV is written there, I don't want it. I ask to replace with B20.	B20

Figure 9: Example of the use of the term 'B20' in in-vivo codes

During the initial coding process, the researcher was also constantly mindful of theoretical sensitivity and used the constant comparative method. The researcher ensured theoretical sensitivity through the use of the self-questioning strategy while analysing the transcribed texts using "Wh" questions. These what, why, where, when, and how questions reminded the researcher to remain focused on the intentions of the study. For example, the researcher continually asked, "What is happening in the data?" (Corbin & Strauss, 2008), "What does the participant profess to think and feel?", "What are the consequences of the process?", and "How does the participant act while involved in the process?" (Charmaz, 2014a, p. 127).

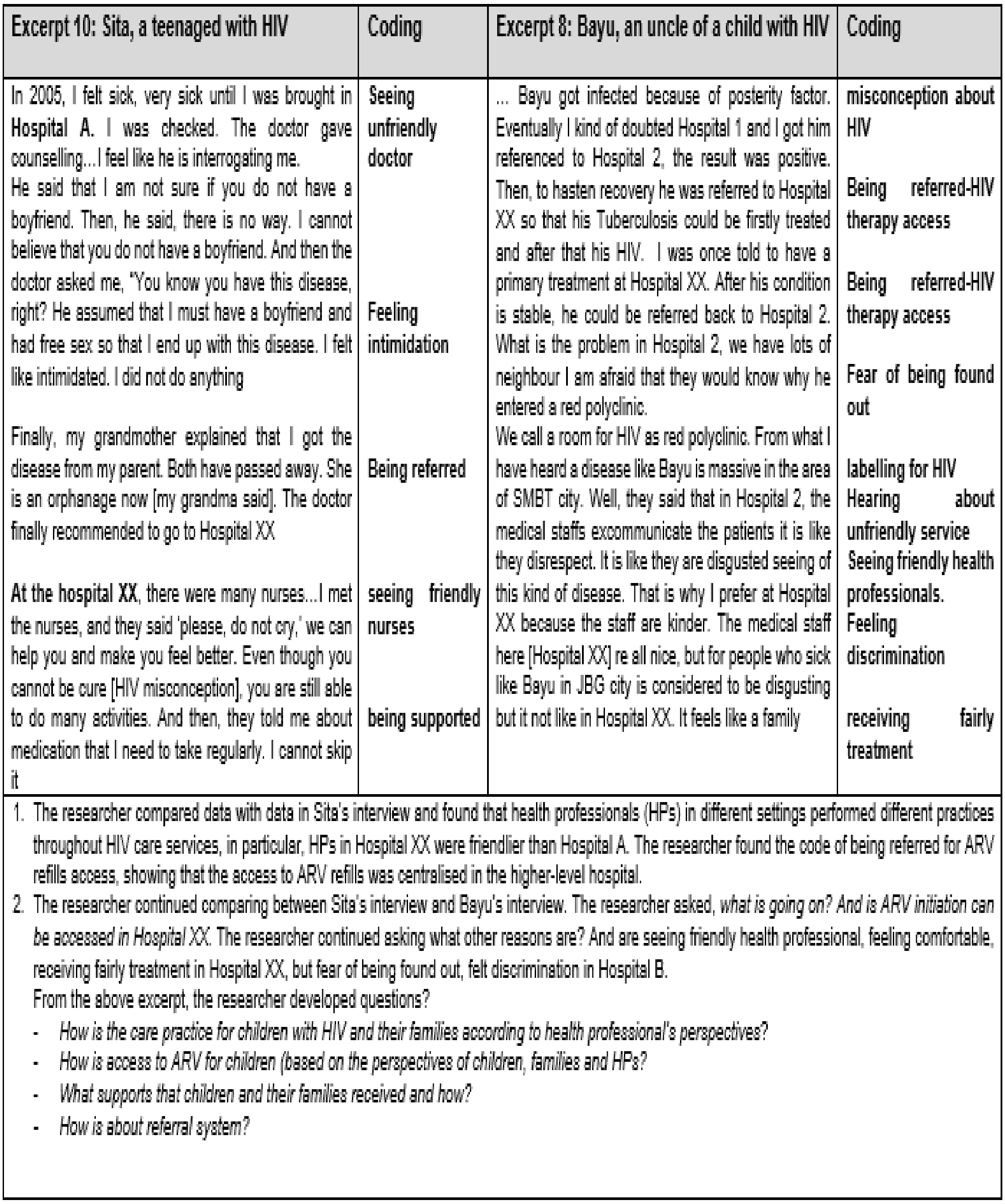


Excerpt 1: Bisma, a mother with HIV of a child with HIV	
… **my son suffers from cough,**	**[a child] getting sick**
I will **immediately [!]**	**Level of importance**
buy drugs from the drugstore.	**Treating [non-prescription drug]**
If my son suffers is getting better, I stop giving him medicine.	
However, if the medicine does not work well, I will take him to the doctor	**Seeking professional help [later]**
because **I am afraid, his condition gets worse.**	**Anticipating “severe” condition**
During analysis, the researcher asked the data *What is going on in the above excerpt?* : the experience of the mother on how she gives care of a sick child: **Caring for a sick child.** The researcher highlighted ‘immediately,’ it shows **timing** that may relate to the level of important. The researcher asked *What gives to a sick child?* And are drugs. The researcher asked *How to get the drugs*: non-prescription at first then prescription later **[sources of treatment].**	

Figure 10: Example of line-by-line coding with self-questioning

In seeking meaning, the researcher paid attention to the participants’ language to reflect their views and meanings. The researcher used self-questioning and sought meaning to improve her interpretations and understandings of what was happening in the data. This process was in line with the philosophical underpinning of constructivism, which acknowledges the construction of meaning arising through multiple perspectives and/or interpretations. Charmaz asserted that “constructing constructivism means seeking meaning, both participant’s meanings and researcher’s meanings” (Glaser, 2002, p. 10).

As well as ensuring theoretical sensitivity, the researcher continually compared data with data for the same participants or for different participants, compared the codes with the data, revisited and re-read each transcript, and then contrasted the codes with the categories. Below is an example of comparing codes with the data within different interviews:



Excerpt 10: Sita, a teenaged with HIV	Coding	Excerpt 8: Bayu, an uncle of a child with HIV	Coding
In 2005, I felt sick, very sick until I was brought in **Hospital A.** I was checked. The doctor gave counselling…I feel like he is interrogating me. He said that I am not sure if you do not have a boyfriend. Then, he said, there is no way. I cannot believe that you do not have a boyfriend. And then the doctor asked me, "You know you have this disease, right? He assumed that I must have a boyfriend and had free sex so that I end up with this disease. I felt like intimidated. I did not do anything Finally, my grandmother explained that I got the disease from my parent. Both have passed away. She is an orphanage now [my grandma said]. The doctor finally recommended to go to Hospital XX **At the hospital XX**, there were many nurses…I met the nurses, and they said 'please, do not cry,' we can help you and make you feel better. Even though you cannot be cure [HIV misconception], you are still able to do many activities. And then, they told me about medication that I need to take regularly. I cannot skip it	**Seeing unfriendly doctor** **Feeling intimidation** **Being referred** **seeing friendly nurses** **being supported**	… Bayu got infected because of posterity factor. Eventually I kind of doubted Hospital 1 and I got him referenced to Hospital 2, the result was positive. Then, to hasten recovery he was referred to Hospital XX so that his Tuberculosis could be firstly treated and after that his HIV. I was once told to have a primary treatment at Hospital XX. After his condition is stable, he could be referred back to Hospital 2. What is the problem in Hospital 2, we have lots of neighbour I am afraid that they would know why he entered a red polyclinic. We call a room for HIV as red polyclinic. From what I have heard a disease like Bayu is massive in the area of SMBT city. Well, they said that in Hospital 2, the medical staffs excommunicate the patients it is like they disrespect. It is like they are disgusted seeing of this kind of disease. That is why I prefer at Hospital XX because the staff are kinder. The medical staff here [Hospital XX] re all nice, but for people who sick like Bayu in JBG city is considered to be disgusting but it not like in Hospital XX. It feels like a family	**misconception about HIV** **Being referred-HIV therapy access** **Being referred-HIV therapy access** **Fear of being found out** **labelling for HIV** **Hearing about unfriendly service** **Seeing friendly health professionals.** **Feeling discrimination** **receiving fairly treatment**

1. The researcher compared data with data in Sita's interview and found that health professionals (HPs) in different settings performed different practices throughout HIV care services, in particular, HPs in Hospital XX were friendlier than Hospital A. The researcher found the code of being referred for ARV refills access, showing that the access to ARV refills was centralised in the higher-level hospital.
2. The researcher continued comparing between Sita's interview and Bayu's interview. The researcher asked, *what is going on? And is ARV initiation can be accessed in Hospital XX*. The researcher continued asking what other reasons are? And are seeing friendly health professional, feeling comfortable, receiving fairly treatment in Hospital XX, but fear of being found out, felt discrimination in Hospital B.
   From the above excerpt, the researcher developed questions?
   - *How is the care practice for children with HIV and their families according to health professional's perspectives?*
   - *How is access to ARV for children (based on the perspectives of children, families and HPs?*
   - *What supports that children and their families received and how?*
   - *How is about referral system?*

Figure 11: Example of comparing the codes with the data for different participants

Once the researcher had completed the initial coding and organised them in NVivo 12 Pro, she reviewed the initial coding through the constant comparison method and began labelling similar phenomena by connecting various codes and mapping them to discover their properties, dimensions, and sub-categories (Birks & Mills, 2011).

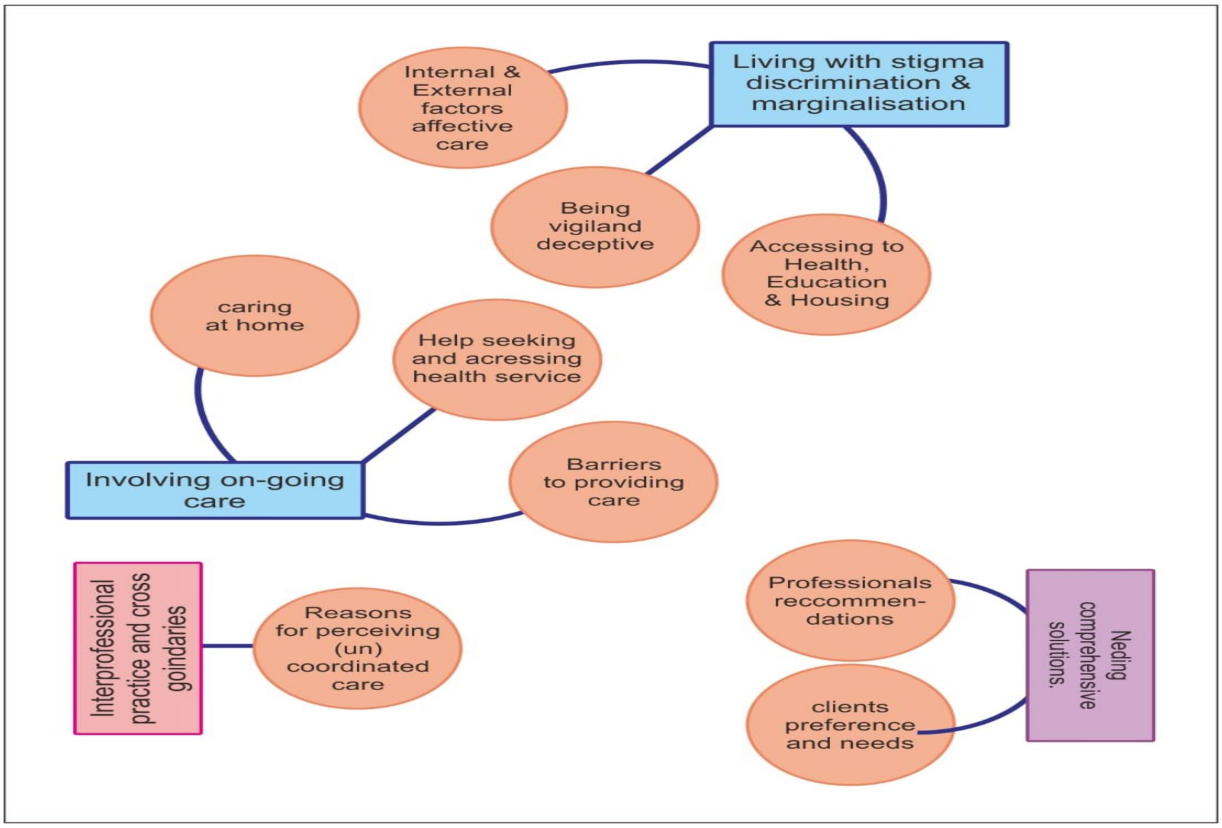


Figure 12: Example of connecting codes

The researcher also laid-out hand-written post-it notes as a coding technique. For example:

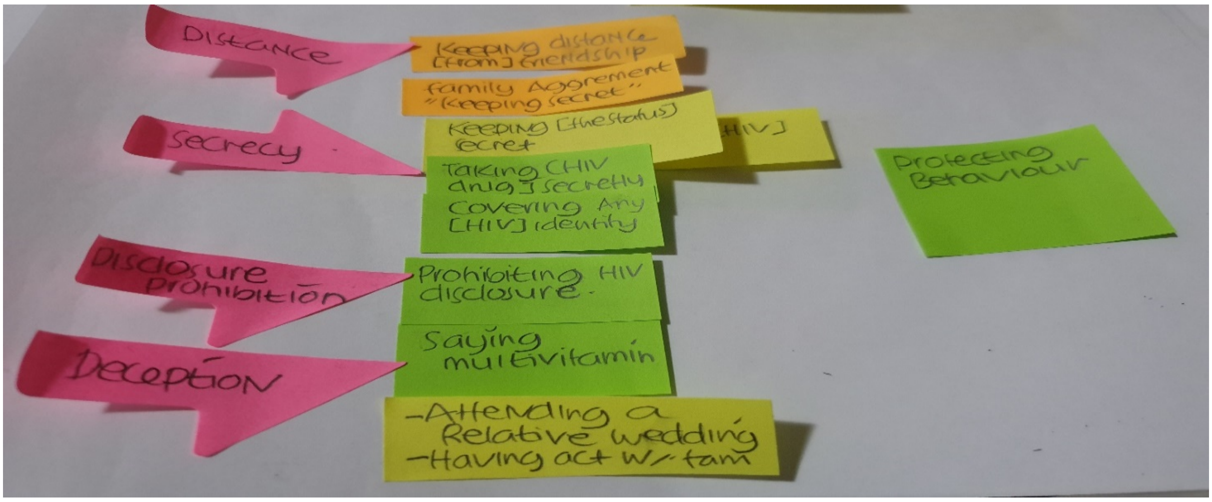


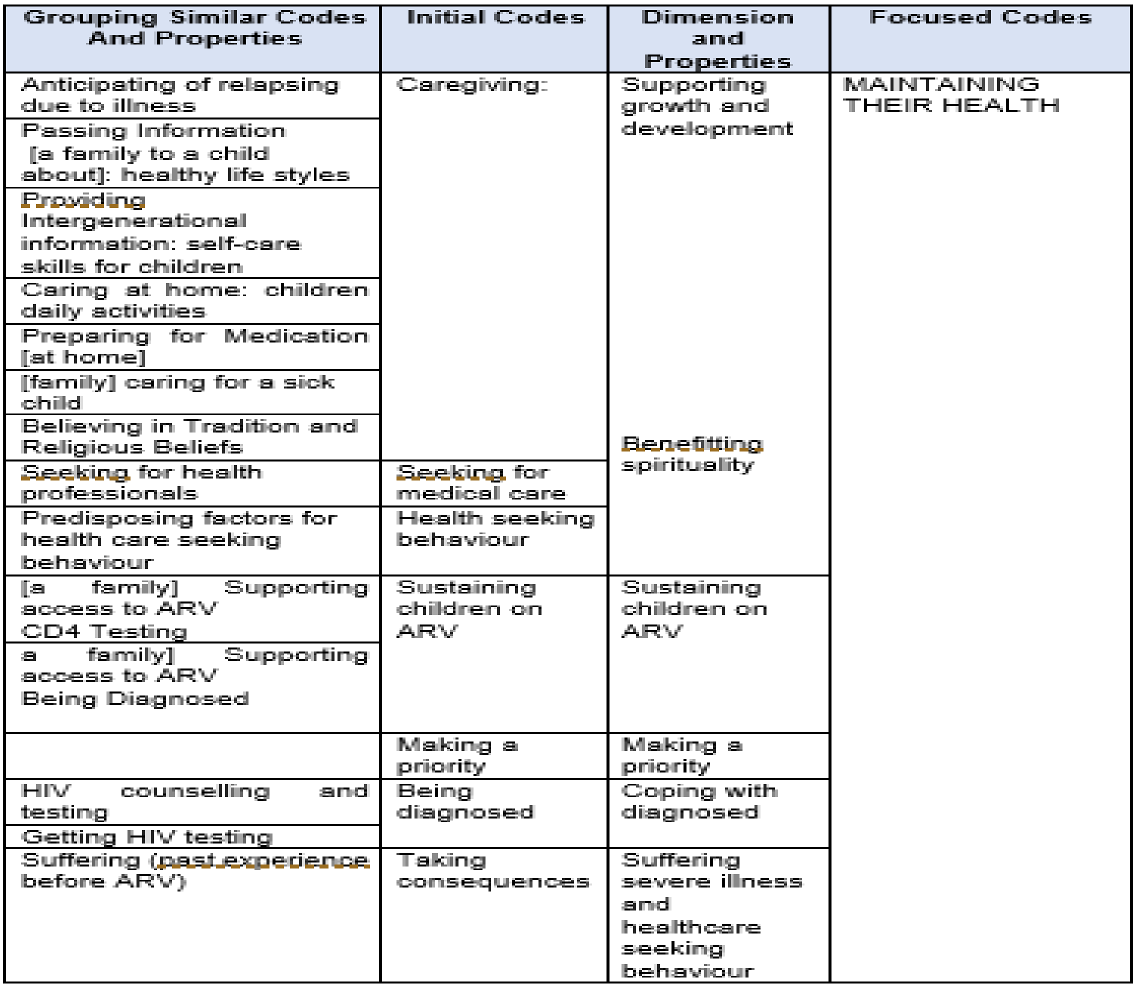
Figure 13: Example of developing a pattern

The researcher again compared (provisional) categories with the data and then re-labelled the provisional category that represented the codes grouped under it to improve the fit of the data. As early data patterns were identified, the researcher explored implicit meanings from the interviews by revisiting the Indonesian language transcription to ensure the analysis was consistent with the data. Revisiting the data and repeated reading of the transcripts encouraged new interpretations, the construction of new codes, and provided meanings and the overall picture of the participants' beliefs and how such beliefs influenced their actions (Charmaz, 2006). In total, the researcher found 9 provisional categories that were useful for a comparative analysis of the dataset. The process for the data analysis is detailed in Appendix. 6, pp.304-330.

The Focused Coding Process

The focused coding process was the second step of the data analysis (Charmaz, 2006). Focused coding aimed to refine the analysis to synthesise and explain larger segments of the data (Charmaz, 2006). The researcher used focused coding after establishing a strong set of initial codes. In the process of focused coding, the researcher moved back and forth between initial and focused coding. While the research was proceeding, the researcher constantly kept the research question of the study in mind. As the focused coding progressed, the researcher ensured theoretical sensitivity through her interpretations and knowledge to find the relationships between the codes and the categories and to find out whether the codes were significant to the processes, situations or events, and the context presented in the data.

The researcher also continually used the constant comparative analysis method. Similar to the process used in the initial coding, the researcher compared codes, codes with data, and then data with data to construct significant categories. The researcher moved across the interviews, comparing the participants' experiences and actions (Charmaz, 2006). The researcher selected and categorised the various codes and the most significant codes. The researcher looked for similarities and dissimilarities, and categorised all codes that contained similar concepts, and then grouped them into significant sets of codes.



Grouping Similar Codes And Properties	Initial Codes	Dimension and Properties	Focused Codes
Anticipating of relapsing due to illness	Caregiving:	Supporting growth and development	MAINTAINING THEIR HEALTH
Passing Information [a family to a child about]: healthy life styles			
Providing Intergenerational information: self-care skills for children			
Caring at home: children daily activities			
Preparing for Medication [at home]			
[family] caring for a sick child			
Believing in Tradition and Religious Beliefs		Benefitting spirituality	
Seeking for health professionals	Seeking for medical care		
Predisposing factors for health care seeking behaviour	Health seeking behaviour		
[a family] Supporting access to ARV CD4 Testing	Sustaining children on ARV	Sustaining children on ARV	
a family] Supporting access to ARV Being Diagnosed			
	Making a priority	Making a priority	
HIV counselling and testing	Being diagnosed	Coping with diagnosed	
Getting HIV testing			
Suffering (past experience before ARV)	Taking consequences	Suffering severe illness and healthcare seeking behaviour	

Figure 14: Example of focused coding

The researcher moved through the interviews to develop meaning, and decided which initial codes made analytic sense to categorise the data precisely (Charmaz, 2006, 2014b; Giles, de Lacey & Muir-Cochrane, 2016a). In the focused coding process, the researcher treated the focused codes as tentative categories as the analysis developed. The researcher continually compared and contrasted the tentative categories against all the data. Through the focused coding process, the researcher generated three major categories in the experiences of Indonesian children with HIV and their families in the continuity of care, maintaining the child's health, living with fear and stigma, and predisposing factors to ineffective care.

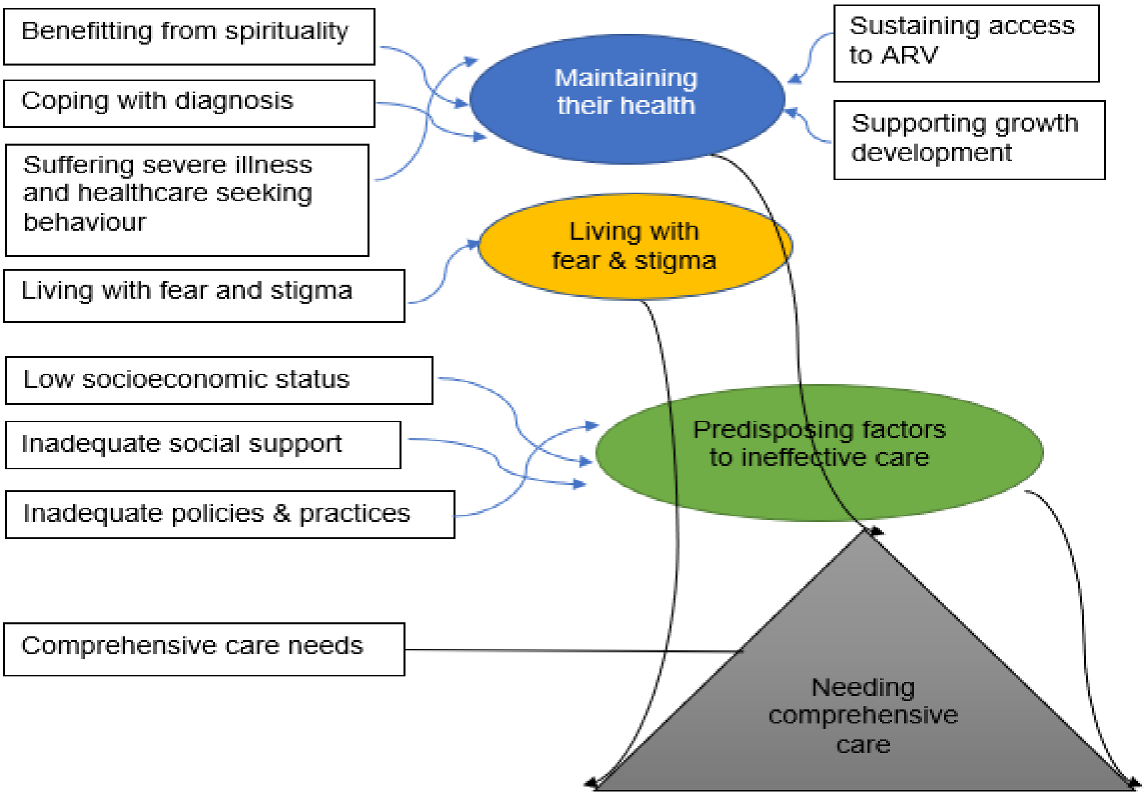


Figure 15: Example of the inter-relationships between provisional categories and major categories

As the study progressed, the researcher also wrote memos to record information and ideas, and the inter-relationships between the data and the categories found in the focused coding process.

Theoretical Coding Process

Theoretical coding is the final level of coding and enables the saturation of the core category that has been identified during the focused coding (Alemu et al., 2015). Theoretical coding moves the analytical story in a theoretical direction (Charmaz, 2006). Theoretical coding provides a way of specifying the potential relationship between categories. The researcher remained actively involved in the data to identify and verify the relationships between categories and sub-categories. The researcher interpreted the experience of care for children with HIV and their families across the continuum. After making multiple rounds of the data analysis, the researcher constructed a core category. The construction of the core category in this study was grounded in the participants' construction of their own experiences (realities). Theoretical coding facilitates the emergent theory until the development of a substantive theory (Charmaz, 2014a). The construction of theory in this study was established after the continuous process of initial, focused, and theoretical coding.

The core category is a central point in grounded theory (Mills, Bonner & Francis, 2006b). This study constructed *needing comprehensive care* as the core category by integrating the three relationships between the categories and their sub-categories. Constructing a core category and building theory around it is an essential activity through the functions of 'integration, density, saturation, completeness, and delimiting focus' (Glaser, 1992; Jeon, 2004). The construction of the core category of 'needing comprehensive care' explained the experience of Indonesian children with HIV and their families in relation to the need for comprehensive care due to the fragmentation of care across the continuum. Rodgers (2005) explained that theory enables the researcher to move from one situation to the next through knowledge of the concepts and relationships in the data, and serves as an essential mechanism for organising knowledge.

The levels of theory have traditionally been classified into grand theory, middle-range theory, micro-range theory, and situation-specific theory (Rodgers, 2005). Apart from theory, conceptual development is another important aspect of research in furthering knowledge development in nursing (Rodgers, 2005). Grounded theory generates the development of middle-range theory at a substantive level (Khanal, 2019; Strauss & Corbin, 1990). Middle-range theories are narrower in scope and less abstract, which is appropriate for guiding research, and is specific enough to guide nursing practice (Rodgers, 2005), compared to grand and formal theory. Substantive theory is defined as addressing specific substantive areas and concerns, and applies to a delimited problem in a specific area (Charmaz, 2006, 2014a; Hallberg, 2009).

There are three alternatives for generating a substantive theory: (1) using a visual coding paradigm, (2) stating a series of propositions or hypotheses, (3) presenting a story or narrative (Corbin, 1998; Khanal, 2019; Strauss & Corbin, 1990). Mills, Bonner and Francis (2006b) developed the theme of writing as a strategy in constructivist grounded theory and described that the writing style needs to be evocative of the participants' experiences. The researcher presented a substantive theory in this study in narrative form based on the voice of the participants, describing what was happening in the situations found in the data, and revealing existing components in these situations (Rodgers, 2005).

The researcher framed this study within the literature and identified the arguments and problems, and sharpened the concepts through writing and rewriting, fostering the analytical process (Charmaz, 1990). After the substantive theory had emerged, the researcher reviewed the literature. Reviewing the existing literature at this stage helps to strengthen the emergent theory, to refine or to challenge and support current theories with existing theories (Charmaz, 2006, 2014a). Glaser, Strauss, and Corbin acknowledged that reading the literature at this stage is crucial as it enhances conceptualisation of the data and theoretical sensitivity (Bluff, 2005). Westra and Rodgers (cited in Rodgers (2005), in their work on the concept of integration, explained that the literature analysis serves as an excellent example of the development of a new concept for use in nursing. This view provides an additional reason to consider the potential for concept-related activities in developing the knowledge base of nursing (Rodgers, 2005).

Theoretical Sorting and Diagramming

The researcher applied theoretical sorting, diagramming, and integration throughout the data analysis and theoretical development process. Sorting was the first step in creating, organising, and refining theoretical links in the grounded theory (Charmaz, 2006). The researcher produced diagrams to express and provide a visual relationship of the emerging categories (Charmaz, 2006; Rand, 2013), and in turn, shared the diagrams with her research supervisors. Creating visual images of emerging theories is an intrinsic part of grounded theory (Charmaz, 2006). Diagrams assist the researcher to find the gaps in the process of developing a conceptual understanding and in directing the researcher on further theoretical sampling (Birks & Mills, 2011). The researcher dated the diagrams to trace the development of the grounded theory over time (Birks & Mills, 2011). When the sorting and integrating of categories had a logical order, the researcher provided detailed diagrams or ideas based on these categories (Charmaz, 2006). The researcher produced a variety of diagrams to illustrate the complex interplay between the categories. For example:

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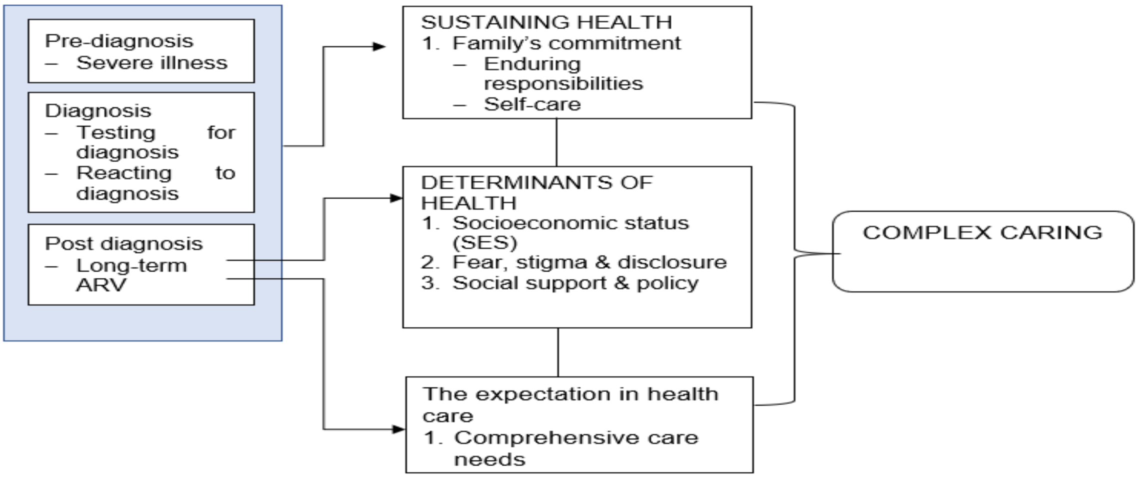

Figure 16: Examples of code integration through a flow diagram

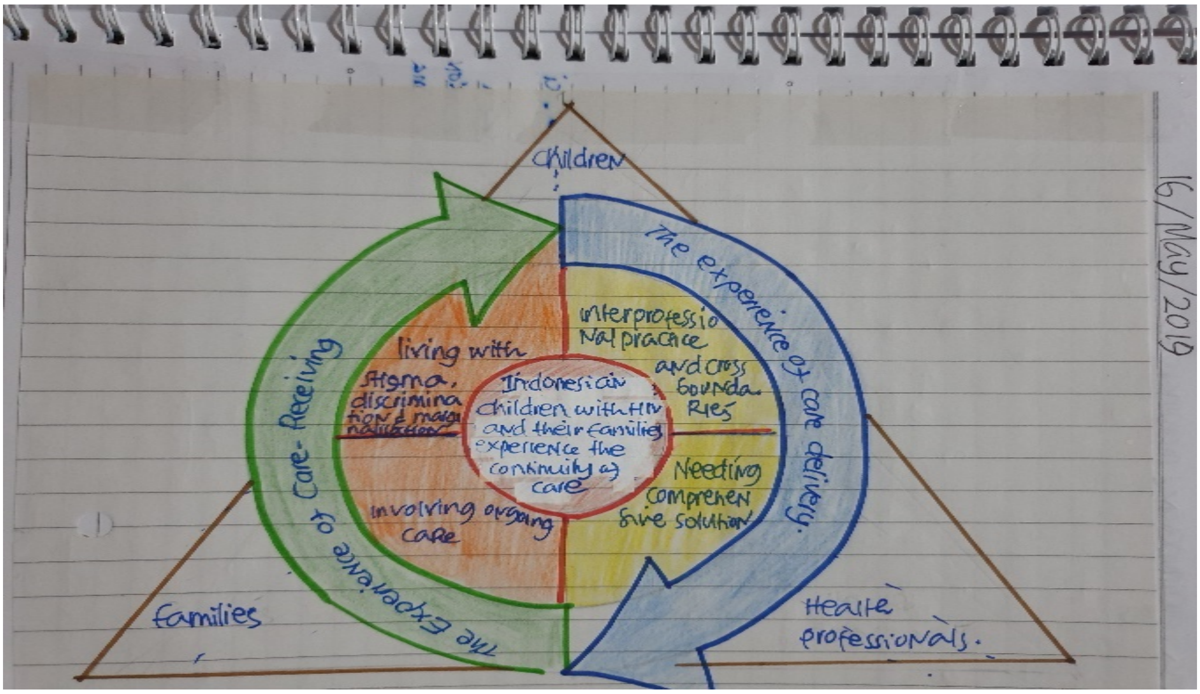

Figure 17: Example of code integration through a cyclic diagram

Constant Comparative Analysis Method

The constant comparative method is the core tenet of grounded theory (Birks & Mills, 2011; Charmaz, 2014a; Giles, de Lacey & Muir-Cochrane, 2016c), and was initially described in 1967 by Glaser and Strauss (1967). The constant comparative method is the analytical process of comparing data against data and comparing each level of analytical work (Charmaz, 2006; Timonen, Foley & Conlon, 2018) to establish an analytic distinction. Birks and Mills (2011) described the constant comparative method as the process of concurrent data collection and analysis until the grounded theory is fully integrated.

In making a comparison between the data, the researcher engaged in five levels of constant comparative analysis:

- Codes were compared with data: the researcher compared data from the same participant at different times, and compared data from different participants (i.e., beliefs, perspectives, actions, and experiences) (Charmaz, 2006).
- Codes were compared with codes.
- Codes were compared with categories.
- Categories were compared with other categories.
- Incidents were compared with incidents.

The researcher compared and asked questions of the data to sharpen the researcher's thinking and to gain an understanding of what was in the data (Jeon, 2004). The researcher went back and forth within the data to facilitate categorisation and conceptualisation, also comparing the data with other project data to look for variations, similarities, and differences across the data to identify potential categories and patterns, resulting in a highly iterative process (Timonen, Foley & Conlon, 2018). The researcher revised and renamed the codes to refine the emerging concepts (Charmaz, 2006; Timonen, Foley & Conlon, 2018). See Appendix 6 for an example of coding analysis and the constant comparative method. Furthermore, as part of the constant comparative analysis method, this study employed memos and ensured theoretical sensitivity to facilitate the development of theory grounded in the research data (Jeon, 2004).

Theoretical Sensitivity

Theoretical sensitivity is about the capability of the researcher to understand the data, to give meaning to the data, and to separate the relevant and the irrelevant from the data (Holloway & Wheeler, 2010; Strauss & Corbin, 1990). Theoretical sensitivity is the ability of the researcher to generate concepts and develop theory from the data through the research process (Glaser & Holton, 2004; Glaser & Strauss, 1967). In this study, the researcher used her level of understanding of the topic matter, previous knowledge or experience, and the types of theory that the researcher has read and used in her research (Birks & Mills, 2011). The researcher acknowledged her previous knowledge and engagement in HIV care and practise for adult clients, which enabled her to explore the unspoken issues during the interviews. Pre-understanding of the context of the study built familiarity with the study setting and the participants, particularly health professionals, which was central to the constructivist approach (Keane, 2014). As the data was generated and analysed, the researcher's theoretical sensitivity developed, contributing to a very focused set of interviews.

As well as using her previous professional experience, the researcher engaged the literature as a source of theoretical sensitivity at the beginning of, and during, the study and particularly in the development of the theory (Strauss & Corbin, 1990). This study built theoretical sensitivity from the literature to form the research question and to justify the methodology used, and then conceptualised a substantive theory and the analytical process in relation to the existing literature (Strauss & Corbin, 1990). Moreover, this study demonstrated theoretical sensitivity through the process of constructing the categories, the interpretation of the categories associated with the constant comparative method, questioning the data, and connecting the codes during the data analysis.

Reflexivity and Relationality

The researcher also engaged in reflexive and relational processes throughout every phase of the study. Reflexivity is the process of self-awareness of the researcher's interactions with, and involvement in, the research process (Hall & Callery, 2001). By using the constructivist philosophy, which accepts the relationship between the researcher and the participants, the researcher engaged in an ongoing process of self-reflection (Birks & Mills, 2011; Keane, 2014). The researcher developed her self-reflections through memo writing and ensuring theoretical sensitivity. Throughout the memo writing, the researcher kept a record of the research process and also used memos to increase awareness of any unknown preconceptions. The researcher ensured theoretical sensitivity throughout the interpretation and coding process, supported by the reflexive self (Hall & Callery, 2001). The researcher used her professional knowledge and experience as an instrument to understand and give meaning to the data throughout the study process. The researcher was aware and self-reflexive about the meanings attributed to the participants' experiences, beliefs, actions, and past and present experiences. The researcher also engaged in an ongoing process of self-reflection through systematic writing and discussion with her PhD supervisors.

Relationality is the relationship between the researcher and the participants with the emphasis being on a balance of power (Hall & Callery, 2001). The researcher maintained the power balance in several ways, firstly by using a fair process for participant recruitment through the use of flyers and by meeting ethical standards (Hall & Callery, 2001). Article 12 of the Convention on the Rights of the Child conveys the notion of the child's right to express themselves (The United Nations International Children's Emergency Fund, 2019a). This study complied with Article 12, providing the children involved with the opportunity to talk about their experiences and needs, and their input was of benefit as a result of their ideas being considering in the care planning process (Harcourt & Sargeant, 2016). The researcher maintained the power balance by respecting the participants decisions on the venue and the time for the interviews. The researcher built a strong rapport with the participants (Keane, 2014) by being empathetic, and also developed a participatory approach to accessing children with HIV and their families and respecting them. The professional experience of the researcher provided her with the opportunity to engage with several adults with HIV and other key populations which further facilitated the building of relationships with children with HIV and their families.

Establishing Rigour

This study ensured credibility, originality, resonance, and usefulness in developing the scientific rigour of the constructivist grounded theory (Charmaz, 2006, 2014a).

Credibility

Charmaz (2014a) suggested that *intimate familiarity with the topic*, and the depth and relevance of the data determines the credibility of a study. Furthermore, Schneider and Whitehead (2016) explained that credibility is the process of establishing the truth of the findings from the perspective of the participants. Credibility refers to how the researcher has achieved familiarity with the topic and how the research provides sufficient evidence to support the researcher's claims. Intimate familiarity with the topic has been demonstrated through the researcher's previous knowledge and experience, the process of undertaking the literature review, and the systematic process of the data analysis. The researcher has been involved in a collaborative project on HIV in Indonesia since 2006, and her involvement has built her experience and knowledge of HIV. The literature has been used to understand what has previously been found in the topic area. This study interviewed 12 children, 8 family members, and 23 HPs from 8 healthcare settings. The individual in-depth interviews, taken from three different groups of participants from PHCs and hospitals, created meaningful data which reflected the daily reality of the participants (Schneider & Whitehead, 2016). The empirical data were sufficient to support the development of concepts and categories, and the argument and analysis. The researcher used memo writing to maintain an audit trail throughout the research process (Birks & Mills, 2011; Schneider & Whitehead, 2016). Memo writing also developed self-reflection and enabled the researcher to stay focused on the topic.

The researcher used the NVivo 12 Pro software to organise the data, maintain the transparency of the data, and to develop high quality grounded theory. Finally, the researcher used the constant comparative analysis method by comparing the data, codes, and categories, and refining the emergent core concept. The constant comparative method demonstrated a systematic comparison that was grounded in the data. In this study, constant comparison analysis together with memo writing and diagramming demonstrated a strong logical link between the data, the analysis, and the arguments, all ensuring that the data were believable and credible (Charmaz, 2006). In addition, the researcher was in regular consultation with her PhD supervisors to discuss the development of the categories and the theory.

Originality

Originality is the gaining of new insight into the phenomenon being studied (Charmaz, 2006), showing the contribution of the findings to challenge existing practices (Alemu et al., 2015). The results of this study are original and offer *new insights* into the conceptual model of comprehensive care for children with HIV which was not previously well identified in Indonesia. HIV care for Indonesian children with HIV and their families focuses more on the delivery of ARV service than other services meeting the needs of the children, leading to fragmentation of care. The conceptual model of comprehensive care derived from patient perspectives consisting of child-centred care and social support to address the fragmentation of care across the continuum. Charmaz (2014a) suggested that providing *a new conceptual rendering of the data* determines originality. Overall, the substantive grounded theory constructed in this study discusses the practical implications of the findings of the study, and this theory does challenge current practice (Charmaz, 2014a, p. 337). In addition, the use of constructivist grounded theory in the study of Indonesian children with HIV was original because most of the qualitative studies have used a descriptive research design.

Resonance

Resonance is how the research makes sense to the participants, and how the data analysis process offers in-depth insights about them (Charmaz, 2006). This constructivist grounded theory was based on the interpretive approach in which the researcher recognised her involvement with the participants in the interview process and through the narrative data. In relation to revealing taken for granted meanings, the researcher ensured an interactive dialogue during the interviews, by answering the patient's questions and clarifying meanings with the participants in anticipating their assumptions. In the process of interaction with the participants' narratives, symbolic interactionism was used to help the researcher to learn the participants' meanings. In addition, using constant comparative methods, theoretical sampling, and reaching theoretical saturation supported the resonance of the findings as being grounded in the data (Alemu et al., 2015; Charmaz, 2006). The findings provide an understanding of the lived experiences of children with HIV and their families across the continuum. In their life experiences, children with HIV and their families also shared their circumstances in the process of family caregiving. The provision of more in-depth insights into the participants' lives, circumstances, and worlds determined the resonance of the study (Charmaz, 2014a, p. 338). The resonance of the analysis was also achieved through critical feedback from the researcher's PhD supervisors.

Usefulness

The usefulness is how research contributes to knowledge, and how knowledge can be applied (Charmaz, 2014a). This study provides a conceptual model of comprehensive care for children with HIV. This model could be an alternative framework to address the problem of fragmentation of care for Indonesian children with HIV and their families. The conceptual model offers comprehensive HIV care components associated with interventions for children based on their preferences, namely child-centred care and child social support. This study demonstrates usefulness because it can be practically applied in HIV care practice, education, and policy, which would enhance continuity of care. The findings can act as baseline data to enhance areas for further research, and is presented in the chapter conclusions and recommendations.

Chapter Summary

This chapter has detailed the application of the constructivist grounded theory method. The research process of grounded theory initially started with the ethics procedures before the recruitment of the participants. The chapter described the in-depth nature of the semi-structured interviews to gather the data, followed by the analysis of the data through the tenets of grounded theory. The tenets of constructivist grounded theory include the constant comparative method and memo writing, as well as ensuring theoretical sensitivity. The criteria for evaluating the rigour of this study were also explained.

The following chapter presents the findings of the study from the coding analysis process, consisting of three major categories and an overview of the core category, presented in two separate chapters. Chapter 5 presents Part A of the findings which explores two categories: ‘maintaining their health’ and ‘living with fear and stigma’, together with its sub-categories. Chapter 6 presents Part B of the findings which describes the third major category of ‘the factors predisposing ineffective care’, as well as an overview of the core category, “needing comprehensive care”.

CHAPTER 5
STUDY FINDINGS PART A

Chapter Five presents how children with HIV and their families experienced continuity of care according to the perspectives of the participant children and their families, and supported by the insights of health professionals (HPs).

This chapter begins with an overview of the participants' profiles. Table 3 presents the profiles of the children and their families. There were 12 children, 8 family members, and 23 health professionals who participated in the interviews. Overall, 8 children were interviewed with their families, while 4 adolescents aged above 16 years were interviewed separately. The age of the children ranged from 9 to 18 years, with 4 females, 6 males, and 2 transgender adolescents. There were 10 children who had acquired HIV through perinatal transmission from their mothers, while the 2 transgender adolescents acquired the virus through sexual activity. The 8 family participants included 3 mothers who were also living with HIV, 2 foster parents, and other relatives including an aunt, an uncle, and a sister who acted as caregivers at home.

Table 3: The profiles of the children and their families

Children's profiles	**N**
Gender	
– Females	4
– Males	6
– Transgender	2
HIV transmission modes	
– Perinatal	10
– Sexual	2
Age Range of Children	
– 6-12 years old	5
– 12-18 years old	7
Children who have lost of one or both parents	12
Family's profiles	
Roles of Caregivers	
– Mother, also living with HIV	3
– Aunt	1
– Uncle	1
– Sister collaborated with her father	1
– Foster parents	2
Age Range of Family Members	
– 25-<35 years	1
– ≥ 35 years old	7
Employment Background of Family Members	
– Seller	5
– Labourer	2
– Government Employee	1
Educational Background of Family Members	
– Primary School	2
– High School	6

Table 4 describes the characteristics of the HPs. The number of HPs interviewed was 23, consisting of 4 males and 19 females. There were 9 general practitioners (GPs) acting as HIV coordinators or as the head of a PHC (known as Puskesmas[3]), 3 nurses, 1 midwife, and 1 nutritionist working across 5 PHCs. Additionally, the researcher interviewed 3 paediatric specialists and 2 nurses acting as Nurse Unit Managers (NUMs), and 4 clinical nurses, working across 3 different hospitals. The age of the HPs ranged from 30 to 55 years. Of this cohort, everyone had received HIV education and training.

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[3] Puskesmas (**Pusat Kesehatan Masyarakat**, Public Health Centre), is a government-mandated first-level healthcare service for the population at the sub-district level, located across Indonesia and monitored by the Ministry of Health.

Table 4: The profiles of the HPs

HP's profiles	**N**
Roles of HPs Working in 5 PHCs	
– GP, HIV Coordinator	5
– GP, Head of PHC	4
– Nurse, HIV counsellor	3
– Midwife, Case Manager	1
– Nutritionist	1
Roles of HPs Working in 3 Hospitals	
– Paediatrician, specialist in tropical and infectious diseases	2
– Paediatrician	1
– Nurse Unit Manager (NUM)	2
– Clinical Nurses	4
HP Qualifications	
– Diploma of Nutrition	1
– Diploma of Midwifery	1
– Diploma of Nursing	6
– Bachelor of Nursing	2
– Master of Nursing	1
– Bachelor of Medicine + General Practitioner	8
– Bachelor of Medicine + Master of Health Science	1
– Specialists	3
Age Range of HPs	
– 25-<35 years	1
– ≥ 35 years old	22
HIV-related training	
– Counsellor	9
– Voluntary Counselling and Testing (VCT)	3
– Care, Support and Treatment (CST)	9
– HIV Recording and Reporting	1
– Prevention of Mother-to-Child Transmission (PMTCT)	9
– Antiretroviral Therapy Prescribing (ARV)	3
– Provider-Initiated Counselling and Testing (PITC)[4]	8
– HIV Therapy Paediatric	2
– Collaborative TB-HIV Management	1
– HIV & Sexual Transmitted Infections (STIs) Screening and Treatment	5
– Monitoring and Evaluation of HIV	1
– Nutritional Management of HIV and Malnutrition	1
– HIV/AIDS Case Management	1
– Standards for HIV and Education Service	1

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[4] PITC health providers recommend HIV counselling and testing for a client as the standard requirement of care practice.

From the data analysis process reported in Chapter 4, this study constructed three major categories and a core category of 'needing comprehensive care'. Three categories emerged: (1) maintaining their health, (2) living with fear and stigma, and 3) predisposing factors to ineffective care. Each of these categories consisted of several sub-categories, as shown in Table 5.

Table 5: Categories and sub-categories of Indonesian children with HIV and their families and HPs' perspectives about the experience of continuum care

Categories	Sub-categories
1. Maintaining their health	1) Benefitting from spirituality 2) Suffering severe illnesses and health-seeking behaviour 3) Coping with a diagnosis 4) Sustaining access to antiretroviral (ARV[5]) therapy 5) Supporting growth and development
2. Living with fear and stigma	1) Developing internalised stigma 2) Experiencing external stigma 3) Believing misconceptions about HIV 4) Disclosing their HIV status 5) Being vigilant and deceptive
3. Predisposing factors to ineffective care	1) Living with low socioeconomic status 2) Experiencing inadequate social support 3) Experiencing inadequate care coordination 4) Experiencing care based on insufficient policies and practices

Chapter Five presents the first two categories: (1) maintaining their health, and (2) living with fear and stigma, and will describe the relationships between the sub-categories. The third category, 'predisposing factors to ineffective care' and the core category, 'needing comprehensive care' will be presented in Chapter Six (Study Findings, Part B).

Maintaining Their Health

The first category recognises that family members performed actions to promote their child's health and daily care tasks throughout the illness trajectory from pre-diagnosis and diagnosis through to post-diagnosis. Families maintained their children's health as a process through which they continually provided care to promote their child's health across their life trajectory. The time points of the children's illness trajectories were classified into pre-diagnosis, diagnosis, and post-diagnosis. In this study, families regularly supported their

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child through ensuring the provision of care by placing the child's health as the most important goal throughout life. Some extended family members took on a primary caregiver's role to support the orphaned children who were without legal guardians.

Most of the children experienced the loss of one or both parents, predominantly from HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome), making some of them orphans. Because of this, the responsibility for caregiving traditionally went to extended family members. Family members in this study included biological mothers (some who also had HIV), a sister, an uncle, an aunt, a grandmother, a foster parent, and joint caregivers between a mother and an aunt. For example, Arjuna was an older sister of one of the children, and described that she took permanent responsibility for providing care for her younger sibling. She was able to achieve this by receiving support from her husband and collaborating closely with her father in her caring role. Kunti, a mother with HIV, valued her sibling's support in raising her twin daughters. Kunti explained that her sibling helped out with the children's daily needs. Other family members (i.e., an uncle and an aunt) took care of their nephew and niece through their spiritual faith, as they believed that they sought Allah's blessing and favour. The families assisted the children's care needs and helped in a variety of ways, although they did not have the formal authority of guardianship.

> *I am the one who wants to protect her. 'Bismillah', I do this because of Allah. There is no written proof [legal guardianship]. However, I do take her (Samba, lines no. 476-477, 518).*

As part of the caregiving responsibilities, Muslim families frequently recited the phrase "Bismillah", meaning in the name of Allah, most gracious and merciful for the caring of their children. Additionally, the families managed their child's health, ensuring that they received medical care. Collectively, the families assisted their children with spiritual care and functional needs, including improving the families' care-seeking behaviour, seeking HIV counselling and testing, sustaining access to ARV therapy, and supporting growth and development. Figure 18 represents that the categories of the code, 'maintaining their health', based on five sub-categories. The following section presents descriptions of each category.

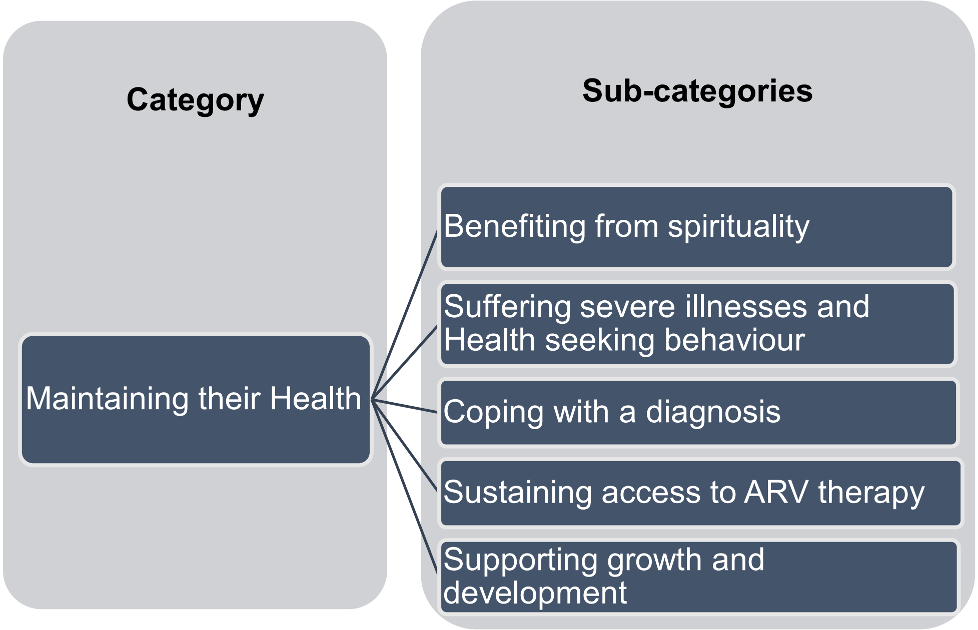

Figure 18: The category of maintaining their health and its sub-categories

Benefiting from Spirituality

The families combined spiritual beliefs with caregiving responsibilities to cope with the challenges that came with caring for their child with HIV. Families stated that they used their spiritual beliefs as a coping response for the hardship of providing care, with always giving thanks to God, being helpful, and communicating with God. For example, some families often said ‘Alhamdulillah’ for the children when they were no longer physically ill. ‘Alhamdulillah’ is an Islamic expression meaning Praise be to God or thank God. Some families also stated that they surrendered their life to God to relieve the anxiety or to solve unexpected problems during caregiving, believing that they were not in complete control of the situation, and so they asked God to take on their problems and solutions. For instance:

> *I am sincere ‘Lillahi Ta’ala’; the thing is that I take care of the child (Barata, line no. 103).*

The families used spiritual care, such as beliefs and faith, to help them face illness and sadness, and to give them strength during a difficult time. Hence, spirituality helped the families to find hope and comfort, and to improve spiritual well-being.

Suffering Severe Illnesses and Health-Seeking Behaviour

Health-seeking behaviour in relation to this study relates to the actions undertaken by the families to seek help to treat their children’s illnesses, and these were influenced by the belief that the child would get better. Advice was sought through external sources such as friends or neighbours. Family members developed their health-seeking behaviours through both professional and non-professional therapies.

All the families looked for medical care to manage the children's illness, from the time preceding their HIV diagnosis, to living with the diagnosis, to alleviating their illness, and then recovering their children's optimal health. The families endured their responsibilities through language and their actions, but also accepted the consequences of their actions. The families gave priority to the child's health:

> *I will not care how much it will cost as long as my son's health is guaranteed (Bayu, lines no. 200-202).*

According to most of the family participants, the children (with perinatal transmission) suffered severe illnesses from when they were young, which required frequent hospitalisations. Due to these recurring illnesses, the children were at times close to death. The families took their children to different health providers and ensured that they took all the medications prescribed to improve their child's health.

The families also sought help through alternative therapies to treat their child's illnesses before their HIV diagnosis. Many family participants believed in myths about treating and preventing severe illness in their children prior to the HIV diagnosis. Some family participants explained that they had received information from friends or neighbours about psychics, shamans, or paranormal healers that could help to heal their children. So, for these families, they believed in, and sought out, alternative and traditional healers. For example, one of the family members stated:

> *In the past, when I was still working with that lawyer, I was also introduced to a paranormal from the city of SDA. That lawyer convinced me because his son, who was supposed to get appendix surgery then taken to paranormal and was healed when checked by Ultrasonography (USG). Eventually, I bring him to a paranormal (Surya, lines no. 642-646).*

One mother believed in a myth that a long name was too 'heavy' and could be a burden on the child. As a result, she renamed her child with a short name, as she believed it would prevent her child from getting ill again.

The children with perinatal transmission of HIV experienced severe illnesses prior to their HIV diagnosis that had a negative impact on themselves and their families. Most of the families explained that their children suffered from conditions that included prolonged diarrhoea, oral candidiasis, malnutrition, lung infections, and tuberculosis that occurred repeatedly and required recurrent hospitalisations. During this period, they did not know that the children were infected with HIV. According to the participants, the children were below normal childhood growth and development and were malnourished. For example, Kunti, a mother with HIV, stated that *"they were only bones and skins" (Kunti, line no. 79).* A mother, Surya, described that her child suffered from recurring severe and prolonged diarrhoea until the age of three years, and he was unable to speak until he reached the age of four. With low cognitive function, Surya described that she enrolled her son in a school with an inclusive education program.

> *He was put into inclusion. Inclusion is basically the same as other students, but the difference is only at the problems in the tests. For normal children lesson for 6th graders will be the same for 6th graders. As children in inclusion, the test is maybe intended for 5th or 4th graders. He is also tutored by his teacher in special tutoring (Surya, lines no. 153-159).*

Similarly, Sita, one of the children with HIV, described how being ill affected her schooling. Due to recurring severe illnesses and the prolonged length of her stays in hospital, she was frequently absent from school, leading to her falling behind in her studies.

Because of the prolonged duration and severity of the illnesses, the families experienced financial stress as a result of the expenditure involved in receiving healthcare. One family participant explained that having an extremely sick child led to high costs for hospital care, necessitating the selling of all her assets, as she did not receive health insurance support from the government. Similarly, another mother explained that she had sold her house to pay for hospital costs due to the recurring hospitalisations of her child.

> *This kid was only spending money! One week he was hospitalised, one month in the hospital again. I do not even have the money to pay for the hospital to hospitalise him. After coming back from the hospital, I sold my house in the city of TGN because I could not pay, my son is sick; then I sold the house, until now we have been living in a rented flat (Indra, lines no. 72-80).*

After suffering severe illness with repeated hospitalisations, doctors would often recommended that the children have HIV counselling and testing. Most of the children had late HIV counselling, testing, and treatment because the virus had already affected their immune system causing severe recurrent infections. Either of two approaches were used: 1) health provider initiated HIV testing, or 2) individuals sought HIV testing. According to the family participants, the children had HIV counselling, testing, and treatment from ages 3 to 17 years. In most cases, testing was recommended by health providers due to the severe recurrent infections the children experienced. The 10 participant children that were diagnosed between 3 and 14 years of age were deemed to have acquired HIV through perinatal transmission from their mothers. The majority of the families reported that their children had been tested for HIV during hospitalisation. The 2 transgender adolescent participants reported having voluntary HIV counselling and testing due to their high-risk sexual behaviour, both receiving a positive result when they were 17 years old.

After testing positive, the families gained the information necessary to initiate ARV therapy, which for children was only available in the provincial hospitals. Few families reported that they were referred from either a PHC or sub-district hospital to the provincial hospital for their child's ARV treatment. For example:

> *He was diagnosed in PHC. I collect my medicines (ARV) here, but he is there, at Hospital X. There are medicines here for the mother but not for the child (Barata, lines no. 327-328).*
>
> *I got him referred to Hospital A; the HIV test result was positive. Then, to hasten the recovery, he was referred to Hospital X. I was once told to have primary treatment at Hospital X. After his condition is stable can be referred back in Hospital A (Bayu, lines no. 176-178).*

The families continued to apply their healthcare-seeking behaviour when illness struck, to maintain the child's health from receiving the diagnosis to living with the diagnosis. According to most of the family participants, the most common symptom suffered by their child was a cough or a fever. The families explained that they had initially used non-prescription drugs, and then later used prescription medications to treat their child's illnesses, as stated:

> *For example, if my son suffers from cough, I will immediately buy drugs from the drugstore. If his condition is getting better, I stop giving him the medicine. However, if the medicine does not work well, I will take him to the doctor because I am afraid if my son's condition drops (Bisma, lines no. 157-161).*

Most of the families reported that they gave an antipyretic when their child had a fever. The families understood that paracetamol helped to reduce the high temperature that triggered febrile convulsions. If the children were still not well, the families explained that they took their child to a private doctor, hospital, or PHC. For example, Kunti explained that the factors influencing her decision to seek treatment were the perceived experience of the PHC, information from neighbours, the family's financial status, and the cost of health services, as stated in the following excerpt:

> *I give them paracetamol. Always that, which is the same as the medicine from a PHC. My neighbours said that if my children are sick, I gave them paracetamol and antibiotic. If it does not get better, then I take them to the PHC. I have no money. So just PHC. If it is PHC, we do not have to pay because we have BPJS insurance. Usually, they got better after the 3rd time going to PHC, probably because of the low-rated medicine. The dosage is low, so I need to go there more than once, until three times (Kunti, lines no. 517; 982-991).*

Kunti explained that the PHC provided generic prescription medicines, which were less powerful for treating the disease than medicines administered by a HP in a hospital or private clinic. She believed that due to the low efficacy of the drugs, her daughter needed frequent PHC visits to make her feel better. As a result, the family was more dissatisfied with the PHC service she received because her child achieved only slow improvements in outcomes, although the PHC provided a free or low-cost service. Some families gave their child multi-vitamin supplements (e.g., ‘Sangobion’ or ‘Stimuno’) to increase the functioning of their immune system. A few mothers reported that they traditionally gave honey and coconut water, as they believed honey developed the immune function, and coconut water helped to neutralise free radicals in a child’s body due to the prolonged use of ARV therapy.

Prior to the children being tested, diagnosed, and treated, it was a very difficult time for the participants with recurring illnesses, repeated hospitalisations, developmental delays, and interrupted education. Most of the children experienced severe HIV-related signs and symptoms, including diarrhoea, oral candidiasis, malnutrition, lung disease, or tuberculosis that required recurrent hospitalisations without knowing they were HIV-positive. Most of the families experienced financial difficulties in paying for their children’s care. However, the families kept going, ensuring that the children’s care was a priority by seeking help from health providers and through alternative therapies. In an attempt to heal their children, the families continued to seek help through professional and non-professional therapies. After the children suffered from severe sickness and recurrent hospitalisations, the doctors therefore recommended that the children had HIV counselling and testing, many of which showed a positive result.

Coping with a Diagnosis

The majority of children received their HIV diagnosis through provider-initiated HIV counselling and testing (PITC) either from a PHC or a hospital. The children, being diagnosed by the healthcare services, were referred to the provincial hospital to begin their ARV treatment. Hence, all of the children received centralised ARV treatment in the highest-level hospitals. Most families coped with denial, sadness, and secrecy in response to their child's HIV diagnosis.

The family participants reported that they were confronted by the child's HIV diagnosis. They responded to the diagnosis of their children in many ways, including through denial, worry, desperation, shock, and/or hopelessness. They also often had misconceptions about HIV, believing it "to be a death sentence". For example, one of the mothers, Barata, was desperate and worried about her son's future, as she believed there was no cure for HIV:

> *I was just sad. Just sad (Crying). He was just a boy; I did not know what would happen when he grew up. It cannot be cured; we have to take medicines everyday (Barata, lines no. 179-182).*

Indra, another of the mothers, felt great shame about her child's HIV diagnosis, but her husband continued their commitment to ensure that their child received the necessary medical care:

> *At the first time of the counselling, I cried. I bathed in tears, this is a disgrace. My husband is, how to say it, it does not matter, then the important thing is that my son has medical attention (Indra, lines no. 252-253).*

However, one family participant, Bayu, believed that having multiple sex partners increased the risk of HIV infection and accepted that his nephew had acquired HIV through perinatal transmission due to the multiple sex partners his mother had engaged in.

All family participants explained that, at first, they had kept their child's diagnosis of HIV secret. Arjuna, a child with HIV, explained how he was not aware of being HIV-positive until he was in high school.

> *At first, I was not explained about the disease yet, except to be told that I had to take the drugs. I only knew that I suffered from lung diseases (Arjuna, lines no. 81-83).*

Sustaining Access to Antiretroviral (ARV) Therapy

The families were informed that their children would need to take ARV for their entire life to decrease the viral load in the body, which would help to prevent opportunistic infections. Most of the family participants reported that their children began HIV treatment immediately, and took a combination of ARV medicines, such as Neviral, Duviral, Efavirenz, Lamivudine, and Abacavir. All the children took a combination of ARV therapies to lower their viral load. Two adolescents stated that they had received a fixed-dose combination (FDC) of three medications. Some children reported side-effects from the treatment; for example, skin hyperpigmentation, and central nervous system (CNS) side-effects such as dizziness, hallucinations, and loss of concentration.

All the families and adolescents who knew their HIV status maintained their ARV treatment. They were accessing monthly ARV refills and setting this as a priority.

> *What is important is the regular monthly check-ups before the medicines run out. I keep in control (Bayu, lines 319-320).*
>
> *The important thing is that my son gets his medication (Indra, lines no.101-102).*

The families had to access their children's ARV treatment in the hospital because the treatment was not available in the PHCs. The families described their experiences in accessing ARV care services in the provincial hospitals. According to all the families, they began the ARV for their children at an Intermediate Care Unit and Infectious Diseases Outpatient Clinic in provincial Hospital X, and accessed the same hospital every month. Convenience and confidentiality played a large part in HIV care for the families to increase their access to ARV. Most of the family participants explained that it was convenient to visit the hospital because the health providers were friendly and kept their child’s diagnosis of HIV a secret. However, Samba, one family participant, stated that after having access for a year, she changed her pick-up of the ARV from hospital X to another hospital closer to her residence due to the length of time taken to get there and the cost of travel. This change proved to be more convenient for her.

The majority of family participants reported that they obtained ARV therapy for their children every month. This visit was supposed to involve a routine care service, which included registration, height and body weight measurements, a physician’s consultation, and ARV collection. However, most of the families explained that they tended to routinely pick up the ARV for their children without bringing them to the hospital. In most cases, many of the children missed the opportunity to receive health checks, such as monitoring of their growth and development. The families stated that they did not want their child to miss school, and they would have to provide false reasons for their child’s absences every month. For example:

> *I do not take him with me because of his school. Every time he took a day off, and he got rebuked by his teacher. If he did not go to school, he would be questioned by his teacher. I am afraid to tell the teacher that he would go to get medical control (Barata, lines no. 219-221).*

On the other hand, the families would bring their children to the hospital if they had a school holiday, or were suffering from symptoms that needed medication or required a blood test, such as a Cluster of Differentiation 4 test (CD4, a laboratory test to check immune system). During these visits, some mothers reported that the doctors were more interested in prescribing for, than educating, the child during the consultation.

> *Due to my son already knows his status, I need the doctor to ask more to him. For example, asking what his condition or what my son needs related to his illness is. The doctor is not only silence or asks his complaint, then writes a prescription only (Bisma, lines no. 148-152).*

As well as not wanting their children to miss school, the mother's own illness was also a barrier to care. Barata described that she sometimes delayed getting her son's ARV in the hospital because of feeling tired or getting sick during the day. Furthermore, she stated that her son was more likely to not have his therapy monitored if she failed to get her son's ARV on time. On the other hand, she stated that if she delayed getting her own ARV from a PHC, a nurse would monitor the delay for picking up ARV, calculate the number of missed pills, and then would warn her about the potential harm of missing the ARV drugs. Furthermore, she stated:

> *… [in the hospital], if his conditions are dropping, it would be easier for us to be taken care of by the doctors. However, I wanted it here [PHC], so it would not be far away. I do not know whether this PHC provides medicines for children, like him or not (Barata, lines no. 320-323).*

Hence, these findings show that the hospital services were more likely not to monitor the children's monthly ARV treatment compliance in the same way that the PHC services monitored adult compliance, leading to negative health outcomes for the children.

In addition to compliance with ARV therapy, all the children were more likely to take their ARVs daily, and most of the family participants described that their children were dependent on their families when taking ARV at home. The families explained that they always reminded their children to take their medicines and/or would administer their medicines. Most of the children agreed that they were dependent on their parents to administer their ARV medication daily. The children stated that they sometimes skipped their medication as they believed it would be fine, highlighting the importance of family assistance. The children sometimes thought they did not need to take their medication. For example:

> *[Mother] I told him to take it by himself. He does not want to take that medicine. The thing I have to prepare it for him. [Son] If mum does not*

> *prepare it. I do not have to take it. It does not matter (Indra, lines 307-309; 397-398).*

Most of the children responded that they did not like the bitter taste of the medication, nor did they like the size of the tablets. They claimed that the tablets were too big and difficult to swallow, and they felt that taking their ARVs daily was a burden. Even with these challenges, most of the family participants described how the children had not experienced further hospitalisations or were never again seriously ill after commencing ARV.

The HPs felt that children with HIV were at higher risk of non-adherence to ARV treatment because of the child's dependency on the parents, the dosing frequency, and a higher pill burden. Anjani highlighted that the children had to take a different number of medicines each day in relation to both their HIV infection and other opportunistic infections, leading to an increase in the pill burden. Because of factors related to non-adherence to ARV treatment, HPs suggested the need for long-term ARV therapy adherence to decrease the morbidity of the HIV infection. Adherence to treatment was defined by the HPs as taking ARV as prescribed at the same time each day without missing a dose.

Most of the HPs and all the families agreed that regular access to ARV medicines would support adherence to therapy. Most of the families wished for the availability of ARV medicines because they were afraid their child would relapse from a severe illness or would die if they did not take their medications. Some of the mothers reiterated that they had heard of a case of HIV mortality because the client had stopped taking their ARV. Similarly, other mothers worried that if the government stopped supporting ARV in the hospitals, they would fail to obtain the medicines or there would be stock-outs of ARV medications which would result in adverse child health outcomes:

> *I hope that the medicine to be provided on time. I am scared if it is provided late. I am scared that if later there is no help in the form of medicine, and she has to stop taking medicines, I am afraid if her condition drops or anything (Samba, lines no.636-638).*

Sukesi, the head of a PHC, stated that families with an HIV-positive member became anxious after they had accidentally heard a conversation between a nurse and another HP talking about the shortages of ARV medicine stocks in the hospital. She suggested that it was important for HPs to communicate effectively with other HPs to minimise rumours in the healthcare setting, which would help to reduce the stress of families.

Most of the paediatricians interviewed stated that the government provided ARV to children in the hospitals, but that the government did not have any particular ARV dosage regimen for children. Most of the paediatricians in the study explained that they used adult ARV and adjusted the dosage by crushing the ARV pills, which might have lessened the effectiveness of the medications. Currently, in Indonesia, there are no child-friendly ARV formulations. One pediatrician explained about the taking of HIV pills and the burden for children:

> *… pill burden. So, to take ARV is not just merely ARV because there are other opportunistic infections (OIs) as well, and the kid is still too young to take a full hand medicine for the OIs, for prophylaxis, for ARV, and so many others as well, so it is a big problem for pill burden (Anjani, lines no. 35-37).*

Anjani highlighted the factors associated with the pill burden, namely taking many different medications concurrently with HIV treatment and the complexity of the dosing regimens.

Some other HP participants explained the need for specific ARV regimens for children, because they still received an adjusted dose of the ARV medicines for adults. The head of a PHC recommended ARV in a fixed-dose combination treatment so that the children would not take a different combination of ARVs twice a day, which was not comfortable. The doctor adopted the TB program in which the children with tuberculosis took a fixed-dose combination for their treatment, and their compliance therapy increased. For example:

> *I want medicine to be only a single dose. Right now, there are drugs that are taken twice to three times, which is quite disturbing. Because it is the medicine for life, so I hope that there are drugs like TB, only single doses, that is one. The second, I hope the medicine does not stop (Sukesi, lines no. 725-728).*

Due to the increased risk of non-adherence to ARV therapy, a few paediatricians described that lessons could be learned from the United Kingdom (UK) to improve adherence to ARV. For example, they explained that in the UK, children completed a 30-minute training course in ARV therapy organised by a psychologist before starting ARV. Another paediatrician explained that another strategy to increase adherence to ARV was by adopting a TB program for treatment with supervision. The paediatrician explained that the TB program had a supervisor who monitored the patients taking their TB medication, and further stated the need for supervision of the monitoring of HIV treatment, enhancing ARV adherence for children with HIV.

> *… So, the TB medicine distribution, cannot run properly to the point which DOTS program is needed to be done. Patients who are taking medication need supervision, and we need to make sure that there is someone we can*

> *pay to supervise the taking of medication. So, even if the medication is free, it is just once in a day. However, without the support from the elites, running on our own, is useless. Even if we campaign for A, B, C, if they will never say, it will not solve anything (Krisna, lines no. 116-120; 424-427).*

Krisna, a paediatric tropical disease consultant, also stated that to implement the supervision of the treatment, support would be needed from the government and policy-makers by allocating a particular budget to pay for them.

Most of the HP participants suggested a scheduling strategy for the picking up of ARV refills, which would help to improve access and retention in ARV treatment, and reduce non-adherence. Some of the HPs explained that if the children's condition was stable, they could access their ARV every three months instead of every month. The HPs explained that the families could reduce the monthly cost of transportation and time if they could get their child's ARV refills every three months. One of the nurses from a PHC explained that at the ARV pick-up, a health professional should ask about the child's condition and make a schedule with the family for follow-up ARV check-ups.

The sub-category of sustaining access to ARV therapy sums up the situation of all the families in the study picking up their monthly ARV refills for their children from a provincial hospital. However, the children were likely to miss out on available routine health checks and did not receive regular monitoring of their ARV therapy as their parents left them in school when collecting their medication. Children with HIV were at risk of non-adherence to ARV, so they required interventions to improve ARV adherence, helping to reduce HIV morbidity and mortality. The participants suggested strategies on how to improve children's adherence to ARV. The suggested strategies included ensuring the availability of ARV therapy and preventing stock-outs, conducting educational sessions on adherence to ARV before the children started ARV treatment, providing an ARV treatment supervisor and monitoring for daily ARV therapy, extension of the 3-monthly ARV refill intervals for stable condition children, providing ARV dosage regimens for children, the use of an age-appropriate fixed-dose combination of ARV medicines, and minimising gossip among HPs in front of patients in the hospital.

Supporting Growth and Development

In addition to medical care-seeking and HIV care and treatment, the families in the study described how they provided care to support their child's growth and development. The families assisted children with the fulfilment of their needs, including activities of daily living, engaging the child's participation in his/her activities, and developing self-care skills.

Most of the families reported that they assisted their children with nutrition, education, play, spiritual activities, and hygiene. These activities helped the children to thrive. The families explained that a nutritious meal would boost a child's immune system to sustain health. For example, one of the uncles, Bayu, prioritised his child's menu in the home:

> *Especially the menu, he has to have a more nutritious meal than the other in the family (Bayu, lines no. 205-206).*

Some families described choosing healthy foods for their child by avoiding instant foods containing high monosodium glutamates (MSG), such as instant flavoured drink sachets, chips, instant snacks, and food with instant sauces.

As well as nutritional support, all families were aware of how important education was for their children. They believed that education would better their children's future life because they could get a job that would help to improve their living conditions. The families explained that they supported children in both formal and informal ways of providing educational support for them.

> *I always emphasise him to study because school is important as well as try to support him what is aspired to so far (Bisma, lines no. 33-35).*

Family members stated that most of the children attended school, in both public and religious schools (e.g., Islamic or Christian schools). Apart from attending formal lessons in the school, the majority of the families explained that they supported informal learning outside of the school setting to support their child's academic achievement through tutoring, private lessons, or extra-curricular activities. Most of the Muslim families also explained that their children had learnt to recite the Qur'an. The majority of the children agreed that they engaged in extra-curricular activities for learning, as stated by one of the children:

> *I go to school, cite the Quran, take courses, and play (Barata, line no. 21).*

As for the religious schooling or Qur'an learning, most of the families explained that the children could learn more about spiritual values and practices, and by instilling these values into their daily practices, they believed it would make them good people in the future. Hence, the families mainly considered that education and spiritual practices were essential for the future of their children in the hope of improving their quality of life.

Apart from the provision of nutrition and education, the families provided information to their children on behaviours to maintain their health. The families encouraged their children to take regular ARV medication and to have enough rest and sleep to keep them healthy for life. For example, all the families reported that they reminded their children to take their medications at the right time every day to avoid getting sick. Additionally, some of the families stated that they had used the threat of death to encourage adherence to ARV medicines for their children at home. The most common threat used was to tell their children that they would die just like his/her parent(s) if they did not take their medicines regularly. This threat of death caused the children to be fearful, which compelled them to take their medication daily, as stated by one of the children:

> *I do not want to die. So that is why do not be late to take medicine (Samba, lines no. 267-268).*

The families knew that without ARV treatment, their children were more vulnerable to infection, so it was vital for them to take it every day.

Most of the families knew that HIV transmission could be transmitted through sharing needles, contact with blood, and through sexual intercourse. They talked to their children about how to prevent the transmission of HIV. For example, one sister informed her sibling about how to do wound dressings when bleeding, to reduce the risk of blood transmission. The sister also stated that she informed her sibling to stay clean, as she believed it would avoid preventing the spread of illness or getting sick.

As well as the family caregiving roles, the children also developed self-care to enhance their health. Self-care was shown when a child actively took personal responsibility in promoting their own individual health, and this was common for all child participants. Five families had disclosed their child’s HIV diagnosis to the child. In this study, those children who knew their HIV status were more likely to participate actively in their healthcare, and in particular, in understanding the importance and responsibility of taking ARV.

Depending on the insight of the children, they performed actions that helped them stay fit and healthy. The children described that they developed self-care through taking responsibility for activities of daily living skills, healthy lifestyles, and learning needs. Most of the participants with HIV in this study participated in routine daily activities in their life across home and school. These daily activities included dressing, eating, playing, and schooling. For example, Sita stated:

> *I study and work on the assignment. I also join some extracurricular activities, just like other students. I also have a schedule for tutoring or extra lessons (Sita, lines no. 34-35).*

The children exercised, slept well, and ate adequate food as a result of their parents' positive influences for establishing healthy lifestyles. For example, one child stated that she wore a mask to prevent airborne disease, as she believed that a child with HIV was more likely to have a low-level immune system. One mother described that she taught her daughter the value of self-care by asking her to do her regular physical activities. For instance:

> *I am saying, kid; please listen, you are in 4th grade, I said so. You are big; you have to study independently; you have to learn independently. Time to drink medicine, you have to drink. I teach her, half past six in the morning before leaving school before you take a bath, there will be a call for prayer on TV, in mosque Allahu Akbar drink. It has taught that (Samba, lines no. 252-258).*

All the families taught their children how to keep their bodies healthy. Additionally, the routine was an important feature of staying healthy. Three mothers described how they set a curfew for their children's daily routine activities that helped them to take responsibility for their own behaviour and to develop their time management skills. Moreover, four children stated that they used online information from the Internet to learn about HIV, HIV medication, and the side-effects of the HIV medication, and this information helped them to look after their own health.

Most of the children who knew their HIV diagnosis described that they had used behavioural strategies, such as reminding tools and positive self-talk to improve their adherence to their medication. For example, most of the children used the shade of the sun as a clock, the mosque prayer call, or a mobile phone alarm as reminding tools to help them remember to take their ARVs. A few children stated that even though they had set their mobile alarm, they sometimes got distracted and forgot. For instance:

> *I turn my alarm on, but if I am busy, I will forget (Arjuna, lines no. 313-314).*

Wisnu used a positive cognitive behavioural technique by changing his mindset about ARV to enhance the regularity of his ARV uptake:

> *ARV is a beauty treatment. I take medicine regularly. It is like a vitamin (Wisnu, lines no. 906).*

Furthermore, Wisnu explained that positive thinking motivated him to accept his HIV status, to not give up on life, to seek a consultation with a doctor if he had a problem, and that this supported his self-care and improved his health.

Similarly, a few children described that they used positive self-talk to improve their uptake of ARV therapy. The children practised positive self-talk by saying '*I should', 'I must', 'I need my life', 'I need longer life span',* and *'Do not do'.* Another child, Subali, constructed his positive talk with '*this is my disease', and 'this is my responsibility'*, meaning that the child was aware of his HIV status and had made a commitment to being responsible for his condition.

In summary of the first major category, 'maintaining their health', children with HIV suffered from the severity of HIV-related signs and symptoms, such as lung infections and malnutrition. The children in the study received their HIV diagnosis between the ages of 3 and 17, and were all on ARV treatment. ARV therapy was understood to make substantial improvements in the life expectancy of children with HIV. However, they also experienced episodes of non-adherence to their ARV therapy, or discontinuity of treatment, because they felt bored, disliked the big size and the taste of the pills, were dependent on their families for taking medicines, and did not receive warnings from the HPs for late ARV pick-up. To ensure that non-compliance with the ARV treatment was prevented, children needed optimal long-term adherence strategies for successful treatment outcomes. For example, some HPs stated that children should receive ARV regimens that were suitable for their age and were a fixed-dose combination allowing once a day rather than twice a day administration, helping to lower the pill burden and optimise the maintenance of their ARV. HPs suggested the need for an ARV supervisor, a three-monthly ARV refill policy, and check-ups for children to enhance their adherence to ARVs. Moreover, the children also engaged in actions to participate in self-care through the activities of daily living and a healthy lifestyle to support and sustain their health.

The families drove the provision of care for their children by taking responsibility for their actions, and for the consequences of the hardships and maintaining their child's health as a priority. The families made strong commitments to maintaining their caregiving responsibilities, and provided complex continuing care to maintain the children's health. They also sought medical care for their children's severe recurrent illnesses before the diagnosis, and experienced shock, denial, and shame in response to the child's HIV diagnosis. Most of the families kept their child's diagnosis a secret from the child until they were adolescents. The families continued to provide ongoing care for their children after the diagnosis by maintaining monthly access to ARV therapy, maintaining the child's growth and development (e.g., physical and spiritual care), engaging children in practising healthy lifestyles, and maintaining activities of daily living. The families accepted ongoing difficulties as a result of their caring role, such as the family's loss of assets to fund the medical care needed. During the process of continuing care and responsibilities, the families acted in these situations by valuing their beliefs, traditions, and experiences through the interaction between their children as care recipients and HPs as care providers.

Living with Fear and Stigma

Fear, stigma, and non-disclosure caused complex problems for families with HIV-positive children. Fear and stigma occurred among children and their families in their healthcare interactions and their social interactions from the time of their diagnosis. Fear and stigma were based on five aspects that emerged from the comparative analysis, 'developing internalised stigma', 'experiencing external stigma', 'believing misconceptions about HIV', 'disclosing their HIV status', and 'being vigilant and deceptive', as illustrated in Figure 19.

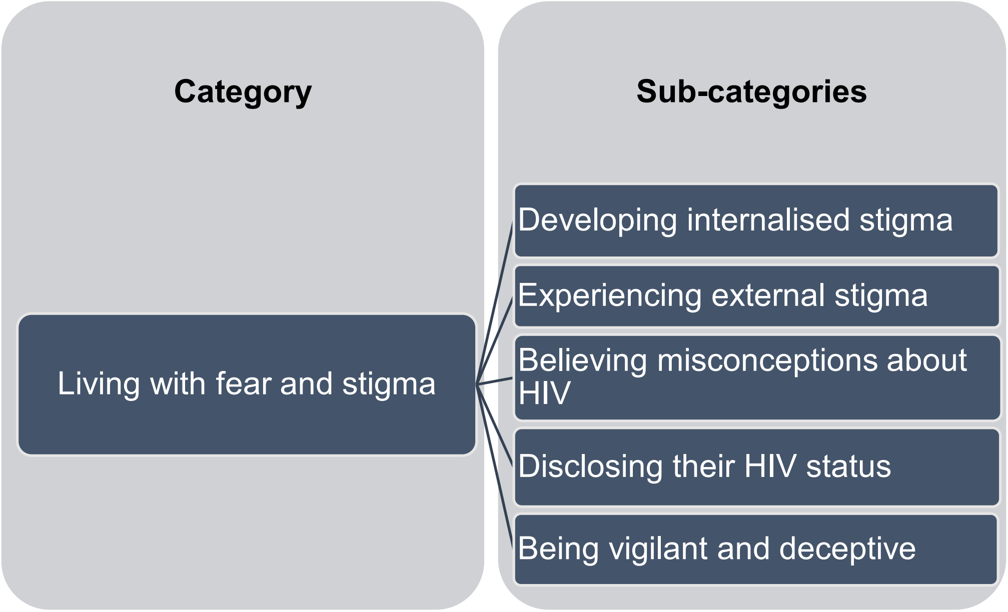

Figure 19: The category of living with fear and stigma and its sub-categories

According to the participants, having HIV lead to moral shame and fear, which were unpleasant emotions stemming from individual and societal beliefs about HIV. These feelings of shame and fear predisposed the families to negative thoughts and attitudes. In this study, the majority of family participants experienced a fear of discrimination. The participants were fearful that the children would experience social isolation, rejection, exclusion, and be shunned from their friends and the community. The fear arose from internal perceptions of negativity and misunderstandings around HIV. In some cases, the participants' fears were shaped by their social relationships and past experiences; for example:

> *The people at school should not know their disease. Because if they do, she might be dropped out of school. There was a case like that before (Kunti; lines no. 829-831).*

Exploring all the participants' perspectives, HIV-related stigma was classified into two types: 1) internalised stigma that came from themselves, and 2) external stigma that related to how the participants experienced adverse treatment from their families, the community, or from HPs. In most cases, many family participants who disclosed their child's diagnosis to other people experienced family rejection or social isolation. Because of the stigma, participants developed individual behaviours to protect their HIV status by being vigilant and deceptive. Being vigilant and deceptive identified a range of actions by the participants to be alert for any negativity regarding their HIV-positive status.

Developing Internalised Stigma

Most of the children and family participants experienced stigma and fear that they internalised. This feeling had a negative impact on their social interactions and health behaviours. Internalised stigma caused the children and family participants to worry about being *'found out'* by their community as they believed it would lead to discrimination and marginalisation.

According to most of the children and their families, they lived with the fear of being expelled from school, the fear of disclosure by others, and the fear of being banned, shunned, or not allowed to play with other children. Some family participants advised their children to avoid creating friendships and prohibited them from declaring their HIV status to others due to this fear of rejection, as stated in this excerpt:

> *I prohibit my son to tell his status to all his friends. I am afraid if others know his status, he will not be accepted in his school, and his friend will send him away because, until now, ordinary people still have not understood about the disease. They only judge if being diagnosis positive HIV is such a mischievous person (Bisma, lines no. 114-119).*

Additionally, one child with HIV described her childhood experience in which she and her grandmother avoided interaction with a neighbour by isolating themselves from other people.

> *When we arrive at home, we close the door. I only go out if my grandma takes me to the shop. She did it to avoid the neighbour. Even when I have a day off, I just stay at home (Sita, lines 260-263).*

Living with internalised stigma and fear was found to reduce access to care and support for children and their families. By not declaring their status, families lost access to government offered milk-formula, available health insurance, and family or peer support groups. For example, some family participants mentioned that they did not access their formula-milk in the PHC because they were afraid of being identified as having a family member with HIV.

> *We do not get the milk now. I never go to a PHC. I am afraid. I am afraid to be asked. I am afraid my neighbours know. Sometimes I got assistance from hospital XX (Indra, lines no. 334-336).*

The HP participants agreed that stigma and fear decreased access to HIV care and support, as some families with HIV were reluctant to seek assistance. HPs asserted that these families were more likely to not use health insurance, which was offered to them for free or at a reduced cost, due to the fear of what this disclosure would bring to them.

> *HIV patients in monitoring them mostly are general patients, not using BPJS insurance. Usually, the reason is that they are scared of the stigma if they use BPJS insurance system, they have to report it to the nearest public health centre, the diagnosis has to be opened to get a reference to hospital. That is usually they do not want to give (Dewi, lines no. 191-195).*

Most of the HPs stated that some families were afraid of being identified by their neighbours or other family members. The families with an HIV-positive child also felt embarrassed and ashamed to check their own HIV status or the status of their other children. Most HPs stated that some families with HIV-positive children rejected home visits or refused to access regular ARV refills in the hospital. This occurred even when the child with HIV was in the most advanced stages of the illness that might cause death. Such was the power of the fear that their neighbours would notice them and learn about their status. The HPs described cases where families chose to stay at home with their dying child rather than visit the hospital. HPs explained that the fear of retribution stopped families from joining HIV peer group activities. The internalised stigma created negative self-judgements, resulting in feelings of fear and shame for these families, which in turn, resulted in little or no social support. For example:

> *[Patients say] “I am afraid if there is someone who recognises me, like that. I feel ashamed if someone recognises me” (Sri, lines no. 416-417).*

Internalised stigma occurred when people applied negative beliefs to the self, resulting in negative self-judgement and feelings of shame. Internalised stigma and fear prevented the participants from disclosing their HIV status to other people, which then hampered access to care and support (e.g., milk-formula, home visits, public healthcare insurance, family or peer group support). Internalised stigma also stopped the participants from being involved in treatments for themselves or their children, leading to physical deterioration and withdrawal from social interaction. Refraining from accessing care, support, and treatment caused marginalisation, and the fear of discrimination was a result of the internalised stigma.

Experiencing External Stigma

Most of the children and family participants experienced external stigma from their family, the community, and/or HPs through being discriminated against and marginalised. All the participants alluded to the disclosure of HIV status resulting in discrimination towards their children and the rest of the family. The participants' experiences identified that disclosure of their HIV-positive status resulted in external stigma, leading to discrimination or unfair treatment, such as social isolation, ignorance, labelling, gossiping, bullying, or negative judgement. For example, in Javanese culture, families share food and eating utensils for any ceremonies, which is known as "Kenduri". Some of the mothers in the study reported that their own families separated food out for them and refused to share their utensils. An aunt reported that her mother was physically abusive to her niece, who was HIV-positive because of the family stigma attached to the condition. One child experienced family marginalisation due to their sweating, for fear that this could lead to transmission. Another child was rejected by his school because of the community stigma. Some children experienced community stigma by being denied the opportunity to sit close to, or share toys with, other children. Some of the children and family participants also experienced verbal abuse from the community through bullying or gossip. For example:

> *We were excommunicated; every time I go out, they avoid me. They said, 'do not get to close, or you will be infected.' Later, I feel like I was ostracised. I was bullied ... 'she got a disease ... it is disgusting', they said … Every time I go out, they always avoid me. For instance, if I touch any toys, the toys will be dumped. They throw the toy that I touch right away. They said, 'do not touch it.' The parents do not let their children play with me; they said to their children 'go home, do not play with her' (Sita, lines no. 169-184).*

Sita witnessed the avoidance of a child with HIV by the community. Many parents prohibited their children from playing with children with HIV. Most of the children and family participants knew how HIV was transmitted, but stated that some community members did not understand the transmission and treatments. There were beliefs in the community, and among a minority of participants, that HIV infection could be transmitted via sweat, food utensils, urine, or the clothes of people with HIV. Because of this belief, stigmatisation, discrimination, and marginalisation occurred.

Most of the HPs supported the notion that community members stigmatised, discriminated against, and marginalised children with HIV and their families. The PHC HIV coordinator stated:

> *Due to stigma and child discrimination, the community were understood if the child was HIV-positive and rejected him (Uma, lines no. 53-54).*

HPs described how when a person with HIV died, personal items and mattresses were burnt, and funeral rejections occurred. Furthermore, the wider society also showed little empathy in supporting children or families with HIV.

> *There is an experience in the field; there are a child and a mother who are HIV-positive, then the citizen does not want to; they do not want to contribute at all. Also, when the child needs food, and the mother does not work, the citizen ignores them (Gendari, lines no. 190-195).*

The views of the HPs also revealed cases of parental or societal rejection in children with HIV that led to reduced access to housing and education.

> *We do not have special space yet that able to, want to take care of them. So, from orphanages, social services that we usually cooperate with, if that kid is not with HIV, they will accept him. However, when they find out the status is HIV-positive, they directly refuse, that is where we are troubled (Dewi, lines no. 149-152).*

Almost all the participants (e.g., children, the families, and HPs) recognised the existence of school rejection of students with HIV. It became evident that HIV stigma caused inequality in education and lead to education-based discrimination for children. For example:

> *When it comes to society's stigma. This thing might affect the long-term caring for HIV children. The worst-case after they are disclosed, they get expelled and let them down to the point where they do not want to take the medication and prefer to be dead, there are cases like that […] What we are concerning about is a possibility of depression (Anjani, lines no. 71-74; 148).*

Anjani, a paediatrician, described that a child with HIV might *'prefer to be dead',* highlighting that stigma negatively affected families and caused problems with treatment compliance, and would then think about their death. As well, a child with HIV might be at increased risk of depression.

Most HPs suggested that the children should complete their education or schooling because of the existence of children being expelled from schools. They stated that the children would have an opportunity of better education and health outcomes for their future. Most of the HPs also described that with good knowledge, children would know what they wanted to be as they grew older. However, only a few paediatricians offered strategies for addressing school rejection. For example, the paediatricians in this study suggested that the government could hire a volunteer teacher to teach, or arrange a home-schooling program for the expelled students to continue their studies at home. The paediatricians also explained that the government should design a school-based life skills education program that provided education and life skills training for children with HIV. A paediatrician asserted that the Ministry of Health and the Ministry of Education should work together to set up a curriculum for rejected children, so that they could continue their schooling.

As well as social stigma, according to all the participants, the community also held the view that children with HIV were inferior, all of which led to social marginalisation. The participants believed that culturally, the community viewed that being HIV-positive was caused by risky sexual behaviour and was a punishment from God. Most of the HPs acknowledged the existence of negative and stigmatising views from the community, which caused people with HIV to be excluded from society, or to be discredited, which lead to social marginalisation. Some children and family participants also believed that community beliefs about being diagnosed as HIV-positive was considered a result of bad karma or being cursed, meaning that it was ‘deserved’, as stated by one of the adolescents with HIV:

> *She got cursed. Villagers believe that if someone suffers from a disease, that person must be cursed (Sita, lines no. 179-180).*

These dominant beliefs in the community contributed to the stigma, marginalisation, and discrimination experienced by the children with HIV and their families, which affected their care and the support they accessed. For example,

> *HIV is a disgrace. So, people with HIV deserve to die. Because it is a disgrace, they are being ostracised. They cannot say anything, they are always inferior; they do not deserve to speak if they have HIV. That is the problem. They should have the right to be the same as those who suffer from another disease, the right to get medicine, the right to live like any other, and this is not karma (Krisna, lines no. 461-465).*

Krisna’s values and rhetoric on rights identified that HIV was also associated with a lack of respect for human rights, which was a contrast to (bad) karma. The paediatrician supported the rights of children and their families, and in particular, the right to access healthcare and treatment and the right to life.

As well as stigma, discrimination, and marginalisation from the community, children and their families also experienced stigma and discrimination from HPs. Most children with HIV and their families had previous experiences of receiving disrespectful behaviour from HPs throughout their care. The participants felt intimidated, judged, or interrogated in receiving their healthcare because the HPs did not communicate with respect. For example:

> *There was a doctor that said, "your condition is disgusting. This is condyloma (tumour). What do you often do?" (Subali, lines no. 172-173).*

Feelings of not being respected in healthcare were also reported by some mothers, and included rudeness or ignorance from nurses and doctors. For example:

> *The nurses, they said my child is contagious. When I arrived at the Emergency Department (ED), Oh no … madam K again. They said that to me. No nurses were willing to touch my child — not even one (Kunti, lines no. 91-92, 152).*

Another mother stated that a HP delayed calling her child, even though they arrived early at the PHC, making them wait for a long period. Surya described a HP separating blood sample specimens of her child from other clients who did not have HIV into a specific area and labelling the blood specimen with a code identifying the specimen as coming from a person with HIV.

Some HP participants recognised that negative attitudes had an impact on the interactions between patients and HPs, negatively affecting the quality of their care. For example, most doctors did not want to provide HIV therapy because they did not want to interact with HIV clients, even though they were knowledgeable about HIV. Other HPs refused to care for the child and did not feel comfortable with providing HIV care due to the stigmatisation that lead to discrimination. For example:

> *With regard to the stigma. There are much of medical assistants who refuse to handle HIV patients like any other patients. So, there will clearly be some differences. Like it or not, it will impact the quality of treatment (Krisna, lines no. 127-129).*

The children and family participants experienced external stigma and discrimination after disclosure of their child's HIV diagnosis. The consequences of stigma led to social discrimination and marginalisation caused by ignorance, rejection, isolation, labelling, bullying, gossiping, social inequality, and the failure to address human rights. External stigma influenced children's adherence to ARV treatment leading to mental health problems, increased social isolation, and school rejection, resulting in poor health outcomes.

Believing Misconceptions about HIV

According to the participants, there were many misconceptions about HIV, and its treatment and transmission. These misconceptions included that a diagnosis of HIV would lead to death, and that a child could stop taking ARV medicines if they were healthy or had a low HIV viral load. The experiences of children and families in relation to misconceptions in the community, led to marginalisation and discrimination.

HIV as a death sentence was a misconception reported by some family participants when their children were first diagnosed. According to the participants, some members of the family stated that there was no cure for HIV or that it could not be managed with ARV. Most of the family participants believed that children with HIV would have a short lifespan, and would only live until the age of 12 or 13 years. As well as perceiving HIV as a death sentence, Bisma, a mother, had a misunderstanding about the ARV dosage regimen for children. She identified that her son had received ARV medicine in the form of tablets. However, she believed that tablet or capsule formulations were better than liquid medicines. She believed that liquid medicines were low potency drugs which were unsuitable for her older child. This example highlighted that Bisma did not trust the administration of the dose for her child, or the effectiveness of the therapy.

According to some of the HP participants, there were misperceptions about HIV treatment that undetectable viral load results meant that the families believed they were cured of HIV and could stop taking ARV medication. Undetectable viral load is a result of the viral load test indicating the virus was not actively attacking the immune system, referring to the effectiveness of ARV treatment. The HP participants explained that often the people who stopped taking ARV medication went to a PHC several months later with severe illnesses, often classed as HIV stage 3 or 4. This finding shows that the families did not realise that if they stopped taking ARV, their viral load would increase and this, in turn, would increase the risk of illness and the advanced stages of HIV infection. Similarly, misconceptions about well-being caused some to stop taking ARV medication. This put the child at risk of non-adherence to ARV therapy when the belief was that they were cured or healthy:

> *Usually, the parent thinks like out from the prison. Yes, so they will delay the control because they think their kids are okay. That is hampering the healing process. They are more comfortable at home, and they forget (Prita, lines no. 244-247).*

Prita’s view identified that because of limited parental health literacy, some families had misconceptions about the treatment.

The head doctor of a PHC explained another misconception about herbal medicine being more ‘organic’ than ARV medicine. They explained how the use of herbal medicine for children on ARV therapy was popular. The doctor mentioned that some families received information about herbal medicine from other HPs, resulting in children taking ARV and herbal medicine concurrently. Meanwhile, other children only took herbal medicine because they felt better and decided to stop taking ARV, despite the herbal medicine being expensive, and the clinical effectiveness as yet unknown:

> *The lure of herbal out there is quite persistent, either from the NGO that works in the field because there may be as for herbal, there is no free herbal, it is paid, [for] as expensive. Even there is a medical officer who offers herbal. By drinking that first, taking ARV, why is herbal fresher? Eventually, some patients decided in the middle of the treatment; they will just take herbal only (Srikandi, lines no. 631-635).*

There were five identified misconceptions about HIV, including: 1) HIV was a death sentence, 2) HIV was seen as being a curse or karma, 3) having an undetectable viral load meant the person could stop taking ARV, 4) having good physical health meant they could stop taking ARV, and 5) herbal therapy was more organic and fresher than ARV. These misconceptions about HIV indicated that the participants, their families, and the community had a lack of knowledge about HIV and were misinformed. This then predisposed them to reducing their adherence to ARV treatment.

Disclosing Their HIV Status

Due to the stigma, discrimination, and marginalisation associated with HIV, the topic of disclosure of HIV was mainly about concealing HIV status. Based on the perspective of the participants, two types of disclosure were identified, namely: 1) planned and intentional disclosure, and 2) unplanned or unintentional disclosure. Planned and intentional disclosure was an action in which families planned and prepared for the disclosure process for their children. Unplanned and unintentional disclosure was a situation in which the child or others unintentionally found out about their HIV status.

Some families intentionally informed the child and others of the child’s HIV diagnosis. One family member asked assistance from a health professional to disclose her son’s HIV diagnosis to him. Two-thirds of children who participated in this study knew of their HIV diagnosis. Of these children, disclosure occurred at ages 9, 13, 15, and 17 years of age.

Apart from intentional disclosure, Arjuna, a child with HIV, stated that before his family disclosed his diagnosis, he unintentionally began to understand his diagnosis and disease after receiving education about HIV at high school. All the child participants who knew their diagnosis stated that they felt very disappointed, shocked, and sad when told that they were HIV-positive. For example, Bisma explained how he was in denial when first diagnosed as HIV-positive, and then finally became resigned to accepting his status:

> *Mother: My son said why mum? Why am I like this? My son sometimes also said that I did not do anything. Son: I have no special feeling. It has already happened (Bisma, lines no. 97-99, 108).*

Similarly, Arimbi, at first responded with shock to her HIV-positive status, and then used her spiritual beliefs to cope with, and accept, her diagnosis:

> *At first, know about the disease; I was shocked. Then, I thought of this as a test from God; a test (Arimbi, lines no. 51-54).*

Some of the families stated that their extended families knew of their child's diagnosis because of the death of a parent from HIV/AIDS, and this had caused negative consequences, such as social discrimination and marginalisation through isolation from the family.

Many family members were hesitant to disclose their child's HIV diagnosis to their child or other family members, due to the fear of the adverse impact of disclosure. The families explained that they might consider disclosing their child's HIV diagnosis to their child if they were adolescents or in high school, as they would have a more mature cognitive understanding than younger children. Apart from considering a child's age, one family participant, Surya, suggested that if there was peer group support for children with HIV, the support could ease the process of HIV disclosure more naturally. Furthermore, he explained that if peer group support was available, his son might have experienced unintentional disclosure through social interaction with his peers:

> *… maybe it would connect him with other kids around his age. There must be some (right) so that they could get close and get to know by themselves. At least if he was at junior high school, they could already keep secrets; it was even dangerous if they had not been able to keep a secret and told a story to their playmates (Surya, lines no. 694-699).*

Most of the children and family participants agreed with forming peer groups for with others with HIV backgrounds, such as peers in sport (i.e., football or basketball). The children stated that sports activities among peers would help them to be able to spend time together in a leisure activity making new friends. One child with HIV described the advantage of being part of a peer group through increasing positive feelings. She stated that she had lost both parents and was more likely to experience loneliness and sadness, so a supportive peer group would be emotionally beneficial for her because she could share her concerns and the children might receive support from each other, as stated:

> *Sometimes I ask myself, is there anyone who loves me? I do not have parents, and this makes me always ask that question to myself. If they are placed in a community, not an awkward community, there will be so much fun, full of compassion so that they will think that they have someone who loves them. Support from other people is important because they do not have support from family (internal) (Sita, lines no. 833-838).*

Some HPs agreed that through peer groups, children could receive informal support and would receive life skills training through a peer-to-peer approach; for instance:

> *Like maybe if it is in PHC, there is KDS (called peer group support), so it is a collection of people with HIV/AIDS. However, maybe if it is me, the special group to handle children with HIV and they are provided with information and skills like children, so that they will be knowledgeable later, like that (Ratih, lines no. 494-496).*

Ratih highlighted the need for peer support for children living with HIV as it would help them to remain engaged in care and have a positive influence on their life and medical outcomes. Peer support for children would benefit and support group members in many ways, contributing to better health outcomes.

Most family members tended not to disclose their HIV status to the children due to the fear of discrimination. Similarly, HPs were also confronted with non-disclosure. Non-disclosure had a negative impact on their child’s care at home, as stated in the following excerpt:

> *Because child patient with HIV is as complex as an adult patient with HIV ... they themselves do not even know the status, so mostly still non-disclosure. Because parents still do not want to show to their children. Then, because many of the caregivers also are not the parents themselves, so the parents are mostly already gone or working. So, the one who takes care of them daily is accompanied by other people, whether it is grandparents or siblings. So, the problem for the children themselves is more complex compared when their parents are the one who is taking care (Dewi, lines no. 27-34).*

Dewi identified that children had multiple problems that differed from those of adults. In particular, children were often raised by other family caregivers without knowing about their HIV status and having little understanding of HIV, which can cause complex problems; for instance, the children could spread HIV to other family caregivers without knowing it.

Other HPs described that non-disclosure created barriers to accessing social support, including food or health support, and therefore they suggested the importance of HIV disclosure within families:

> *They have disclosed their status to the community, so they receive support from the head of the municipal district. Due to administrative procedures; the client needs some letters approved by the head of the village. For example, she does not have BPJS insurance, and we advise them to go to the hospital. So, we are forced to open her status (Uma, lines no. 281-287).*

HPs suggested a number of strategies on how to disclose HIV-positive status to a child. A paediatrician suggested the need to disclose HIV status simply, as stated in the following:

> *What we want, we want to create like maybe a program or the pilot, so the disclosure does not look complicated in the future. For now, maybe if we want to talk is still (odd) to the child. Us as the doctors feel like that, let alone the parents well that is what we want, we want to learn further how to make disclosure feel easier and easier for parents too (Dewi, lines no. 255-259).*

Dewi's views highlighted that guidelines for the disclosure process were not currently available. She suggested the importance of disclosure guidelines and processes in the healthcare setting to create better outcomes for children and their families.

HPs and one of the child participants suggested strategies to facilitate natural disclosure. For example, most of the HPs suggested the need for guidelines on HIV disclosure to be age-appropriate, so that children would be able to better accept their infection status, take responsibility for their lives, and lead the normal life of any child, as stated by one doctor from a PHC:

> *This only thing is the psychological aspect. How can this child later be ready to accept his status and be able to live a normal life like other children? (Sukesi, lines no. 535-537).*

One of the paediatricians suggested that the process of disclosure could be started when a child was aged from 7 to 10 years with the support of a psychiatrist. The paediatrician explained the HIV disclosure program in Thailand, where the process of HIV disclosure was conducted in a camp for children and parents. Parents opened the conversation by explaining the importance of consuming ARV medicines every day. This recommendation was supported by a paediatrician:

> *Theoretically, disclosure can be done during school age. So, it is ideal when the children are 12 years old, that is when they should have understood. However, the preparation should be done in advance, from 7 to 8 years old*

> *it should be talked about, little by little. There are those who start earlier when the children have started asking why they should take medication. At that moment, if the parents are ready, it can be done already at 5 or 6 years old. Then, if it is possible, during their junior school, at the age of 12 to 13, where they can already do activities without supervision, such as dating, when their hormones start to build, and so on like at puberty phase, we should know when the time comes. The importance is obvious, first about the responsibility in taking the medication, second is about the contagiousness. So, practically at the age of 12 years old, the disclosure can be done already. For the ones who are still starting a disclosure, mostly do not open up much. I do not know if they are depressed. What we concern about is the possibility of depression (Anjani, lines no. 94-98; 106-110; 145-146).*

Anjani highlighted the strategies of intentionally planned disclosure. She suggested that the disclosure of a child's HIV-positive status could begin between ages 8 and 12 years, or when the child starts asking why they have to take daily medication. At these ages, children would have some level of cognitive maturity and would be able to receive information, to communicate effectively, and to understand the consequences of disclosure. For the disclosure of HIV status to children, it is essential to inform them about adherence to ARV therapy and the prevention of HIV transmission, and to provide psychological support for them. A child participant with HIV expressed her beliefs about how to talk about disclosure with children. She stated that HPs could ask open-ended questions (e.g., what do you think? or what do you know about it?) to minimise emotional distress and then continue explaining the signs and symptoms of HIV, and prevention of the illness. Furthermore, she added that HPs should also provide positive reinforcement or encouragement for children.

Moreover, most of the HP participants also suggested the need for psychological support for children and their families to improve their mental health, due to the adverse effects of stigma and disclosure. For example, the HPs said that when a child experienced disclosure, he/she would often have an emotional reaction and would need psychological support, but currently, there is only limited psychological support for children. Similarly, some family participants agreed that children needed psychological care to improve their mental health, because they were likely to feel insecure in the community. A child with HIV stated that she was planning to self-disclose to her boyfriend, who did not know her HIV status, but she was afraid of rejection and needed health professional support. Apart from psychological support, another child with HIV and one of the mothers suggested that the counselling a child receives should include information about HIV prevention and transmission before the disclosure process.

Most of the families concealed their child's diagnosis from them until their teen years due to the fear of disclosure and the resulting consequences. However, both disclosure and non-disclosure had negative implications for children and their families. The negative aspects of disclosure for children and their families were social stigma and discrimination. Non-disclosure reduced the ability of children and families to access government support, including nutrition and healthcare support. HPs suggested that a simple disclosure process was needed, which would enhance therapy compliance, and that this should be combined with the children receiving social and psychological support.

Being Vigilant and Deceptive

The participants were strongly aware of the negative effects of stigma that can lead to discrimination and marginalisation. Through social interaction, through thought and action, the participants determined how they should behave in anticipating the negative effects of the stigma. All family participants stated that they became more acutely aware of HIV-based stigma and made a conscious decision to implement different behaviours in order for the HIV status to remain hidden from others. Most of the families asserted that they were advised by the HP to keep their child's diagnosis a secret to reduce the risk of social stigma and discrimination. The participants reported several strategies they used to keep their child's diagnosis of HIV secret. They stated that they accomplished this by being deceptive, keeping secrets, telling lies, providing false statements, or travelling long distances. For example, some family participants lied, stating that their child suffered from malnutrition or a lung disease instead of having HIV.

> *I am afraid to tell the teacher. I told his teacher that he is going to a medical check-up. I told him that my son has a lung infection, that is all. I do not have the courage to tell the teacher about this disease. I am afraid he will be avoided by his friends (Barata, lines no. 223-226).*

Other family participants made excuses; for example, they were attending a family wedding or visiting relatives instead of visiting the HIV care service. Moreover, some family participants explained that their family members died of “Sawan” or “Santet” to cover their HIV status from their neighbours. In the Javanese tradition or culture, the “Sawan” or “Santet” was a disease caused by a supernatural thing or witchcraft.

Similarly, some child participants stated that they had given false reasons for covering up their HIV diagnosis due to the fear of disclosure and rejection. For example, Arjuna described how he managed to avoid telling the school authorities:

> *… I will secretly take the drugs in order not to be identified by somebody else if I have a disease like this. If someone finds me taking the drugs, I will say taking a multivitamin to them. Furthermore, if I am absent from school, I will need a stamp from the hospital, which usually is written XX outpatient clinic. The written XX stamp must be covered. Most of the people know that XX outpatient clinic is a place for a contagious disease that is deadly, and the disease is hard to heal it. So, the school will not be suspicious. What is the exact word? So, we will not be isolated if we are identified as suffering from this contagious disease (Arjuna, lines no. 40-46).*

Arjuna stated that keeping secrets, telling lies, and hiding were individual strategies he applied because of his anticipation of social isolation.

One of the mothers used language as a symbol in the interaction between her and her daughter. The significant words were exemplified when referring to where the medicines were kept. The mother reported that she used a specific language when instructing her child in front of others to minimise social stigma and discrimination, such as “go to the toilet”, “in the bathroom”, or “do not forget at 6pm”. The mother and her daughter had agreed in advance on the meaning of bathroom, toilet, and 6pm when referring to the HIV medication.

In addition to the deception and secrecy strategies, some family participants and children with HIV reported using the travelling distances to faraway services as another strategy to protect themselves from being found out by their local community:

> *From PG to here, it takes 2 hours. This is important for me. If I want to purchase medicines there. I am afraid that my neighbours will know. That is why I have to go here (Arimbi, lines no. 556-562).*

Most of the HP participants reiterated that families with HIV used services that were at a distance to access ARV medicines due to social stigma and the fear of disclosure, as stated in the following excerpt:

> *Some patients come from far away, from XXX, even far away from XXX outside of the island, we have patients from outside of the island, they come from far away. They do not want to reveal their identity (Gandawati, lines no. 622-626).*

Other HPs reported the use of colour codes, such as ‘the blue room,’ instead of the HIV room in the healthcare setting. This room was not labelled as being used for HIV patients, but was specifically mislabelled to help HIV families be more comfortable when they received care. Besides using colour codes, most of the HPs also used the ICD code B20, meaning the code description for HIV. If a client with HIV was admitted to the hospital, she/he would be reported as B20. Another HP participant described the use of code B20 as also being part of maintaining the privacy of the client, as stated in these excerpts:

> *People are used to it and used to writing B20. The code of ICD for HIV is B20 (Srikandi, lines no. 684-685).*
>
> *We in Hospital XX use the code of B20 to keep the privacy of the patient and the family. Because society already knows what HIV is (Ratri, lines no. 154-156).*

Moreover, most of the HPs indicated that the government should develop stigma-reduction interventions. These interventions should include delivering a HIV information campaign through mass media to enhance community understanding about HIV and influence community opinion in tackling HIV-related stigma. Similarly, some of the family participants agreed that increased socialisation of HIV knowledge could enhance understanding of HIV in the community. One child with HIV also stated that HIV information should not only be directed for clients with HIV, but also to the wider community because this information would bring a further understanding of HIV, which would help to reduce the stigma and marginalisation in the wider community. She stated:

> *In my opinion, this information is not only important for people who are infected but also for everyone. Even though they do not get this disease, they need to know about the infection and medication for this disease. This information is very important to avoid any negative thought; for instance, they do not need to avoid contact with people who got HIV, how the disease spread and for those who lived with this disease, will not be inferior because they have sufficient information about that the disease is and how it is spread (Sita, lines no. 607-612).*

In the summary of this second major category, living with fear and stigma was a complex problem that remained a prominent concern for Indonesian children with HIV and their families. All participants experienced two main types of stigma, internalised and external stigma. Internalised stigma occurred within an individual participant and influenced the negative perceptions and attitudes as a consequence of feelings of shame of being HIV-positive. External stigma accounted for the negative perceptions constructed by the participants' families, the wider community, and HPs, leading to social discrimination and marginalisation for the children and their families. This stigma manifested in actions such as isolation, disclosure avoidance, secrecy, deception, gossiping, and social rejection. This stigma also contributed to devaluation and power inequalities in the communities for children with HIV and their families, being considered to be inferior or of a secondary position, causing social marginalisation. Both internalised and externalised stigmas increased barriers for accessing care, support, and treatment, leading to physical and mental problems, or even death. Because of these stigmatisations, many children with HIV and their families decided not to disclose their HIV status and used personal stigma reduction behaviour strategies. These strategies involved telling lies, keeping secrets, keeping distance, or using symbols or codes for covering up their HIV status and for distancing themselves from the community in anticipation of social discrimination and marginalisation. HPs also reported that children were most likely to have mental health issues associated with stigma and disclosure because psychological support was not available to them. All the participants suggested that stigma could be reduced by implementing HIV prevention and transmission education for children, families, and the wider community, through the use of mass media such as television, in collaboration with the government and HPs. Moreover, all participants suggested that the child's age or cognitive maturity should be considered, using an open communication style to help the children understand and providing psychological support for the children's disclosure of their HIV.

Chapter Summary

The findings of this study have provided evidence on how complex family care is for children with HIV. The extended families and single parents were key caregivers taking on the caring responsibilities for children orphaned by HIV-AIDS. The domain of their caregiving responsibilities included health and medical care, assistance with activities of daily living, physical and spiritual care tasks, and teaching children to learn self-care skills by creating healthy lifestyles and setting curfews for them. Additionally, the families used their knowledge of HIV prevention and transmission to teach their children how to do wound care dressings at home. The children agreed that they participated in self-care activities every day, such as learning activities, routine physical self-care, and using online self-help to stay healthy. The families continued to provide ongoing care, although the care was complex by setting the child's health as a priority. The families encountered complicated health, financial, and psychosocial issues as a consequence of their caregiving responsibilities. These issues included maintaining optimal ARV adherence by the children, and dealing with financial hardship, disclosure, and living with stigma and fear, which lead to social discrimination and marginalisation. The families also applied their values, beliefs, and experiences to their ongoing caregiving responsibilities as well as creating interactive caregivers' activities with HPs across their children's lifespans.

The families and children continuously lived with stigma and fear, creating complex problems. They experienced a negative view about the self (of the child) being HIV-positive, constructed from individual and/or societal beliefs because of the stigma associated with HIV. This stigma resulted in feelings of fear and shame, and had a negative impact on social discrimination and marginalisation for children and their families, such as rejection, isolation, ignorance, and verbal harassment. Living with stigma lead to a burden of care and the families avoided disclosing their child’s diagnosis, and also avoided social interactions for fear of disclosure. Because of this stigmatisation, children also experienced inequality in health, education, accommodation, and social support, leading to physical and mental health problems, and even death, among children with HIV. Furthermore, misconceptions about HIV increased social stigma and discrimination as well as non-adherence to ARV among children and their families due to a lack of knowledge and misinformation. Children and their families were aware of stigma and developed strategies to reduce the adverse effects of the stigma with secrecy, deception, lying, distance, symbols, and codes. Additionally, because of the HIV-related stigma, disclosure among the children remained low and caused barriers to receiving HIV care, support, and treatment. The HPs informed that there was a need for disclosure procedures for children, to support their health outcomes.

The following chapter presents the other major categories according to the experience of children, families, and HPs relating to predisposing factors to ineffective care, and a detailed exploration of the core category of the analysis.

CHAPTER 6
STUDY FINDINGS PART B

The overall findings dealt with three categories, including ‘maintaining their health’, ‘living with fear and stigma’, and ‘predisposing factors to ineffective care’, according to the insights of children, families, and HPs. In particular, this study centred on the experience of HIV care for Indonesian children living with HIV and their families across the continuum. The previous chapter presented two major categories to structure the findings, namely: (1) ‘maintaining their health’ and (2) ‘living with fear and stigma’. This chapter, Chapter Six, focuses on the third category: (3) ‘predisposing factors to ineffective care’ and the relationships between the sub-categories to inform the entire findings. Apart from the presentation of the third category, this chapter also presents an illustration and description of the core category ‘needing HIV comprehensive care’.

Predisposing Factors to Ineffective Care

The third category identifies the predisposing factors to ineffective care for children with HIV and their families. These factors were based on four dimensions: (1) living with low socioeconomic status (SES); (2) experiencing inadequate social support and suggestions for improvements; 3) experiencing inadequate care coordination; and 4) experiencing care based on insufficient policies and practices, as illustrated in Figure 20, and this in turn had negative impacts on the health of children with HIV.

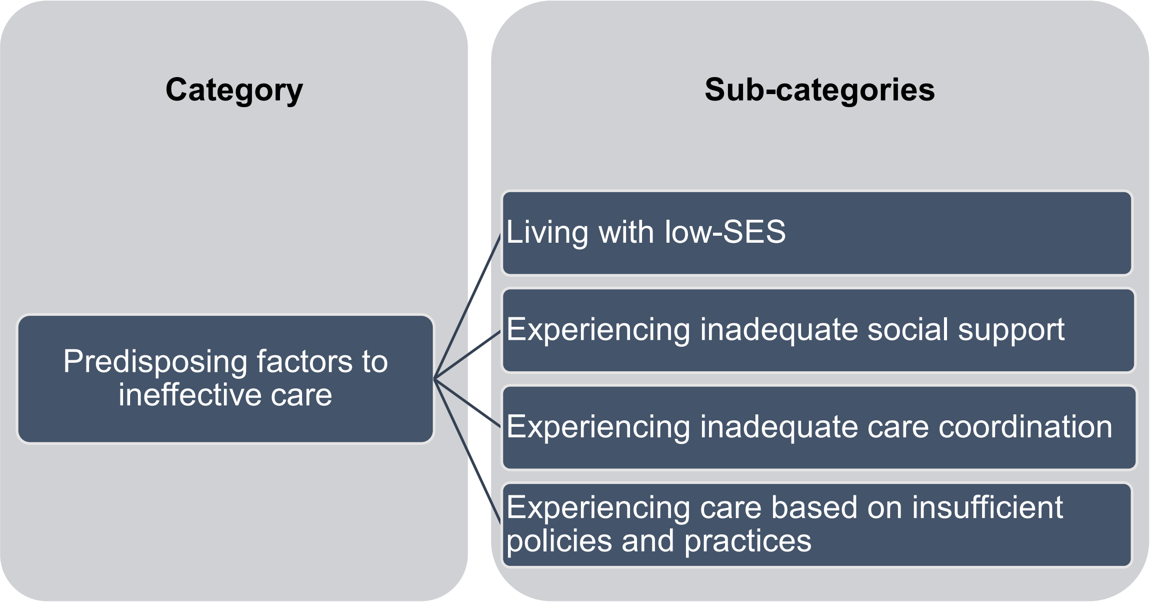

Figure 20: The category of predisposing factors to ineffective care and its sub-categories

Socio-economic status (SES) is a crucial factor that influences health outcomes for people with HIV. The majority of children were from families with a low socio-economic background linked to low income, educational disadvantage, and poverty. Due to this, they were more likely to receive ineffective care, increasing the fragmentation of their care. This status lead to a reduction in the quality of life for the children, because the families were unable to provide necessary resources, such as food, CD4 testing, and school fees. Besides SES, social support was an essential factor in improving health outcomes. Based on the perceptions of the participants, social support referred to the various types of products and sources of support specific to children with HIV. However, the children and their families received inadequate social support and services from the Indonesian government and the private sector due to inadequate funding. In addition to low-SES and inadequate social support, insufficient coordinated care and policies affected the continuity of care across the children's life-span, leading to the fragmentation of care. The policies referred to government regulations, including guidelines or procedures, which directed practice, but were lacking. The next section presents the factors leading to ineffective care.

Living with Low SES

SES status is the representation of a person's social class relative to others, and is determined by income, education, and socio-demographic factors. In this study, most of the families were disadvantaged and poor due to their low income, poor education, and other socio-demographic factors, such as their age and resident status. Most of the families lived in tiny spaces and worked in low-income jobs such as being a laundry worker, a snack seller, or a shop worker.

> *The economic status of Mrs RT was very alarming. So indeed, when we found out she was renting a flat, sometimes she cannot eat (Sukesi, lines no. 495-496).*

Only one family had a member in a permanent full-time government position with a steady income. The occupations of the family participants reflected poor incomes, and may be associated with parents' relatively low levels of education, with most only having had primary and/or secondary school education, which influenced the quality of their care for their children.

Being low-SES had a negative impact on the quality of life for children with HIV and their families. Some of the mothers in this study stated that they had an irregular income, so they found it difficult to pay for school fees, materials, and stationery requirements, or to pay the basic healthcare premiums[6] for their children. One of the mothers stated that she had lots of things to pay for and found it difficult to afford milk-formula for her son because financial assistance was not available. Another mother did not have enough money to cover her monthly expenses and worked two jobs (as a laundry worker) to earn more money, resulting in physical weakness and exhaustion because of her own HIV infection.

The majority of HPs agreed that having a low-SES background had a negative impact on the children and their families. The children were more likely to have poor health, while the families had to deal with the burden of caring. According to most of the HPs, some low-income working families could not afford adequate food and healthcare, and this influenced the child's health outcomes and well-being. Not being able to afford food caused malnutrition. Some other HPs explained that most of the family participants could not afford the cost of CD4 count testing because of their lack of income. For example, the head of a PHC stated:

> *The CD4, but they cannot do it because they do not have the money, right? If there is no subsidy from the government, they must pay for themselves. We give motivation that the CD4 examination is compulsory, but if there is no money, what can we do? (Larasati, lines no. 410-414).*

Based on Larasati's view, she pointed out that the six-monthly CD4 testing to monitor the effectiveness of ARV therapy was less likely to be undertaken due to limited money and the government did not provide routine subsidised CD4 for children.

One midwife explained that due to a lack of money, one child lived with her family in a small room and an unhealthy environment with no ventilation. Often, the family could not afford the transport cost if they needed to go to a PHC. Furthermore, the midwife explained that another family, due to a lack of income, sold their child's formula support to buy food. Because of the lack of money to buy food, the family also skipped their child's ARV, as the mother believed that ARV was supposed to be taken after a meal or when consuming food.

> *Every month, the patient gets four cans of milk-formula support, and the milk will be sold, the issue is that bad. People say that a can of milk is sold 128 thousand at the store, she sold it. Maybe she did that to buy food for the family. It has become a problem. Furthermore, if HIV patients did not report*

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[6] The government of Indonesia established Jaminan Kesehatan Nasional (JKN) scheme to implement Universal Health Coverage since 2014, and this was officially administered by the social security agency Badan Penyelenggara Jaminan Sosial Kesehatan (BPJS). This scheme covered a range of treatments via the health services from either public or private providers that have joined the scheme. BPJS Kesehatan premiums must be paid at least every month, depending on the number of family members and the level of cover and benefits they have.

> *[their HIV status] themselves, they would not get help (Tara, lines no. 449-455).*

Tara highlighted that children lived under financial stress and in unhealthy environments. Moreover, she highlighted that the ‘disclosure issue’ resulted in children and their families not receiving support.

Low-SES affected the functioning of the family in relation to child-rearing. Some of the HPs explained that children from families with low incomes tended to lack attention from their parents because low-SES parents had to work long hours for minimum wages. As a result, families were unable to provide for the physical and emotional needs of their children at home. One HP stated:

> *They [children with HIV and their families] tend to come from a poor family, and the mother was a female sex worker, or singer at a bar, karaoke. It is really hard to educate the mother [about HIV]. She is not the one who takes care of the child. She lives in a rented room, so the child is being taken care of by anyone [in the neighbourhood] who is not working at that time (Gendari, lines no. 877-892).*

According to Gendari, apart from families living on low-incomes, low levels of education were also associated with socioeconomic factors, which resulted in family members often having difficulty understanding the healthcare information provided by health providers, which contributed to sub-optimal health outcomes for the children.

Socio-demographic factors (i.e., age and resident status) also influenced access to healthcare services and support. Most of the HPs explained that a child with HIV was likely to have lost their parents, leaving a grandparent or aunt/uncle to be the caregiver for the child. Grandmothers, who were often old and weak, often did not pick up the grandchild’s ARV which then affected the child’s adherence to therapy.

> *The problem with their grandparents, most grandparents, have their health condition weak as well. So sometimes they do not come to control, the grandparent is sick during the control time, or during the time to take medicine (Anjani, lines no. 31-34).*

Most of the HPs in the PHCs recognised that apart from the elderly caregivers, some families living in the province came from rural areas and did not have a residence card[7], which was needed to access support from the provincial government. Because the families were not

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[7] A resident identity card (or Kartu Tanda Penduduk KTP) is an official card issued by the government, showing that a person stayed in the region permanently.

residents, they were less likely to receive support (i.e., milk-formula, or low-cost or affordable public hospital healthcare facilities) from the provincial government.

Low-SES was associated with reduced access to healthcare quality and outcomes. The majority of children with HIV were from families with low incomes and low levels of education. HPs agreed that a low income, certain types of occupation, place of residence, and the age of caregivers (i.e., middle age) indicated low-SES, which then had a negative impact on the children’s health. In addition to place of residence, children and their families who did not have a residence card did not meet the eligibility requirement to access support from the provincial government, which affected the child’s health outcomes.

According to most of the HP participants, the implications of being low-SES negatively affected children’s quality of life; for instance, children were more likely to have inadequate healthcare, poor nutrition, poor education, and a lack of care. The following section looks at inadequate social support contributing to children being at heightened risk of adverse health outcomes, which lead to the fragmentation of their care.

Experiencing Inadequate Social Support

Social support ideally ensures optimal health for children with HIV and their families, enhancing their continuity of care. However, children with HIV and their families faced inadequate and inconsistent social support, which in turn, increased their risk of care fragmentation. The participants’ defined social support as a supportive process which aimed to improve children’s health outcomes. Children and their families received various forms of support, such as instrumental support through the provision of subsidised ARV treatment, *BPJS Kesehatan* healthcare coverage for poor people, free milk-formula, and subsidised CD4 testing, sourced from both the government and the non-government sector. Meaning support was not consistently available to families. Inadequate social support often leads children with HIV and their families to lower healthcare service use leading to poor quality of care which adversely affects children’s health outcomes.

Lacking instrumental support

Children and their families received instrumental support, in the form of various types of tangible products from the government and non-government sectors. These products included food and nutrition, free or low-cost ARV therapy, free or low-cost CD4 testing, education funding, public health insurance support, and charity. Still, in some cases, support was lacking. For example, most of the mothers and an uncle stated that they received food and pocket money at least once a year during AIDS day celebrations, provided by a Non-

Government Organisation (NGO) concerned with HIV. One mother stated that she received charity from the spiritual community group every month, as well as gaining education funding from the government due to her low-income status:

> *At school, my kids got* ***Kartu Pintar (Smart Card),*** *and with the card, they received a pencil, crayon, bags, shoes, books, and uniforms. It is being given every once a year along with a 400.000 money (40AUD) (Kunti, lines no. 816-820).*

Kunti identified that the Indonesian government provided financial assistance through a Smart Card for school students with or without HIV from low socio-economic backgrounds. The card had a certain amount of money to be used for school stationery.

As well as non-government or private sector support, most of the families received subsidised ARV on a monthly basis and other support from the government. For example, the government allocated free milk-formula, but for the past few months, some mothers had not been able to access free milk-formula due to limited stocks in the PHCs. One mother said:

> *His milk [from the government] is not available now. I feel very heavy. I also do not know why it still not available, these past five months we had not to get the milk, maybe it is running out from the PHC (Surya, lines no. 476-477).*

Most of the HP participants agreed that the provincial and/or district government provided support, such as monthly subsidised ARV, milk-formula, and CD4 testing. The HPs explained that the district government supplied milk-formula support for children with HIV, leprosy, malnutrition, and tuberculosis. However, the support was limited to residents with a permanent resident identity card.

HPs also identified other reasons for inconsistent support. Some families or children could not access free or subsidised (low-cost) CD4 testing from the government every six months due to a shortage of CD4 test reagents. One paediatrician participant highlighted that children not only received limited support for CD4 testing, but access to HIV Viral Load (a laboratory test to measure the amount of HIV copies in the body) testing for children was also limited:

> *CD4, I do not know about now, but a few years ago it is just fine. It can be catch up unless the patient is financially incapable. However, the viral load cannot; the stocks given were too limited. The adults have their own priority (Krisna, lines no. 347-350).*

Krisna recognised that children received limited monitoring of their viral load and CD4 count testing compared to adults with HIV.

Children received routine subsidised ARV therapy, but most were likely not to receive adequate monitoring for the effectiveness of the ARV therapy through CD4 cell count and Viral Load testing. Additionally, they also were more likely to suffer from inadequate food nutrition due to the minimal supply of milk-formula or not having proof of permanent residency for accessing support. In particular, children from a low socio-economic background family could apply for a school card provided by the government, offering assistance to pay for stationery.

Complicated Procedures for Public Healthcare Insurance

According to most of the family participants, the government provided health support through the Indonesian public health insurance system for free or at low cost in the PHCs. They could also use it to access free ARV. However, the family participants were not willing to use the insurance unless their children needed hospitalisation. For example, when accessing ARV, most families chose to be treated as a private patient in the public hospitals without using the public or government health insurance. These families explained that using government or public health insurance required long waiting times and complicated procedures; thus, it was not perceived as a friendly service. As a result, most of the family participants did not want to use the government insurance to access ARV for their children. Two participants (Barata and Samba) did use government or public insurance to access ARV therapy. Barata (one of the mothers) explained the requirements of the referral documents from the local neighbourhood and all reference documents from the PHC before proceeding with the ARV referral for her son. Samba, an aunt of one of the children, stated that she used government support to receive free ARV treatment through the public or BPJS health insurance, but she had to wait for a long time and complete the referral procedures before she could be served. Samba described that she initially requested a PHC referral form and prepared copies of the public health insurance or BPJS and Family Card documents to receive the free ARV service.

As well as long waiting times and the complicated procedures, other families and children described feeling bored waiting for a long time in the queue for their ARVs, and if they used public health insurance, they would have a longer waiting time in the ARV clinic than would non-public patients. Additionally, they stated that the outpatient clinic did not provide physical facilities for children, such as a playground, a library corner, toys, or a play equipment area in the waiting rooms to overcome boredom. Sita, a child with HIV, explained that she felt discriminated against in the service with long waiting times due to using public health insurance compared to attending as a self-funded private client. She suggested that the government should keep the required procedures for public health insurance simple:

> *I feel saturated. I am bored when I need to queue. There are thousands of people queueing in the general sections, and I should wait a very long time to get my turn. I need to make a JKN[8] claim first. I need to register at the general section/main locket, wait until they give a recommendation and then go to Intermediate Care Unit and Infectious Diseases. It will be better if the public health insurance like JKN is simplified; they made it complicated. The government pays JKN. However, their service is very discriminative. They give a different treatment for people who use JKN and who pay directly. I felt like they are prioritising the one who pays directly. For us who use JKN, they just told us to wait. Sometimes, If I may ask, I want them to give equal treatment. So, people who want to use it, feel reluctant. They just like 'it will not be recognised, and I must wait for a long time' (Sita, lines no. 415-424; 682-689).*

In relation to public health insurance, Sita also suggested that HPs should be able to convey empathy without being judgemental during their interactions with clients. The HPs should be friendly, and treat clients with respect, by stating that '*the nurses or doctor at the hospital do not judge the patient' (Sita: teenage HIV, lines no. 729-730).* Moreover, she implicitly explained the transitioning needs of adolescents with HIV. She experienced the transition from the child to the adult care setting when she was aged 17. As part of this transition, she was only informed about the different day on which she would be able to access ARV, and did not receive any information about her care transition. She stated that she could not see any difference between ARV care service delivery in the child and adult settings.

In relation to health insurance, most HPs reiterated that the Indonesian government provided public health support through insurance that covered free basic healthcare services and hospitalisation. The majority of HPs reiterated that the use of the Indonesian health insurance system required a complicated administrative procedure. For example, the families initially required a certificate from the village to say they were disadvantaged, and then a referral letter from the PHC. Due to these procedures, many families tended not to use the health insurance support. Apart from the complicated procedures, other HPs identified that the lack of interest in the use of the Indonesian health insurance system

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[8] JKN *(Jaminan Kesehatan Nasional)* is The Indonesian National Health Insurance for Indonesian citizens with choosing the payment a premium in tiered systems of first, second or third.

among children and their families was because of stigma, due to the requirement for a diagnosis disclosure:

> *HIV patients in monitoring mostly are general patients, not using BPJS insurance. Usually, the reason is that they are scared of the stigma if they use BPJS insurance system, they have to report it to the nearest public health centre, the diagnosis has to be opened to get a reference to hospital. That is usually they do not want to give (Dewi, lines no.191-195).*

The government facilitated public healthcare insurance for citizens, with children with HIV and their families being able to use it to receive free ARV therapy. However, they preferred to pay for the services themselves because of the complicated procedures, the extended waiting period, and the fear of disclosure of an HIV diagnosis associated with public health insurance. Moreover, one child stated that not receiving adequate transition from paediatric HIV care to adult care services lead to their disengagement from care.

Limiting Services for Sexual and Reproductive Health Education

According to most of the HPS in this study, the prevalence of lesbian, gay, bisexual, and transgender (LGBT) people had increased, as had the number of pregnancies among adolescents due to high-risk sexual behaviours. Due to the limited nature of the sexual and reproductive health services, the majority of HPs suggested strategies on how to increase information about sexual and reproductive health education, aiming to prevent the spread of HIV transmission among adolescents. For example, some HPs explained that sex education about condom use would reduce the transmission of sexually transmitted diseases among adolescents without HIV and LGBT adolescents, and would help in the prevention of HIV/AIDS transmission. However, some of them stated that they were worried that if they advised general adolescents to use condoms to prevent HIV transmission, that they would think that free sex would be acceptable. One of the doctor participants described the need for sexually transmitted infection (STI) screening tests for adolescents, sexually active girls, and female sex workers. This screening would help with early detection and treatment of adolescents with sexually transmissible infections before they developed complications. The findings show that adolescents were at the highest risk of getting an HIV infection, but that adolescent-friendly sexual and reproductive health services were not available in the healthcare setting, leading to discontinuities in health and social care.

According to Sukesi, the head of a PHC, because of accidental pregnancies, some adolescents were forced to get married even though they were not ready to be parents, which affected their psychosocial and emotional development. This contributed to an increased potential for reduced care across the HIV continuum as adolescents' females were burdened with marriage and childcare responsibilities. Furthermore, the doctor described that being unprepared for parenthood often contributed to divorce. Sukesi highlighted that interventions to reduce risky HIV-related sexual behaviour among adolescents needed a commitment from all disciplines, including HPs, scholars, and policy-makers. However, one midwife stated that she did not know how to provide sex counselling for adolescents with or without HIV, or how to inform HIV-positive people and his/her partner about preventing the transmission of HIV to others.

> *Then where I have to take these reactive (HIV positive) teenagers? Moreover, then what should we do to them? Can they get married? Later on, until the old LGBT continues like that. I also do not know (Tara, lines no. 930-932).*

There was a need for friendly information about sexual health for adolescents because many adolescents were shy about discussing sex with their parents, as stated by one of the children with HIV:

> *Particularly concerning sexual health, because it must be very awkward if the kids ask about this topic to their parents/family. They will confuse and do not know where they can find this information. If they ask their friend or wrong person, they might be exposed to negative risks (Sita, lines no. 553-557).*

Sita stated that adolescents were at risk of HIV transmission if they received incorrect information about intercourse and HIV, or about how to deter them from taking part in sexual activity. Most of the mothers were also worried that as the children grew older, they would not find a partner or get married due to their HIV status.

Insufficient social support, therefore, influenced engagement in HIV care and quality of life resulting in fragmentation of care for children and their families. Children received subsidised ARV treatment every month; however, were not likely to receive adequate monitoring for the effectiveness of the ARV therapy due to inadequate CD4 cell count and Viral Load support. Children received milk-formula, CD4 laboratory testing, healthcare support, food, charity, and education funding, but not other instrumental support. Furthermore, in some cases, supports were lacking. Children with HIV were unlikely to use public healthcare insurance because of the complex procedures involved, and the fear of disclosure of an HIV diagnosis associated with public health insurance. Participants reported that sexual and reproductive health services for adolescents were lacking. The participants made some suggestions to reduce HIV transmission and STI among adolescents, including condom use, sexual and reproductive health education and counselling services, and also pre-marriage education support.

Experiencing Inadequate Care Coordination

The participants pointed out that inadequate coordination was a barrier to effective care, also suggesting ways to improve care coordination. HPs identified that collaboration and coordination meant working together with team members from different professional backgrounds in a variety of settings, both inside and outside of healthcare delivery organisations for children with HIV and their families. However, some HPs identified that a lack of adequate coordination and an inadequate budget were barriers that lead to inconsistent support, and which contributed to a range of negative outcomes and fragmentation of care, as stated in the following excerpts:

> *At the beginning of the year like this, usually, the program [CD4 testing, milk-formula] exists, but at the end of the year, they run out of money (Gendari, lines no. 764-765).*
>
> *With the NGO, there is one or more NGOs who attract doctors with regards to education and treatment. Moreover, because these NGOs depend on the clinician, so the work is pretty much well even though it is not systematic because it is based on their budget. It usually happens sporadically, not as a continuous project (Krisna, lines no. 93-97).*

One of the paediatricians in the study agreed that non-government HIV organisations carried out their health promotion programs based on grant-based project funding; however, because of limited funding, HIV education programs were often discontinued. Tara recognised that there was inadequate multi-sector collaboration and integration for HIV care programs for children which lead to inconsistent care and support. She suggested that if the health and social departments developed a collaborative partnership, they could deal with the issues for children with HIV more effectively:

> *If the collaboration is integrated and sustainable, the social department could take part in and assist. However, in practice, there is no assistance from the social* department *(Tara, lines no. 162-164).*

Due to inadequate care coordination, most of the HPs suggested a range of strategies for improvement, as they believed that building collaboration and coordination would enhance the quality of children's care. These strategies included strengthening collaboration at multiple levels across departments, building inter-professional coordination, and building community partnerships.

Most HPs in the PHCs identified that the poor quality of care coordination stemmed from the inadequate referral system. For example, most HPs across the PHCs experienced poor return-referral documentation from the hospital to the PHCs. Some of them stated that they hardly ever received feedback from a paediatrician in the hospital, even though they had completed the standard procedures for referral, such as completing all the assessment forms and the general blood tests. Agni, a doctor and HIV coordinator in a PHC, mentioned a case in which she could not monitor the child's condition in the community because a paediatrician had not provided any information about follow-up care, which lead to the child's death, as stated below:

> *Well, at that time, the child stays in the hospital for almost a month, then the child was sent home, but when the child got home, the child dies. There are no notes from the hospital that states anything that should be done by us, the PHC (Agni, lines no. 408-411).*

Agni described that the inadequate referral system from the hospital to the PHC reduced coordination and follow-up care and caused fragmentation of care for children with HIV. She suggested that the doctors working in the hospital should understand the referral system procedures and documentation, which would improve care coordination between the hospital and the PHC. Due to inadequate referrals to the PHC, children with HIV were more likely to experience adverse impacts on their care outcomes, causing fragmentation of care in the community. HPs in the PHCs agreed that strengthening the referral system, and collaboration between the PHCs and the hospitals improved referrals and coordination of services, which enhanced continuity of care for children with HIV.

The HPs explained that children with HIV required a multidisciplinary team with coordinated and collaborative delivery of care due to the complexity of their care needs, as stated in the following excerpts:

> *Comprehensive means 'in a whole'. Comprehensive means needing many people involved in the care. Not only doctor to provide the treatment. Other factors need attention [for children with HIV] such as nutritional status; environmental health have to be involved, sanitation such as assessing the environmental condition of the house does is liveable or not. For nutritional status, children with HIV need to be monitored their body weight as a growth indicator. By suffering from HIV, does it affect their growth and development, or midwives could monitor growth and development? Does HIV infected child have different development from a normal child, does it affect his psychologic? So, it is not only a doctor, pharmacist, report recording staff. Children are the new generation, so if we initially prepare them from the beginning although they are sick, it will be good (Utari, lines no. 736-748).*

> *It is no longer the field for a child's doctor. So, we have to ask for a comprehensive with other colleagues (Anjani, lines no. 159-160).*

Utari, a GP and HIV counsellor in a PHC, identified that children with HIV needed comprehensive care to address their complex healthcare needs in a holistic way. This care includes life-long ARV retention, and good environmental health, nutrition, and psychosocial care to support their optimal growth and development. She also explained that care should be implemented collaboratively with multiple HPs, including doctors, nutritionists, pharmacists, midwives, psychologists, and workers for HIV recording and reporting.

Anjani, a paediatrician, agreed on the need for multidisciplinary collaborative care to achieve optimal growth and development for children with HIV. Additionally, Anjani stated the importance of establishing a rapport with children and their families, helping them to respond better to treatment. She explained how to build trusting relationships, such as through effective communication and maintaining patient confidentiality, as she believed that families would not be happy if other doctors identified their child's condition.

Due to inadequate care coordination, building interprofessional relationships was suggested by most of the HPs in the PHCs as a way of enhancing effective collaborative care. The HPs identified a number of ways to develop interprofessional relationships, such as creating a WhatsApp group, having coordination meetings to gather HPs to respond to HIV care for children, continuing the education program for HPs, and strengthening the HIV information system. Some doctors working in the PHCs agreed that all HPs dealing with HIV care in the district government should become a member of a WhatsApp group. A doctor in a PHC explained the benefit of using WhatsApp through which every member could privately share information, discussions, and up-to-date HIV care information from within the group itself, facilitating the appropriate delivery of healthcare services and enhancing care coordination between HPs. Additionally, the doctor described that if HPs in the PHCs could set up at least three-monthly meetings to discuss the barriers to HIV care practice, this would also help to improve care coordination.

As well as communication and regular team meetings, some of the HPs described the need for interprofessional education on HIV training for HPs as they believed it would increase their knowledge, skills, and competence in relation to HIV, and would improve care coordination within the team. Apart from the need for a HIV training course for HPs, some other HPs also agreed on the need for increasing the workforce, supporting optimal delivery of HIV care, and ensuring effective care coordination, as stated by one paediatrician:

> *The resources, specifically, the training needs to be done continuously, once is not enough. There should be more and more training, and the team needs to be added (Krisna, lines no. 582-584).*

A paediatric consultant in the study explained that developing internal team coordination through preparing for professional practice would enhance effective care. He stated that the day before ARV day service, doctors within the HIV team should identify children who might be accessing ARV, as well as preparing their health records. The team should then continue to discuss the client's condition, starting with the client's identity, medication history, laboratory results, and major complaints. He believed that understanding the client's situation before the day of the ARV service would improve effective coordination and communication within the team, and would improve client care. Moreover, he also suggested that the unnecessary rotation of staff to maintain care coordination should be stopped. He explained that staff rotation could cause the team to lose trained health professionals. Having a health professional who did not specialise in HIV management caused adverse consequences for team care coordination and increased the risk of outpatient fragmentation of care for children, because the children would see a different physician at each visit:

> *There is no rolling. People who placed there handle the same matter for years. However, for most reasons and a few considerations, when the patient comes to the clinic and sees the same doctor after years, maybe the consistency will be more settled. However, in the facility of the general practitioners, the doctor changes every time the patient comes (Krisna, lines no. 237-240).*

However, in most cases, the paediatric consultant and some HPs in the PHCs identified that many children and their families saw a different doctor at each visit when accessing their ARV treatment, and this reduced the continuity of care for the child and the family.

Gendari, who had delivered HIV care for adults in a PHC, explained that a single health provider could not provide optimal HIV care delivery. She stated that the delivery of HIV care needed a case manager and a HIV cadre[9] from the local community working together as one. For instance:

> *Then for the support, actually if we want to say, we cannot work alone, in my experience, if there is no case manager, no assistance, or cadres from the society, it cannot be done. The term is that it is 'a joint project' (Gendari, lines no. 839-841).*

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[9] Cadre is a person or a group of people who receive health training and act as an associate health worker in the community.

Some HPs suggested that the building of a partnership between the PHC and the local community would improve the quality of care for children with HIV. Other HPs in the PHCs agreed with strengthening community partnerships, particularly using community-based surveillance. According to the HPs, community-based surveillance would be a working partnership between a cadre and PHC staff in their local area which would aim to detect, report, respond to, and monitor a child with HIV in the local community. To achieve this goal, the HP suggested guidelines or pathways on how to collect, report, and monitor a child with suspected signs and symptoms of HIV, and how to control the spread of HIV in the community, as stated by one of the HPs:

> *The networks should be strengthened, the networks. For example, later, there is a child with HIV, the flow, the direction, all of them should be known. Oh, later there is a child with HIV, later will be netted, later the direction, we know it all. So, it means monitoring is not only done by health workers but also from society. Maybe it starts with socialisation from mass media or communication, television media, maybe through there. What if there is a case of a child with HIV with conditions like this with the flows. Admitted to, through community health centre first, or through cadre, like that. So later, it will build such a continuous network, whoever in their care and then society get the knowledge not to stigmatise but know it is for, oh this kid indeed needs the service. This kid needs service provided in here (Suhita, lines no. 717-727).*

Suhita, the head of a PHC, identified that HPs should continuously work together with a local cadre in the community, and they could develop a partnership to reduce community stigma. Furthermore, she stated that the promotion of HIV information via mass media could be another strategy to reduce stigma.

According to a clinical nurse implementing a recording and reporting system for HIV patients, another strategy has been implemented by the Indonesian government which had developed an Information System for HIV-AIDS (called Sistem Informasi HIV/AIDS-SIHA). This system used the Resident Identity Card (RIC, called Kartu Tanda Penduduk/ KTP); however, it was not online and did not synchronise with other information. For example, if a health professional entered a child's name into the system, the system could not filter the data, leading to significant data redundancy, as stated:

> *Sometimes, I have got a national register in BKR ... it turns out he moved to another place, he did not admit that he had ever received ARVs in BKR. Finally, the national register is double. For example, in which province did he register again recently … the biggest problem in RR is data duplication, we have to be able to prevent duplication. Duplication occurs because we do not have filters (Brahma, lines no. 219-220).*

For this reason, designing enhancements to the HIV electronic medical record databases for children with HIV would improve the implementation of a comprehensive electronic medical record program across the country. A few HPs believed that the Indonesian government should improve the HIV electronic database system in which each child should have an individual online barcode for identification. The online barcode system would help to track and store the child's information in a computer software system and would reduce data duplication. The system should also contain comprehensive detail on each child with HIV. HPs described that through a good HIV data system, HPs could share HIV care information for each child, thereby enhancing clinical care coordination, and improving continuity of care for children with HIV.

To sum up, inadequate communication and coordination among HPs in different healthcare settings and in the community, the inadequate referral system, and limited information management systems in HIV/AIDS care contributed to the fragmentation of care. HPs suggested that coordinating services within and across healthcare settings, engaging in community partnerships, strengthening the HIV information system, integrating care, and synchronising electronic medical records would increase the continuity of care for children with HIV and their families. According to HPs, they should develop interprofessional collaborative practice with effective communication, and receive education and training to help them deliver better care and improve team coordination. The following section identifies how insufficient policies and practices are barriers that contribute to the fragmentation of care for children with HIV.

Experiencing Care Based on Insufficient Policies and Practices

Policies were identified by HPs as a set of procedures or guidelines that directed HPs on how they should provide care services. According to most of the HP participants, the provincial government did not have a clear policy to regulate HIV care delivery for children; in particular, the initiation of ARV treatment, as stated in the following excerpts:

> *… there is no policy (for the initiation of ARV for children). Indeed, the provisions stated that healthcare is allowed to do ARV initiation (Agni, lines no. 364-365).*

> *Some policies are still controversial on which model shall be followed as sometimes there are still some dissenting opinions among us, but we usually talk it out. With the city of East Java, because the city of East Java usually has no specialist in the level of a consultant, the city of East Java usually listens well on what the consultants have said (Krisna, lines no. 90-93).*

Krisna, a paediatric consultant, recognised that the provincial government did not have a transparent model of clinical service delivery for children with HIV. The limited model of HIV clinical service delivery caused debate among the HPs. Furthermore, Krisna explained the existence of a hierarchy of power among HPs within the hospital's hierarchical structure. The paediatric consultant was in a senior clinical position and contributed to health policy-making in healthcare settings and in the healthcare bureaucracy. Krisna believed that the government and policy-makers should have a stronger commitment to developing a strategic plan for the comprehensive care and treatment of children with HIV:

> *I mean nationally, whoever in the ministry or whomever the leader needs to have commitment. And they need to realise that commitment through the strategic plan. Build a foundation that is willing to help, especially in East Java, it can be placed in Surabaya, a comprehensive treatment, the doctor is being paid, the medication can be fulfilled, the lab can be fulfilled, the formula can be given for those who do not take breast milk, the idea sounds really great. Thailand can do that, Malaysia as well, but we cannot because no-one is consistent. A foundation to help people with HIV is not appealing (Krisna, lines no. 518-526).*

Krisna went on to highlight that the provincial government should initiate a comprehensive care and treatment program for children with HIV so that they could receive adequate support for treatment, laboratory testing, and nutrition. Additionally, he criticised the Indonesian government for lacking consistency in the implementation of an HIV program and service, which caused Indonesia to lag behind Thailand and Malaysia in their policies and practices.

In the case of ARV treatment services for children, there were different perceptions between HP participants working across PHCs and paediatricians in the hospitals, leading to the centralisation of ARV treatment for children in the region. Most of the doctor participants working in the PHCs stated that in 2017, the District Level Health Office (DLHO) referring to the Ministry of Health, announced that PHCs could provide ARV treatment services for children with HIV. In reality, PHCs could only provide service delivery approaches to HIV counselling and testing and ARV for adults. Most of the HP participants working in the PHCs stated that the PHCs did not have any authority to provide ARV medicines for children. Because ARV therapy for children was not offered in the PHCs, children who tested positive would be referred to a major hospital, as stated by one of the doctors below:

> *We are not authorised to provide paediatric ARV; due to treating paediatric HIV treatment is not one of the PHC authorities, the clients are referred. Something like that. It is not a PHC authority. It means that access ARV will*

> *facilitate in the hospital where is higher service level (Uma, lines no. 8; 87-89).*

Despite not being able to offer ARV therapy, PHC staff conducted HIV counselling and testing for children.

One doctor in a PHC agreed that the provision of an ARV service and the management of long-term ARV treatment for children were not available in the PHCs:

> *Long-term treatment, especially children who have barriers. The barrier is that treatment system management is not available as an adult have. The coverage service is not available yet (Utari, lines no. 801-804).*

Utari (GP) identified that she provided ARV services for adults, but not for children.

Besides lacking authority to provide ART treatment for children, the HP participants in the PHCs stated that the paediatricians working in the hospitals considered that GPs in the PHCs were less competent than paediatricians. Some of the GPs in the PHCs explained that they had only limited skills and knowledge because the PHCs did not provide HIV care for children, as stated by one doctor:

> *I have limited experience with children because PHC does not have service for paediatric HIV treatment (Utari, lines no. 278-279).*

Most of the paediatricians working in the hospitals disagreed with the implementation of ARV services for children in PHCs for the following reasons. The paediatricians asserted that they understood better how to calculate the ARV medication based on the child's weight, and also how to monitor the side-effects of the ARV therapy. Due to the complexity of these side-effects, the paediatricians did not allow doctors in the PHCs to initiate the provision of ARV for children. One paediatrician, Anjani, explained that doctors in the PHCs were not specialists, and had only limited knowledge and experience on HIV care for children:

> *I do not agree to do it at the health centre. Because the side-effects of the medicine should be supervised well, if they are not a child doctor, they might not understand how. We still do not allow the health centre to run a diagnosis or to start the treatment, so it should be referred to the hospital first. But just a doctor. They do not understand when it comes to giving Duviral in one powered or giving ART after the fungi are gone then stopped to be changed … it used to be like that. So, we demand the child doctor take a direct part in, that is for the hospital (Anjani, lines no. 314-315; 456-465).*

One consultant paediatrician, Krisna explained that if the PHCs provided ARV medicines for children, the risks of non-adherence in HIV-positive children would increase. In anticipating the risk, he asserted that PHCs would provide a far better service:

> *So, there are more bad outcomes if HIV treatment reaches the PHC level. Mrs Mayor maybe wants the treatment to reach the PHC, but I do not want to … But generally, to open treatment in PHC will increase the risk of medicine-resistant (Krisna, lines no. 129-216).*

Moreover, Krisna explained that the district government wanted the ARV treatment service for children to be situated at the PHC level, but as a consultant paediatrician, he disagreed with this. The control of the provision of ARV therapy for children with HIV was limited to the hospitals. However, one paediatrician, Anjani, explained that doctors in the PHCs might continue the ARV treatment services for children if they were stable. However, the children still needed to go to the hospitals for HIV monitoring and testing every three or six months. Anjani explained that before the doctors in the PHCs delivered ARV services for children, they should know about HIV symptoms, the risk factors, and the management of ARV therapy regimens and the associated pill-burden for children. The provision of ARV therapy seemed to be concentrated and centralised in the hospitals, which were under the authority of paediatricians.

Most HPs explained that the HIV care management guidelines for children received little attention compared to adult HIV services. These limited guidelines on HIV monitoring, VCT, disclosure management, and the management of physical neglect, negatively influenced care delivery and placed children at high risk of fragmentation of care. For example, one of the doctors in the study experienced the loss of contact with one of the mothers and children with HIV due to this limited policy on HIV monitoring which caused fragmentation of care, as stated in the following excerpt:

> *We found a mother and child who got HIV at that time. The mother and the child were HIV-positive; then at that time, we lost their contact because the management was not right. The patient could not be contacted at that time. That is how it looks like back then. That means the management was not good (Gandawati, lines no. 35-42).*

Moreover, feeling overloaded at work was also stated by some HPs as contributing to children missing out on HIV services.

Other HPs working in the PHCs described that the management of disclosure of HIV status for children was also not well-structured, resulting in a number of challenges. Several HPs did not understand what information should be delivered to the children so that they could understand and accept their status:

> *I told you earlier; we still do not have a concept of how (to disclose). I already have two children. How his future will be, then what should we do if they*

> *complain? They do not want to take medicine and all kinds of things. I want these great kids to be able to be open. How do I say it? I cannot talk about it like that. That is my challenge. How will I make these children succeed? Who can socialise well? Who can get a good education? These are the challenges (Sukesi, lines no. 683-690).*

As well as the lack of disclosure guidelines, one of the midwives in a PHC described that the district government had limited guidelines on how to respond to child neglect, including physical and medical neglect. She explained that she was overloaded at work, but still had to respond to the other problems for children with HIV. In one case, she helped to provide a child's basic needs and even paid for a mortuary handling fee for a child's corpse, as stated in the following extract:

> *I hope there is a clear certificate regarding HIV neglect, what is the procedure? Then the extent of the duties and responsibilities of the Constitutional Court. I had been overloaded. Then, the case of HIV neglect regarding a client who died; who took care of death/corpse?, who had to pay for death/corpse? I had to pay too. The officer did not know the procedure (Tara, lines no. 1035-1037).*

The provincial government had limited policies on HIV care management for children, relating to the model of HIV clinical care service delivery, ARV treatment, disclosure management, HIV monitoring, and physical and medical neglect. These limited policies meant that many children did not receive comprehensive HIV care and management. The issues of limited knowledge and skills about HIV, and work overload among HPs, were identified as barriers to effective care, leading to the fragmentation of care. Additionally, based on the HP and family perspectives, the healthcare service in the provincial government was divided into the PHC and the hospital care services. With regards to HIV service delivery for children with HIV, the PHCs provided some limited services, but in the main, the implementation of ARV treatment was centralised at the hospital level.

In summary of this third major category, the predisposing factors to ineffective care were mainly social factors encompassing low-SES, lack of social services, inadequate care coordination, and a lack of policies, which in turn, caused complex problems for children with HIV and their families, leading to the risk of fragmentation of care. The majority of the children lived in low-income families, characterised by poverty, lack of income and education, and not having proof of permanent residence. Living with low SES had negative impacts on the children and their families. Children had subsequent problems regarding inadequate nutrition, low levels of education, and a lack of care, resulting in a sub-optimal level of physical health, psychological well-being, and non-adherence to treatment. Low-SES also caused difficult life situations for the families in relation to paying for necessities, such as food, healthcare, transportation, and school. The overall burden of low-SES contributed to the fragmentation of care for children with HIV, and there was a similar relationship between inadequate support and a lack of policies.

The local government subsidises HIV care, in the form of CD4 testing, and milk formula. However, as a quota is attached to the number of children who receive subsided CD4 testing, not all children are eligible. In addition, even though milk formula is subsidised the demand for it often exceeds supply, therefore some families miss out. As well as quotas and lack of supply these services are only available for residents with proof of identity (POI)[10]. However, families do receive food and charity from NGOs or the community. Children did not receive an adequate package of collaborative and coordinated care; instead, their care was characterised by inadequate referrals and a lack of an adequate HIV information, which negatively affected their continuity of care. Furthermore, the provincial government had an insufficient policy for comprehensive HIV care and management of children with HIV, which in turn, contributed to a lack of continuity of care. Apart from the limited policies, procedures, and guidelines on disclosure management, a model of HIV clinical care services, psychological support, medical and physical negligence, and the centralisation of ARV services in the hospitals were insufficient. The children also tended to receive inadequate care because of a shortage of staff, the high workload of the HPs, and the lack of knowledge and skills of HPs. HPs explained that the building of coordination, collaboration, and partnerships between HPs, the community, policy-makers, and stakeholders would enhance continuity of care in the future. The HPs suggested that coordinating care across all levels through inter- and multi-sectoral collaboration, effective communication, and the involvement of policy-makers and stakeholders was crucial to achieving coordinated and collaborative care. For these families, HPs explained that children should be assured of receiving integrated care and services by engaging them and their families, and working together with the community, and the primary and secondary care sectors, to improve health outcomes for children with HIV.

The following section presents the core category of ‘needing comprehensive care’, in relation to enhancing continuity of care for children with HIV and their families.

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[10] Residents with proof of identity (POI) are people who do not belong to the local government district they are living. This mean they will not receive financial subsidies from the local government.

The Core Category of ‘Needing Comprehensive Care’

The subjective nature of the three main categories was derived from the perspective of children with HIV, their families, and HPs from their past and present experiences. Throughout, the analysis provided an insight into how the children and their families constructed different meanings around their interpersonal relationships and healthcare access. Perceptions and actions in the provision of care and in their healthcare interactions were shaped through the participants’ values, beliefs, and experiences. It was revealed that central to the data was the issue of how families provided care for their children, the care the children received, what they perceived as barriers to care, and what they perceived was needed for the care of HIV-positive children and their families.

The core construct from the findings has been labelled as ‘needing comprehensive care’. Within the over-riding category are the three sub-categories of *maintaining their health*, *living with fear and stigma*, and *predisposing factors to ineffective care* that are strongly related to the central category. Throughout the findings, family members drove all healthcare for their children’s lives, and took all measures to maintain their child’s health as a priority throughout the period before the diagnosis and then when living with the diagnosis. Children and their families were faced with the psychosocial issues of stigma and the fear of discrimination, causing negative consequences for access, support, and quality of care. Additionally, children with HIV and their families faced many barriers to effective care, predisposing them to a fragmentation of care. These predisposing factors included their low socioeconomic status (SES), inadequate care and support services, a lack of care coordination, inadequate policies related to care for children with HIV and their families, and living with fear and stigma, which caused marginalisation and discrimination.

It was evident that children with HIV had complex problems related to physical, psycho-social, and emotional difficulties. The relationship between the three major categories revealed that Indonesian children with HIV and their families experience fragmentation of care. The risk of discontinuous care across the continuum was due to complex care needs that were not being met, and reflected a need for the provision of comprehensive HIV care to enhance continuity and improve health outcomes. Children required not only long-term ARV medication, but also needed non-medical supportive care to improve their well-being, enhance the continuity of their care, and maintain their health. The elements of needing comprehensive care will be further discussed in the next chapter.

Chapter Summary

The predisposing factors to ineffective care in this study are low-SES and social conditions together with inadequate services and support, inadequate care coordination, and insufficient policies and practices. These contribute to poor continuity of support for children and their families. These factors lead to poor health outcomes. The majority of the children in this study were from low-SES families, lived in poor housing, and received low incomes, and as a result, were often poorly educated. Living with low-SES caused multiple stressful life situations, such as family financial hardship and adverse parenting behaviours. The financial hardship faced by the families lead to non-adherence to the therapy, poor quality healthcare, inadequate nutrition, and reduced educational attainment for the children, which contributed to a lack of well-being. Apart from low-SES, the Indonesian government provided subsidised ARV, free milk-formula, and low-cost CD4 testing. However, children and their families were more likely to not access support because the support was limited, did not meet requirements, and due to internalised stigma. The Indonesian government provided low-income families with financial assistance for education and the state-run health insurance scheme, but only a couple of children and their families accessed this support due to the complicated procedures involved, the lengthy waiting periods, and the internalised stigma that went with these. In addition, children received inconsistent support from NGOs and the community, particularly in relation to charity and food aid. Inadequate care coordination and insufficient policies also caused fragmentation of healthcare delivery, and had an adverse impact on children’s health outcomes. These policies included limited clinical and community service delivery models, lack of psychosocial support, limited guidelines for the management of disclosure and for the management of physical and medical negligence, and increased centralisation of ARV services into the hospital sector. Children were more likely not to receive optimal healthcare because of the shortage of HPs, HPs’ heavy workloads, and the lack of knowledge and skills on HIV of some HPs.

Taken together, the three main categories generated a core category within which Indonesian children with HIV and their families expressed the need for comprehensive HIV care due to their experience of fragmented care. Children with HIV were identified as being at higher risk of fragmentation of care because they were less likely to receive the complex care they needed. Children and their families needed ongoing and comprehensive care in supporting their complex conditions, involving bio-psycho-socio-emotional care and support throughout their lifespan, through adequate care coordination and collaboration.

The following chapter presents a discussion of the core category established through the grounded theory. Significant results are also discussed to support the core category.

CHAPTER 7
THE CORE CATEGORY

This study has explored the experiences of children with HIV and their families in relation to HIV care across the continuum in the Indonesian context, with the aim being to construct a substantive grounded theory using the constructivist grounded theory method (Charmaz, 2006, 2014a). Chapters 5 and 6 provided an understanding of the experience of living with HIV from the perspectives of the children in the study, their families, and health professionals. These previous chapters described three major categories, namely: (1) 'maintaining their health', (2) 'living with fear and the stigma', and (3) 'predisposing factors to ineffective care'. Among the findings were a wide range of contextual factors which the participants believe affected care, and which lead to fragmentation of care.

The core category of 'needing comprehensive care' was formed through the integration of these three categories. This chapter discusses the core category of the substantive grounded theory, 'needing comprehensive care', and positions it in relation to the existing literature.

The Core Category of 'Needing Comprehensive Care'

This study has constructed a theoretical explanation of the core category of 'needing comprehensive care' to conceptualise the meanings and actions of children with HIV and their families in relation to HIV care across the continuum. "*A substantive theory is a theoretical interpretation of delimited problem in a particular area*" (Charmaz, 2014a, p. 344). The construction of the theoretical explanation of the core category of 'needing comprehensive care' was established through Blumer's symbolic interactionism where the process of 'interpretation of the action' through meaning, language, and symbols from individual participants within a society are used (Blumer, 1969). This study employed the constructivist philosophical paradigm, as described in Chapter Three (pp. 35-51). Consistent with this philosophical assumption, this study employed a grounded theory method to identify the core problem. The experiences of three different participant groups (children with HIV, their families, and health professionals) on HIV care for children across the continuum in Indonesia were explored. The researcher interpreted and analysed the data together with undertaking a systematic analysis of the initial codes, the focused codes, and the constant comparative method to construct the core category.

The core category of ‘needing comprehensive care’ demonstrated how the sub-categories linked together to explain the experience of the participants, which is the experience of care across the continuum. The core category of ‘needing comprehensive care’ captures the individual lived experience of children with HIV and their direct family members responsible for maintaining the children’s health along with the contextual barriers to care and their care needs. The core category demonstrates the meanings and interactions experienced by the participants, and allows the reader to understand the cause of the problem and to identify solutions that take the individual ideas, thoughts, and experiences of the participants into consideration. Underpinning this core category are the sub-categories of ‘maintaining their health’, ‘living with fear and stigma’, and ‘the predisposing factors to ineffective care’ (see Figure 21).

Figure 21: A representation of the core category of 'needing comprehensive care'

'Needing comprehensive care' is crucial for Indonesian children with HIV and their families, because the children had experienced incomplete care across the continuum. The category of maintaining their health described that caring for children with HIV required a range of responsibilities that influenced care-giving demands. For example, supporting a child with

HIV created a strain on the family financial resources. Families in this study could not afford medication, nutritional food, and the aids needed for routine daily needs. This, in turn, affected the emotional well-being of the family. Being unable to afford the elements of care also increased family stress. Families did acknowledge that they received tangible support from the government and the private sector to help manage their needs. However, the support did not meet their care demands. If the Indonesian government were to provide financial support, families would experience less distress. The financial and other challenges faced by Indonesian families living with children with HIV were barriers to achieving continuity of care.

Children with HIV and their families also experienced negative emotions associated with the HIV diagnosis. Children with HIV and their families felt a sense of hopelessness when first diagnosed. This was followed by denial, shock, and anger at first hearing of the HIV status of the child. These negative emotions were associated with a lack of acceptance of their child's status and a lack of understanding of HIV prevention, transmission, and prognosis. In addition to not accepting the diagnosis, families also experienced stigma as a result of the actions of their extended families, health professionals, and the wider community.

In addition, the majority of children with HIV experienced internal and external stigma. Children and their families constructed negative meanings from the stigma they experienced, increasing the feelings of negativity in their lives. For example, internal stigma lead to feelings of shame, telling lies and deception. This perceived stigma from others also influenced their attitudes and behaviours, such as being vigilant in relation to the disclosure of a child's HIV status, and the fear of discrimination. The stigma experienced by the participants shows that stigmatisation occurs at the individual, community and healthcare levels. The participants experienced bad behaviours towards them, such as being rejected from school. These negative experiences made them aware of stigma and discrimination, which caused psycho-emotional distress. The lack of psycho-emotional support is lacking in the day-to-day care of children with HIV and their families.

The severe illnesses associated with HIV infection required recurrent hospitalisations for these children. The majority of participants coped through spiritual and religious practices and beliefs. Spirituality helped the participants to control their stress and motivated them to continue providing care for their children, which in turn resulted in positive behaviours. The experience of individualised spiritual beliefs encouraged children with HIV and their families to maintain their children's health. Xu (2016) explained that religious beliefs, values, and practices are dynamic coping processes that enhance individual strength to find meaning and purpose. Such meaning supports the family to deal with contextual and circumstantial stress, supporting good health, positive well-being outcomes, and spiritual growth. The implication for family care is that spiritual beliefs affect decision-making about care, promoting the continuity of care and caring.

Families were motivated to maintain their children's health through developing family caregiving responsibilities to sustain the uptake of ARV treatment while promoting the child's growth and development. As the families in this study perceived HIV as a severe illness, the benefit of ARV treatment was held in high regard and raised the emotional awareness of the children with HIV and their families about the importance of ARV treatment. To support the availability of free ARV refills in the hospital, children with HIV and their families relied on the Indonesian government.

The families in the study acknowledged that once the children were regularly taking their HIV treatment, they did not experience severe illness or require hospitalisation; nevertheless, to maintain their health, they needed to participate in daily self-care. For example, they were adhering to their ARV regimen to sustain their treatment, and used positive self-talk for motivation and phone alarms as reminder tools. The desire of the families to maintain the ARV treatment influenced them to use a range of symbols, such as 'at 6pm' or telling the child, 'if you do not take your drugs, you will die like your parents', thereby engaging their child in taking the ARV treatment.

In the hospital context, there is a dynamic interplay between context and competing perspectives, which is evident in the current study. The experiences of interaction between children, their families, and the HPs shaped their experiences, with families reporting that the physicians were more interested in prescribing medicines than in providing health information during consultations.

Such experiences raised awareness that children with HIV and their families wished that health professionals would be more communicative and involve the children in their own care while also being friendly and respectful. Glanz, Rimer and Viswanath (2008) argued that patient participation in consultations facilitates the physician's understanding of the patient's values and preferences, and might also help in discovering possible perceptions the patient might have in relation to their disease or treatment. Furthermore, physician-patient communication could improve patient knowledge, with patients participating in decision-making that would fulfil their needs and circumstances, leading to improved health outcomes.

The families in this study wanted the HPs to provide health information to the children about their illness. The families expressed that the doctors focused more on prescribing medications than on educating the child or the family during the consultations. For example, one child transitioning to an adult setting received little information about her transition, and only received information on which day she could access ARV as an adult patient. This anecdote reflects that children and adolescents did not take part in care planning, which demonstrates insufficient child-centred care. These experiences appeared to shape their views of sub-optimal health professional [physician]-patient communication in the hospitals. They stated that having a good working relationship with clear and respectful communication while facilitating the transition to other services would enhance the therapeutic framework of trust and hope between HPs and the children. However, these provisions are all too often not implemented in HIV care for children in Indonesia.

Effective communication between children, their families, and HPs would encourage the participation of children and their families, thus promoting child-centred care. Capacity building and effective communication with children of different ages would deliver optimal care for children with HIV (Mutambo, Shumba & Hlongwana, 2019). Furthermore, different forms of communication in care would help to foster a good relationship between HPs and children to provide health information through education, and make them feel valued and cared for, which would improve their healthcare outcomes.

In this study, children with HIV and their families experienced an absence of financial support, a lack of psycho-emotional support, and sub-optimal health professional [physician]-patient communication. In addition, the collective meanings of the participants revealed that their care experiences in the hospitals were made up of inadequate [tangible] social support and insufficient care services to meet the needs of the child. Their experiences and thoughts affected their preferences and needs for ARV treatment, disclosure of HIV status, sexual and reproductive health, transition care, psychosocial care, and social support as part of comprehensive HIV care for children.

HPs agreed that the implementation of HIV care for children was sub-optimal. They recognised the constraints within the healthcare system, including insufficient policies oriented towards children with HIV, an inadequate referral system, and poor care coordination. Furthermore, socio-economic circumstances, stigma, and discrimination influenced the children's daily lives and lead to poor health outcomes. Reflecting on the participants' experiences, their common goal was that children with HIV would receive comprehensive care across the continuum, which would meet their child's needs, and which would address the fragmentation of their care. The comprehensive care they need includes child-centred care, ARV treatment, disclosure of HIV status, transition care, psychosocial care, social support, and care coordination, which would promote optimal health outcomes. Marzorati and Pravettoni (2017) asserted that patient values and preferences help to evaluate practice and situations, and should be integrated into clinical decisions.

Defining 'Needing Comprehensive Care'

'Needing comprehensive care' was a priority for the participants because it reflects the belief that children with HIV and their families needed comprehensive care that would fulfil the needs of the child across the continuum through the coordination of multidisciplinary teams due to the fragmentation of their care. The families were motivated to maintain the children's health to support optimal health outcomes. However, all the participants recognised the contextual risk factors that lead to the fragmentation of care. When they discussed these contextual factors, they explicitly shared their desire for improvement. Health professionals in this study concurred that children with HIV needed comprehensive care across the continuum, because HIV care and services for children was sub-optimal. These experiences influenced and shaped the construction of a conceptual model of comprehensive care for children with HIV.

A Conceptual Model of Comprehensive Care for Children with HIV

A conceptual model of comprehensive care for children with HIV is a theoretical model that sets out the collective experiences and perspectives of Indonesian children with HIV and their families. This model presents the components of comprehensive care that address the fragmentation of care for Indonesian children with HIV and their families across the continuum. This model has been derived through the constructivist paradigm, looking to construct subjective knowledge from the participants' life experiences through their own meanings and interpretations.

From the perspectives of children with HIV, their families, and HPs, Indonesian children with HIV and their families experienced fragmentation of care due to a complex interplay between insufficient comprehensive care that did not meet the needs of the child, poor coordination of care, and an inadequate healthcare system associated with contextual barriers based on the social determinants of health. These contextual barriers included low-SES, stigma and discrimination, inadequate social support, and inadequate policies and regulations. These experiences did not support comprehensive care for children with HIV and their families, leading to fragmentation of care across the continuum. Understanding children's needs and preferences forms the foundation of the development of a framework for the comprehensive care of children with HIV.

Figure 22 represents a conceptual model of comprehensive care for children with HIV. This conceptual model offers components of comprehensive care based on the needs of the child across the continuum, delivered by adequate integration and coordination of care through a healthcare service. The core of comprehensive care for children with HIV consists of two components, namely child-centred care and social support. Examples of the services are presented below for each component:

- Child-centred care ensures that Indonesian children with HIV receive care depending on their needs and age-appropriate development across the continuum. Examples of child-centred services are ARV treatment and adherence, guidance on disclosure of HIV status, adolescent sexual and reproductive health, transition care, and psychosocial care. To achieve this, health professionals [nursing] should learn to involve, communicate, and collaborate with the children and their families to develop relevant goals. [Nursing] goals together with intervention strategies, are determined mutually between the child, their family or caregiver(s), and the HPs to meet the child's needs related to the health issue.
- Child social support ensures that children with HIV receive social support and their due rights, addressing the social determinants of health across the continuum. Examples of child social support services are stigma reduction, financial assistance, CD4 and viral load testing, nutrition, and housing and education assistance associated with the harmful effects of stigma and discrimination. To achieve this, health professionals [nursing] should practise via ethical principles and commit to being an advocate for the child or client, facilitating comprehensive care to enhance optimal health outcomes.

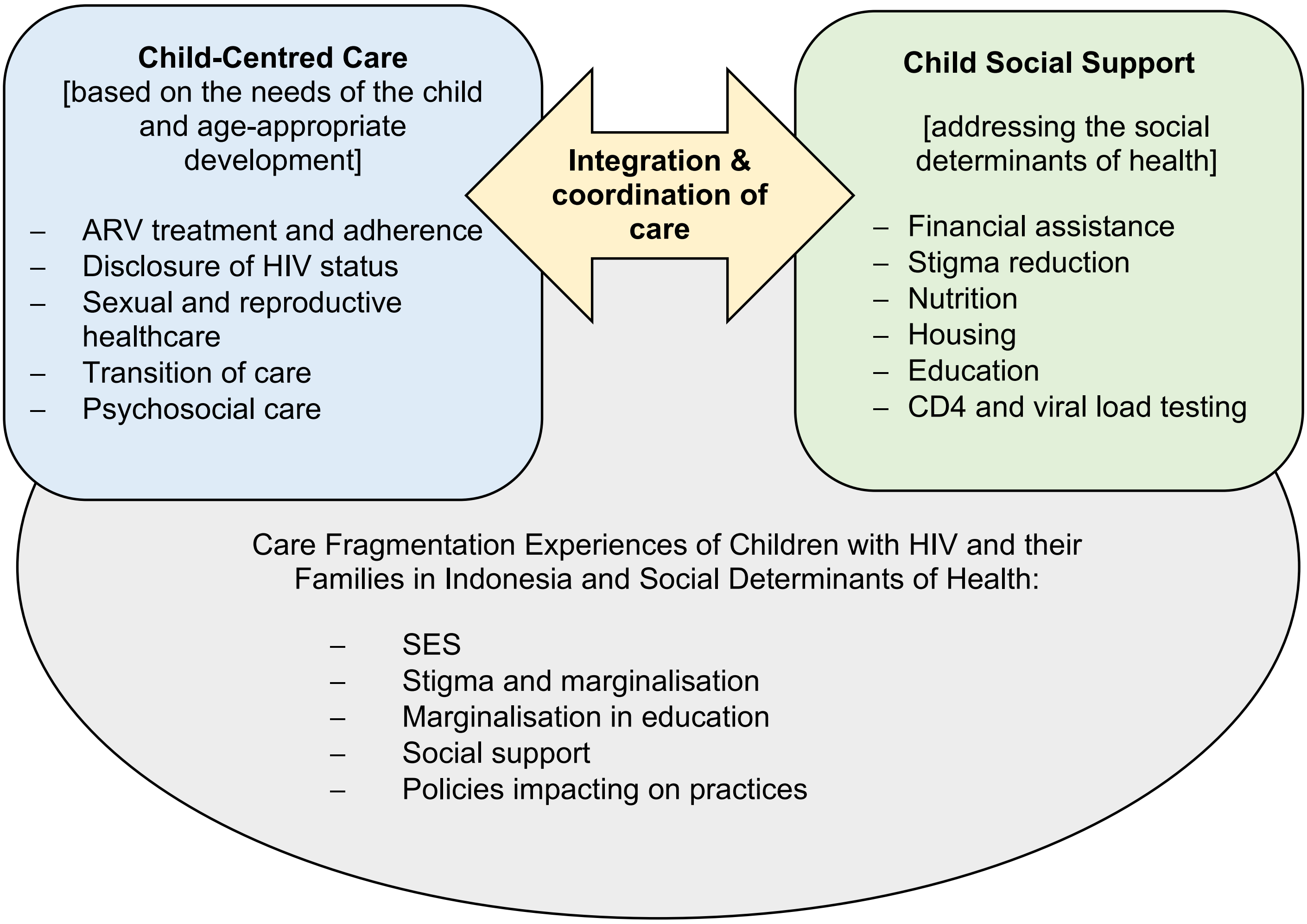

Figure 22: A conceptual model of comprehensive care for children with HIV in Indonesia

The resulting model of comprehensive care was structured on child-centred care and social support, delivered by adequate integration and coordination of care through a healthcare service. The following section discusses the concept of child-centred care, integration and coordination of care through a healthcare service, and the social determinants of health context within which child social support is embedded. These concepts are complementary terms which are relevant to support a discussion of the theoretical explanation, particularly in reference to (Healthy People, 2019; Minkman, 2012; World Health Organization, 2018).

Child-Centred Care

The implementation of child-centred care promotes the continuum of healthcare needs for the child, supporting optimal health and development (Chingono et al., 2018). The core tenets of child-centred care are responding to patient needs and preferences and developing individual care plans (Van der Heide et al., 2018). Children should be at the centre of their care, and their care needs require the interconnectedness of practice interventions tailored to the individual child's health needs across the continuum (Bekker et al., 2018; World Health Organization, 2018). Furthermore, in recognition of the multiple needs of children, the programs revolve multidisciplinary team to provide comprehensive care, including prevention, diagnosis, treatment, and psychosocial care (World Health Organization, 2015). Children are involved in making decisions about their care and treatment options to make solutions intervention based on individual's needs (World Health Organization, 2015). The children in this study [aged between 8-18 years] were more likely to miss their monthly check-ups, as their family members attended the hospital to collect the ARV refills because the families did not want them to miss school. Other families did not bring their children to the hospital because they worried about the child's teacher becoming suspicious and asking why the child is absent every month.

The developmental milestones of children aged eight years suggest that they begin to become more independent from the family and have an increased attention span. A child of this age learns to set his/her own goals and develops a sense of responsibility (Centers for Disease Control and Prevention, 2020). Children aged eight years start becoming increasingly involved in their own care, learning how to be more independent and self-manage (Centers for Disease Control and Prevention, 2020). Struckmann et al. (2018) and Van der Heide et al. (2018) found that involving patients and developing an individualised plan based on the patient's preferences increases engagement with care processes and improves shared decision-making. The individual care plan should consist of the child's needs, including their growth and development needs (Mutambo, Shumba & Hlongwana, 2019). Regarding the participants' experiences, this study identified that the involvement of children with HIV in their own care was limited and overall they were passive recipients of care. However, it was also highlighted that the HIV care service was only open during school hours, which restricted the opportunity for children to attend clinic. Furthermore, feeling bored with spending lengthy periods in a hospital waiting room caused children to be unwilling to visit the hospital. Children with HIV in this study also suggested that play equipment should be present in outpatient HIV care, such as a playground or toys that would comfort them while they were waiting, in addition to the presence of friendly health professionals. Regarding the participants' experiences, this study suggests that the opening of an HIV clinic for children after school hours would enhance the opportunity for families to bring their children to the clinic, thus enhancing children's attendance and participation in their care. The adolescents in this study suggested that the use of a phone would aid them in setting their care plans and preferences. The World Health Organization (2018) stated that the use of information and communication technologies supports the management of children's care, enhancing continuity in care and care coordination. The use of electronic health or mobile applications helped children or adolescents with HIV to understand and manage their health condition (Claborn et al., 2017; Otte-Trojel et al., 2015). The use of the Short Message System (SMS) and web patient portals can help adolescents to make online appointments, thereby improving patient health outcomes (Claborn et al., 2017; Otte-Trojel et al., 2015).

The HPs recognised that children with HIV often saw different physicians for their ARV pick-up in an HIV outpatient clinic due to the rotation of doctors in this setting. Management continuity involves case management, consistent contact with the same clinician, and a well-maintained coordination of services (Tobon, Reid & Brown, 2015).

The implementation of child-centred care in HIV service delivery for children in Indonesia is still minimal. Mutambo, Shumba and Hlongwana (2019) suggested that the application of child-centred care in the provision of HIV services for children with HIV is limited in resource-constrained settings and can potentially be applied to the care of children with HIV, improving children's participation and the quality of care. The factors influencing child-centred care include patients' knowledge, skills, and attitudes, factors associated with health professionals' inadequate knowledge, skills, and attitudes, and inadequate support for patients and caregivers (Van der Heide et al., 2018). Additional factors include inadequate collaboration between health professionals and a lack of procedures for patient-centred care (Van der Heide et al., 2018). Due to limited child-centred care, the core category of 'needing comprehensive care' constructs how children with HIV and their families could receive child-centred care, after which associated interventions would be developed, which would support comprehensive care. The World Health Organization (2018) explained that all patients should have equal opportunities to access quality comprehensive healthcare services to meet their individual healthcare needs across the continuum, thereby promoting patient safety and increasing efficiency. The health system needs to address the multiple needs of healthcare service users simultaneously, which would require the interconnectedness of practice interventions to be tailored to the individual child's needs across the continuum, supporting effective care for children with HIV (Bekker et al., 2018; World Health Organization, 2018). While patient experiences are central to patient-centred care, children with HIV and their family's preferences for involvement in the patient's care are not always considered by HPs. Patient-centred care and patient involvement are essential components of comprehensive care, which promote continuity of care over time across the continuum.

In this study, children with HIV and their families shared their needs by attempting to inform HPs about what they needed for future care to meet the child's needs in line with child-centred care. In turn, their experiences would benefit from addressing the fragmentation of children's services, and enhancing continuity of care. Marzorati and Pravettoni (2017) suggested that the unique preferences of each patient help to evaluate practice or the situation, and need to be integrated into a clinical decision in keeping with the tenets of child-centred care. The following section presents the needs of the patients in this study.

ARV Treatment and Adherence

ARV treatment and adherence is the cornerstone of the management of HIV infection, as it benefits children with HIV. The families in this study acknowledged that they received free ARV treatment provided by the Indonesian government. They recognised that ARV treatment reduces severe illness or opportunistic diseases for their children. The families perceived the benefits of ARV treatment, which in turn, increased their understanding of the importance of ARV. Families provided support for accessing ARV refills for their children and reminded the children to take their medication.

However, even though the families recognised the importance of ARV, some HPs stated that there was a high risk of non-adherence to ARV. Adherence to ARV treatment increased CD4 counts, reduced the incidence of opportunistic infections or infectious complications, improved health and immune function, and enhanced growth outcomes for children with HIV (Mehta et al., 2016; Naidoo, Munsami & Archary, 2015). The children stated that they often felt bored and disliked the taste of the medication. As a result, they sometimes skipped the medicine or delayed taking it. Similar to the findings of previous studies (Almeida-Brasil et al., 2018; Coetzee, Kagee & Bland, 2015; Kheswa, 2017; Mehta et al., 2016; Nabukeera-Barungi et al., 2015; Nyogea et al., 2015; Okawa et al., 2018; Olds et al., 2015; Vreeman et al., 2015), children were also forgetful, and depended on family members. Some of the families in this study crushed the tablets to administer the medication for their children. Schlatter, Deathe and Vreeman (2016) suggested that crushing the pills reduced the bioavailability of the ARV, having a negative impact on targeted therapeutic exposure and promoting viral resistance. Additionally, some of the families believed that traditional medicines could also be used as they were organic. Health professionals offered another perspective, stating that HIV care services for children lacked psychosocial support and counselling to address the complexity of the ARV regimen.

The provision of ARV treatment was centralised to hospital-based services. The centralisation of HIV care to the hospitals contributed to the risk of medication non-adherence due to the distances some families had to travel. Some of the families stated that they sometimes delayed obtaining their ARV refills due to distance. Other reasons given were sickness or forgetting to give the medicines to the child, leading to non-adherence to ARV treatment. The implementation of centralisation of HIV care and treatment in Indonesia contradicts the WHO statement that care coordination should be provided along the entire pathway, from home, community service, and emergency care, through to hospital care (World Health Organization, 2018). The World Health Organization (2018) stated that continuity of care should be a core value of primary care practitioners as they should provide effective care to respond to the needs and circumstances of their individual patients. HIV care and treatment should be delivered as community-based care, as this would offer more decentralised and connected care closer to children with HIV and their families (World Health Organization, 2018). A quantitative study in South Africa found that community-based care was more effective than centralised care, as evidenced by successful treatment outcomes (58% vs. 54%) (Loveday et al., 2015). Therefore, even though children with HIV and their families perceived the benefits of the ARV treatments, children with HIV were at high risk of medication non-adherence.

Continuity of ARV treatment and adherence are critical elements of HIV care interventions in achieving optimal health outcomes for children across the continuum. Support for ARV treatment and adherence are part of the comprehensive care goals to optimise long-term care across the continuum. The HPs in this study recommended that through the provision of a treatment supervisor, lessons on adherence to ARV for family members before their children began ARV initiation, family counselling, and peer support were strategies to improve adherence to ARV therapy. Furthermore, child-friendly ARV formulations, particularly fixed-dosed combination, and improved taste of ARV formulation were strategies to improve adherence to therapy. According to the HPs in this study, fixed-dose combinations combining two or three ARV treatments into a single pill would increase adherence for older children, because many children with HIV need to take more than three pills every day or twice a day. Child-friendly formulations of ARV will help children and their families to administer and take the medication, supporting successful long-term ARV therapy adherence (Schlatter, Deathe & Vreeman, 2016). Furthermore, fixed-dose combinations combining two or three ARV treatments into a single pill would increase adherence for older children, because many children with HIV need to take more than three pills every day or twice a day. A liquid formulation ARV for young children would help families to ease administration of the drugs, as young children have difficulty swallowing pills or tablets (Schlatter, Deathe & Vreeman, 2016).

Furthermore, the HPs recommended that the extension of 3-monthly ARV refill visits as a strategy to improve adherence to ARV therapy could be adopted. Duncombe et al. (2015) found that a clinic-based model offering 6-monthly clinical appointments with nurses and 3-monthly ARV refill visits reduced waiting times and clinic staff workload in Malawi. As a result, children with HIV and their families may not require multiple separate ARV refill visits and may reduce cost of travel to hospitals. Intervention approaches to support adherence to ARV need to be integrated into the comprehensive care program for children with HIV to increase children’s health outcomes across the continuum. Therefore, the provision of ARV treatment and strategies to enhance adherence to treatment for children with HIV are major challenge and need to be addressed throughout the implementation of the comprehensive care.

Disclosure of HIV Status

Disclosure of the child’s HIV status to the child was a major challenge in the caring process for the children and their families in the Indonesian context. The families in this study acknowledged that they did not disclose their child’s HIV status to them. The reasons for non-disclosure are similar to previous studies (Brown et al., 2011; Ekstrand et al., 2018; Kalembo et al., 2019; Lencha et al., 2018), and included the fear of an adverse emotional reaction, social discrimination, the fear of the child’s refusal to take ARV treatment, the fear of being blamed, the young age of the children, and a lack of knowledge on how to disclose.

Disclosure enhances the child’s participation in their treatment. The children in this study knew of their HIV diagnosis at ages 9, 13, 15 and 17 years. The few children who experienced full disclosure in this study practiced self-management strategies to enhance their adherence to their medication. For example, they used mobile phone alarms as reminders and developed positive self-talk for motivation to take their ARV, which promoted adherence to therapy. Children independently used ‘self-talk’ to develop their ability to manage and control their ARV treatment in the home. These examples show that full disclosure of HIV status facilitated the development of self-management in adolescents, building their sense of responsibility for their care behaviour and promoting medication adherence. Disclosure had a positive impact on, and increased, ARV administration among children with HIV (Nichols, Steinmetz & Paintsil, 2017). However, the families in this study were still reluctant to disclose the child’s HIV status to the child because of stigma and discrimination. The current study’s findings show that the relationship between stigma, disclosure of HIV status, and ARV medication adherence had a direct impact on the process of care across the HIV continuum.

While some families were reluctant to disclose the child’s HIV status to the child, other families in this study considered disclosing the child’s HIV status when they were of high school age or were teenagers, considering the child’s age level and cognitive maturity. Similar to the findings of a previous study (Elsland et al., 2019), the families in this study considered the timing of disclosure when children were at a higher school level. Older children have the cognitive and emotional maturity to engage in conversation and participate in their own care (Elsland et al., 2019). Furthermore, older children can cope with disclosure and its adverse impacts, such as distress or other negative feelings. Nigerian caregivers perceived that the most appropriate age for disclosure to children was when they reached the ages of 5 to 20 years (Brown et al., 2011). The WHO guidelines on ‘HIV disclosure counselling for children up to 12 years of age’ recommended that school-age children should be told about their HIV status, as it is vital to their well-being and health. Process-oriented disclosure should accommodate the child’s cognitive and skills maturity to understand the disclosed information (World Health Organization, 2011).

The families in this study often used false information to disclose a child’s HIV status to the child. For example, some families told their children they were taking a multivitamin instead of HIV medication. Other families told their children, ‘take your drugs, as it helps you live longer, or you will die like your parents’. On the other hand, Brown et al. (2011); Ekstrand et al. (2018) used truthful language for children and only used the term HIV for full disclosure; for example, children aged 4 and 15 years were told they were suffering from a chronic illness for a partial disclosure. Children who experienced full disclosure were told they were HIV-positive (Brown et al., 2011; Ekstrand et al., 2018). This study identified that Indonesian families did not always tell the truth to their children about ARV. For example, they used the term ‘multivitamin’ and did not tell the child the real purpose of medication. The families played a pivotal role in providing health information for their children in the home. The families used language appropriate to the cognitive level of the child to gradually inform them of their health condition. This implies that language, communication, and HIV disclosure appear to be inter-related and need to pay attention to the level of the child's cognitive development. Therefore, it is deemed necessary for continued care and treatment for children to be guided developmentally in the disclosure of their HIV status, providing continuity of care for each child across the healthcare continuum.

The participants in this study stated their preferences on how to disclose a child's HIV status would be in a child-friendly manner. For example, the families in this study described the strategies they used to disclose HIV status to the child, including open-ended questions, such as "tell me what you know about why you take these medicines?", in a friendly and non-threatening environment. Arrivé et al. (2018); Lencha et al. (2018); Verma and Sahay (2019) explained that disclosure is a complex process and needs a comprehensive assessment to anticipate its negative consequences. Such an assessment includes the presence of social support, the duration of the ARV, the level of the child's cognitive and psychological development, involvement with a supportive environment, and psychological support from a psychotherapist or psychologist.

Lowenthal et al. (2014) described five practical elements of disclosure of HIV status to children with HIV in Botswana. These practical elements were: (1) educating family members or caregivers to communicate truthfully with their young children; (2) using age-appropriate terminology and non-judgemental language in the disclosure; (3) inviting children to join the "teen club" which provided a monthly meeting with psychosocial support; (4) giving reinforcement; and (5) documenting the child's understanding and building the child's knowledge in subsequent visits. However, HPs recognised that in the Indonesian healthcare setting, there were no HIV disclosure guidelines and processes for children. Psychosocial care for children was also limited, contributing to the lack of continuity of care. Therefore, the patients' preferences for a disclosure of HIV status service would need to be part of comprehensive care, supporting optimal health outcomes across the continuum. The participants preferred disclosing a child's HIV status to the child in an appropriate way to reduce adverse effects.

Adolescent Sexual and Reproductive Healthcare

Sexual and reproductive health is an essential aspect of comprehensive care in the Indonesian context. In this study, the children stated that they needed a friendly sexual education service, as they felt embarrassed talking about sexual matters with their family members. Similarly, South African adolescents living with HIV wanted to know about sexual and reproductive health, including receiving accurate information about the risks of unprotected intercourse (Vujovic et al., 2014). Furthermore, they said that they needed separate adolescent clinic services, where they could feel “at home” and talk with friendly staff, as the subject of sex is a cultural taboo and adolescents feel embarrassed talking about sexual matters with family members (Vujovic et al., 2014). Hodgson et al. (2012) identified six areas of sexual and reproductive health for supporting the psychosexual well-being of adolescents with HIV, including family planning information, knowledge about condom use, psychosocial care, disclosure care with truthful and correct information, a safe environment and friendly health providers, and privacy at the clinic. Interventions to improve sexual and reproductive healthcare in the clinical setting include sexual health education and counselling, promoting the use of contraceptives, the availability of condoms, and self-disclosure (Baryamutuma & Baingana, 2011; Hodgson et al., 2012; Salam et al., 2016). Culturally, in Indonesia, it is essential for people [adolescents] to refrain from having sex before marriage. Providing sexual and reproductive health services in a HIV comprehensive care program for adolescents would increase sexual well-being along the continuum of development.

The importance of a sexual and reproductive health service for adolescents with HIV was seen as a necessary part of a comprehensive HIV care intervention. Studies from Indonesia and South Africa reported that governments provided free condoms and sexual and reproductive health counselling programs in HIV clinics or outpatient clinics as part of national HIV prevention programs (Kementerian Kesehatan Republik Indonesia, 2012b; Vujovic et al., 2014). However, the programs were aimed at key adult populations with HIV (Kementerian Kesehatan Republik Indonesia, 2012b; Vujovic et al., 2014). The absence of sexual and reproductive health services for the participants in this study indicates the existence of fragmented HIV care services for children in Indonesia. Sexual and reproductive healthcare interventions for participants are crucial for preventing HIV transmission or sexually transmitted diseases. This study makes a strong case for the creation of comprehensive sexual and reproductive healthcare services for adolescent children being integrated into HIV care in either children’s clinics or the healthcare setting, to enhance coverage and continuity of care.

Transition Care

As well as having a poor experience while visiting the doctors, some of the children did not receive information about transition care when they moved from a child to an adult care setting. The participants experienced sub-optimal health professional [physician]-patient communication in the hospital. These experiences reflected the patients' participation in care planning, while recently, decision-making in healthcare has received little attention compared to medical treatment in HIV care for children.

Adolescent children in this study recognised that they only received information if their care had been transferred from the child to the adult setting. Transition care is not only about the physical transfer of the child to the adult care setting, but is also a process for maintaining uninterrupted care throughout children's lives by supporting care across the continuum (Lee & Hazra, 2015). Lee and Hazra (2015) identified that poor transition care resulted from the absence of the development of a formal plan between children, their family members, and HPs during the adolescent transition period. Similarly, in India, adolescents aged 10-18 years did not receive a well-prepared transition, which in turn, caused trauma because they were accustomed to having a long-term protective environment in a child-focused setting (Verma & Sahay, 2019). According to the experiences of the adolescents in this study, HIV care in the children's services did not provide adequate transition care, which contributed to the fragmentation of care. Kovacs and McCrindle (2018) stated that slow progress on transition practice reflected inconsistent commitment to such programs, which may have been related to limited resources, poor institutional support, and a lack of leadership, which contributed to the discontinuity of the care transition, and reduced the effectiveness of care.

The adolescent children in this study need information during the transition process in response to the absence of a children's age-appropriate care transition in Indonesia. The adolescent children moved from a child's health service to an adult service between 17-18 years of age for their ongoing treatment. Adolescent children did not experience effective transition care. They experienced poor quality transfer of care, causing them to worry when they had to access their care in the adult care setting. Inadequate transition care can have a negative impact on long-term health outcomes if adolescent children were not ready or settled enough to care for themselves. This contributed to a lack of continuity in adolescents' care. The absence of transition care reflected that this was not part of HIV care for children in Indonesia, and underscored the lack of continuity in HIV care management in relation to transition care planning.

The transition process should support children in gaining knowledge and self-management skills; in turn, their responsibility for their healthcare management should also increase (Kovacs & McCrindle, 2018). Transition care should involve individualised planning for children's education and skill development to improve their self-management skills (Kovacs

& McCrindle, 2018; Sharma et al., 2014). For example, the Botswana-Baylor Clinical Centre of Excellence has implemented the Baylor “Kalogo” Transition model for adolescents with HIV. This model consists of five tools, namely: (1) a transition roadmap to assess knowledge, skills, and adherence; (2) a risk-screening tool to assess risks for adherence or non-adherence prior to transition; (3) a tool for HPs to assess the readiness of transition; (4) homework assignments to reinforce health education at clinic visits; and (5) an educational module on transition through peer group support (Dahourou et al., 2017). The Kalogo model is conducted by a facility-based multidisciplinary transition team, and has achieved successful transitions for adolescents with HIV through the involvement of peer educator adolescents (Dahourou et al., 2017).

Sharma et al. (2014) identified that the process of transition could be initiated by the age of 12. Kovacs and McCrindle (2018) agreed that transition could be initiated by the age of 12, but that a flexible age of transition allowed for the tailoring of the developmental, maturational, and physical condition of each participant. In contrast, Fair, Sullivan and Gatto (2011); Tulloch et al. (2014) identified that children felt the difficulty of the transition from the child to the adult care setting because they were leaving their long-established interactions with the child-focused health professional teams. The children worried that they would not be able to meet with the same doctor, and their friends, so they did not feel ready for the transition (Tulloch et al., 2014).

Effective transition care maintains continuous access to healthcare services and the achievement of developmental milestones for children, requiring policies, guidelines, clinical performance tools and measures, and psychosocial support (Sharma et al., 2014; Verma & Sahay, 2019). The success of transition can be evaluated at the individual adolescent level through ARV medication adherence, the results of CD4 testing, the viral load remaining stable, and behavioural understanding when they are sick, as well as knowledge of how to set up appointments and communicate with a health professional in order to seek help (Fair, Sullivan & Gatto, 2011; Sharma et al., 2014). Due to transition being stressful, well-planned transition care consisting of health education and self-management skills would enhance children’s participation in their care and would support the continuity of their treatment. Effective transition care management should be integrated into comprehensive HIV care for children, as it improves their participation in their own care, which in turn, increases participation in their treatment across the continuum.

Psychosocial Care

In this study, children with HIV, their families, and HPs needed care addressing the emotional and social problems of the children to support optimal health outcomes. HPs concurred on the need for psychosocial care due to it not being available in the healthcare setting. The experience of the participants in this study highlighted that living with HIV had a negative impact on the psychosocial well-being of Indonesian children with HIV and their families. Many children with HIV had experienced the loss of one or both parents from HIV and associated illnesses. This, in turn, caused trauma leading to mental health issues. The majority of family members also experienced difficulties in caregiving due to financial hardship, which in turn, exacerbated their stress. Both children with HIV and their families had experienced internalised stigma and discrimination, the issue of disclosure, and the challenge of adherence to ARV treatment. These experiences were related to psycho-emotional challenges which often triggered mental health problems. For example, children with HIV and their families in this study stated the need for peer support. McCleary-Sills et al. (2013) found that support groups acted as a peer network which included appropriate role models, a type of support that should be available to children immediately after they find out their HIV status. Providing psychosocial care specific to children with HIV is crucial, and should be integrated into comprehensive HIV care, which would go some way to addressing the problem of fragmentation across the continuum.

Approaches to providing psychosocial support for children with HIV should address factors related to chronic HIV disease and consider the profound impact of stigma and discrimination and the challenges around disclosure, retention in HIV care and treatment, and helping children cope with the loss of parents and/or caregivers (Amzel et al., 2013; McCleary-Sills et al., 2013). Similarly, a psychosocial needs assessment with stakeholders dealing with HIV in Kenya found that adolescents with HIV needed stigma reduction, education about HIV transmission and treatment, and the provision of their material needs, such as food, clean water, and shelter (Chenneville, 2017).

Both a study conducted in Southern India and another in Southern Africa found that the provision of psychosocial assistance provided good physical and psychosocial functioning for children with HIV (Barenbaum & Smith, 2016; Lang et al., 2014). The positive impacts of the assistance included reducing the risk of problem behaviour and reduced scores for depression and anxiety (Barenbaum & Smith, 2016; Lang et al., 2014). In Southern India, Lang et al. (2014) found that orphaned children with HIV aged between 5 and 12 years had good health and quality of life after they received physical and psychosocial support. The support included housing, nutrition, medical care, and values-based education and vocational preparation based on the children's needs or preferences. In Southern Africa, children with HIV from a low income background, or who were living in poverty, experienced positive well-being after they had received comprehensive care, including shelter, healthcare, food, clothing, financial support, and education, such as school supplies and uniforms (Barenbaum & Smith, 2016). In this study, Indonesian children with HIV and their families needed psychosocial care and social [tangible] support to address physical and emotional issues, supporting the existing literature (Barenbaum & Smith, 2016; Lang et al., 2014). Psychosocial care and social support need to be integrated into comprehensive HIV care to contribute to optimal health outcomes across the continuum, and to enhance continuity of care.

In the context of child-centred care, the implementation of HIV care for children did not centre on the child, which caused fragmentation of care. For example, the focus of the HIV outpatient was on ARV delivery rather than other services meeting the needs of the child in an Indonesian context. Children with HIV tended to be passive care recipients because they often missed their routine monthly check-ups, as their families did not want them to miss school. In addition, the clinic did not provide after school services. As a consequence, the children's involvement in care decisions was also limited. Children with HIV and their families identified several services that did not meet their needs. These included the lack of HIV status disclosure, adolescent sexual and reproductive health advice, transition care, and psychosocial support services. In addition, age-appropriate supportive facilities were not set up for children, such as lack of toys. Children with HIV and their families identified the services they needed, which supported comprehensive care across the continuum. Their care preferences included ARV treatment and adherence, disclosure, adolescent sexual and reproductive healthcare, transition care, and psychosocial care services supporting HIV comprehensive care.

Integration and Coordination of Care in Healthcare Services

Integration and coordination of care have become increasingly prominent in the healthcare system, which supports comprehensive care. Stadnick et al. (2019) stated that the core concept of the integrated care approach is the 'whole patient'. They defined integrated care as the process of organisational coordination across healthcare services and systems to achieve continuous care, focused on patient's needs and a holistic view of the patients

(Stadnick et al., 2019). Children with HIV did not receive comprehensive care to meet their needs because the Indonesian healthcare system is inadequate. A healthcare system consists of people, institutions, resources, and activities that aim to promote, restore, and maintain health (The United States Agency for International Development, 2015). As service users, children with HIV and their families acknowledged that they had received tangible social support from the Indonesian government through the provision of free ARV treatment, milk-formula, and subsidised CD4 testing; however, the support was not consistently available. Furthermore, they recognised sub-optimal care in relation to the absence of child-centred care, transition care, psychosocial care, and sexual and reproductive health for adolescents. In this study, children with HIV experienced a considerable risk for fragmented care across the continuum due to inadequate comprehensive care associated with healthcare system factors. In developing countries such as Indonesia, healthcare challenges are often more likely about the organisational capabilities for implementation (Pusat Kebijakan dan Manajemen Kesehatan Fakultas Kedokteran Universitas Gadjah Mada, 2015). This study has shown that strengthening the healthcare system would influence the quality of care and improve positive health outcomes for children and their families.

HPs agreed that the factors contributing to ineffective care at the healthcare system level lead to the fragmentation of care. They recognised that inadequate coordination of care, limited funding, insufficient skill and knowledge of HPs, the short-term nature of most programs, and inadequate policies and regulation had a negative impact on service delivery for children with HIV. The experiences of inadequate comprehensive care and insufficient care coordination were a manifestation of the poor performance of the care services for children with HIV, which lead to the fragmentation of the HIV care delivery system. Swanson et al. (2015) found that national health policies, regulations, and financing affected the capacity of the health system, and in turn, affected the ability to deliver effective health interventions. This study shows that there is a relationship between the poor performance of HIV care services and the fragmentation of the healthcare system. Inadequate healthcare systems also influence the types and quality of care for children with HIV. The need for comprehensive care becomes imperative to addressing the problem of healthcare service fragmentation. The delivery of comprehensive care is essential because it reduces fragmentation within the healthcare system and enhances better services appropriate to children’s needs (Minkman, 2012) and improves quality and continuity of care (Mounier-Jack, Mayhew & Mays, 2017; Stadnick et al., 2019).

Strengthening the healthcare system is a crucial contributor to establishing comprehensive care. The Indonesian government has an HIV program with a similar focus to program interventions in Myanmar, Kenya, and Swaziland, which include ARV therapy and HIV testing and counselling (Htun et al., 2019; Minn et al., 2018; Obure et al., 2015). However, the Indonesian government only provides general interventions targeting adults and does not provide specific programs for children (Limardi et al., 2019; Tromp et al., 2015). This study shows that care for children with HIV is not a priority in the Indonesian government's agenda.

The HPs in this study recommended the importance of financing the system, and putting in place regulations on policies, guidelines, and procedures in HIV care for children. They also recommended that policy-makers should have a strong commitment to the implementation of HIV care for children. Policy-makers should have a strong political commitment to influence decisions and to ensure that children with HIV receive comprehensive care. A strong commitment would have a significant impact on successful health system performance, promoting the implementation of continuity of care in the Indonesian context. Swanson et al. (2015) argued that a healthcare system relies on the capacity of local organisations and their interactions, and the engagement of stakeholders, such as the Ministry of Health, healthcare facilities, non-government organisations, and community-based organisations. Strengthening the healthcare system is essential to creating fundamental changes to comprehensive HIV care for children in Indonesia. This would require leadership competencies of policy- and decision-makers, and a commitment to leadership by health professionals and healthcare service managers. Borgermans et al. (2017) argued that effective leadership should meet the criteria of building transformational leadership, effective role-modelling and communication, flexibility, engagement with patients and families, and support for care coordination.

As well as strengthening the healthcare system, the need for comprehensive care for children with HIV in Indonesia needs to be integrated into clinical care and adequately coordinated (Kuramoto, 2014). For the successful implementation of comprehensive care, the health system needs patient-centred policies and inter-organisational communication to enhance patient participation in an integrated system (Oldfield et al., 2019). The health system should assess for, and address, the social risk factors of the patients, such as their financial ability to buy food or to cover the cost of transport to optimise integrated service delivery (Oldfield et al., 2019). Stadnick et al. (2019) suggested that contextual factors need to be considered carefully due to these having an influence on implementation, such as client characteristics, leadership commitment, the healthcare payment model, networks, the knowledge of health professionals in integrated care, and the actions of stakeholders (Stadnick et al., 2019). The following section presents the contextual factors of this study, referred to as the social determinants of health.

Coordination of Care

Coordination of care is central to the operation of the healthcare organisation to support comprehensive care and improve the quality of care for children with HIV and their families (Bower, 2016; Miguelez-Chamorro et al., 2019; Wang et al., 2016). Bower (2016) stated that effective coordination relates to patient-centred care, providing care based on patient needs and decisions. Based on the collective experiences of the participants, children with HIV and their families did not receive child-centred care in this study, reflecting poor care coordination in HIV care for children which lead to a lack of continuity of care. HPs in this study recognised that incomplete referral documentation and communication between HPs influenced poor care coordination, thus leading to the fragmentation of care. In this study, the absence of child-centred care and insufficient comprehensive care and coordination lead to inadequate HIV services for children which resulted in the fragmentation of their care in an Indonesian context. Fragmentation of care leads to missed treatment opportunities for patients (Kilbourne et al., 2018) and makes it difficult for families to get the care the children need (Kuo et al., 2017). Coordination of care is a crucial function to coordinate and organise patient care activities effectively in the healthcare setting. A paper published by Kilbourne et al. (2018) stated that a framework for effective care coordination should include child-centred care, interaction and coordination across health professionals, coordination across facilities, support systems such as the community and the family, and continuity over time.

Referrals in a healthcare system support the implementation of comprehensive patient care and care coordination. The findings from HPs working in PHCs revealed that incomplete return-referral documentation resulted in poor care for children because they could not follow-up on the child’s condition in the community, again leading to the fragmentation of care. HPs might be able to learn and accomplish tasks by following rules and instructions from a hospital if the hospital were to provide complete return-referral documentation. HPs working in PHCs would accept responsibility for continuing to provide care for children in the community if they received complete return-referral documentation. According to Ramelson et al. (2018); Sawe et al. (2016), referrals involve documentation and multiple levels of communication between providers and between providers and patients (or the child) to support high quality care. Both of these studies found that the referral system was often fragmented because of incomplete documentation and communication breakdowns, leading to incomplete follow-up of patients (Ramelson et al., 2018; Sawe et al., 2016). Sawe et al. (2016) found that in Tanzania, a low rate of referral documentation (35.7%) in medical records lead to low levels of follow-up care for children with HIV.

Communication between health professionals improves coordination of care (Van der Heide et al., 2018). The HPs shared their thoughts on strategies to improve professional communication and coordination through referral documentation. Referral documentation is vital because it communicates the child's information at the time of referral, and is not well-implemented in Indonesia. Receiving completed written documentation and instructions from one health professional to another enables HPs to communicate and follow-up care. Referral documentation contains explicit information about a child's condition and may ensure continuous learning across all health services. Clear referrals consisting of adequate process and completed documentation result in efficient healthcare delivery and improve children's health. In such a scenario, children would receive ongoing care at an appropriate level, which would result in optimal continuity of care. This study provides an example of incomplete referral documentation, which lead to children with HIV experiencing the fragmentation of their care because HPs did not follow-up on their care in the community. Incomplete referral documentation has a negative impact on the quality of care information, resulting in poor care by other HPs. The Government of Indonesia and UNICEF (2015) identified that the poor referral system within PHCs, and the lack of coordination between healthcare organisations were barriers to the uptake of HIV care services in Indonesia. Moreover, the World Health Organization (2018) stated that sharing electronic health records enhances the continuity of information among HPs in various healthcare settings. HPs across the healthcare setting should therefore understand all facets of referral, follow-up, documentation, and administration, which would promote communication and coordination among professionals and support continuity of care.

In summary, the lack of integration and coordination of care in the Indonesian healthcare system resulted in children with HIV and their families currently receiving fragmented care as they did not receive comprehensive care that met their child's needs across the continuum. HIV care for children was sub-optimal because of the inadequate healthcare system and inadequate care coordination.

Child Social Support Addressing Social Determinants of Health

Child social support ensures that children with HIV receive social support and their rights to comprehensive care, addressing the social determinants of health. Addressing social determinants of health enhances access to high quality care and improves health outcomes.

The findings from Chapters 5 and 6 have identified the factors that influence care and health outcomes for Indonesian children with HIV and their families. These factors include low socio-economic status, stigma and discrimination, and inadequate policies and regulations. This study did not explore the social determinants of health. However, according to Kuo et al. (2017); The United Nations International Children's Emergency Fund (2019b), income, education, social problems, social support, neighbourhood and environmental health, and the quality of healthcare are known as the social determinants of health. The findings of this study have shown that SES, stigma, discrimination, social support, and policies and practices caused inequitable health outcomes for Indonesian children with HIV and their families. These findings show that contextual factors in this study are related to the social determinants of health. The nature of contextual factors in Indonesia is complex, multifactorial, and inter-related.

The social determinants of health drive the health of the population and result in disparities or inequalities in functioning, quality of life, health outcomes, and risk (Abgralla & Amo, 2016; De Andrade et al., 2015; Healthy People, 2019; LaBrec, Butterfield & Corporation, 2017; Wilson, 2019). This, in turn, causes health inequities, increased morbidity, and premature mortality (Abgralla & Amo, 2016; De Andrade et al., 2015; Healthy People, 2019; LaBrec, Butterfield & Corporation, 2017; Wilson, 2019). In this study, the social determinants of health contributed to inequality in health and human rights for children with HIV. For example, a child with HIV was rejected from a school due to stigma related to their diagnosis. Consideration also needs to include religious beliefs, delaying disclosure of HIV status, being an orphan, experiencing physical neglect, and inadequate transition care and knowledge of rights, which all influence care and cause health and social inequalities for these children in Indonesia.

The fragmentation of care for Indonesian children with HIV and their families continues to grow in complexity due to contextual social determinants of health, such as low SES, and stigma and discrimination. These determinants need to be addressed and must be part of an integrated social service that supports comprehensive care (Kuo et al., 2017; The United Nations International Children's Emergency Fund, 2019b). The areas of contextual determinants of health and social support among children and their families in this study are discussed below.

Socio-economic Status (SES)

SES is a crucial factor in determining health outcomes. The findings of this study revealed that SES contributed to a broad range of disadvantages for children with HIV and their families leading to the fragmentation of care. Similar to the findings of previous studies (Diniz et al., 2019; Mafune, Lebese & Nemathaga, 2017; Merten, Ntalasha & Musheke, 2016; Osafo et al., 2017; Rachlis et al., 2016), this study shows that mothers were not able to afford food and that it was difficult to pay school fees because of the low SES of these families. Families also had difficulty paying for CD4 testing and family expenses due to their low SES. The Global Fund reported that in Indonesia, patients living with HIV/AIDS from a low-economic background often did not seek care due to the fear of it being too expensive. Patients living with HIV/AIDS worried that they would have to pay the cost of baseline HIV testing, at approximately IDR 600.000 (AUD$50-60), which was meant to be free. Furthermore, the patients worried that they would be asked to pay for ARV treatment when their ARV treatment ran out (The Global Fund, 2019).

Low SES affects children’s quality of life in relation to education, food, the fulfillment of daily needs, and health outcomes. A lack of income concerned the patients living with HIV, particularly if they were asked to pay for HIV testing or treatment due to the support not being available. In addressing SES, previous studies have explored the benefits of financial assistance for adolescents with HIV, such as increasing education, improved use of healthcare services, promotion of safer sexual behaviour, and engagement in HIV care (Bassett et al., 2015; Heise et al., 2013; Kranzer et al., 2018; Njuguna et al., 2018). A qualitative study conducted in Tanzania found that adolescent girls received financial help (approximately USD$31) every 3 months for 18 months, which could reduce the risk of HIV infection due to reducing dependence on the male sex partner (Pettifor et al., 2019). Low SES is associated with the care fragmentation problem for children with HIV. Reducing SES disparities in health can address problems related to supporting comprehensive care delivery that are linked to improved continuity of care across the healthcare continuum.

Stigma and Discrimination

Stigma and discrimination are the foremost barriers to care for children with HIV and their families; these factors had a negative impact on a range of social problems which contributed to a lack of access to healthcare services. The majority of children with HIV and their families in this study experienced living with fear and stigma, which in turn, led to discrimination and marginalisation. For example, due to stigma, children with HIV experienced rejection from schools and isolation from the community. Children with HIV and their families also experienced negative perceptions and emotions concerning the stigma, such as feelings of shame and embarrassment. HPs concurred with the harmful effects of stigma among children with HIV and their families. These included accommodation refusal, social rejection, bullying, and hampering of access to care and support. Similar to the findings of previous studies (Busza et al., 2018; Gyamfi et al., 2017; Kerrigan et al., 2017; Sangowawa & Owoaje, 2012), the findings of this study revealed that due to stigma, families refused to accept home visits, but also did not access the HIV care services.

The Global Fund reported that in Indonesia, stigma and discrimination, gender inequality, rural living, and economic and social inequality were barriers to the availability and accessibility of HIV care services for children under 18 years of age (The Global Fund, 2019). Similar to the findings of the current study, the Global Fund report described Indonesian children being rejected by their families, being forced to stay in orphanages, and being enrolled in schools in a different city from their hometown (The Global Fund, 2019). Stigma and discrimination cause complex problems in regards to health, education, treatment, accommodation, and social interaction, which negatively influence the quality of life for children with HIV in Indonesia. Stigma and discrimination lead to infringements of the right to education, shelter, and housing, social interaction, and health; basically, the abuse of children's human rights. Stigma and discrimination are being discouraged in the provision and continuity of healthcare and social support for children with HIV and their families in Indonesia. Rooting out stigma and discrimination will provide a valuable opportunity to ensure continuity of care for children with HIV and their families.

Almost all the participants in this study recognised the need to address stigma. Most of the participants suggested that education on stigma was not only for patients, but also for the wider community. The community needed information and knowledge on HIV infection, prevention, and transmission to reduce social stigma and discrimination. The participants suggested approaches to reduce stigma through the use of mass-media campaigns, such as on television. A multiple case study in South Africa found that after a three month time-intensive community workshop, the community gained knowledge about the stigma surrounding HIV, and understood more about stigma and disclosure (French et al., 2015). The findings of the case study revealed that the community understood that they should treat people with HIV with dignity and respect and help them to feel supported (French et al., 2015). Two studies, one conducted in Bangladesh, the other in Colombia, both found that adolescents showed improved positive attitudes after they received broadcasts of HIV health promotion (Geibel et al., 2017; Kerr et al., 2015). For example, in Colombia, Kerr et al. (2015) used popular television and radio channels among adolescents for a 16 month campaign to increase HIV knowledge and reduce stigma. The results of the previous studies showed that education about HIV prevention and stigma developed understanding, knowledge, and improved attitudes, which in turn, lead to behaviour change in the community in relation to stigma. Looking at the positive impact of the role of media in education, and with the current emphasis on participants' preferences, mass media interventions for reducing stigma could be integrated into a comprehensive care intervention program. All the participants suggested providing psychological support for the children's disclosure of their HIV, and that the child's age and/or cognitive maturity should be considered using an open communication style to help the children understand. Providing emotional support and information for children and their families is essential for procuring continuity of care to meet children's comprehensive health needs.

Marginalisation in Education

Stigma in education is a social determinant of health which influences the quality of life for children with HIV. The categories of 'maintaining their health' and 'living with fear and stigma' from Chapter 5 highlighted that family members prioritised the importance of education for their children. From the perspective of the families, education would help their children to learn and think, and would support their care and their future. The families supported their children's education even though they struggled with financial hardship. However, several children with HIV stated that they did not continue their schooling due to rejection, stigma, and disclosure of HIV status. All the participants recognised the existence of school rejection among students with HIV. The findings of this study are supported by the previous research conducted in Indonesia (Ganug Nugroho Adi, 2019; Handayani et al., 2017; Lestari, 2019). Indonesian students with HIV experienced school rejection as a result of disclosing their HIV status, the social stigma, and the fear of HIV transmission (Ganug Nugroho Adi, 2019; Lestari, 2019). A cross-sectional study conducted in 10 cities in Indonesia found that only 42.9 per cent of children with HIV aged over 12 years, were still in school due to high dropout rates (Handayani et al., 2017). Rejected students with HIV experience negative emotions, such as disappointment, sadness, depression, and anger because they are excluded from their social relationships, leading to a discontinuity in education and a range of emotional problems. School rejection influences the long-term health of children with HIV. According to Shankar et al. (2013), well-educated children and families would be better informed, which in turn, would mean that children would engage in their own care. Educated families made good health-related decisions for their children. In the long term, educated children would have more employment opportunities which are a significant determinant of economic resources. Therefore, educational support should be a priority for expelled students with HIV, and plays a vital part in the comprehensive care program, because education leads to an increase in healthy behaviours, and contributes to improved health outcomes and better health-related behaviours.

Even though the participants in this study acknowledged the existence of expelled students with HIV from schools due to stigma, only HPs provided strategies on how to address the issue of school rejection, which were either home-schooling or a school-based life skills education program, which was similar to the findings of three previous studies by Delany-Moretlwe et al. (2015); Lang et al. (2014); Sarma and Oliveras (2013). Financial assistance and educational schemes to avoid children dropping out of school and to provide nutritional aid have had a positive impact on children in addressing social and health inequalities in developing countries (Sanfilippo, Neubourg & Martorano, 2012; The United Nations International Children's Emergency Fund, 2019c). As part of Indonesia’s national education system, it is compulsory for every child to attend 12 years of education, which consists of 6 years of elementary education and 3 years each of junior and then secondary education. Public primary schools and junior high schools are free, while there are small fees for secondary school (The Government of Indonesia & UNICEF, 2015). In the case of stigma in education, the Indonesian government attempted to mix children with HIV together with other students. Having mixed children with and without HIV in the same school might eradicate the social stigma if they receive equal treatment as the regular students. In turn, children with HIV could live healthily (Prabandari et al., 2018). The participants in this study revealed the existence of stigma and school rejection. Mixing children with and without HIV in the same school may pose a challenge.

Stigma and discrimination negatively affects children with HIV and their families’ right to healthcare, education, and protection, which has a negative impact on children’s rights. The Convention on the Rights of the Child [Articles 13, 24, and 31] states that a child has rights to freedom of expression, to protection through national security, to healthcare services, and rest and leisure appropriate to the age of the child (The United Nations International Children's Emergency Fund, 2019a). Receiving comprehensive care reduces stigma and discrimination, such as addressing rejection from school or refusal of HIV accommodation.

Apart from education on HIV prevention, transmission, and stigma reduction for the wider community, the Indonesian government should establish a conducive policy framework to address stigma and discrimination. For example, the government should review relevant legislation and provide timely technical assistance to address the issue of school rejection of students with HIV/AIDS. Education is a basic human right for all, and promotes optimal growth and development outcomes for children. The Indonesian government could design a child protection system to protect the rights of children with HIV to education, housing, food, and health.

Social Support

In this study, children with HIV and their families recognised the lack of social support. For example, they acknowledged that subsidised CD4 testing and monthly milk-formula were not regularly available, unlike the free ARV treatment. The cost of these two items was around AUD$80-100. Insufficient support would increase unpleasant feelings for Indonesian families because they were also dealing with low-income circumstances, which negatively influenced children's optimal health outcomes. Inadequate social support is a crucial obstacle to achieving continuity of care. The participants in this study stated the need for adequate social support to sustain the comprehensive care approach. The availability of social support may influence children's quality of life and addresses fragmented social care across the continuum. To do so, the Indonesian government should have sufficient money to design a financial incentives program. National per capita income in Indonesia has increased every year from 2011 to 2018 (Hirschmann, 2019), even though Massola and Rompies (2019) claimed that Indonesian gross national income was still below the US$4.60 per day poverty line set by the World Bank. The Indonesian government should strengthen social protection for children in the healthcare system, thereby reducing the fragmentation of care. Child protection policies and practices are crucial due to the abuse of rights for children with HIV. These programs should prioritise children's rights to an adequate standard of living, health, social security, and education throughout their lives through strengthening political commitments (Chaudhari, 2019; Manning & Gagnon, 2017; The United Nations International Children's Emergency Fund, 2019b).

Housing or shelter assistance is an essential support for protecting children with HIV from stigma and discrimination leading to infringements of the right to shelter, and housing because of their HIV status. In Southern India and Southern Africa found that children with HIV from a low economic status experienced good quality of life after they received comprehensive care, such as shelter and clothing (Barenbaum & Smith, 2016; Lang et al., 2014). The United Nations International Children's Emergency Fund (2019b) asserted that the government should establish a conducive policy framework and design the implementation of a child social protection programs, prioritising children’s rights to an adequate standard of living throughout their life cycle. These interventions included housing and social support, and transportation at an individual and population health level (Chaudhari, 2019).

Achmat and Pramono (2015) found that the Indonesian government had implemented a care, support, and treatment program for all patients with HIV. The program provided treatment for HIV and opportunistic infections, a nutrition consultation service, and psychological support. However, from the perspective of the participants, they needed financial support for essential items such as milk-formula and CD4 testing. Strengthening social support provision in the HIV healthcare system needs to be taken into account by the Indonesian government due to the benefits it can have for reducing fragmentation of care for children with HIV and their families.

Milk-formula is essential for children with HIV because they need extra nutrition and energy to cope with the disease. Good nutrition supports the body to battle other diseases and infections, and strengthens the immune system (Raghavendra & Viveki, 2019). The continuity of milk-formula support would support the children’s’ growth and development and strengthen their immune system, thus enhancing optimal health.

CD4 monitoring is essential for HIV surveillance to detect opportunistic HIV-related infections, such as Cryptococcus (Ford et al., 2017; Rice et al., 2019). The latest WHO guidelines have recommended viral load as the preferred way to monitor treatment efficacy, because the CD4 count provides little added information if clients with HIV are stable on ARV treatment (Ford et al., 2017; Rice et al., 2019). Routine viral load support should be available at 6 and 12 months after ARV initiation, and every 12 months afterwards to monitor potential treatment failure (World Health Organization, 2017c). Adherence to ARV is a crucial predictor of viral suppression (Almeida-Brasil et al., 2018; Rivet et al., 2019). The findings of previous research have shown that the focus on children taking ARV is not only about monitoring the laboratory testing, but also for maintaining ARV adherence. Adherence to ARV treatment increases health outcomes, with CD4 and viral load being indicators of health status. An ARV adherence rate of 95 per cent increases the CD4 count and reduces the viral load level and opportunistic infections, which enhances the health of children with

HIV (Mehta et al., 2016). Although the participants perceived the need for the availability of subsidised or free CD4 and viral load testing, this study adds new knowledge about strategies to support ARV adherence for children with HIV. Inadequate social support has a negative impact on children's health outcomes. The social support needs of children with HIV and their families are identified in the core category of the thesis, 'needing comprehensive care'. Social support could be integrated into comprehensive care intervention programs within the fragmented Indonesian healthcare system to improve participation across the care continuum for children with HIV. Support interventions need to be integrated into clinical care and reach children and their families in the community to optimise positive outcomes (Amzel et al., 2013). The Convention on the Rights of the Child states that children have the right to access healthcare, education, nutrition, and special protection to meet their optimal level of health and development (The United Nations International Children's Emergency Fund, 2019a).

Policies Impacting on Practices

Policies and regulations are an essential part of the healthcare organisation, which in turn, influence care practice and the quality of HIV care outcomes. Policies and regulations, legislation, a financing system, and a professional education program determine performance in healthcare, and act to strengthen the healthcare system (Minkman, 2012; Uebel et al., 2013). The fragmentation of care among children with HIV and their families has occurred because of insufficient policies and the state of the healthcare system. HPs concurred that insufficient policies and regulations on HIV care for children influenced the delivery and quality of healthcare, leading to fragmentation of care.

Policies and procedures in healthcare are crucial as they establish roles, responsibilities, and a regulatory framework which guides HPs in shaping their care delivery effectively, enhancing the quality of HIV care for children in Indonesia. Policies and regulations provide guidance and decision-making in routine care for HPs in the healthcare setting. The availability of policies and regulations creates standardisation to help health professionals to understand their roles, responsibilities, and authority within the healthcare setting (Minkman, 2012; Uebel et al., 2013). Policy-makers or healthcare decision-makers should establish childcare policies and guidelines for standard comprehensive care for children with HIV (Minkman, 2012; Uebel et al., 2013). Miranti et al. (2013) stated that Indonesian local government is in a better position to develop credible policies and action programs based on what children actually need. The central government has delegated substantial authority to local government with two major powers, namely political authority and fiscal authority due to the decentralisation of governance (Miranti et al., 2013). Due to their authority, local governments can use their decision-making powers to review and/or re-design HIV programmes focusing on HIV for both orphans and other children. Child-oriented HIV policies and regulations are crucial for HPs working in HIV care, which supports the implementation of comprehensive care to meet the needs of the child across the continuum.

Apart from the lack of child-oriented HIV policies and regulations, children with HIV and their families were not happy with the procedures for the use of public healthcare insurance. The participants experienced having to apply for a referral letter from a PHC before visiting a hospital or spending a long-time accessing ARV refills in the hospital. The children and their families in this study felt that the administrative procedure for accessing public healthcare insurance was too complicated and needed to be simplified.

The Indonesian government provides health support for all its citizens. Public health insurance requires the receipt of a valid referral letter from two tiers of health facilities before the service can be accessed. Umukoro (2013) identified that the government established social health security through the provision of the *Program Jaminan Kesehatan Nasional (JKN)* scheme. It is compulsory for all Indonesian residents to register for the JKN program (Umukoro, 2013). A national survey found that 54 per cent of Indonesian residents did not know about the insurance or how to register for it (Dartanto, 2017). In addition, 20 per cent of them did not have the money, while 6 per cent stated that the cost and benefits of the insurance were not advantageous (Dartanto, 2017). In Indonesia, the social or public healthcare insurance scheme is not only faced with access problems due to the complicated official procedures, but also because of the financial cost and the issue of health insurance literacy. The participants stated that they needed to gain a new referral letter from a PHC every time they visited the hospital when they wished to access the monthly ARV refill. Participants' preferences for simplifying the public healthcare procedure might be useful for Indonesian children with HIV and their families, as they would enhance participation in care, and strengthen the national health insurance system and the comprehensive care program. Jackson (2017) stated that lowering costs and simplifying healthcare administrative procedures would improve access to long-term care, enhancing continuity of healthcare coverage for patients.

HPs working across PHCs recognised the issue of data duplication in the HIV national system. Pramono, Rokhman and Nuryati (2018) explained that the Indonesian government had implemented several national health information systems for monitoring and evaluation. These systems included recording and reporting of TB/HIV data variables on the SITT and the SIHA (HIV-AIDS Information System). Pramono, Rokhman and Nuryati (2018) claimed that entering data into the separate national electronic health information systems increased the problem of double entries. A health information system serves the government in monitoring and evaluation, rather than for the sharing of information between HPs, which would enhance the coordination of care.

In Indonesia, low SES, stigma and discrimination, insufficient social support, and inadequate policies interrupt the quality of care for children with HIV and their families. These contextual determinants are significant barriers to healthcare, interrupting the continuity of care. These contextual determinants need to be addressed and included as part of comprehensive care and continuity of care for children. To improve overall health, the government must lead in the effort to address the contextual determinants of health.

Chapter Summary

The construction of the core category from the findings emerged from the data, Blumer's symbolic interactionism, and the process of the constructivist grounded theory method. Throughout the process, this study has constructed a theoretical explanation of the core category. The core category of 'needing comprehensive care' is central to the study, and integrates three major categories and their sub-categories. The data was explored from three different participant perspectives, children with HIV, their families, and HPs on the experience of HIV care for children and their families across the continuum in Indonesia. Indonesian children with HIV and their families experienced fragmentation of care across the continuum. The factors that caused fragmentation included the absence of child-centred care to meet the needs of the child, and inadequate integration and coordination of care in the healthcare setting.

Indonesian children with HIV and their families did not receive comprehensive care that focused on the needs of the child, showing that child-centred care was not available in the HIV care service for children. The HIV care service for children was only available in school hours, which reduced the involvement and participation of the children in their own care. HIV care for children was more focused on the provision of medical and HIV treatment, than comprehensive HIV care. The absence of child-centred care influenced their preferences for future care to meet their child's need for comprehensive care. Children with HIV and their families preferred comprehensive care based on the child's preferences. Their preferences included the delivery of child-friendly healthcare, ARV treatment and adherence, disclosure of HIV status, education on sexual and reproductive health, transition care, and psychosocial care.

HPs agreed that the healthcare system was inadequate, and that the lack of coordination of care caused poor performance in healthcare delivery, leading to the fragmentation of care. The Indonesian government has established HIV care programmes, but with little attention paid to children. The integrated healthcare system for children with HIV was sub-optimal due to inadequate coordination of care, a poor referral system, a lack of communication among HPs, and inadequate child-focused policies and regulations. This study has identified the contextual social determinants of health that influenced the fragmentation of care for Indonesian children with HIV. The contextual determinants of health included SES, stigma and discrimination, a lack of social support, inadequate policies and regulations, an inadequate national healthcare insurance system and associated procedures, and an ineffective national health information system. HPs recommended strengthening the healthcare system through better financing, improving policies and regulations for HIV care for children, and supporting the implementation of comprehensive care.

The experiences of the participants in relation to the fragmentation of care informed the construction of a conceptual model of comprehensive care for children with HIV in an attempt to resolve the problem of fragmentation of care for children with HIV in the Indonesian context. This conceptual model offers two components of child-centred care and social support associated with interventions. Indonesian children with HIV and their families need child-centred care depending on their needs and age-appropriate development across the continuum. Examples of interventions for child-centred care are ARV treatment and adherence, disclosure of HIV status, adolescent sexual and reproductive health, transition care, and psychosocial care. Furthermore, Indonesian children with HIV need child social support, such as stigma reduction, financial incentives, housing, education, and social support addressing the social determinants of health and human rights. All these interventions need to be delivered through adequate integration and coordination of care in healthcare services, enhancing the implementation of comprehensive care across the continuum and reducing the problem of fragmentation of care.

The next and final chapter presents a conclusion along with the recommendations arising from the study. The chapter outlines the implications of the theory and highlights the strength and limitations of this study. The recommendations for policy, clinical practice, nursing education, and future practice will also be presented.

CHAPTER 8
CONCLUSIONS AND RECOMMENDATIONS

Chapter Seven presented the core category of the findings, ‘needing comprehensive care’. The identification of this category was prompted by the need to address the issue of fragmentation of care for children with HIV and their families in the Indonesian context. Prior to this study, there were no research findings which explored the subjective experiences of HIV care for Indonesian children across the continuum. The category of ‘needing comprehensive care’ incorporated the essence of the participants’ lives, as they experienced living with HIV, the risk factors for the fragmentation of care, and the need for comprehensive care. The final product of this study is a conceptual model of comprehensive care for children with HIV and their families. The conceptual model provides an understanding of which interventions could meet the needs of the child with HIV across the continuum. The critical point of the conceptual model is in establishing comprehensive care interventions or services due to the experiences of fragmentation of care for children with HIV and their families. The comprehensive care interventions include a child-centred care approach and social support which would meet the needs of the child, be relevant to the child’s developmental stage, and would ensure the child’s rights across the continuum. Furthermore, the implementation of care interventions would need integration and coordination within the healthcare setting to enhance continuity of care.

This chapter will revisit and answer the objectives of this study based on the methodology and methods used, and will provide an overall view of the contribution of the study to the research literature. This chapter will then present the implications of the study before identifying the strengths and limitations of the research, and concluding with a series of recommendations arising from the research.

The Objectives and Contributions of the Study

The objectives of this study were articulated at the beginning of the thesis. The findings and discussion of the core category have also been addressed. Overall, this thesis has realised the study objectives and has made a significant and original contribution to [nursing] knowledge about HIV care for children and their families across the continuum in the Indonesian context based on the subjective experiences of the participants. The participants were children with HIV, their families, and HPs. The two study objectives and their contribution are:

Objective one: to explore the experience of children with HIV and their families in relation to HIV care across the continuum in the Indonesian context.

The findings of the study revealed three major categories derived from the multiple subjective experiences of children with HIV, their families, and HPs. The findings fulfilled the research objectives. These findings provided an understanding of:

The experience of the fragmentation of care for children with HIV and their families.

Children with HIV and their families experienced fragmentation of care across the continuum. The absence of child-centred care, the inadequate healthcare system, and the contextual determinants of health, and inadequate social support caused the fragmentation of care for children with HIV and their families. Contextual determinants included low SES, stigma and discrimination, inadequate social support, lack of coordination of care, the limited referral systems and associated documentation, and insufficient child-focused policies. Children with HIV and their families did not receive care and services for disclosure of HIV status, sexual and reproductive health, transition care, and psychosocial care.

This study found that the relationship between the inadequate healthcare system and the deficient performance of HIV care services for children led to the fragmentation of care. For example, HPs working at the hospital level did not provide adequate referral documentation for HPs working at the PHC level. As a result, children did not receive follow-up care in the community, leading to the fragmentation of their care. This inadequate communication among HPs contributed to fragmented care and had a profound impact on children's health outcomes. Insufficient child-focused policies and programs, such as for disclosure of HIV status, influenced practices regarding when and how to provide adequate disclosure of a child's HIV status to the child. Thus, this study highlighted that HIV care for children focused on medical treatment care rather than the provision of holistic HIV care.

The lived experiences of children with HIV and their families across the continuum.

Apart from the experience of fragmentation of care, this study also provided an exploration of the life experiences of children with HIV and their families across the continuum. Many of the children with HIV in this study experienced the loss of one or both parents due to HIV. They experienced severe physical illness requiring hospitalisation, which had a negative impact on school enrolment and/or school attendance. However, once ARV treatment commenced, they no longer needed constant hospitalisation. Family members and/or single mothers with HIV continued to provide daily care for the children, maintaining the children’s health. Families in this study experienced difficulties, such as financial hardship and stress. However, spirituality motivated the families to provide care to maintain the children’s health. The families provided food and nutrition, education, and health information, as well as engaging the children in practising healthy lifestyles, and activities of daily living at home, thereby supporting the children’s growth and development. The families also assisted their children with picking up the monthly ARV refills from the hospital. Both children with HIV and their families experienced increased emotional stress related to being diagnosed with HIV for the first time, such as shock, anger, and denial. They also experienced stigma which lead to social discrimination and marginalisation, such as rejection, isolation, and ignorance. Internalised stigma and the fear of discrimination lead to negative emotions and stress. Stressful life events existed because many families were afraid to disclose the child’s HIV diagnosis. As well, they lacked social support and had challenges with adherence to ARV medication.

Objective two: to generate a substantive grounded theory on HIV care for children and their families across the continuum in the Indonesian context.

This study aimed to generate a substantive grounded theory about HIV care for children across the continuum in Indonesia from the multiple perspectives of children with HIV, their families, and HPs. This study was underpinned by the constructivist paradigm. A relativist ontology, an interpretive epistemology, and the theoretical perspective of symbolic interactionism guided the construction of the reality of the individual’s experiences and perspectives. This study constructed knowledge based on people’s experiences through meaning and interpretation. Consistent with the constructivist paradigm, the aim of the study was achieved through the application of the constructivist grounded theory method. The application of grounded theory allowed an understanding of the experience of living with HIV, experiencing fragmentation of care across the continuum due to barriers of care, and sharing preferences for future care for children with HIV and their families in the Indonesian context.

The main contribution of the study is to provide knowledge about the importance of comprehensive care based on the perspectives of children with HIV and their families in the Indonesian context. Providing comprehensive care will overcome the problem of fragmentation of care among Indonesian children with HIV and their families. The findings have identified the core category of ‘needing comprehensive care’. From the development of the core category, this study has constructed a theoretical explanation of ‘needing comprehensive care’. The underpinning of this theoretical explanation has been built through the integration of the major categories and sub-categories established through the data analysis process: ‘maintaining their health’, ‘living with fear and stigma’, and ‘predisposing factors to ineffective care’. The core category of ‘needing comprehensive care’ explained the barriers to effective care which lead to the fragmentation of care and provides solutions for comprehensive care interventions based on the needs of the children and their families. This theoretical explanation provides new knowledge to explain comprehensive care interventions based on the client’s perspectives. ‘Needing comprehensive care’ addresses the challenges of the fragmentation of care, enhancing optimal care across the continuum among Indonesian children with HIV and their families.

This study has provided a conceptual model of comprehensive care for children with HIV and their families in the Indonesian context. The components of comprehensive care interventions and services are designed according to the child’s needs and preferences. Indonesian children with HIV and their families desire child-centred care and children’s social support delivered through adequate integration and coordination of care in healthcare services. Examples of services are ARV treatment and adherence support, sexual and reproductive health, transition care, and psychosocial care. Indonesian children with HIV desire enhanced social support, such as financial incentives, housing, education, CD4 and viral load testing, stigma reduction interventions, and addressing the social determinants of health. The model can be used as a strategic framework for the improvement of HIV care delivery, centering on the child’s needs to promote comprehensive care on a global basis, as the accomplishment of the second objective of this study. Overall, this constructivist grounded theory has answered the research question: “How do Indonesian children with HIV and their families experience care across the continuum in Indonesia?”

Implications

This study has provided a theoretical explanation of ‘needing comprehensive care’ for children with HIV and their families to enhance health outcomes for children with HIV in Indonesia and could be applied to other countries which have a similar healthcare and social context to Indonesia. The following section presents the applicability of this theory for nursing practice policy, education, and research.

Implications for Nursing Education

The theory of ‘needing comprehensive care’ has profound implications for nursing education, preparing nurses’ performance standards or practices for the provision of care, and possibly even for those with other forms of chronic disease. The theoretical explanation describes comprehensive care interventions based on the perspectives of children with HIV, their families, and HPs. This knowledge implies that nurses should care for children with HIV in a friendly way, and also, how nurses should enhance the participation of children and their families in their care, by exploring the individual patient’s preferences within the child-provider interaction. This finding increases the routine scope of practice for nurses, such as engaging in a therapeutic relationship and effective collaboration among health professionals, supporting critical thinking, analysing practice, and being able to develop an age-appropriate comprehensive plan based on children’s needs. Furthermore, an elective course and/or continuing education program for nurses could be designed on HIV care for children to mitigate the impacts of HIV on children and their families.

Implications for Policy

The theoretical explanation of ‘needing comprehensive care’ for children with HIV and their families provides interventions to support comprehensive care to address complex health and social needs based on the children’s perspectives. The findings and discussions presented indicate that policies and procedures may need to be designed or reformed based on children’s rights and child-focused practice to provide quality and accessible healthcare for children with HIV to support continuity of care.

There is a need to strengthen governance for the care of children with HIV in Indonesia which will need political support. All levels of government working together through effective decision-making is crucial. Governments should act within their statutory power to strengthen the healthcare system and to construct child-focused policies that respond to the needs of children with HIV and their families, and that promote optimal comprehensive care. These changes could include policies and guidelines for standard comprehensive care for all children with HIV, and child support in the context of HIV, to promote comprehensive care across the continuum. This may require the allocation of more funding to scale-up public health interventions, such as stigma reduction interventions and financial incentives for children from low SES backgrounds.

Implications for Nursing Practice

The theoretical explanation of ‘needing comprehensive care’ pointed out the fragmentation of care and provided knowledge about comprehensive care interventions based on the perspectives of the participants. This theory provides knowledge which would help nurses to resolve such problems and make effective decisions to improve practice, as nurses are in a critical position to lead optimal care delivery, being the first point of contact for patients. Through the knowledge of comprehensive care interventions for children with HIV, nurses would understand that children with HIV would not only receive ARV treatment, but also other interventions depending on their needs, preferences, and age. These interventions may include ARV treatment, and to enhance adherence, disclosure of HIV status, sexual and reproductive healthcare, the transition of care, and psychosocial care. Nurses could involve children in their care as active recipients of healthcare services, thereby enhancing children’s participation in their own care. To do so, nurses need to understand how to deliver friendly care and use age-appropriate language to enhance professional communication with children. Furthermore, nurses could improve the coordination of care and communication with other health professionals through understanding and implementing all facets of referral, follow-up, documentation, and administration, supporting appropriate care at the level of the healthcare setting to improve comprehensive care. The provision of collaborative interprofessional practice may also enhance the delivery of a comprehensive plan, improving children’s health outcomes.

This study presents a new conceptualisation of how to enhance the delivery of comprehensive HIV care for children through exploring patient’s preferences and perspectives. The practice of exploring patient’s preferences may be useful for nurses in clinical practice, where they could use their abilities to explore the needs of their clients about their care, resulting in improved outcomes for children. Exploring individual patient preferences is a strategy which will help nurses to design a care plan based on client needs, thereby improving client satisfaction.

Implications for Nursing Research

The findings also have implications for nursing research. The findings provide evidence-based practice for HIV care for children in Indonesia based on the multiple perspectives of children with HIV, their families, and HPs. Nurses are in an important position to be able to promote nursing research which would support and improve adequate care for children with HIV.

Strengths of the Study

This section presents the strengths and limitations of the study. The strengths are that the study provides new knowledge on the experience of care for children with HIV and their families across the continuum in the Indonesian context. The outcome, a conceptual model of comprehensive care for children with HIV and their families, is the major contribution of the study. This study is the first major piece of research that has explored the experience of care for children with HIV and their families across the continuum in Indonesia using a constructivist grounded theory method. Consistent with the constructivist paradigm and grounded theory methods, as presented in Chapter 3 and 4, this model provides knowledge on how to understand the experience of care, and how to use the participants' experiences and perspectives to improve the care. Understanding children's preferences is crucial, because it informs solutions to clinical decisions and helps solve healthcare problems. The number of different participants, including children with HIV, their families, and the HPs across eight different healthcare settings, allowed the researcher to gather rich and diverse data, which contributed to the building of solid knowledge on the subject of HIV care for children across the continuum.

Another strength of the study is that the researcher demonstrated the application of grounded theory procedures, including initial, focused, and theoretical coding, the constant comparative method, and theoretical sensitivity, as presented in Chapter 4. The researcher employed memo writing, starting from data generation to constructing a substantive theory, which can also be used as a record of the research process. The researcher kept a comprehensive record of the sources of the data, including the audio-recordings of the interviews, the analytical procedures, and the implementation process of theory development, providing evidence on methodological congruence and practices. As well, the researcher received critical feedback on a monthly basis from the study supervisors. All these activities increased the rigour of the study, as detailed in Chapter 4.

The researcher was aware of being a novice grounded theorist, although she had previously undertaken qualitative research. The researcher broadened her knowledge through reading a wide range of literature and seminal books about philosophy, methodology, and the grounded theory method before conducting the study. As well, the researcher employed a hands-on data analysis process with the supervisors who had expertise in grounded theory methods. The final product of the theory demonstrated 'knowing in practice', as the researcher was able to use her knowledge and embed it in practice, supported by regular meetings with her supervisors. Furthermore, the use of participant quotes strengthened the study, which brought the participants' voices to the findings.

Limitations of the Study

The aim of this study has been achieved, with some difficulties and limitations acknowledged. In line with the grounded theory method, three groups of participants were recruited to build knowledge about the phenomenon, obtained through interview data. Because of the scope and methods of this study, it has been difficult to establish reliability and validity due to the subjectivity of the participants' perspectives and experiences. However, this study established sufficient rigour for a constructivist grounded theory study.

Another potential limitation is that the data generation and analysis should ideally have been conducted concurrently, but it was not practical to do so in this study. Due to time constraints, the researcher needed to fit in with the participants' available times for the interviews. The researcher also collected data in different locations which posed difficulties in analysing all the data in tandem with the data generation. Timonen, Foley and Conlon (2018) described several factors that hinder data collection and analysis in tandem, such as location, time constraints, and ethics restrictions. The researcher managed these constraints by writing memos and directing data generation to understand the phenomenon based on the initial coding to optimise the concurrent process of data generation and analysis.

The substantive grounded theory constructed in the study only provided an interpretation and understanding of the experience of care for children with HIV across the continuum in the Indonesian context. The findings of the study may not be transferable to all environments within or outside of Indonesia, even though similar experiences may be found in other countries experiencing the HIV epidemic. This study did not represent the entire Indonesian context because the participants involved in the study were from East Java only. The Indonesian government has decentralised governance, with each local government having different healthcare policies. Therefore, the lack of a complete Indonesian context could be seen to be a limitation. However, this study may provide an overview for HPs who wish to explore HIV care for children across the continuum in the hospitals or PHCs within their own healthcare system.

Recommendations

The findings of this study provide several recommendations for future policy, nursing practice, education, and research.

Policy

This study has revealed several contextually based determinants of the fragmentation of care for children with HIV that need to be addressed to enhance comprehensive care. This study provides several recommendations associated with the healthcare system, policies, and programs. Informing local governments of the study findings may have great importance and influence them to review, develop, and strengthen the healthcare system, policies, and practices to support the implementation of comprehensive care for children with HIV, thus promoting comprehensive care.

Recommendation 1: Strengthening the healthcare system

Strengthening the healthcare system would be a crucial contributor to the implementation of comprehensive care. To provide comprehensive care for children and families, policy-makers or government decision-makers should make efforts to address the critical issue of the establishment of a framework for a comprehensive care delivery system which is oriented around the needs of children. The current system focuses almost exclusively on medical treatment, such as the administration of ARV treatment and HIV counselling and testing.

As well as changes in health policies to improve comprehensive care, improving care coordination and communication among HPs across different settings is crucial to improving the quality of care. For example, improving the referral system and documentation is a good place to start. HPs suggested that regular team meetings between HPs, preparing teamwork coordination for practice, and the use of mobile applications such as WhatsApp, would increase communication among health professionals. Furthermore, an increase in the number of health professionals and opportunities for training is another strategy to enhance optimal comprehensive care in the HIV care setting, such as training in communication skills. Strengthening the referral system, improving communication among HPs, and enhancing the healthcare workforce would enhance the coordination of care and support the implementation of comprehensive care. In delivering comprehensive care, considering these children’s needs would enhance continuity of care for children with HIV and would address the fragmented nature of HIV care for children in Indonesia.

Recommendation 2: Improving and designing the delivery of comprehensive care for children with HIV

The participants in this study recommended a number of interventions to optimise comprehensive care for children with HIV, including:

1. Providing a friendly environment for HIV care for children

Delivering a HIV service after school hours or on the weekend might be useful for enhancing children's participation, because they are currently less involved in their own care due to their education commitments. For healthcare institutions, providing child-friendly equipment, such as a playground or a toy corner in the HIV care outpatient clinic would be a comfort for children with HIV. Designing a friendly HIV clinic for children would enhance the linkage to HIV care and treatment. Hence, involving families in their children's care and engaging children in their own care also need to be improved.

2. Providing support for ARV treatment and adherence

The Indonesian government provides free or subsidised ARV treatment along with monitoring for HIV treatment, such as CD4 monitoring. The participants wanted greater availability of ARV treatment and routine CD4 and viral load monitoring.

Children with HIV and their families in this study experienced the perceived benefit of ARV treatment for their children. However, in this study, children with HIV were at considerable risk of medication non-adherence. The experiences of the participants in managing HIV treatment, as well as the perceived benefits of ARV treatment influenced their preferences to improve their medication adherence. Children with HIV in this study received multi-pill ARV drugs and did not like the large size and taste of the pills. Suggested strategies to overcome this issue include the introduction of child-friendly formulations with innovations in the taste of the drugs and simplifying dosing regimens to once-a-day formulations or a fixed-dose combination.

Furthermore, the HPs in this study recommended that through the provision of a treatment supervisor, lessons on adherence to ARV for family members before their children began ARV initiation, family counselling, and peer support were other strategies to improve adherence to ARV therapy. HPs recommended that the extension of 3-monthly ARV refill visits as a strategy to improve adherence to ARV therapy could be adopted. Intervention approaches to support adherence to ARV need to be integrated into the comprehensive care program for children with HIV to increase children's health outcomes across the continuum.

3. Designing a mobile application for effective patient communication

The use of a mobile application would be another strategy to enhance child-health professional communication, enhancing child-centred care and participation. Mobile phones are popular among adolescents in Indonesia. Providing sexual and reproductive healthcare services for adolescents

4. Providing sexual and reproductive healthcare services for adolescents

The adolescents with HIV in this study wished for the establishment of specific clinics associated with care interventions for adolescent sexual and reproductive health. According to the perspectives of HPs, the number of adolescents who identified as lesbian, gay, bisexual, and transgender (LGBT) has increased every year. Their attitudes about sexual orientation and gender identity contributed to the risk of sexually transmitted diseases, including HIV infection and transmission. Adolescents were susceptible to HIV infection because of unsafe sexual behaviours and inadequate knowledge of practices relating to HIV infection and prevention.

Sexual and reproductive healthcare services aim to educate people about sexual and reproductive health, and to prevent sexually transmitted infections because many Indonesian adolescents are involved in premarital sexual activity and unsafe sex. This service could help people to learn about, and anticipate, the negative consequences of unsafe sexual behaviours, unwanted pregnancies, and HIV infection and transmission. Sexual health interventions from the findings of previous studies could be adopted in Indonesia, achieving optimal sexual and reproductive health across the care continuum, such as increased education about HIV prevention, sexual health education and counselling, family planning information, promoting the use of contraceptives, the availability of condoms, psychosocial care, a safe environment and friendly health providers, and privacy at the clinic, self-disclosure, and disclosure care with truthful and correct information.

5. Providing a transition care service

Indonesian children with HIV need transition care before they move from their care as a child to an adult clinic to facilitate self-management and promote comprehensive care. The transition process should involve individualised planning for children's education and skill development, supporting children in gaining their knowledge and self-management skills. Furthermore, a gradual transition with flexible processes may ease the challenge of transition for children or adolescents with HIV in anticipation of the significant changes ahead.

6. Reviewing the implementation of the centralisation of HIV care and treatment for children into the hospital setting

Local governments have implemented centralised HIV care and treatment for children at the hospital level. However, this study found that a few families delayed picking up their ARV refills for their children due to the distance they had to travel and being sick themselves, leading to a lack of medication adherence. Therefore, implementing decentralised HIV care and treatment for children at the Puskesmas or PHC level might need to be considered, as distance is one of the barriers to accessing treatment on schedule. Children with HIV and their families do not take long to travel to their local hospital. This, in turn, would enhance their access to the service in a timely manner, promoting adherence to ARV treatment, which is part of the goals of comprehensive care.

Recommendation 3: Reviewing the national information health system and supplying a valid date of referral letter for the use of public health insurance

Health professionals recommended that using an online barcoding system would prevent the duplication of the data in the HIV electronic medical record. Designing electronic medical records as part of the HIV information system is crucial, because it would enhance health information exchange and the coordination of care among HPs to support optimal care for children with HIV across the continuum. A health information technology system should also be designed to secure clinical patient data sharing between health professionals, thereby enhancing continuity of information and care.

Families are required to take a referral letter when using public health insurance. Therefore, families would like to have the date of the referral letter[11] lengthened, so that they do not need to acquire a new referral for each visit. Understanding the experiences of the participants, this study has shown that providing an extended validity time of the referral letter from a PHC from one to three months might enhance the use of public health insurance in accessing monthly ARV treatment in the hospitals. Therefore, enhancing the national

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[11] Patients with public healthcare insurance (JKN insurance) require a referral letter from a primary care facility, such as a PHC or Puskesmas before seeking further treatment to a hospital.

health information system and the national healthcare insurance scheme and associated procedures would be a contributor to the implementation of comprehensive care, and would strengthen the healthcare system.

Recommendation 4: Involving stakeholders and policy-makers in the healthcare system

The implementation of comprehensive care for children with HIV not only involves HPs, children with HIV, and their families, but should also involve policy-makers. Improving the knowledge and skills of policy-makers will reduce stigma for families, increase awareness of HIV prevention, and improve awareness in addressing social issues among children with HIV and their families.

Recommendation 5: Developing child-focused policies and guidelines

The grounded theory demonstrated inadequate practice-oriented policies on HIV care for children, which contributed to the fragmentation of their care. The Indonesian government follows a decentralised system, so local governments at the district/city level have the authority for the development of health policies and standards to meet local needs. Health professionals have recommended a review and re-design of the effectiveness of policies to support the implementation of a comprehensive care program to meet the needs of children with HIV. The availability of child-focused policies and guidelines for children with HIV will provide direction and guidance to improve health professional practices in HIV care for children. HPs would need practical guidelines for the disclosure of HIV status, psychosocial care, transition care, and sexual and reproductive health for adolescents in HIV care for children. For example, disclosure guidelines and procedures need to be developed to guide the effective implementation of disclosure. HPs have suggested that a simple disclosure process is needed to enhance therapy compliance in combination with the children receiving social and psychological support. Ethical guidelines and procedures for disclosure will also guide HPs in supporting professional relationships with children and their families, and to protect them against inappropriate disclosure of the child’s health information and status.

Recommendation 6: Providing social support for children with HIV

The issue of health and social equity for children with HIV negatively influences their health outcomes. The participants in this study wished for the establishment of adequate social support for children with HIV. Providing financial assistance, housing, education, and nutrition support for children with HIV from low SES backgrounds would enhance optimal health outcomes. Indonesian children with HIV from low-income families would also need cash or financial help to support their care, which would further support the delivery of comprehensive care based on the needs of children across the continuum.

The Indonesian government has established a national education system, but there is still limited attention on marginalised groups of children with HIV. HPs recommended that the government should provide home-schooling or a school-based life skill education program for students with HIV who have been expelled due to stigma. A stigma reduction program associated with housing is also crucial due to the number of refusals for HIV accommodation among children with HIV.

All the participants in this study suggested that stigma could be reduced by implementing HIV prevention, and transmission education for children, families, and the wider community, through the use of mass media, particularly television, in collaboration with the government and HPs. All the participants suggested providing psychological support for the children's disclosure of their HIV, emotional support and information for children and their families are essential to meet children's comprehensive health needs. The provision of social assistance could be integrated into the comprehensive care program for low SES children with HIV in Indonesia.

Nursing Practice

Capacity building of health professionals would facilitate reliable performance, enhancing the coordination of care, and promoting optimal quality of care for children with HIV in the healthcare setting. Proposed capacity building would include training or mentorships on the standard of HIV care delivery for children, communicating with children, understanding children's developmental stages, and quality management. In addition, strategies for effective communication among HPs and clients would provide for the opportunity to enhance the participation of children in their own care and improve their clinical outcomes. Health professionals need to involve children and their families in the care to enhance decision-making and to improve child-centred outcomes.

Health professionals need to enhance their performance depending on their roles and responsibilities, and promote effective teamwork within healthcare teams to increase the coordination of care.

Nursing Research

This study has contributed to knowledge about the provision of HIV care for children and their families. Further research, particularly action research, is needed to examine the implementation of comprehensive care interventions for children with HIV. There is also the need to test such models to evaluate the effectiveness of comprehensive care interventions. The effectiveness of single or multiple comprehensive care interventions for children with HIV can be designed through the use of a Randomised Controlled Trial (RCT) or an experimental study. Such a model could alternatively be tested in a population of children with a chronic disease in different cultural contexts or regions.

Nursing Education

The theoretical explanation of ‘needing comprehensive care’ will be published in an article for an international audience, such as in the Journal of Paediatric Health Care. This theory can be disseminated to academics and professionals, providing an opportunity for them to be involved in the improvement of care for children with HIV across the continuum in particular, or for children with chronic diseases in general. The researcher plans to share knowledge about the key findings with the Indonesian National Consortium of Paediatric Tropical Diseases and Infections, as the researcher is one of the co-founders of the Indonesian National Paediatric Nurses Association, which should help to strengthen collaboration among a multitude of organisations. The report of the findings will also be circulated to the institutions involved in this study.

Conclusion

The provision of care among children with HIV identified a wide range of barriers leading to reductions in optimal care for children with HIV in developing countries. Barriers to effective care included the familial context, the healthcare system, and stigma and discrimination. The literature review described that there was a lack of recognition of the perspective of children with HIV and their families across multiple healthcare settings, and the majority of the reviewed studies were from HPs’ perspectives. Yet, in Indonesia, the number of children with HIV has increased over the last five years, and inadequate national HIV programs have focused on children.

The nature of children living with HIV causes challenges for children with HIV and their families, namely physical, financial, and social problems. The nature of children living with HIV depended on their parents or family members. The child’s dependency on their parents or family members also invariably influenced their health outcomes. The nature of care for children living with HIV was that they were hospitalised if they suffered from a severe illness and then continued their HIV treatment in the PHC or Puskesmas. This thesis has identified the ad-hoc nature of participants' experiences regarding care for children with HIV and their families across the continuum.

Unique to this thesis is an enhanced understanding of children's needs and preferences from the collective experiences and perspectives of Indonesian children with HIV and their families in relation to HIV care across the continuum which was not previously well identified. This thesis offers new insights into the intervention of comprehensive care for children with HIV and their families across the continuum to address the problem of fragmentation of care that combines child-centred care and social support based on the needs of the child and age-appropriate development and addressing the social determinants of health. Their experiences and perspectives affected their preferences and needs for ARV treatment and adherence, disclosure of HIV status, adolescent sexual and reproductive health, transition care, psychosocial care, stigma reduction, financial incentives, CD4 and viral load testing, nutrition, housing, and education. There is an urgent need for supporting the implementation of comprehensive care for children with HIV and their families across the continuum based on individual preferences to enhance optimal health outcomes for children with HIV across the continuum. Furthermore, this thesis provides a unique perspective into the lived experiences and the experience of fragmentation of care for children with HIV and their families across the continuum. The provision of care for children with HIV focuses more on medical treatment rather than on comprehensive care interventions. Low SES, stigma and reduction, and the inadequate healthcare system caused the delivery of ineffective quality care in the healthcare setting, leading to fragmentation of care for children with HIV.

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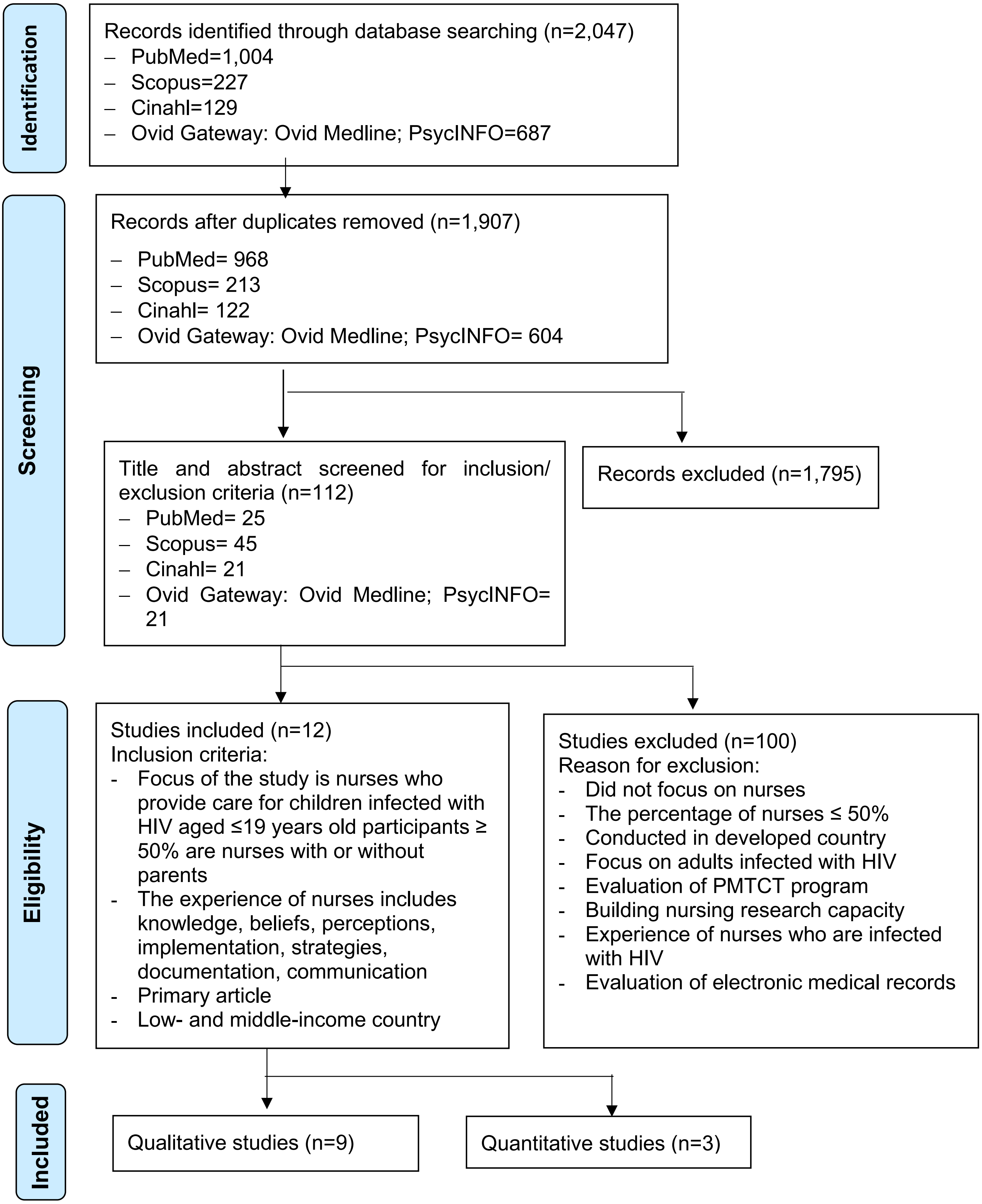
APPENDICES

Appendix 1. The review process of an integrative review

1) The use of the Prisma flow process for included articles
2) Summary table of reviewed articles
3) Qualitative and quantitative appraisal for included articles
4) List of LMIC countries based on World Bank 2015
5) Strength and weakness for included articles

Appendix 1.1 The use of Prisma flow process of included articles



Appendix 1.2 Summary table of reviewed articles

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design I. Method II. Study Design III. Data Collection/ Instruments IV. Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
1.	Achema and Ncama 2016 Nigeria	Analyzing empathic-supportive care given to children living with HIV in Nigeria	To analyse the nature of care given to children with HIV in Nigeria to improve quality of care	**I.** Qualitative Research adopted with grounded theory (Strauss and Corbin) **II.** FGD and Interviews **III.** Thematic analysis by starting with open coding and axial coding	• 20 Nurse Practitioners (NP) • 16 children aged 11-14 years with their caregivers with total of 16 people • 2 stakeholders from agencies for the control of HIV Instrument: audio recorder Two hospitals (a government health institution and a faith-based organization) KwaZulu	Nurse practitioners reported that: - Giving a listening ear, which is a good component of empathic care helped children to be relaxed, open up, and cooperate in their care. This would also reduce withdrawal, issues with self-worth, and discrimination. - Empathic care would help to reduce children's self-worth issues. - Society and caregivers need to be educated to continue empathic care. - Giving listening care may support empathic care. - Acceptance should begin in the home and in society. - Children with HIV need to be accepted as normal human beings, should be treated as normal children. - Children with HIV, who were not accepted within the healthcare setting would negatively affect the goal of care. - Empathic-compassionate care was recommended for HIV-positive

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design I. Method II. Study Design III. Data Collection/ Instruments IV. Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						children because the majority were orphans. - During home visits, nurses found that caregivers often did not provide good nutrition for HIV-positive children. Therefore, nurses expressed that children with HIV required good nutrition to boost their immunity. Not only adequate food support, children with HIV also need need clothing, and other things to fulfill their basic needs. - Children with HIV require counseling from time to time to cooperate in their care. - Love and encouragement are important care components. - Rejection and discrimination affected the care of HIV-positive children. Caregivers reported that: - Despite the need for antiretroviral therapy, children with HIV need supportive care, such as nutrition, education, and psychosocial support. - Children with HIV also need support, love, and cooperation

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						from family members and the community. - Communities should minimise discrimination for HIV-positive children. Stakeholders reported that: - They developed policy for HIV-positive children as part of supportive care, such as nutritional, educational, psychosocial support, and economical support.
2.	Achema and Ncema 2016 Nigeria	Exploring family-centred care for children living with HIV and AIDS in Nigeria	To analyse the role of family members in the provision of care for children with HIV	**I.** Qualitative Research adopted grounded theory (Strauss and Corbin) **II.** FGD **III.** Open, axial, and selective coding	• 16 members of each hospital (8 children, aged 10-14 years old and 8 caregivers) • 4 children and 4 caregivers were recruited through theoretical sampling Instrument: audio recorder	Nurses reported that: - Family values general care for African children by identifying and providing for the needs of their children. - Child tends to get better when people are around them. "sickness runs away from people". - Orphan children with HIV often did have adequate treatment due to not having money to pay. Therefore, family member have to get a loan to pay hospital bills. - Family members were in fear to see the doctors, which caused

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
					Total in 2 hospitals	them to not disclose their HIV-positive children to others. - When children were sick, they would affect their whole families. For example, other families would visit them, or may provide assistance for them. - Nurses often educated families about HIV prevention, such as mode of transmission, blood screening during blood transfusion, not sharing needle syringes or other sharp objects, and medication for HIV-positive children. - Some families often did not accept their HIV-positive children due to stigma and discrimination. - Families need counselling to understand the problem of their children. - Families' poverty was a barrier for healthcare-seeking behaviour. Due to lack of money, families could not provide basic needs of their children, such as school access. Caregivers reported that: - Family places value on the care of their HIV-positive children by

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						providing children with medication at the right time, providing food for children to protect their children from sickness. - Love and care within families is important, which positively support children with HIV.
3.	Campbell et al. 2011 Zimbabwe	A good hospital: Nurse and patient perceptions of good clinical care for HIV-positive people on ARV in rural Zimbabwe - a mixed-methods qualitative study	To explore the perceptions of patients and healthcare providers on ARV care	**I.** Qualitative research **II.** N/A **III.** Interviews, focus group discussions, ethnographic observation of treatment settings, extensive detailed notes **IV.** Thematic content analysis	• 25 health staff (nurses, HIV counselors, pharmacists, and a clerk) for interviews and FGDs • 53 ARV users • 40 carers of children Settings: • Catholic clinic • Anglican hospital • Government hospital	Health providers reported that: - There were conflicting perceptions about nurses working in government hospitals and a Catholic clinic. Nurses in Catholic clinic expressed that spiritual counselling was better provided than in government hospital. However, nurses who worked in government hospital were better because they only paid attention to government regulations. - Nurses at Christian sites felt patients preferred religious-based care (provided only in the Catholic clinic). - Healthcare providers were satisfied when their patients' conditions improved and their adherence to ARV was good - Healthcare providers were confident about the quality of their

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						counseling services, which positively supported patients with the challenges of HIV and ARV. - Nurses explained that kindness, understanding, confidentiality, and stigma reduction were important. - Being friendly with patients built relationships between health providers and patients, which supported positive clinical interactions. - Nurses and patients said that listening skills, understanding the difficult circumstances of patients with HIV, maintaining confidentiality, counselling, and a supportive environment are components of good clinical care, which developed optimal adherence strategies. - Patients expressed dissatisfaction with nurses because they often did not listen to what the patients tried to explain to them. - Nurses felt frustrated because patients often missed review dates due to their life situation, such as being unable to cover transport costs to visit a clinic.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						- Shaking hands with nurses built positive interactions with patients. - When patients were in good condition, they often did not attend a clinic. - Nurses and patients had different perceptions about AR V refills. Nurses scheduled a monthly visit for patients to anticipate adverse side-effects, the adherence problem, and opportunistic infections by providing a small amount of pills. However, patients wanted several months' supply of ARVs at a time because they lived far away from the health centres. - Patients reported that they wanted a large ARV supply because they had to wait for a long time in the queue, and often did not have the money to pay for transport and the consultation fee. On the other hand, patients suggested that they had been punished by nurses by only receiving a few pills due to a lack of money. - Nurses reported that surveillance was part of good clinical care. However, the process of

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						surveillance was not well-described. - Nurses pointed out the importance of seeing patients in a timely manner in relation to queues and waiting times for each refill to reduce severe discomfort. - Lack of clear guidelines about patient payments caused stressful interactions between nurses and clients, and between clients and different hospital departments.
4.	Campbell et al. 2012 Zimbabwe	Building adherence-competent communities: factors promoting children's adherence to antiretroviral HIV/AIDS treatment in rural Zimbabwe	To analyse children's medication adherence by identifying community relationships between children and health providers, examining social norms through social capital had a positive impact on adherence.	**I.** Qualiatative **II.** N/A **III.** Interviews, FGDs **IV.** Thematic analysis using Attride-Stirlings approach with Atlas.Ti software program	25 Nurses 40 guardians of children on ARV program selected using snowball sampling Setting: three rural health facilities	- Families reported that they often borrowed money from community members, neighbours, relatives, or fellow church members to pay for medical expenses. - Distance to health facilities often lead to families not attending their monthly consulation for getting ARV medications in the health facilities. - Communities have gradually realised that HIV is a national problem, they were well-informed and often accepted children with HIV by sharing plates with HIV-positive children. - Religion has been shown to affect the care participation of families.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design I. Method II. Study Design III. Data Collection/ Instruments IV. Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						Families believed that they would accept reward from God when they looked after HIV-positive children. - NGOs have contributed to improving adherence to therapy by: (1) providing health education about HIV-AIDS and stigma reduction; (2) child-centred and community-based counselling and HIV testing programs; (3) distributing food aid for HIV infected children, specifically children with HIV who lived in poverty. - ARV programme was very effective for children with HIV because they could access ARV for free. - CD4 machines have been operating at district health facilities to determine the stage of HIV progression and treatment efficacy, which has a positive affect on monitoring the side-effects of therapy. - Only a few participants reported shortages of ARV supplies. - The availability of ARV has had a positive impact on clients and nurses. For example, building trust

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						between clients and nurses within health services, playing an effective role in prolonging HIV-infected children's lives, transforming HIV from a disease of death to a chronic disease, motivating nurses to do their job more seriously, improving client-family nurse relationships, and supporting adherence to therapy. - Health providers expressed that engaging the knowledge, emotions, and practices of guardians and treatment partners, and providing support groups and counselling on how to look after children with ARV might support adherence to therapy. - Nurses expressed that they often were challenged on how to provide care, and in treating HIV-positive children the same as normal children. - Nurses reported that they needed to ensure that adults who lived in the same house with children with HIV, assisted with the care of HIV-positive children, and collaborated with nursing staff to monitor medication.

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						- Nurses expressed that child carers required knowledge of paediatric ARV, the importance of nutrition and timely medication, and the importance of seeking urgent medical assistance for their children who may have complications or side-effects of the therapy. - NGOs and hospital counsellors encouraged child carers to cope their fear of stigma and explain why HIV-positive children were on medication. - Nurses found that children who were aware of their status were more likely to attend monthly consultations and to pay attention to their adherence to the therapy. - Social factors contributing to children's adherence to medication were: (1) commitment among community, children, guardians, and nurses; (2) recognition of children's social value that children with HIV should be treated as normal children, recognition of children's right to take control of their health, and recognition of the value of caring as an activity; (3)

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						having assistance and ethical care from community members, NGOs, and cooperation between NGOs and health facilities for improved care; (4) enhancement of agency and emporwerment, such as restoration of nurses' role in saving children's lives, restoration of hospitals as healthcare providers, enhancement of guardian's and children's agency.
5.	Govender et al. 2006 South Africa	Pediatric nursing in the context of the HIV/AIDS epidemic in resource-poor settings - Balancing the "Art and the Science"	To develop an in-depth understanding of the dilemmas facing pediatric nursing in the context of HIV/AIDS	**I.** Qualitative methodology adopted with grounded theory (Strauss & Corbin) **II.** Discussion, videotaping, observation of consultation report **III.** Thematic Analysis	All nursing staff (senior nursing staff members, registered nursing staff, student nurses, and general nursing assistants (with the number of nurses not being provided) Setting: a pediatric ward in a tertiary hospital	- Nurses experienced that the goal of pediatric nursing has changed from health and recovery to palliative care due to the number of children dying being higher than those recovering. - Nurses expressed that due to the stress of having children with HIV, mothers often did not participate in the care of their children. - Nurses expressed that they often did not have the skills or time to provide emotional support for children with HIV. - Nurses explained that due to the limited number of nurses, they were busy with routine procedures, so they often did not have time to play with HIV-positive children.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						- Nurses expressed that working with HIV increased their feelings of sorrow and frustration. - Nurses expressed that dealing with children's distress was very hard. Nurses felt frustrated and helpless with few resources when providing care for children's distress. - Many nurses noted that they did not have the skills for providing care for children with HIV, who have special needs. - Nurses expressed that providing feeding for HIV-positive children was stressful and time-consuming, especially if the ward was busy and the number of nurses was limited. - Nurses expressed that they often did not know how to reduce pain for the children. - Palliative and psychosocial services for HIV-positive children should be widely available, but nurses often did not implement such care due to a lack of time, resources, and skills. - Nurses were conflicted about infectious disease protocol and empathic care. For example, having visitors for children with HIV

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						was nice, but the children may have a risk of infection from them. - Due to imbalances in the workplace, nurses experienced distress, burn-out, and emotional exhaustion. - Nurses see themselves as mothers when they provide care for sick children, so they felt guilty because they left their children at home to go to work. - Nurses face a dilemma between providing empathic care and maintaining infection protocols. - Nurses explained that they found themselves more distant with children in order to cope with their distress and death.
6.	Haskins et al. 2016 South Africa	Fragmentation of maternal, child, and HIV (MCH) services: A missed opportunity to provide comprehensive care	To investigate the provision of MCH services at PHCs well-child clinics and to describe service delivery at the PHC	**I.** Quantitative research **II.** Cross-sectional descriptive survey **III.** Observation, structured questionnaire, structured checklist **IV.** Entering data in EpiData 3.1 and	87 nurses (professional nurses, enrolled nurses, enrolled nurses assistants) and 26 HIV counselors Setting: 12 primary	- Not all PHC clinics provided comprehensive care. - Some clinics did not provide certain services, such as measuring or screening growth and development, post-natal checks on mothers at six weeks post-partum. - Equipment was available in the clinic, but it was scattered around the clinic.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
				Descriptive data analysis using Stata 13 for Windows	healthcare (PHC) clinics	- The flow of mother-baby pairs was different from HIV-positive mothers and uninfected mothers in 12 clinics. - HIV-positive mothers routinely met with professional nurses in well-child services in 9 clinics, but in 3 other clinics, they saw a HIV counsellor. - Mother-baby pairs routinely met with registered nurses during their immunisation in 7 clinics, but in the other 5 clinics, immunisation services were conducted without a professional nurse. - Community health workers weighed babies and assessed mothers about their HIV status in the waiting room. - HIV-positive mothers were directed to a HIV counsellor before going to the immunisation room, and if the mother was HIV-negative, she was directed to the immunisation room after she left the clinic without seeing a professional nurse. - HIV-positive mothers often left the clinic without seeing a professional nurse, by-passing essential post-natal PMTCT services.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						- Health workers expressed that enrolled nurses should play a role in providing child health services, and HIV counsellors should take part in the provision of HIV care. - HIV-positive mothers were more likely to be assessed on their baby's health, to be discussed with health workers privately, and to be given advice on infant feeding compared to HIV-negative mothers - HIV counselling and testing was delivered by a lay counsellor (89.7%; 100%).
7.	Horwood et al 2010 South Africa	Routine checks for HIV in children attending primary healthcare facilities in South Africa	To describe the attitudes, experiences, implementation of routine checks for HIV in the context of Integrated Management of Childhood Illness (IMCI) implementation, from the perspective of caregivers and nurses	**I.** Qualitative research **II.** N/A **III.** FGDs and observation notes **IV.** Manual content analysis	• 5 IMCI trained nurses • 5 mothers and caregivers of children under 5 years PHC clinics in two provinces: Limpopo and KwaZulu-Natal (KZN), South Africa	- Nurses expressed fear and were reluctant to discuss HIV with mothers. - Nurses reported that speaking about HIV, particularly with HIV-negative mothers, with mothers, caused them to avoid clinics, while the HIV-related questions in every consultation were difficult. - Nurses expressed that it was unacceptable to mothers for the nurse to ask about the HIV status of the child, or to check the child even though the required examination was not specific to HIV.

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						- Nurses expressed that they were afraid about the possible outcomes of routine checks for HIV which might cause them to be sued by mothers, or that mothers would not come to the clinics or make a complaint in the future. - Nurses were hostile towards implementing the HIV guidelines. - Nurses expressed that checking a child without obvious signs of HIV or a child who was in good condition was not necessary. - Nurses mentioned that they often did not routinely check for HIV, because some of the children were healthy. - Nurses did not openly express stigma or discrimination, but they often showed judgemental attitudes related to a particular racial or socioeconomic group. - Nurses reported that IMCI does not have clear guidelines about recording the IMCI classification of suspected symptomatic HIV on the child's card. - Nurses felt like they had inadequate training and knowledge of HIV, and they were sometimes

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						unable to answer the mother's questions, and they did not have anyone to refer to for advice. - Nurses expressed that they often felt less confident when they used IMCI/HIV guidelines due to the uncertainties associated with the instruction. - Nurses expressed that they felt untrained unless they attended a two week AIDS counselling course. Therefore, they asked the mothers to go to a HIV counsellor without explanation, because they were not allowed to talk about HIV without formal AIDS counselling training. - Nurses suggested that supervision would improve the implementation of care. - Nurses recommended that all IMCI-trained health workers needed training in HIV-AIDS counselling and PMTCT. - Nurses expressed that implementing the HIV guidelines was time-consuming, and that IMCI guidelines did not provide clear instruction for the provision of

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						care for a child, who attends without their mother. - Nurses reported that services for HIV were fragmented. Therefore, mother and their children have to see different health professionals to receive the services they need. - Nurses reported that mothers were willing to disclose their HIV status and nurses had improved confidence when HIV-positive children showed improved condition as a result of their medication. - Nurses reported that the well-functioning antenatal PMTCT program enabled nurses to implement HIV guidelines because the mothers understood the need to follow-up with their baby. - Nurses reported that consistent information given to mothers, and relevant information recorded on patient care supported nurses in HIV care delivery. - Nurses expressed that community health workers and support groups helped the clinical support nurses in providing HIV care

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						- Caregivers reported that it was better to know the HIV status of their children, so they could receive early treatment. - Caregivers expressed that they were worried about their confidentiality if nurses would discuss their HIV status among themselves, even though they had no experience of stigma and discrimination from health providers. - Caregivers reported that HIV status should not be recorded on the card because it might be possible to be read by others. Furthermore, they reported that HIV status should be kept private. - Caregivers felt that they could be judged or stigmatised by other community members if they received HIV services, such as follow-up visits or infant formula supply. - Caregivers argued that due to the PMTCT service being separated from other routine services, that this would lead to stigmatisation. - Women expressed that their partners or husbands did not want

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						to practice safe sex by using a condom, or to be tested for HIV. Some women explained that they did not need to ask permission from their partners to test their child for HIV, but they expressed frustration or less power in their relationship.
8.	Koerich et al. 2015 Brazil	Management of nursing care of the adolescent living with HIV/AIDS	To describe the characteristics of management care for adolescents with HIV and proposing strategies for the transition from this service based on nurses' performance and the perceptions of health professionals	**I.** Qualitative research **II.** Exploratory and descriptive study **III.** Semi-structured interviews, participant observation **IV.** Content of analysis by Bardin	• 5 nurses • 5 other health professionals (psychologist=1, social worker=1, doctors=2, nurse technician=1) In patient and day hospital services	- Health professionals expressed that adolescents with HIV required privacy for talking, and different approaches were needed for each adolescent. - Health professionals reported that HIV-positive adolescents often experienced stigma and discrimination, causing them difficulty in managing their care. - Health professionals reported that HIV-positive adolescents had the right to know their diagnosis, but disclosure of HIV status was still a challenge. - Health professionals expressed that they encouraged families to disclose HIV diagnosis. Some families did so, but others did not. - Health professionals discussed that centralising care onto

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						physicians avoided multidisciplinary care and referrals. - Nurses expressed that they often had difficulty in building relationship with doctors, as doctors were very covert and closed. Nurses often felt undervalued, inferior, and/or frustrated due to the feeling of HIV topic unpreparedness. - Nurses expressed that many doctors asked social workers, psychologists, and nurses to talk to patients, as sometimes patients had social, psychological, and adherence problems. - Health professionals expressed that the adult referral service was unlike the child service in which multidisciplinary teams were not provided in the clinics. - Health professionals reinforced that nursing consultation programs had great relevance for the management of adolescent HIV care among other duties of nurses, because these included adherence to drug therapy and sexuality. - Health professionals reported that nurses often ignored the

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design I. Method II. Study Design III. Data Collection/ Instruments IV. Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						importance of the transition process, and from adolescent to adult services in the referral centres. - Health professionals believed that nurses were articulators of services and the healthcare team. - Health professionals reported that planning and implementation in both child and adult services were conducted by medical professionals. - Nurses expressed that they had little involvement in the transition process for teenagers, and had no participation in the planning and implementation services. - Nurses expressed that if they had enough nurses, they could divide tasks for every nurse to participate. - Nurses expressed that new adolescents with HIV visited the hospital, but the nurses did not know their historical status because they came with a referral from a doctor. - Health professionals stated that the transition of adolescents with HIV in the referral system needed to be provided to continue

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						monitoring when adolescents with HIV were young adults. - Health providers expressed that they discussed and prepared families with HIV-positive children who did not know their diagnosis. - Health professionals expressed that nurses should be managers on the ward, so they can understand what is happening on the ward. - Nurses expressed that there was a lack of preparation in the adult referral service to welcome adolescents with HIV, with the service interaction being restricted to medical staff. - Nurses expressed that prejudice from nurses was still apparent as they felt frightened if they were invited to work in a hospital. - Nurses expressed that continuity of care should be implemented before HIV-positive adolescents left the clinic. - Nurses expressed that adolescents with HIV should have privacy and a friendly environment, which was not only about the doctor-patient interaction when

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						discussing sex or condoms, while the role of nurses was also important. - Health professionals reported that working in an interdisciplinary team could achieve comprehensive care and seeing a human being as a whole being were the best way to work. - Nurses expressed that they needed to keep up-to-date, know the service, have a passion for working with the HIV population, and be non-judgemental, and have no prejudice stigma towards HIV. - Nurses expressed that home care conducted by nurses could be an alternative approach to avoid drop-out from the services. - Nurses expressed that communication between the nurses from the child and adult services should be built in to support a humane transition and consultation to address issues of treatment adherence, the disease process, sexuality, and creating a bond. - Strategies such as planning care, building knowledge and initiative

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						within the team, improving communication between child and adult referral services, home care and nursing consultations, minimising prejudices, and working collaboratively with a multidisciplinary team would be part of continuity of care for managing adolescents with HIV.
9.	Olaleye et al 2016 South Africa	I don't know what I am doing because I am doing everything: perceptions and experiences of nurses about HIV counselling and testing among children in Free State	To explore the perceptions and explain the experiences of trained professional nurses on HIV Counselling and Testing (HCT)	**I.** Qualitative research **II.** N/A **III.** FGD, interview guided: open-ended questions **IV.** Thematic analysis with Atlas.ti version 7 software	47 trained professional nurses Sub-districts in Mangaung municipality: Thaba Nchu, Botshabelo, and Bloemfontein	- Nurses expressed that mass counseling for HIV was usually conducted in antenatal and general outpatient clinics, irrespective of the ages of the clients. - Nurses expressed that children who were HIV-positive were tested by HIV counsellors in a clinic and a hospital, after which they would be referred to the professional nurses for continued care and treatment. - Nurses expressed that children should not be concerned with getting HIV tested, as they have limited knowledge, and it would causing them stress. - Nurses expressed that obtaining informed consent from parents or guardians was the initial step before HIV testing.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						- Nurses expressed that if the parents were HIV-negative, children would not need to have HIV testing, as it would cause a waste of resources. - Nurses expressed that only children who were ill needed HIV testing. - Nurses expressed that children below 5 years posed no problem for HIV counselling as they usually came to the clinic with their parents/guardian, but for children (5-14 years), it was difficult as they would only visit the clinic when they were sick. - Nurses expressed that they were busy and overworked, so many children with HIV-negative results were not recorded in the patient documentation. - Nurses emphasised that the first significant activity before testing children with HIV were to seek informed consent from their parents or caregivers. - Nurses expressed that the major barrier to seeking informed consent were that parents refused informed consent as they often did

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						not have adequate information to make a decision to allow their children to be tested. - Nurses reported that due to the limited nursing workforce, they had a higer workload, which caused them frustration and lead them to use the wrong documentation for the wrong patients. - Nurses expressed that the shortage of nurses was a challenge in HIV testing among children. - Nurses reported that simplifying or removing informed consent from parents/guardians would improve the number of children being tested. - Nurses reported that the mode of seeking consent to testpregnant women for HIV could be adopted in the care of children. - Nurses recommended that health education for the community via mass media, and delivering adequate health teaching in the community could reduce stigma and could promote confidentiality.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						Nurses recommended that there should be an increase in the number of nurses, and that full nursing capacity could increase HIV testing among children and could improve the competency of nurses, such as on-the-job training in obtaining blood samples from children for HIV testing.
10.	Richter et al. 2012 South Africa	Evaluation of a brief intervention to improve the nursing care of young children in a high HIV and AIDS setting	To evaluate the impact of the intervention on caregivers' overall psychological well-being and the perception of caregivers on the support provided by nurses during hospitalisation	**I.** Quantitative research **II.** Pre-post intervention phase **III.** Questionnaires: Nurses measurement included compassion fatigue scale-revised (CF-R), Moos Ward Atmosphere Scale (WAS), Maslach	107 caregiver-child pairs 15 nurses on duty in the ward Setting: public hospital	- Nurses have compassion fatigue - Nurses have low patient involvement in the ward, low levels of staff support for patients, and endorsed high levels of both personal development and system maintenance on the ward. - Nurses in the pilot study experienced emotional exhaustion, low level depersonalisation, and average levels of personal accomplishment.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
				Burnout Inventory (MBI). Caregivers measurements included parenting stress index (PSI), nurse-parent support tool (NPST), general health questionnaires (GHQ), Edinburgh postnatal depression scale (EPDS). Child measurement: alarm distress baby scale (ADBB) **IV.** ANOVA		
11.	Weigel et al 2012 Malawi	Managing HIV-infected children in a low-resource, public clinic: a comparison of nurse vs. clinical	To compare nurse's prescriptions of pediatric ARV, adherence calculation, and	**I.** Quantitative **II.** Operational study **III.** Paper assessment	Eight nurses in Lighthouse Trust Hospital	- There is a small bias between nurses and clinical officers on calculation adherence, where nurses calculated correctly - with pen and paper.

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
		officer practices in ARV refills, calculation of adherence, and subsequent appointments	next appointment date determination with their clinical officer peers	form and daily spot-checks **IV.** STATA 10, summary statistic and frequency tables		- The ARV formulation prescribed by nurses differed from the clinical nurses, which was at about 13 out of 704 visits (0,02%), there was stronger bias related to remaining pills left at home today, remaining pills brought today, and remaining pills at the last visit. - There was larger bias on the date of the last dispensing visit (recorded the previous visit closer to the current visit), the calculation of the number of pills to be dispensed today (prescribed more pills), and the date of the next visit by providing later appointment dates compared to clinical officers.
12.	Richter, Chandan, and Rochat 2009 South Africa	Improving hospital care for young children in the context of HIV/AIDS and poverty	To provide a detailed picture of service delivery implemented to improve the care of acutely ill children through interventions directed at nursing staff and caregivers	**I.** Qualitative **II.** Observational study **III.** Video documentation, film footage, observation, monthly meeting **IV.** N/A	Participants: N/A Settings: pediatric wards	- Delivery of care was stressful, and nursing staff performed routine activities and other rules and protocols - Five areas to reduce the burden of care on nurses included providing caregiver psychosocial support; child psychosocial support; ensuring active response feeding by maintaining sufficient nutrition for children, positioning, and social regulation relevant to feeding activities; pain management;

No	Author Year Country	Title Study cond	Aim/Objectives	Methodological Design **I.** Method **II.** Study Design **III.** Data Collection/ Instruments **IV.** Data Analysis	Sample /Participants Characteristics and Setting	Key Findings/ Outcome Measures
						providing good home-based care through discharge planning and follow-up.

Appendix 1.3 Qualitative and quantitative for included articles

Review Criteria for **Qualitative Study/** No. Article	Author (Year) / Study Number								
	Horwood (2010)	Campbell (2011)	Achema and Ncama (2016a)	Campbell (2012)	Govender (2006)	Koerich (2015)	Olayele (2016)	Richter (2009)	Achema and Ncema (2016b)
	7	3	1	4	5	8	9	12	2
1. Title and abstract									
a. Is the title of the research paper concise, clear and congruent with the text?	Y	Y	Y	Y	Y	Y	Y	Y	Y
b. Were the aims and/or objectives stated? What are they?	Y	Y	Y	Y	Y	Y	Y	Y	Y
c. Did the abstract contain sufficient information about the stages of the research process (e.g. aims, research approach, participants, data collection, data analysis, findings)?	I	Y	I	I	N/A	I	I	I	Y
2. Identifying the phenomenon/ phenomena of interest									
a. Is the phenomenon focused on human experience within a natural setting?	Y	Y	Y	Y	Y	Y	Y	Y	Y
b. Is the phenomenon relevant to nursing, midwifery and/or health?	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Structuring the study									
a. Is it clear that the selected participants are living the phenomenon of interest?	Y	Y	Y	Y	Y	Y	Y	Y	Y
b. How is published literature used in the study?	Y	Y	Y	Y	Y	Y	I	Y	Y

Review Criteria for **Qualitative Study/** No. Article	Author (Year) / Study Number								
	Horwood (2010)	Campbell (2011)	Achema and Ncama (2016a)	Campbell (2012)	Govender (2006)	Koerich (2015)	Olayele (2016)	Richter (2009)	Achema and Ncema (2016b)
	7	3	1	4	5	8	9	12	2
c. Does the question identify the context (participant/group /place) of the method to be followed?	Y	Y	Y	Y	Y	Y	Y	Y	Y
d. Does the theoretical framework clearly stated?	Y	Y	Y	Y	Y	N	N	Y	Y
e. Does the theoretical framework fit the research question?	Y	Y	Y	Y	Y	N	N	Y	Y
f. Is the method of data collection and anlysis clearly specified?	Y	Y	Y	Y	Y	Y	Y	Y	Y
g. Does the qualitative method of data collection chosen fit the research question (e.g. grounded theory, ethnography)?	N	Y	I	Y	Y	Y	U	Y	Y
h. Are the limitation of the study stated?	Y	Y	Y	Y	N	Y	N	Y	Y
4. Research question and design									
a. Was the research question determined by the need for the study? How was this determination made?	Y	Y	Y	Y	Y	Y	Y	Y	Y
b. Are the data collection strategies appropriate for the research question?	Y	Y	Y	Y	Y	Y	Y	Y	Y
c. Do the data collection strategies reflect the purpose and theoretical framework of	Y	Y	Y	Y	Y	Y	Y	Y	Y

Review Criteria for **Qualitative Study/** No. Article	Author (Year) / Study Number								
	Horwood (2010)	Campbell (2011)	Achema and Ncama (2016a)	Campbell (2012)	Govender (2006)	Koerich (2015)	Olayele (2016)	Richter (2009)	Achema and Ncema (2016b)
	7	3	1	4	5	8	9	12	2
the study (e.g. in-depth interviewing, focus group)?									
d. Can the data analysis strategy be identified and logicaly followed?	N	Y	Y	Y	N	Y	Y	N	N
5. Participants									
a. How were the participants and setting selected (e.g sampling strategies)?	Y	Y	Y	Y	I	Y	Y	I	Y
b. How was confidentiality of the participants assured?	Y	U	Y	Y	N	Y	N	N	Y
c. How was the anonymity of participants assured?	Y	Y	Y	Y	N	Y	N	N	Y
d. What ethical issues were identified in the study?	Y	Y	Y	Y	Y	Y	Y	Y	Y
e. How were the ethical issues addressed?	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Data analyses									
a. How were the data analysed?	Y	Y	Y	Y	Y	Y	Y	N	
b. Is the analysis technique congruent with the research questions?	Y	Y	Y	Y	N	Y	Y	N	Y
c. Is there evidence that the researcher's interpretation captured the participants' meaning?	Y	Y	Y	Y	Y	Y	Y	Y	Y
d. Did the researcher say how the criteria for judging the scientific rigour of the study were	Y	Y	Y	Y	Y	Y	N	I	Y

Review Criteria for **Qualitative Study/** No. Article	Author (Year) / Study Number								
	Horwood (2010)	Campbell (2011)	Achema and Ncama (2016a)	Campbell (2012)	Govender (2006)	Koerich (2015)	Olayele (2016)	Richter (2009)	Achema and Ncema (2016b)
	7	3	1	4	5	8	9	12	2
maintained in terms of credibility, auditability, fittingness and confirmability?									
7. Describing the findings									
a. Does the researcher demonstrate to the reader the method (e.g. audit trail) by which the data were analysed?	Y	Y	Y	Y	Y	Y	Y	Y	Y
b. Does the researcher indicate how the findings are related to theory?	Y	Y	Y	Y	Y	Y	Y	Y	Y
c. Is there a link between the findings to existing theory of literature, or is new theory generated?	Y	Y	Y	Y	Y	Y	Y	Y	Y
8. Researcher's perspectives									
a. Are the biases of the researcher reported (e.g., researcher/participant expectations, researcher bias and power imbalance)?	Y	Y	N	Y	N	N	N	N	N
b. Are the limitations of the study acknowledged?	Y	Y	Y	Y	N	Y	N	N	Y
c. Are recommendation suggested for futher research?	Y	Y	Y	Y	Y	Y	Y	Y	Y
d. Are implications for healthcare mentioned?	Y	Y	Y	Y	Y	Y	Y	Y	Y
TOTAL SCORE (n=33)	30	31	30	32	24	28	22	23	30
Criteria (Y=yes, N=no, U=unclear, I=incomplete)									

Review Criteria for **Quantitative Study**	Author and Study Number		
	Weigel (2012)	Haskins (2016)	Richter (2010)
	11	6	10
1. Title and abstract			
a. Is the title of the research paper congruent with the text?	Y	Y	Y
b. Were the aims and/or objectives stated? What are they?	Y	Y	Y
c. Did the abstract contain sufficient information about the stages of the research process (e.g. aims, hypothesis, research approach, sample, instruments and, findings)?	I	I	I
2. Structuring the study			
a. Is the motivation for the study demonstrated through the literature review?	Y	Y	Y
b. Is the literature cited current, relevant and comprehensive? Are the references recent?	Y	Y	Y
c. Are the stated limitations and gaps in the reviewed literature appropriate and convincing?	Y	Y	Y
d. Was the investigation carried out?	Y	Y	Y
e. Is the hypothesis stated?	N	N	N
f. Which hypothesis is stated: the scientific hypothesis or the null hypothesis?	N	N	N
g. Does the hypothesis indicate that the researcher is interested in testing for differences between groups or in testing for relationships?	N	N	N
3. The Sample			
a. Is the sample described?	Y	Y	Y
b. Is the sample size large enough to prevent an extreme score from affecting the summary statistic used?	Y	N	Y
c. How was the sample size determined?	Y	N	N
d. Was the sample size appropriate for the analyzed used?	Y	Y	N
4. Data Collection			
a. How were the data collected (i.e. Questionnaires or other data collection tools)?	Y	Y	Y
b. Who collected the data?	Y	Y	N
c. Are the data adequately described?	Y	Y	I
d. What is the origin of the measurement instruments?	Y	N	Y
e. Are the instruments adequately described?	Y	Y	Y
f. How were the data collection instruments validated?	Y	N	Y
g. How was the reliability of the measurement instruments assesed?	Y	N	N
h. Were ethical issues discussed?	Y	Y	Y
5. Data Analysis			
a. Are descriptive and/or inferential statistics reported?	Y	Y	N

6. Data Analysis			
b. Are descriptive and/or inferential statistics reported?	Y	Y	N
c. What tests were used to analyze the data: parametric or non-parametric?	Y	Y	N
d. Was the descriptive statistics/inferential statistics appropriate to the level of measurement for each variable?	Y	Y	N
e. Were the appropriate tests used to analyze the data?	Y	Y	Y
f. What is the level of measurement chosen for the independent and dependent variables?	Y	U	N
g. Was the statistics appropriate for the research question and design?	Y	Y	N
h. Are there appropriate summary statistics for each major variable?	Y	Y	N
i. Was the statistics primarily descriptive, correlational or inferential?	Y	Y	N
j. Identify the outcome of each statistical analysis?	Y	Y	N
k. Explain the meaning of each outcome?	Y	Y	N
7. Finding			
a. Were the findings expected? Which findings were not expected?	Y	Y	U
b. Is there enough information present to judge the results?	Y	Y	I
c. Are the results clearly and completely stated?	Y	Y	I
d. Describe the researcher's report of the findings?	Y	Y	I
e. Identify any limitations or gaps in the study stated?	Y	Y	Y
f. Were suggestions for further research made?	Y	Y	Y
g. Did the researcher mention the implications of the study for healthcare?	N	Y	Y
h. Was there sufficient information in the report to permit replication of the study?	N	Y	Y
TOTAL SCORE (n=40)	34	30	17

(Adapted from Schneider and Whitehead 2016, p. 293)

Appendix 1.4 List of LMIC countries based on World Bank 2015

Low and Middle-Income Countries					
A-B Afghanistan Albania American Samoa Angola Argentina Armenia Azerbaijan Bangladesh Belarus Belize Benin Bhutan Bolivia Bosnia and Herzegovina Botswana Brazil Bulgaria Burkina Faso Burundi	C-D Cabo Verde Cambodia Cameroon The Central African Republic Chad Colombia Congo, Dem Rep Congo, Rep Cote d'Ivoire Cuba Djibouti Dominica Dominican Republic	G-H Gabon Gambia Georgia Ghana Grenada Guinea Guinea-Bissau Guyana Haiti Honduras	I-J India Indonesia Iran, Islamic Rep Iraq Jamaica Jordan	K-L Kazakhstan Kenya Kiribati Korean, Dem. People's Rep Kosovo Kyrgyz Republic Lebanon Lesotho Liberia Libiya	
M-N Macedonia, FYR Madagaskar Malawi Malaysia Maldives Mali Marshall Islands Mauritania Mauritius Mexico Micronesia, Fed. Sts Moldova Mongolia Montenegro Morocco Mozambique Myanmar Namibia Nepal Nicaragua Niger Nigeria	P-R Pakistan Palau Panama Papua New Guinea Paraguay Peru Philuppines Romania Russian Federation Rwanda	S Syrian Arab Republic Samoa Sao Tome and Principe Senegal Serbia Sierra Leone Solomon Islands Somalia South Africa South Sudan Srilanka St. Lucia St. Vincent and the Grenadines Suriname Swaziland	E-F Ecuador Egypt, Arab Rep Elsavador Equatorial Guinea Eritrea Ethiopia	T Tajikistan Tanzania Thailand Timor Leste Togo Tonga Tunisia Turkey Turkmenistan Tuvalu	U-V-W-Z Uganda Ukraine Uzbekistan Vanuatu Venezuela, RB Vietnam West Bank and Gaza Yemen, Rep Zambia Zimbabwe

Source: www.worldbank.org

Appendix 1.5 Strength and weakness for included articles

A. Qualitatitive Studies

No	Components	Strength	N=...... (Number of articles)	Weakness	N=....... (Number of articles)
1.	Title and abstract	Aims and title concise	N=8 (No.1,2,3,4,5,7,8,9,12)	Abstracts are available; however, any of the information (e.g. aims, research approach, participants, data collection, data analysis, findings) were was not well-informed.	N=8 (1,2,3,4,5,7,8,9,12)
2.	Identifying phenomenon/Interest	Well-explained in all articles	N=8 (No.1,2,3,4,5,7,8,9,12)		
3.	Structuring the study	3 articles meet this component completely	N=3 (No. 3,4,12)		
4.	Research questions and design	5 articles meet this component completely	N=5 (No. 1,2,3,4,8,9)	Data analysis strategy can't be followed	N=3 (No. 7,5,12)
5.	Participants recruitment	Ethical issue has been addressed in all articles	N=8 (No.1,2,3,4,5,7,8,9,12)	3 articles did not explain how confidentiality and anonymity were assured even though they used pseudonym.	N=3 (No.5, 9, 12)
		4 articles meet this component completely	N=4 (No. 1,4,7,8)		
6.	Data analysis process	5 articles meet this component completely	N=5 (No. 1,2,4,7,8)	1article did not mention rigour	N=1 (No. 9)
		7 articles meet rigour of research	N=7 (No. 1,2,3,4,5,7,8)		
7.	Describing the findings	8 articles meet this component completely	N=8 (No. 1,2,3,4,5,7,8,9,12)	3 articles did not mention limitation of the study	N=3 (No. 5,9,10)
8.	Researcher perspectives	3 articles meet this component completely	N=3 (3,4,7)		

B. Quantitative studies

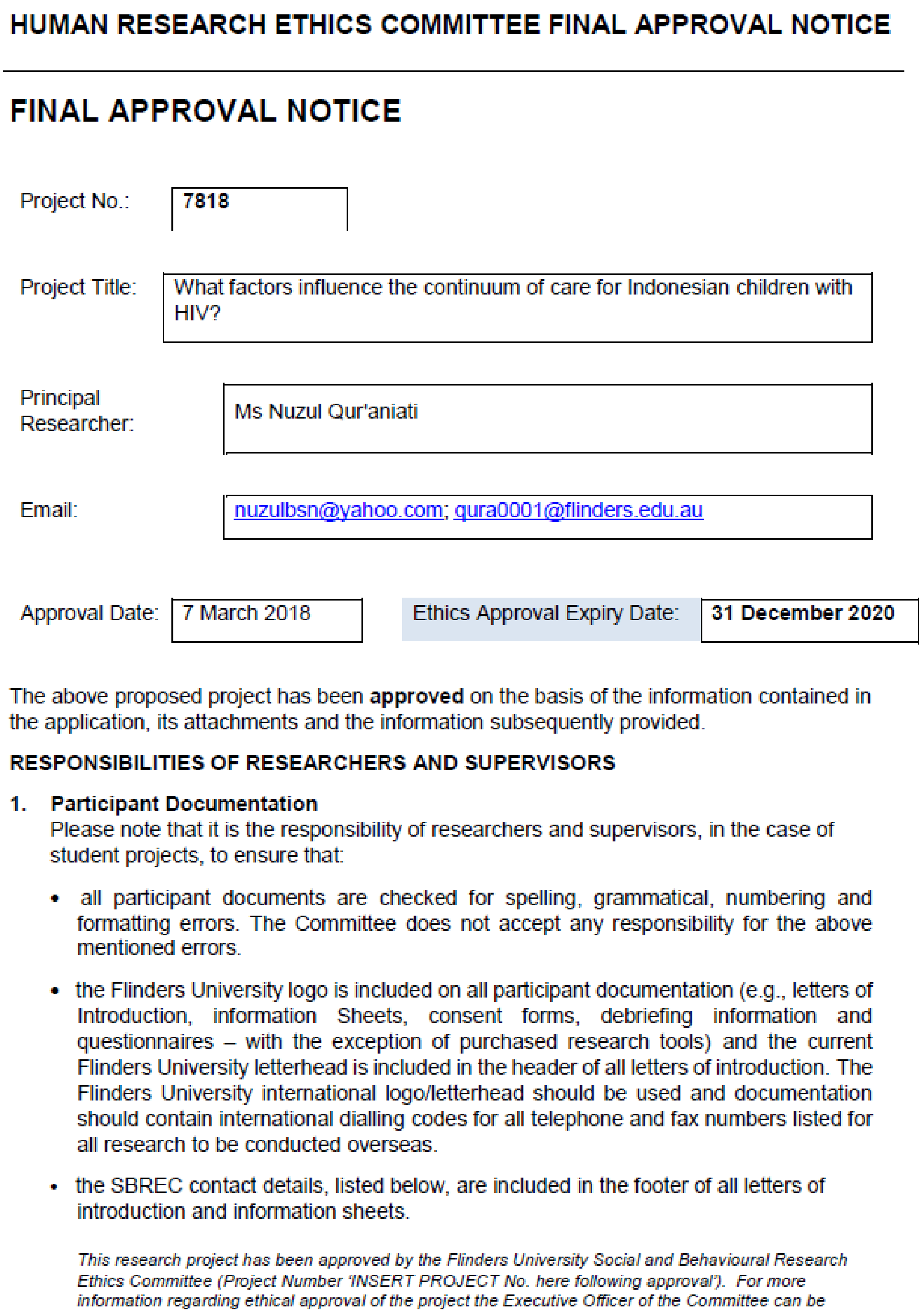
No	Components	Strength	N=...... (Number of articles)	Weakness	N=....... (Number of articles)
1.	Title and abstract	Aims and objective are concise	N=3 (No. 6,10,11)	Abstract incomplete	N=3 (No 6,10,11)
2.	Structuring the study	Limitation and gaps are well-stated	N=3 (No. 6,10,11)	Hypothesis is not well-stated	N=3 (No. 6,10,11)
3.	The sample	1 articles meet this component completely	N=1 (No. 11)		
4.	Data collection	1 articles meet this component completely	N=1 (No. 11)	Validity and reliability of instruments is not well-stated	N=1 (No. 6)
		Ethical issue has been addressed in all articles	N=3 (No. 6,10,11)		
5.	Data analysis	2 articles meet this component completely	N=2 (No. 6,10)		
6.	Finding	Well-explained in all articles	N=3 (No. 6,10,11)		

Appendix 2. Ethics approval

This study had four ethics Ethical approval from the Ethics Committee(s):

1) The Social and Behavioural Research Ethics Committee (SBREC), Flinders University
2) The hospital Rumkital Dr. Ramelan, *Jawa Timur*
3) The hospital RSUD Dr. Soetomo, *Jawa Timur*
4) The Faculty of Nursing, *Universitas Airlangga*

Appendix 2.1 Ethics approval from SBREC, Flinders University



HUMAN RESEARCH ETHICS COMMITTEE FINAL APPROVAL NOTICE

FINAL APPROVAL NOTICE

Project No.: **7818**

Project Title: What factors influence the continuum of care for Indonesian children with HIV?

Principal Researcher: Ms Nuzul Qur'aniati

Email: nuzulbsn@yahoo.com; qura0001@flinders.edu.au

Approval Date: 7 March 2018

Ethics Approval Expiry Date: **31 December 2020**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

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 ethical 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 (March 2007)* an annual progress report must be submitted each year on the **7 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 **7 March 2019** 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 complete and submit the*Modification Request Form* which is 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 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather | Monday - Friday	T: +61 8201-3116 | E: human.researchethics@flinders.edu.au
Ms Rae Tyler | Monday, Wednesday and Friday mornings	T: +61 8201-7938 | E: human.researchethics@flinders.edu.au
A/Prof David Hunter | SBREC Chairperson	T: +61 7221-8477 | E: david.hunter@flinders.edu.au
Dr Deb Agnew | SBREC Deputy Chairperson	T: +61 8201-3456 E: deb.agnew@flinders.edu.au
Dr Peter Wigley | Manager, Research Ethics and Integrity	T: +61 8201-5466 | E: peter.wigley@flinders.edu.au
SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

Research Development and Support |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

MODIFICATION (No.1) APPROVAL NOTICE

Project No.:	**7818**
Project Title:	What factors influence the continuum of care for Indonesian children with HIV?
Principal Researcher:	Ms Nuzul Qur'aniati
Email:	nuzulbsn@yahoo.com; qura0001@flinders.edu.au

Modification Approval Date:	12 July 2018	Ethics Approval Expiry Date:	**31 December 2020**

I am pleased to inform you that the modification request submitted for project 7818 on the 9 July 2018 has been reviewed and approved by the SBREC Chairperson. Please see below for a list of the approved modifications. Any additional information that may be required from you will be listed in the second table shown below called 'Additional Information Required'.

Approved Modifications	
Extension of ethics approval expiry date	
Project title change	
Personnel change	X
Research objectives change	
Research method change	
Participants – addition +/- change	
Consent process change	
Recruitment process change	
Research tools change	
Document / Information Changes	X
Other (if yes, please specify)	X

Addition of translation service for transcribed interview text

Additional Information Required
None.

MODIFICATION (No.2) APPROVAL NOTICE

Project No.: 7818

Project Title: Indonesian Children with Human Immunodeficiency Virus (HIV) and Their Families' Experiences of Care across the Continuum

Principal Researcher: Ms Nuzul Qur'aniati

Email: nuzulbsn@yahoo.com; qura0001@flinders.edu.au

Modification Approval Date: 3 July 2020

Ethics Approval Expiry Date: 31 December 2020

I am pleased to inform you that the modification request submitted for project 7818 on the 3 July 2020 has been reviewed and approved by the Chairperso. A summary of the approved modifications are listed below. Any additional information that may be required from you will be listed in the second table shown below called 'Additional Information Required'.

Approved Modifications	
Extension of ethics approval expiry date	
Project title change	*
Personnel change	
Research objectives change	
Research method change	
Participants – addition +/- change	
Consent process change	
Recruitment process change	
Research tools change	
Document / Information Changes	
Other (if yes, please specify)	

Additional Information Required
None.

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.

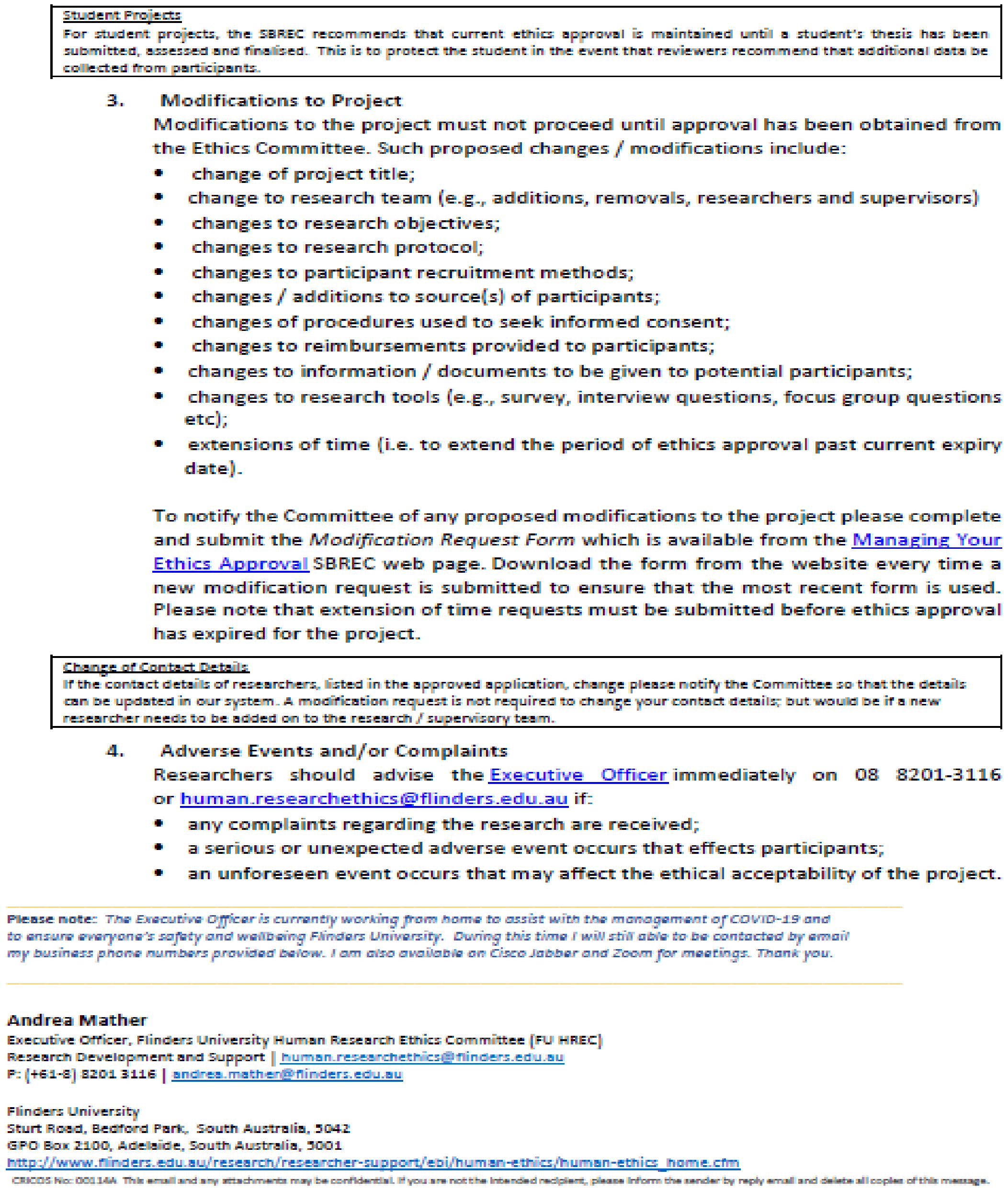
2. **Annual Progress / Final Reports**

   In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)*; please be reminded that; an annual progress report must be submitted each year on the 7 March (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval web page.

   Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

   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 either submit (1) a final report; or (2) an extension of time request (using the modification request form).

Next Report Due Date:	**7 March 2021**
Final Report Due Date:	**31 December 2020**



Student Projects
For student projects, the SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

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, researchers and supervisors)
- 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 to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is 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 must be submitted before ethics approval has expired for the project.

Change of Contact Details
If the contact details of researchers, listed in the approved application, change please notify the Committee so that the details can be updated in our system. A modification request is not required to change your contact details; but would be if a new researcher needs to be added on to the research / supervisory team.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer immediately on 08 8201-3116 or human.researchethics@flinders.edu.au if:

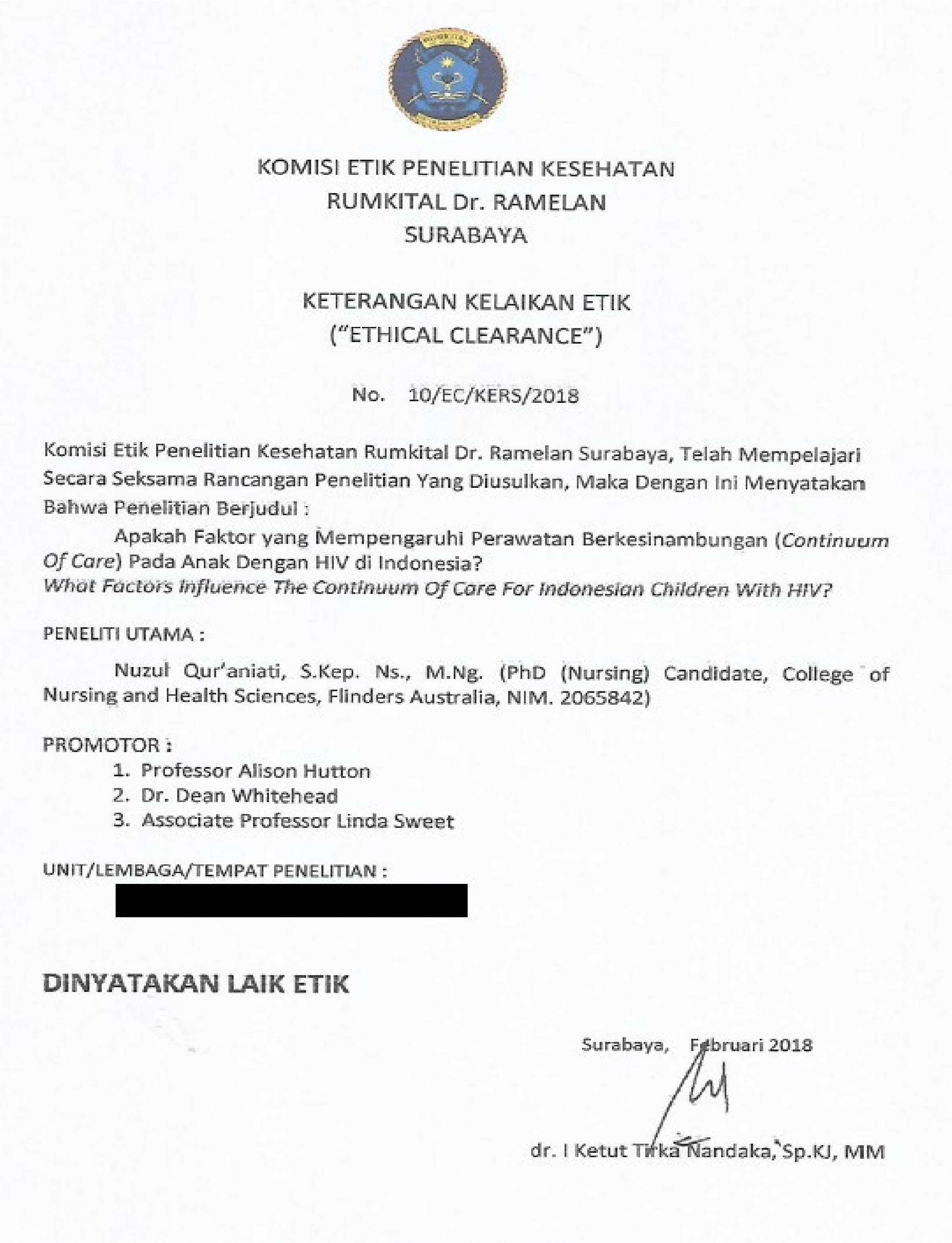
- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Please note: *The Executive Officer is currently working from home to assist with the management of COVID-19 and to ensure everyone's safety and wellbeing Flinders University. During this time I will still able to be contacted by email my business phone numbers provided below. I am also available on Cisco Jabber and Zoom for meetings. Thank you.*

Andrea Mather
Executive Officer, Flinders University Human Research Ethics Committee (FU HREC)
Research Development and Support | human.researchethics@flinders.edu.au
P: (+61-8) 8201 3116 | andrea.mather@flinders.edu.au

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001
http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

Appendix 2.2 Ethics approval from Rumkital Dr. Ramelan Hospital



KOMISI ETIK PENELITIAN KESEHATAN
RUMKITAL Dr. RAMELAN
SURABAYA

KETERANGAN KELAIKAN ETIK
("ETHICAL CLEARANCE")

No. 10/EC/KERS/2018

Komisi Etik Penelitian Kesehatan Rumkital Dr. Ramelan Surabaya, Telah Mempelajari Secara Seksama Rancangan Penelitian Yang Diusulkan, Maka Dengan Ini Menyatakan Bahwa Penelitian Berjudul :

Apakah Faktor yang Mempengaruhi Perawatan Berkesinambungan (*Continuum Of Care*) Pada Anak Dengan HIV di Indonesia?
What Factors Influence The Continuum Of Care For Indonesian Children With HIV?

PENELITI UTAMA :

Nuzul Qur'aniati, S.Kep. Ns., M.Ng. (PhD (Nursing) Candidate, College of Nursing and Health Sciences, Flinders Australia, NIM. 2065842)

PROMOTOR :
1. Professor Alison Hutton
2. Dr. Dean Whitehead
3. Associate Professor Linda Sweet

UNIT/LEMBAGA/TEMPAT PENELITIAN :

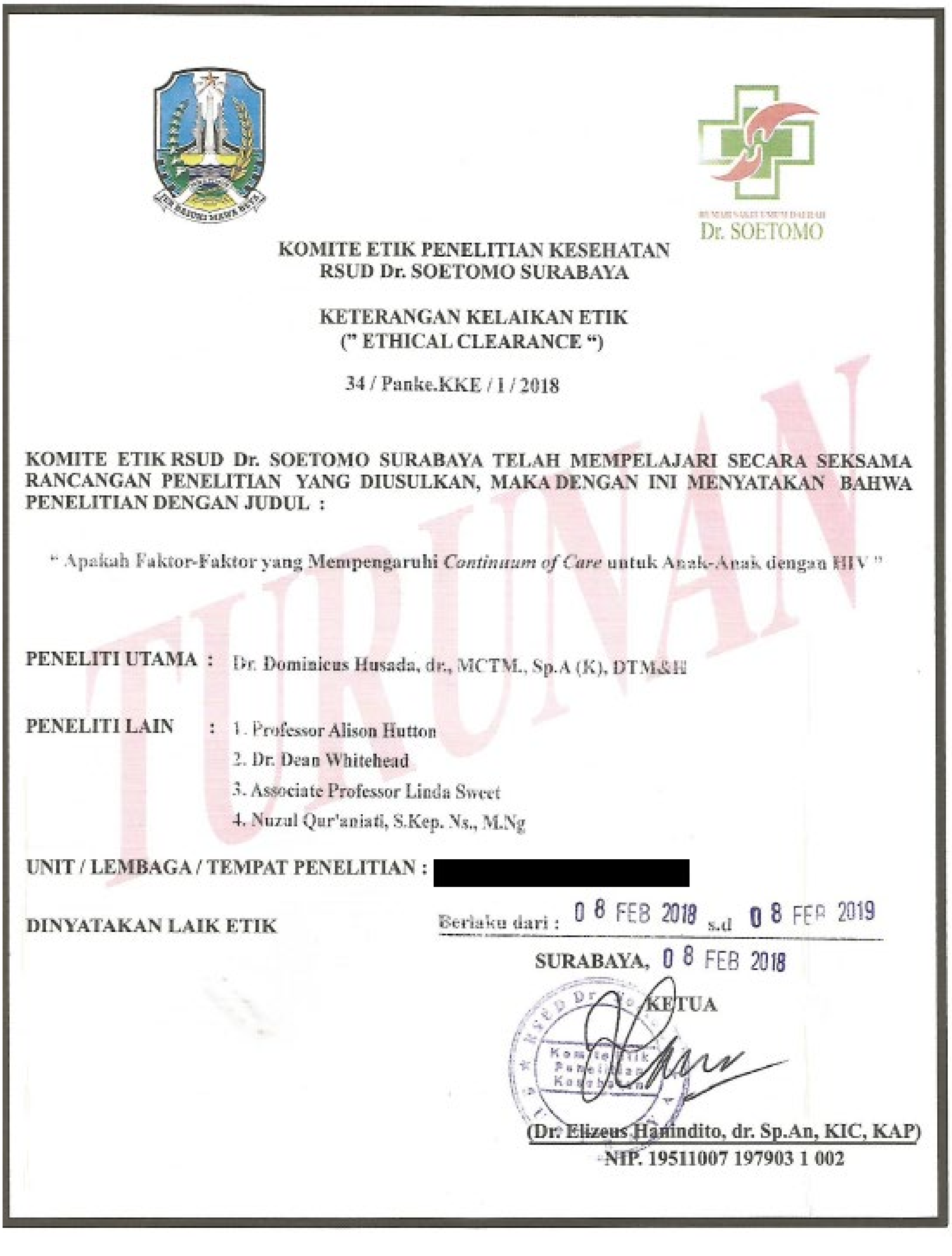
[redacted]

DINYATAKAN LAIK ETIK

Surabaya, Februari 2018

dr. I Ketut Tirka Nandaka, Sp.KJ, MM

Appendix 2.3 Ethics approval from RSUD Dr. Soetomo Hospital



RUMAH SAKIT UMUM DAERAH
Dr. SOETOMO

KOMITE ETIK PENELITIAN KESEHATAN
RSUD Dr. SOETOMO SURABAYA

KETERANGAN KELAIKAN ETIK
(" ETHICAL CLEARANCE ")

34 / Panke.KKE / I / 2018

KOMITE ETIK RSUD Dr. SOETOMO SURABAYA TELAH MEMPELAJARI SECARA SEKSAMA RANCANGAN PENELITIAN YANG DIUSULKAN, MAKA DENGAN INI MENYATAKAN BAHWA PENELITIAN DENGAN JUDUL :

" Apakah Faktor-Faktor yang Mempengaruhi *Continuum of Care* untuk Anak-Anak dengan HIV "

PENELITI UTAMA : Dr. Dominicus Husada, dr., MCTM., Sp.A (K), DTM&H

PENELITI LAIN :
1. Professor Alison Hutton
2. Dr. Dean Whitehead
3. Associate Professor Linda Sweet
4. Nuzul Qur'aniati, S.Kep. Ns., M.Ng

UNIT / LEMBAGA / TEMPAT PENELITIAN : [redacted]

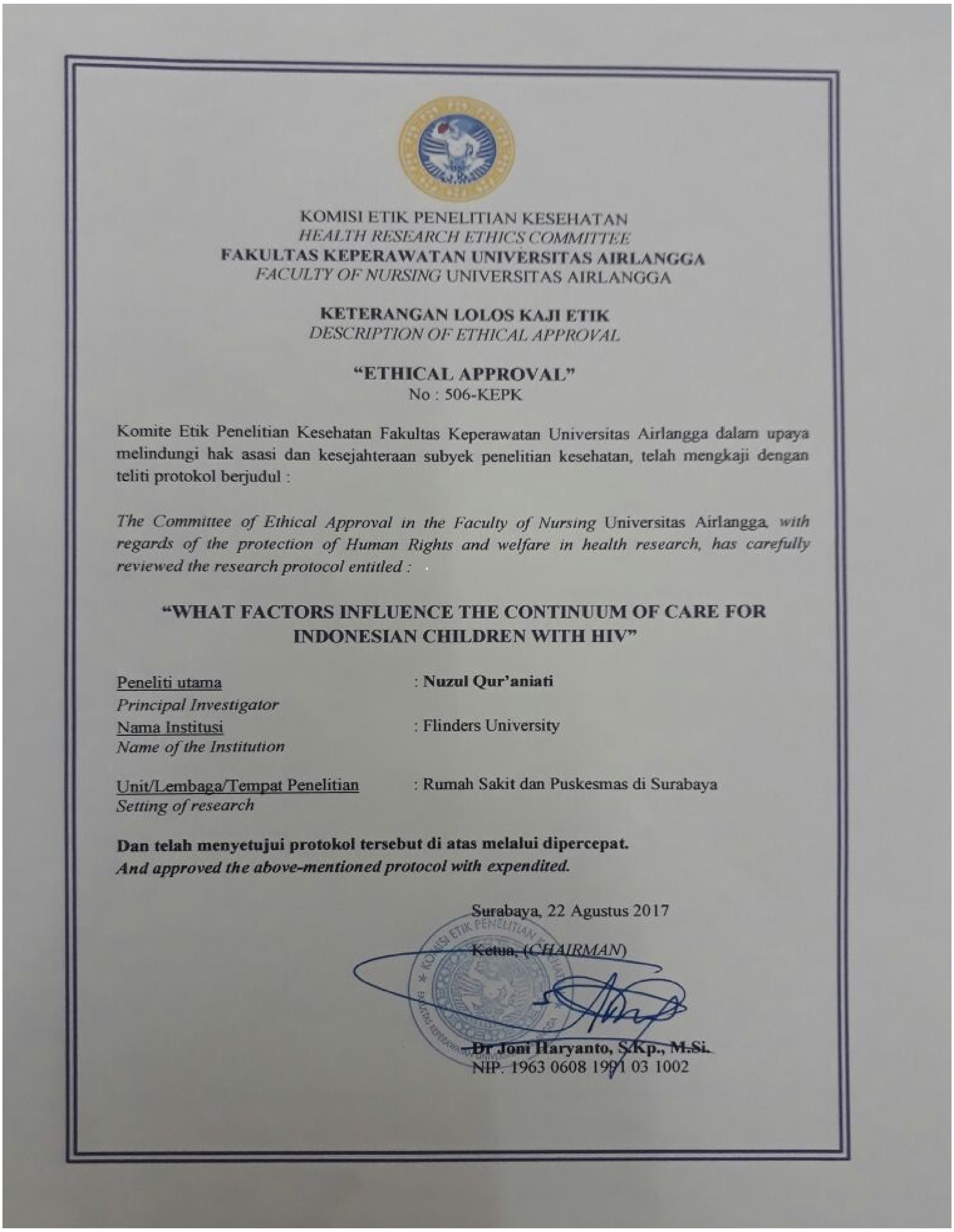
DINYATAKAN LAIK ETIK Berlaku dari : 0 8 FEB 2018 s.d 0 8 FEB 2019

SURABAYA, 0 8 FEB 2018

KETUA

(Dr. Elizeus Hanindito, dr. Sp.An, KIC, KAP)
NIP. 19511007 197903 1 002

Appendix 2.4 Ethics approval from Faculty of Nursing, *Universitas Airlangga*



KOMISI ETIK PENELITIAN KESEHATAN
HEALTH RESEARCH ETHICS COMMITTEE
FAKULTAS KEPERAWATAN UNIVERSITAS AIRLANGGA
FACULTY OF NURSING UNIVERSITAS AIRLANGGA

KETERANGAN LOLOS KAJI ETIK
DESCRIPTION OF ETHICAL APPROVAL

"ETHICAL APPROVAL"
No : 506-KEPK

Komite Etik Penelitian Kesehatan Fakultas Keperawatan Universitas Airlangga dalam upaya melindungi hak asasi dan kesejahteraan subyek penelitian kesehatan, telah mengkaji dengan teliti protokol berjudul :

The Committee of Ethical Approval in the Faculty of Nursing Universitas Airlangga, *with regards of the protection of Human Rights and welfare in health research, has carefully reviewed the research protocol entitled :*

"WHAT FACTORS INFLUENCE THE CONTINUUM OF CARE FOR INDONESIAN CHILDREN WITH HIV"

Peneliti utama *Principal Investigator*	: **Nuzul Qur'aniati**
Nama Institusi *Name of the Institution*	: Flinders University
Unit/Lembaga/Tempat Penelitian *Setting of research*	: Rumah Sakit dan Puskesmas di Surabaya

Dan telah menyetujui protokol tersebut di atas melalui dipercepat.
And approved the above-mentioned protocol with expendited.

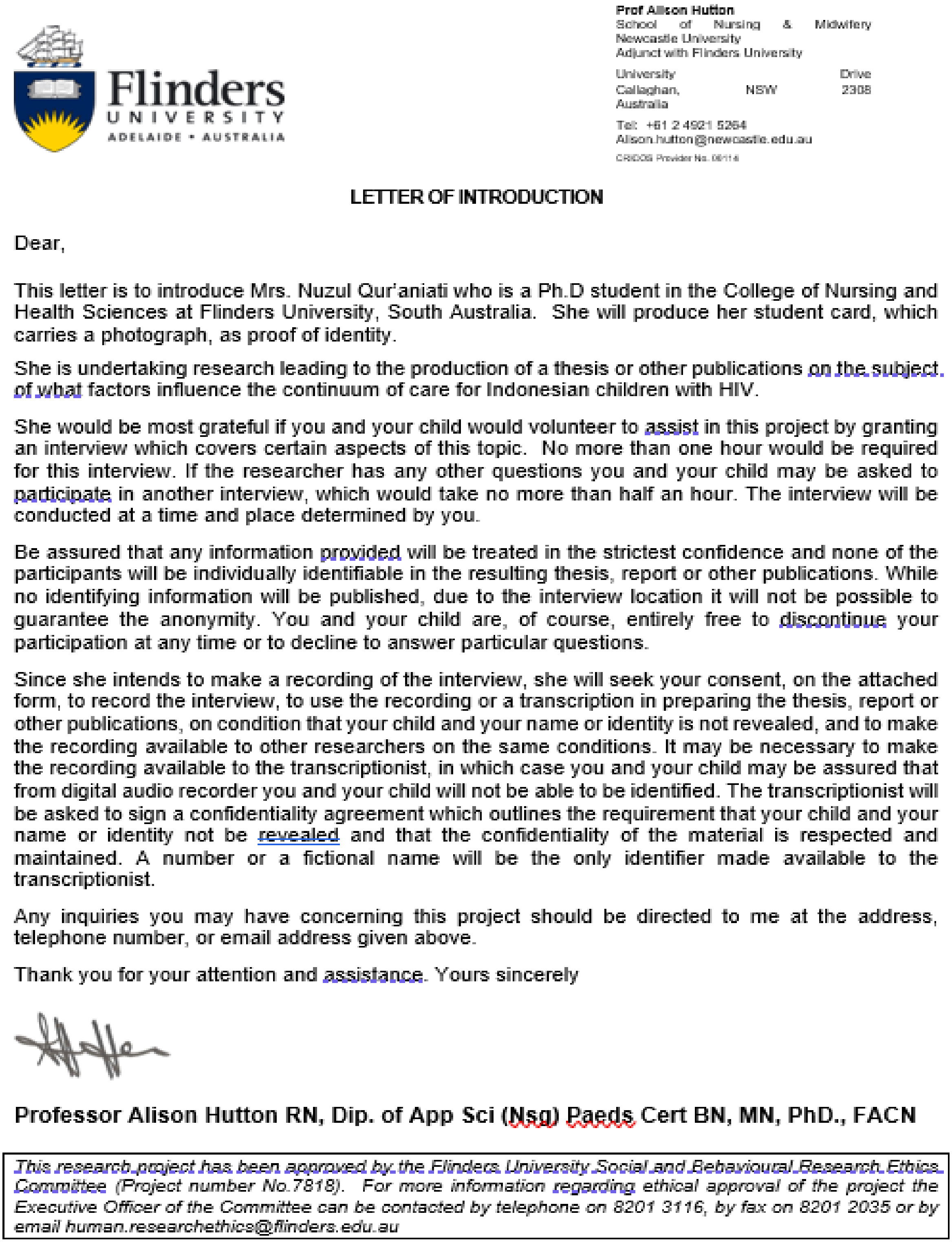
Surabaya, 22 Agustus 2017
Ketua, (*CHAIRMAN*)

Dr Joni Haryanto, S.Kp., M.Si.
NIP. 1963 0608 1991 03 1002

Appendix 3. Research information package for children with HIV and their families and health professionals

1) Letter of Introduction
2) Letter of Introduction (Indonesian Language)
3) Information sheet (English)
4) Information sheet (Indonesian language)
5) Consent Form for participation in research (English)
6) Consent Form for participation in research (Indonesian language)
7) Parental consent form
8) Parental consent form (Indonesian Language
9) Interview guideline for children with HIV and their families (English)
10) Interview guideline for health professionals (English)
11) Interview guideline for children with HIV and their families (Indonesian language)
12) Interview guideline for health professionals (Indonesian language)
13) Flyer for children with HIV and their families (English)
14) Flyer for children for health professionals (English)
15) Flyer for children with HIV and their families (Indonesian language)
16) Flyer for health professionals (Indonesian language)

Appendix 3.1 Letter of introduction



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Tel: +61 2 4921 5264
Alison.hutton@newcastle.edu.au

CRICOS Provider No. 00114

LETTER OF INTRODUCTION

Dear,

This letter is to introduce Mrs. Nuzul Qur'aniati who is a Ph.D student in the College of Nursing and Health Sciences at Flinders University, South Australia. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of what factors influence the continuum of care for Indonesian children with HIV.

She would be most grateful if you and your child would volunteer to assist in this project by granting an interview which covers certain aspects of this topic. No more than one hour would be required for this interview. If the researcher has any other questions you and your child may be asked to participate in another interview, which would take no more than half an hour. The interview will be conducted at a time and place determined by you.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. While no identifying information will be published, due to the interview location it will not be possible to guarantee the anonymity. You and your child are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make a recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your child and your name or identity is not revealed, and to make the recording available to other researchers on the same conditions. It may be necessary to make the recording available to the transcriptionist, in which case you and your child may be assured that from digital audio recorder you and your child will not be able to be identified. The transcriptionist will be asked to sign a confidentiality agreement which outlines the requirement that your child and your name or identity not be revealed and that the confidentiality of the material is respected and maintained. A number or a fictional name will be the only identifier made available to the transcriptionist.

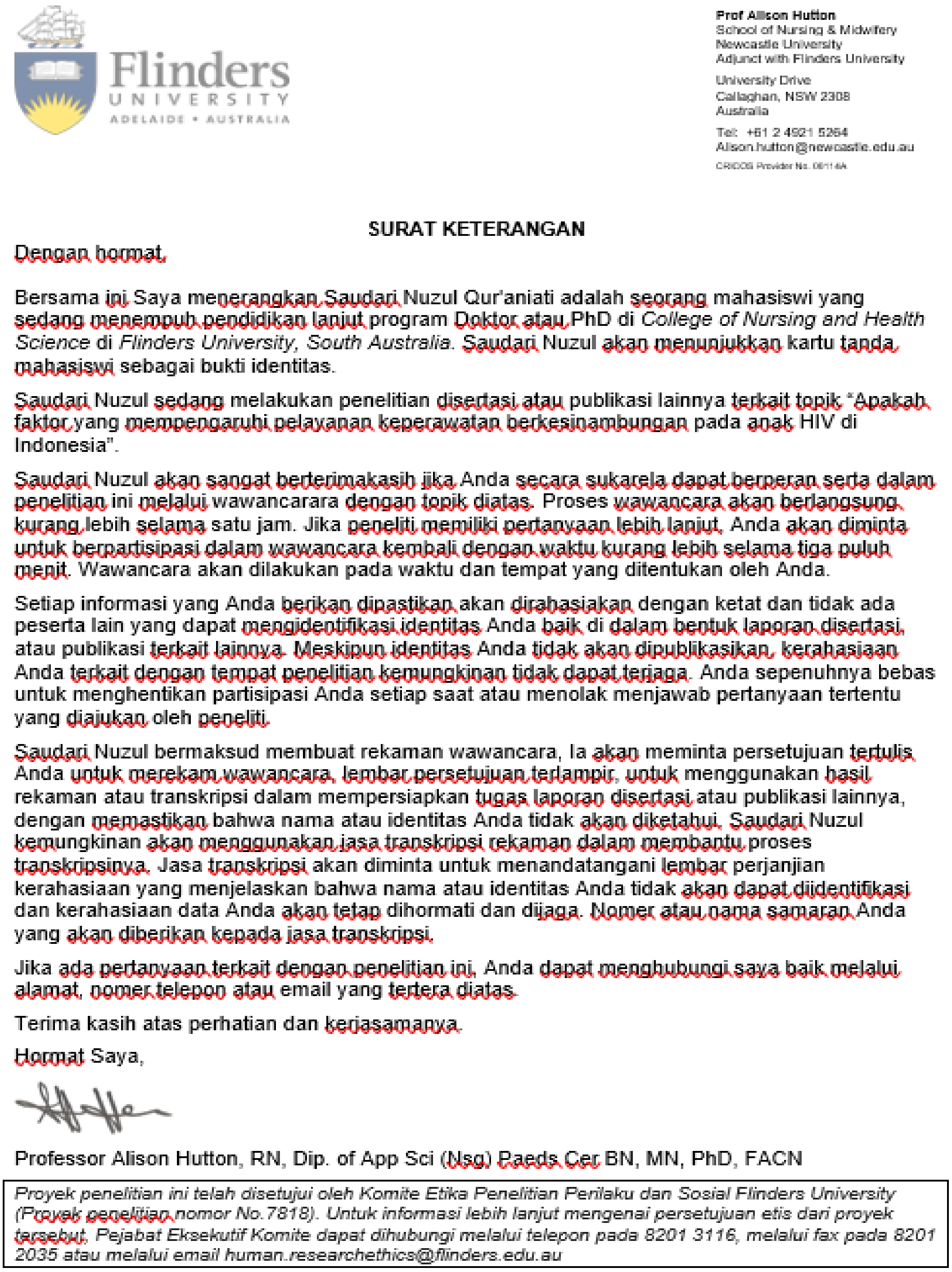
Any inquiries you may have concerning this project should be directed to me at the address, telephone number, or email address given above.

Thank you for your attention and assistance. Yours sincerely

Professor Alison Hutton RN, Dip. of App Sci (Nsg) Paeds Cert BN, MN, PhD., FACN

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number No.7818). For more information regarding ethical 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

Appendix 3.2 Letter of introduction (Indonesian language)



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SURAT KETERANGAN

Dengan hormat,

Bersama ini Saya menerangkan Saudari Nuzul Qur'aniati adalah seorang mahasiswi yang sedang menempuh pendidikan lanjut program Doktor atau PhD di *College of Nursing and Health Science* di *Flinders University, South Australia*. Saudari Nuzul akan menunjukkan kartu tanda mahasiswi sebagai bukti identitas.

Saudari Nuzul sedang melakukan penelitian disertasi atau publikasi lainnya terkait topik "Apakah faktor yang mempengaruhi pelayanan keperawatan berkesinambungan pada anak HIV di Indonesia".

Saudari Nuzul akan sangat berterimakasih jika Anda secara sukarela dapat berperan serta dalam penelitian ini melalui wawancarara dengan topik diatas. Proses wawancara akan berlangsung kurang lebih selama satu jam. Jika peneliti memiliki pertanyaan lebih lanjut, Anda akan diminta untuk berpartisipasi dalam wawancara kembali dengan waktu kurang lebih selama tiga puluh menit. Wawancara akan dilakukan pada waktu dan tempat yang ditentukan oleh Anda.

Setiap informasi yang Anda berikan dipastikan akan dirahasiakan dengan ketat dan tidak ada peserta lain yang dapat mengidentifikasi identitas Anda baik di dalam bentuk laporan disertasi, atau publikasi terkait lainnya. Meskipun identitas Anda tidak akan dipublikasikan, kerahasiaan Anda terkait dengan tempat penelitian kemungkinan tidak dapat terjaga. Anda sepenuhnya bebas untuk menghentikan partisipasi Anda setiap saat atau menolak menjawab pertanyaan tertentu yang diajukan oleh peneliti.

Saudari Nuzul bermaksud membuat rekaman wawancara, Ia akan meminta persetujuan tertulis Anda untuk merekam wawancara, lembar persetujuan terlampir, untuk menggunakan hasil rekaman atau transkripsi dalam mempersiapkan tugas laporan disertasi atau publikasi lainnya, dengan memastikan bahwa nama atau identitas Anda tidak akan diketahui. Saudari Nuzul kemungkinan akan menggunakan jasa transkripsi rekaman dalam membantu proses transkripsinya. Jasa transkripsi akan diminta untuk menandatangani lembar perjanjian kerahasiaan yang menjelaskan bahwa nama atau identitas Anda tidak akan dapat diidentifikasi dan kerahasiaan data Anda akan tetap dihormati dan dijaga. Nomer atau nama samaran Anda yang akan diberikan kepada jasa transkripsi.

Jika ada pertanyaan terkait dengan penelitian ini, Anda dapat menghubungi saya baik melalui alamat, nomer telepon atau email yang tertera diatas.

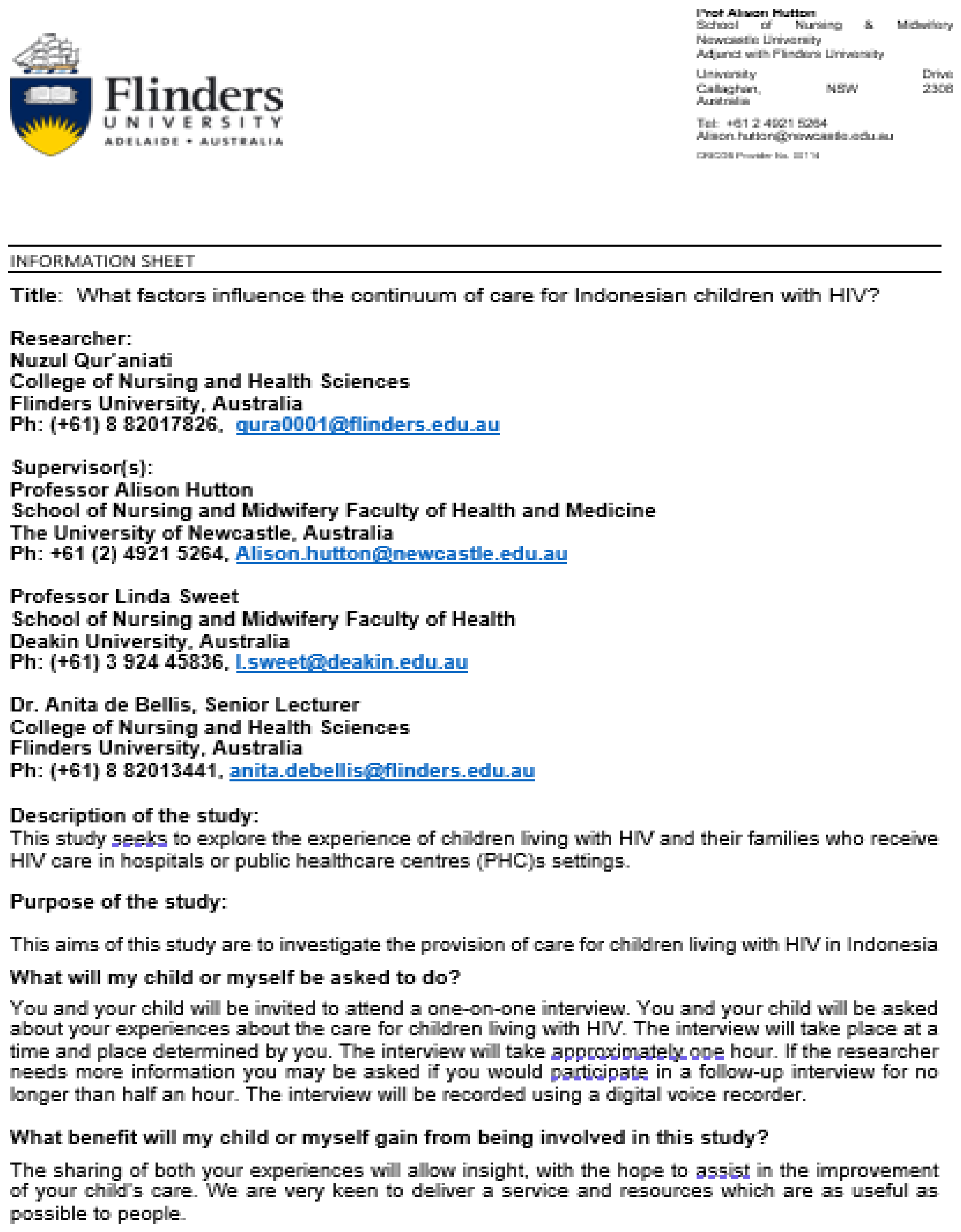
Terima kasih atas perhatian dan kerjasamanya.

Hormat Saya,

Professor Alison Hutton, RN, Dip. of App Sci (Nsg) Paeds Cer BN, MN, PhD, FACN

Proyek penelitian ini telah disetujui oleh Komite Etika Penelitian Perilaku dan Sosial Flinders University (Proyek penelitian nomor No.7818). Untuk informasi lebih lanjut mengenai persetujuan etis dari proyek tersebut, Pejabat Eksekutif Komite dapat dihubungi melalui telepon pada 8201 3116, melalui fax pada 8201 2035 atau melalui email human.researchethics@flinders.edu.au

Appendix 3.3 Information sheets



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CRICOS Provider No. 00114

INFORMATION SHEET

Title: What factors influence the continuum of care for Indonesian children with HIV?

Researcher:
Nuzul Qur'aniati
College of Nursing and Health Sciences
Flinders University, Australia
Ph: (+61) 8 82017826, qura0001@flinders.edu.au

Supervisor(s):
Professor Alison Hutton
School of Nursing and Midwifery Faculty of Health and Medicine
The University of Newcastle, Australia
Ph: +61 (2) 4921 5264, Alison.hutton@newcastle.edu.au

Professor Linda Sweet
School of Nursing and Midwifery Faculty of Health
Deakin University, Australia
Ph: (+61) 3 924 45836, l.sweet@deakin.edu.au

Dr. Anita de Bellis, Senior Lecturer
College of Nursing and Health Sciences
Flinders University, Australia
Ph: (+61) 8 82013441, anita.debellis@flinders.edu.au

Description of the study:
This study seeks to explore the experience of children living with HIV and their families who receive HIV care in hospitals or public healthcare centres (PHC)s settings.

Purpose of the study:

This aims of this study are to investigate the provision of care for children living with HIV in Indonesia

What will my child or myself be asked to do?

You and your child will be invited to attend a one-on-one interview. You and your child will be asked about your experiences about the care for children living with HIV. The interview will take place at a time and place determined by you. The interview will take approximately one hour. If the researcher needs more information you may be asked if you would participate in a follow-up interview for no longer than half an hour. The interview will be recorded using a digital voice recorder.

What benefit will my child or myself gain from being involved in this study?

The sharing of both your experiences will allow insight, with the hope to assist in the improvement of your child's care. We are very keen to deliver a service and resources which are as useful as possible to people.

Will my child or myself be identifiable by being involved in this study?

Your child and your identity will remain confidential throughout the study and in any publications or presentation of the final results. While no identifying information will be published, due to the interview location it will not be possible to guarantee anonymity.

Once the interview has been typed-up and saved as a file, the voice file will then be destroyed. Any identifying information will be removed and the typed-up file stored on a password-protected computer that only the researcher and the research supervisors will have access to. Your comments will not be linked directly to you.

Are there any risks or discomforts if I am involved?

Within this interview both of you and your child may be asked questions that may be of a sensitive nature. If during the interview, either of you experience emotional discomfort or have any questions regarding anticipated or actual risks or discomforts, please raise them with the researcher. The interview can be stopped at any time. Should both of you need support, free counseling and support services is provided without referral. This is free service *HIV Counselling Service, Dr. Soetomo Hospital Phone: (+62) 31 5501435/ 5501436.*

How do I agree to participate?

Being is this study is voluntary. You and your child may answer 'no comment' or not to answer any questions. You are free to withdraw from the interviews at any time without consequences. There is a consent form with this information sheet. If you agree to participate please, you contact me on +62 821 32439529.

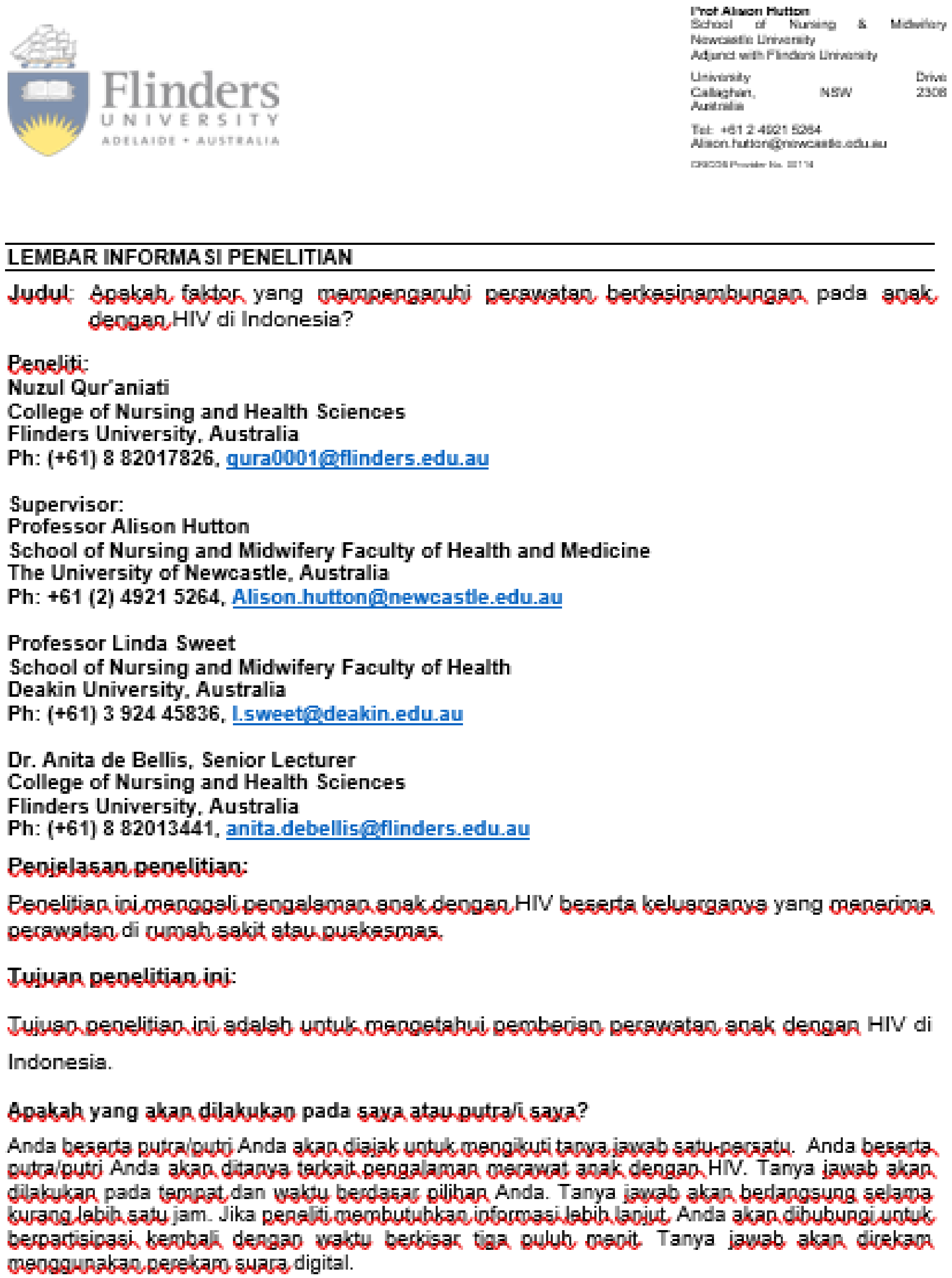
How will I receive feedback?

If you would like to see what the study found let the researcher know and she will send them to you via post or email.

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 No.7818). For more information regarding ethical 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

Appendix 3.4 Information sheets (Indonesian language)



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CRICOS Provider No. 00114

LEMBAR INFORMASI PENELITIAN

Judul: Apakah faktor yang mempengaruhi perawatan berkesinambungan pada anak dengan HIV di Indonesia?

Peneliti:
Nuzul Qur'aniati
College of Nursing and Health Sciences
Flinders University, Australia
Ph: (+61) 8 82017826, qura0001@flinders.edu.au

Supervisor:
Professor Alison Hutton
School of Nursing and Midwifery Faculty of Health and Medicine
The University of Newcastle, Australia
Ph: +61 (2) 4921 5264, Alison.hutton@newcastle.edu.au

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Deakin University, Australia
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Dr. Anita de Bellis, Senior Lecturer
College of Nursing and Health Sciences
Flinders University, Australia
Ph: (+61) 8 82013441, anita.debellis@flinders.edu.au

Penjelasan penelitian:

Penelitian ini menggali pengalaman anak dengan HIV beserta keluarganya yang menerima perawatan di rumah sakit atau puskesmas.

Tujuan penelitian ini:

Tujuan penelitian ini adalah untuk mengetahui pemberian perawatan anak dengan HIV di Indonesia.

Apakah yang akan dilakukan pada saya atau putra/i saya?

Anda beserta putra/putri Anda akan diajak untuk mengikuti tanya jawab satu-persatu. Anda beserta putra/putri Anda akan ditanya terkait pengalaman merawat anak dengan HIV. Tanya jawab akan dilakukan pada tempat dan waktu berdasar pilihan Anda. Tanya jawab akan berlangsung selama kurang lebih satu jam. Jika peneliti membutuhkan informasi lebih lanjut, Anda akan dihubungi untuk berpartisipasi kembali dengan waktu berkisar tiga puluh menit. Tanya jawab akan direkam menggunakan perekam suara digital.

Apakah manfaat yang saya atau putra/i saya dapatkan dari keterlibatan dalam penelitian ini?

Hasil informasi pengalaman Anda beserta putra/putri Anda akan meningkatkan wawasan, dengan harapan dapat membantu peningkatan perawatan putra/i Anda. Kami sangat berharap dapat memberikan pelayanan yang berguna bagi masyarakat.

Apakah saya atau putra/i saya dapat dikenali ketika terlibat dalam penelitian ini?

Identitas Anda beserta putra/i Anda akan senantiasa dirahasiakan baik pada saat penelitian, dan segala bentuk publikasi lain ataupun presentasi hasil akhir. Meskipun identitas putra/putri Anda tidak akan dipublikasikan, namun terkait dengan lokasi wawancara kemungkinan kerahasiaan Anda beserta putra/putri Anda tidak dapat terjaga.

Setelah hasil tanya jawab diketik dan disimpan dalam sebuah file, rekaman suara akan dimusnahkan. Segala bentuk identitas akan dihapus dan data file akan disimpan pada komputer yang dilindungi dengan kata sandi serta peneliti dan pembimbing yang dapat mengaksesnya. Segala informasi Anda beserta putra/putri Anda tidak akan terhubung secara langsung dengan Anda. Komentar Anda tidak akan berhubungan dengan Anda secara langsung.

Apakah resiko atau ketidaknyamanan jika saya terlibat dalam penelitian ini?

Dalam tanya jawab Anda beserta putra/putri Anda akan ditanyakan pertanyaan yang mungkin bersifat sensitive. Jika selama tanya jawab, Anda atau putra/i Anda mengalami ketidaknyamanan emosi atau mempunyai pertanyaan terkait ketidaknyamanan tersebut silahkan diinformasikan kepada peneliti. Tanya jawab dapat dihentikan setiap saat. Jika membutuhkan penanganan, Anda beserta putra/putri dapat menghubungi layanan konseling gratis tanpa rujukan yang telah disediakan, yaitu: *Pelayanan Konseling HIV, RS. Dr. SoetomoTelepon: (031) 5501435/ 5501436.*

Bagaimana jika saya setuju untuk berperan serta?

Keikutsertaan dalam penelitian ini bersifat sukarela. Anda beserta putra/i Anda dapat "tidak berkomentar" atau tidak menjawab beberapa pertanyaan yang diajukan dan bebas untuk mengundurkan diri dari proses tanya jawab kapan saja tanpa efek samping apapun. Terdapat lembar penjelasan penelitian beserta lembar persetujuan. Jika anda setuju untuk berpartisipasi, mohon berkenan untuk mengubungi peneliti di +62 821 32439529.

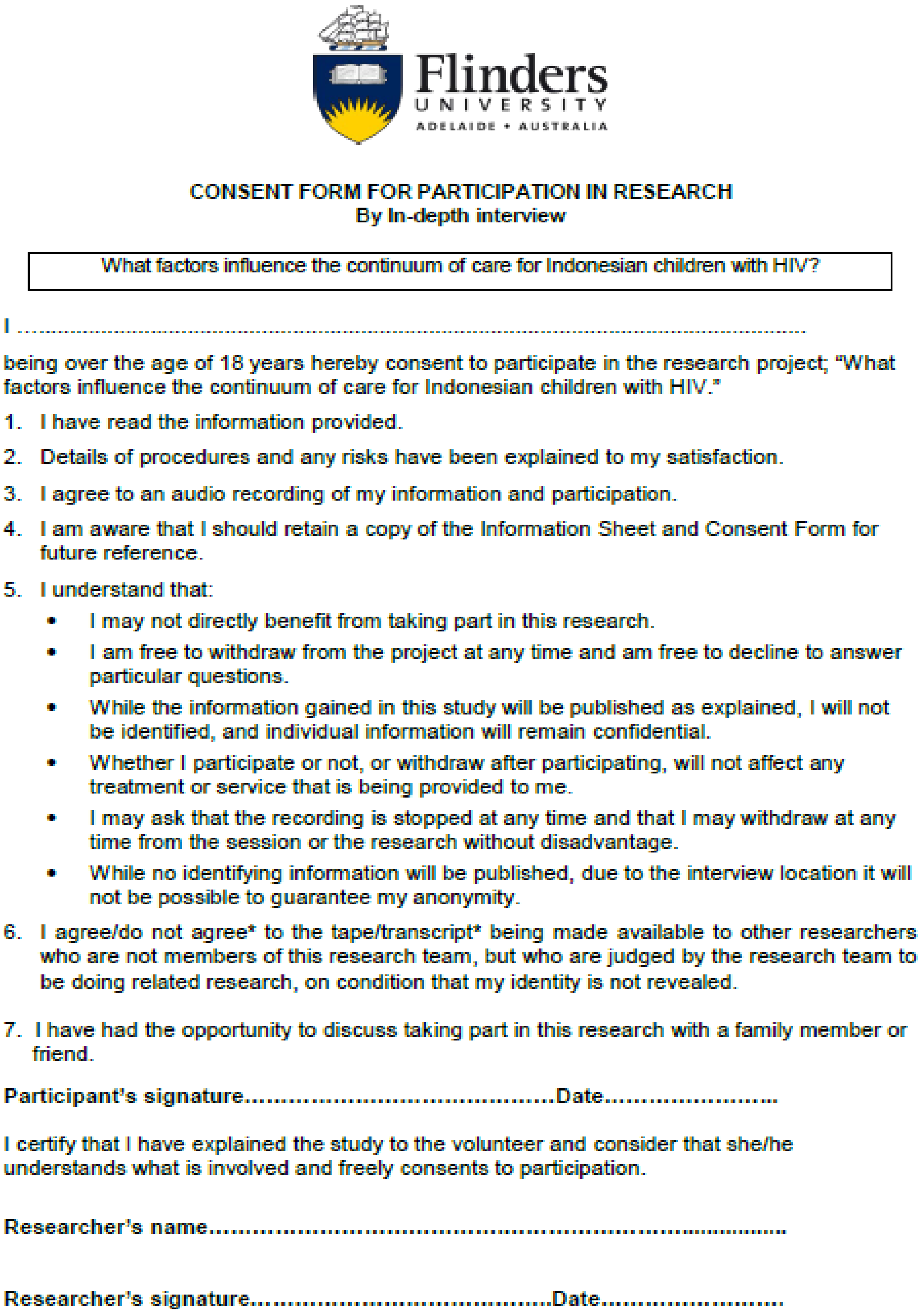
Bagaimana saya akan menerima umpan balik?

Jika Anda berkeinginan untuk mengetahui hasil penelitian, Anda dapat memberitahu peneliti dan Ia akan mengirimkannya kepada Anda melalui pos atau email.

Terima kasih telah meluangkan waktu untuk membaca lembar informasi ini dan kami berharap Anda dapat menerima ajakan kami untuk terlibat dalam penelitian ini.

Proyek penelitian ini telah disetujui oleh Komite Etika Penelitian Perilaku Sosial Flinders University (Proyek penelitian nomor No.7818). Untuk informasi lebih lanjut mengenai persetujuan etis dari proyek tersebut, Pejabat Eksekutif Komite dapat dihubungi melalui telepon pada 8201 3116, melalui fax pada 8201 2035 atau melalui email human.researchethics@flinders.edu.au.

Appendix 3.5 Consent form for participation in research



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CONSENT FORM FOR PARTICIPATION IN RESEARCH
By In-depth interview

What factors influence the continuum of care for Indonesian children with HIV?

I ……

being over the age of 18 years hereby consent to participate in the research project; "What factors influence the continuum of care for Indonesian children with HIV."

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to an 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.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will not affect any treatment or service that is being provided to me.
    - I may ask that the recording is stopped at any time and that I may withdraw at any time from the session or the research without disadvantage.
    - While no identifying information will be published, due to the interview location it will not be possible to guarantee my anonymity.
6. I agree/do not agree* to the tape/transcript* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.

7. I have had the opportunity to discuss taking part in this research with a family member or friend.

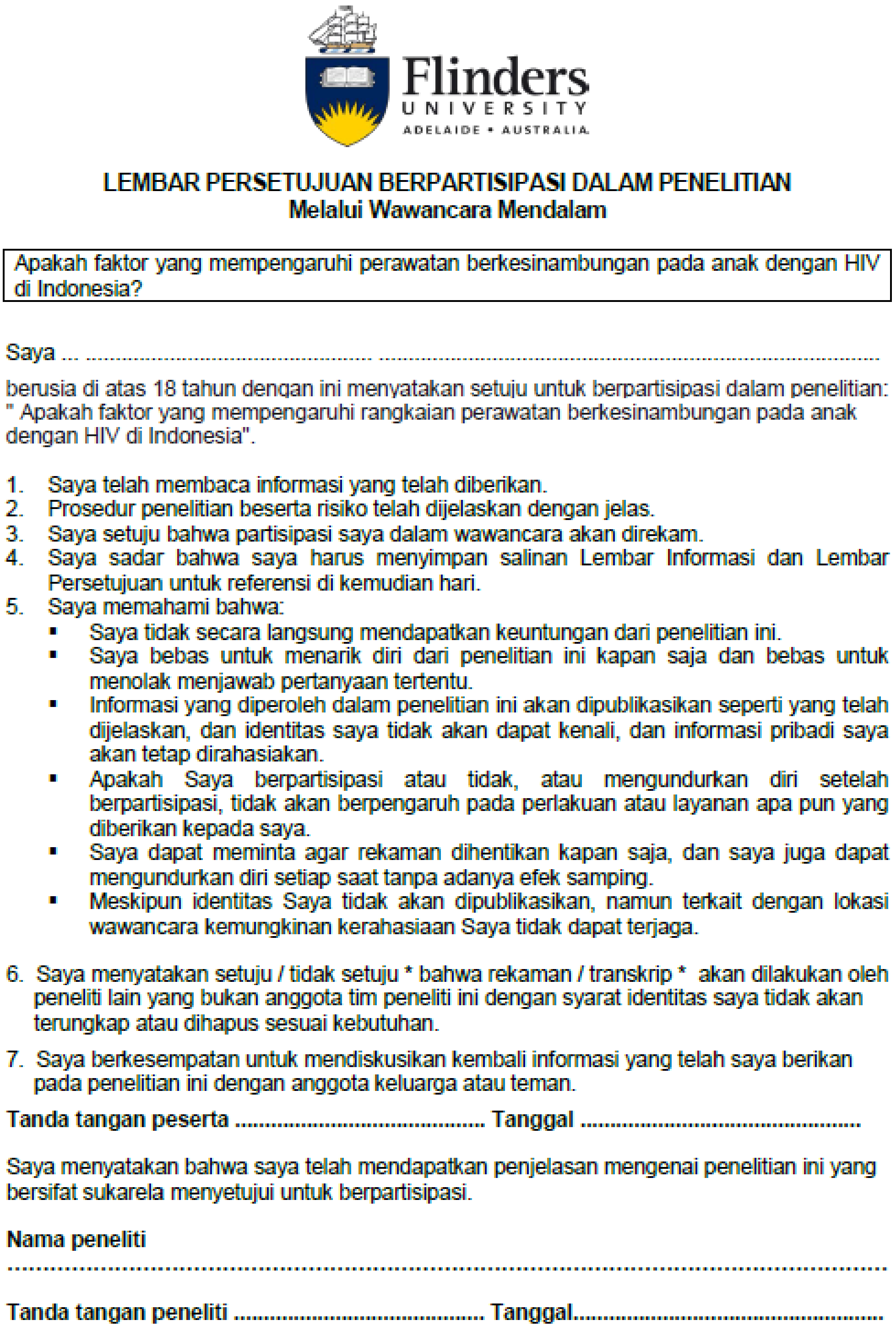
Participant's signature……………………………………Date……………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………………………………

Researcher's signature……………………………………Date……………………

Appendix 3.6 Consent form (Indonesian language)



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LEMBAR PERSETUJUAN BERPARTISIPASI DALAM PENELITIAN
Melalui Wawancara Mendalam

Apakah faktor yang mempengaruhi perawatan berkesinambungan pada anak dengan HIV di Indonesia?

Saya ... .

berusia di atas 18 tahun dengan ini menyatakan setuju untuk berpartisipasi dalam penelitian: " Apakah faktor yang mempengaruhi rangkaian perawatan berkesinambungan pada anak dengan HIV di Indonesia".

1. Saya telah membaca informasi yang telah diberikan.
2. Prosedur penelitian beserta risiko telah dijelaskan dengan jelas.
3. Saya setuju bahwa partisipasi saya dalam wawancara akan direkam.
4. Saya sadar bahwa saya harus menyimpan salinan Lembar Informasi dan Lembar Persetujuan untuk referensi di kemudian hari.
5. Saya memahami bahwa:
    - Saya tidak secara langsung mendapatkan keuntungan dari penelitian ini.
    - Saya bebas untuk menarik diri dari penelitian ini kapan saja dan bebas untuk menolak menjawab pertanyaan tertentu.
    - Informasi yang diperoleh dalam penelitian ini akan dipublikasikan seperti yang telah dijelaskan, dan identitas saya tidak akan dapat kenali, dan informasi pribadi saya akan tetap dirahasiakan.
    - Apakah Saya berpartisipasi atau tidak, atau mengundurkan diri setelah berpartisipasi, tidak akan berpengaruh pada perlakuan atau layanan apa pun yang diberikan kepada saya.
    - Saya dapat meminta agar rekaman dihentikan kapan saja, dan saya juga dapat mengundurkan diri setiap saat tanpa adanya efek samping.
    - Meskipun identitas Saya tidak akan dipublikasikan, namun terkait dengan lokasi wawancara kemungkinan kerahasiaan Saya tidak dapat terjaga.

6. Saya menyatakan setuju / tidak setuju * bahwa rekaman / transkrip * akan dilakukan oleh peneliti lain yang bukan anggota tim peneliti ini dengan syarat identitas saya tidak akan terungkap atau dihapus sesuai kebutuhan.

7. Saya berkesempatan untuk mendiskusikan kembali informasi yang telah saya berikan pada penelitian ini dengan anggota keluarga atau teman.

Tanda tangan peserta .... **Tanggal** ....

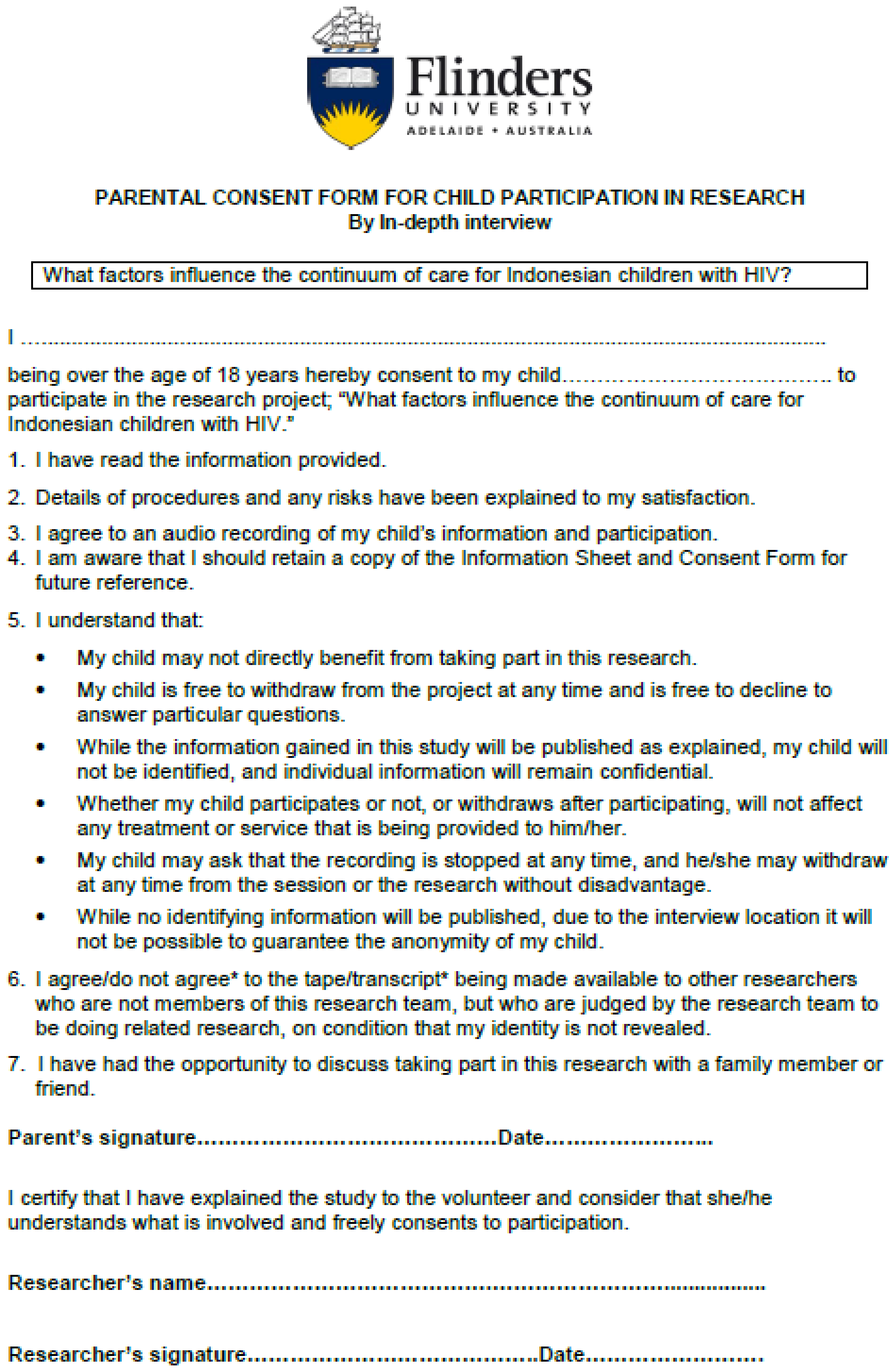
Saya menyatakan bahwa saya telah mendapatkan penjelasan mengenai penelitian ini yang bersifat sukarela menyetujui untuk berpartisipasi.

Nama peneliti

....

Tanda tangan peneliti .... **Tanggal**..

Appendix 3.7 Parental consent form



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PARENTAL CONSENT FORM FOR CHILD PARTICIPATION IN RESEARCH
By In-depth interview

What factors influence the continuum of care for Indonesian children with HIV?

I ....

being over the age of 18 years hereby consent to my child.. to participate in the research project; "What factors influence the continuum of care for Indonesian children with HIV."

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to an audio recording of my child's 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:
   - My child may not directly benefit from taking part in this research.
   - My child is free to withdraw from the project at any time and is free to decline to answer particular questions.
   - While the information gained in this study will be published as explained, my child will not be identified, and individual information will remain confidential.
   - Whether my child participates or not, or withdraws after participating, will not affect any treatment or service that is being provided to him/her.
   - My child may ask that the recording is stopped at any time, and he/she may withdraw at any time from the session or the research without disadvantage.
   - While no identifying information will be published, due to the interview location it will not be possible to guarantee the anonymity of my child.
6. I agree/do not agree* to the tape/transcript* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

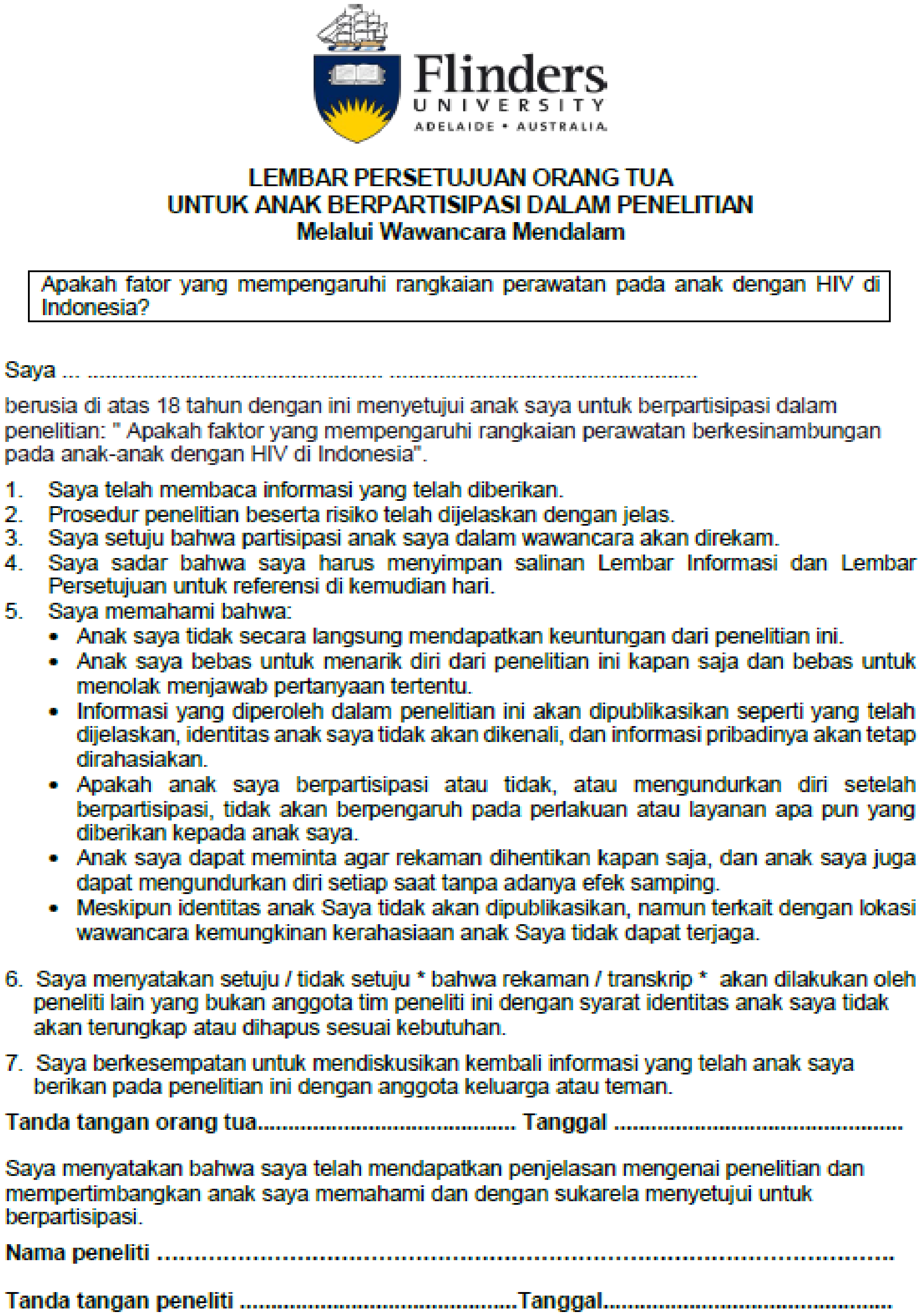
Parent's signature...Date.........................

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name..

Researcher's signature...Date.........................

Appendix 3.8 Parental consent form (Indonesian language)



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LEMBAR PERSETUJUAN ORANG TUA
UNTUK ANAK BERPARTISIPASI DALAM PENELITIAN
Melalui Wawancara Mendalam

Apakah fator yang mempengaruhi rangkaian perawatan pada anak dengan HIV di Indonesia?

Saya ... .

berusia di atas 18 tahun dengan ini menyetujui anak saya untuk berpartisipasi dalam penelitian: " Apakah faktor yang mempengaruhi rangkaian perawatan berkesinambungan pada anak-anak dengan HIV di Indonesia".

1. Saya telah membaca informasi yang telah diberikan.
2. Prosedur penelitian beserta risiko telah dijelaskan dengan jelas.
3. Saya setuju bahwa partisipasi anak saya dalam wawancara akan direkam.
4. Saya sadar bahwa saya harus menyimpan salinan Lembar Informasi dan Lembar Persetujuan untuk referensi di kemudian hari.
5. Saya memahami bahwa:
    - Anak saya tidak secara langsung mendapatkan keuntungan dari penelitian ini.
    - Anak saya bebas untuk menarik diri dari penelitian ini kapan saja dan bebas untuk menolak menjawab pertanyaan tertentu.
    - Informasi yang diperoleh dalam penelitian ini akan dipublikasikan seperti yang telah dijelaskan, identitas anak saya tidak akan dikenali, dan informasi pribadinya akan tetap dirahasiakan.
    - Apakah anak saya berpartisipasi atau tidak, atau mengundurkan diri setelah berpartisipasi, tidak akan berpengaruh pada perlakuan atau layanan apa pun yang diberikan kepada anak saya.
    - Anak saya dapat meminta agar rekaman dihentikan kapan saja, dan anak saya juga dapat mengundurkan diri setiap saat tanpa adanya efek samping.
    - Meskipun identitas anak Saya tidak akan dipublikasikan, namun terkait dengan lokasi wawancara kemungkinan kerahasiaan anak Saya tidak dapat terjaga.

6. Saya menyatakan setuju / tidak setuju * bahwa rekaman / transkrip * akan dilakukan oleh peneliti lain yang bukan anggota tim peneliti ini dengan syarat identitas anak saya tidak akan terungkap atau dihapus sesuai kebutuhan.
7. Saya berkesempatan untuk mendiskusikan kembali informasi yang telah anak saya berikan pada penelitian ini dengan anggota keluarga atau teman.

Tanda tangan orang tua... **Tanggal** ....

Saya menyatakan bahwa saya telah mendapatkan penjelasan mengenai penelitian dan mempertimbangkan anak saya memahami dan dengan sukarela menyetujui untuk berpartisipasi.

Nama peneliti ....

Tanda tangan peneliti ....**Tanggal**...

Appendix 3.9 Interview guidelines (Children with HIV and their families)

Flinders
UNIVERSITY
ADELAIDE • AUSTRALIA

INTERVIEW GUIDELINE
(For children and their families)

Introduction

Anything that you share here today will be strictly confidential. This interview will take approximately one hour. If you need a break or discontinue at any time, please do not hesitate to let me know. Do you have any questions before we begin?

Thank you very much for joining me today and participating in this interview. As previously mentioned, today we will be discussing you and you child experience..

Interview questions

A. A child

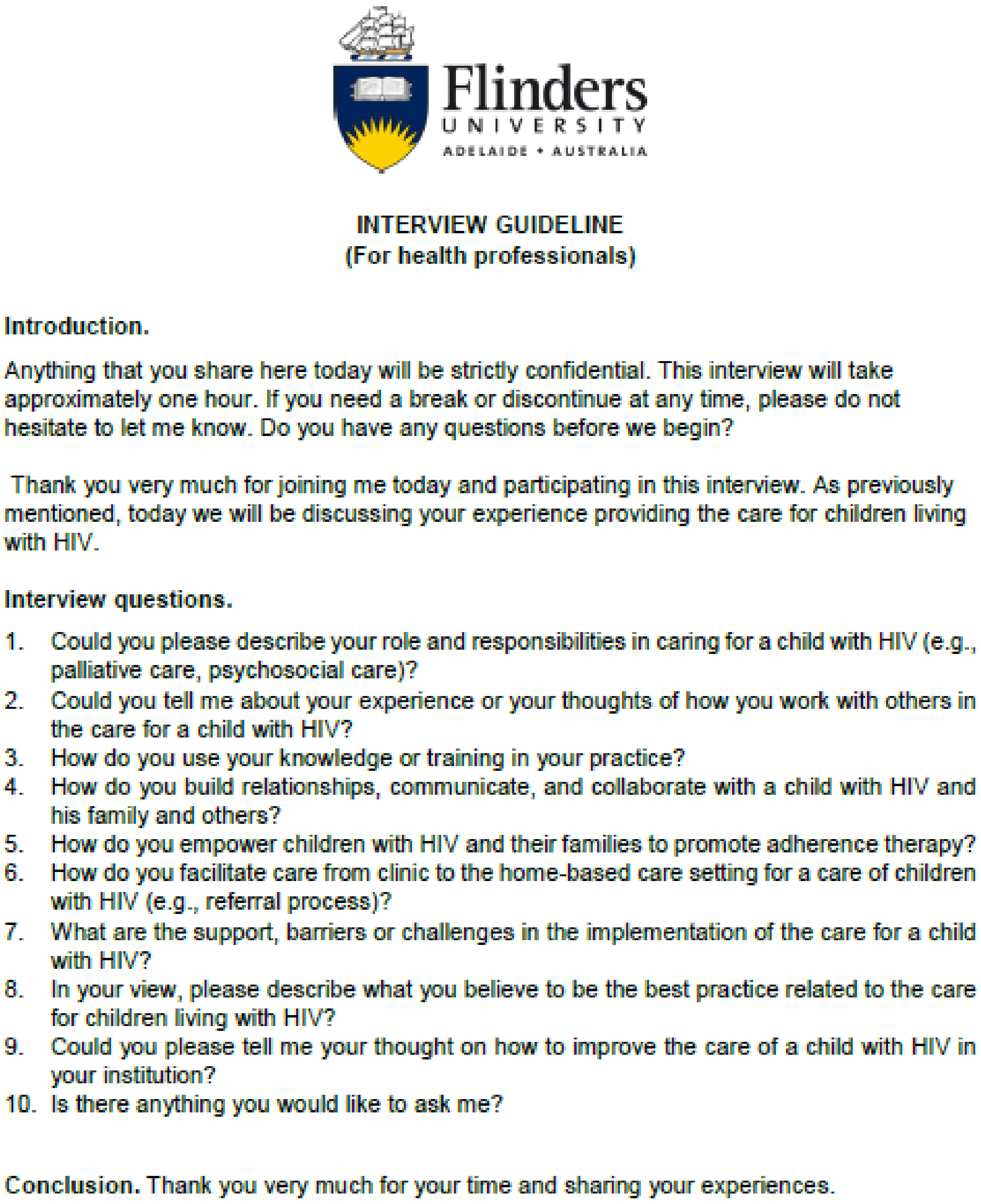
1. Could you tell me about your experience of receiving the care?
2. How do doctors or nurses provide care with you?
3. Could you please describe how the care affects your activities (e.g., school life)?
4. In your view, what care do you need to have and should be given better to you?
5. Is there anything you would like to ask me?

B. Family member

1. Could you please describe your experience of how do you provide care for your child at home?
2. Could you please describe your experience of how your child receives his/her care and what types of the care that your child has been received?
3. Could you please describe how the care of your child affects your life (e.g., family life, community living)?
4. What are the support, barriers or challenges in providing the care for your child?
5. How do you build relationships, communicate, and collaborate with doctors or nurses to promote the adherence therapy of your child?
6. Now that your child is no longer acutely ill how do you manage his/her sickness on a daily basis or if you need to go to a doctor where you go now?.
7. Could you please tell me in your view, what care do you need to have and should be given better to your child?
8. Is there anything you would like to ask me?

Conclusion. Thank you very much for your time and sharing your experiences.

Appendix 3.10 Interview guidelines (Health professionals)



Flinders
UNIVERSITY
ADELAIDE • AUSTRALIA

INTERVIEW GUIDELINE
(For health professionals)

Introduction.

Anything that you share here today will be strictly confidential. This interview will take approximately one hour. If you need a break or discontinue at any time, please do not hesitate to let me know. Do you have any questions before we begin?

Thank you very much for joining me today and participating in this interview. As previously mentioned, today we will be discussing your experience providing the care for children living with HIV.

Interview questions.

1. Could you please describe your role and responsibilities in caring for a child with HIV (e.g., palliative care, psychosocial care)?
2. Could you tell me about your experience or your thoughts of how you work with others in the care for a child with HIV?
3. How do you use your knowledge or training in your practice?
4. How do you build relationships, communicate, and collaborate with a child with HIV and his family and others?
5. How do you empower children with HIV and their families to promote adherence therapy?
6. How do you facilitate care from clinic to the home-based care setting for a care of children with HIV (e.g., referral process)?
7. What are the support, barriers or challenges in the implementation of the care for a child with HIV?
8. In your view, please describe what you believe to be the best practice related to the care for children living with HIV?
9. Could you please tell me your thought on how to improve the care of a child with HIV in your institution?
10. Is there anything you would like to ask me?

Conclusion. Thank you very much for your time and sharing your experiences.

Appendix 3.11 Interview guidelines for children with HIV and their families (Indonesian language)

PANDUAN WAWANCARA
(Untuk anak beserta orang tua)

Pengantar

Informasikan yang Anda sampaikan disini hari ini akan bersifat rahasia. Wawancara akan berrlangsung kurang lebih satu jam. Jika Anda memerlukan istirahat,silahkan jangan ragu untuk menyampaikan kepada saya. Apakah Anda mempunyai pertanyaan yang ingin Anda sampaikan sebelum mulai?

Sebelumnya saya mengucapkan terima kasih banyak telah bergabung dengan saya hari ini dan berpartisipasi dalam wawancara ini. Seperti yang telah disebutkan sebelumnya, hari ini kita akan mendiskusikan pengalaman Anda terkait dengan perawatan untuk anak dengan HIV

Pertanyaan wawancara

A. Anak

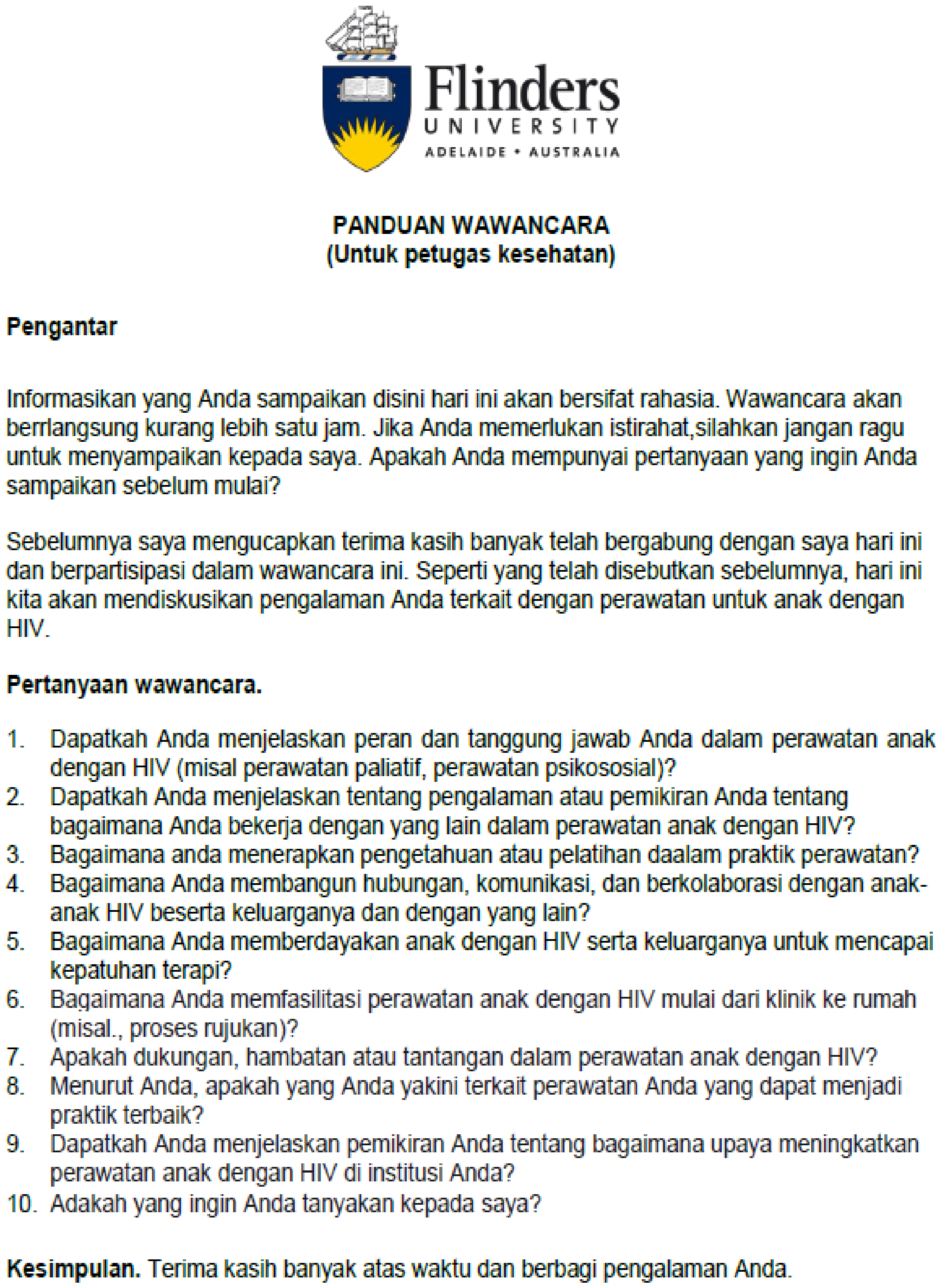
1. Dapatkah Adek menjelaskan pengalaman pada saat meneriman perawatan?
2. Bagaimana dokter dan perawat memberikan perawata kepada Adek?
3. Dapatkah adek menjelaskan apakah perawatan yang adek terima mempengaruhi kegiatan adek (misal., kehidupan sekolah)?
4. Menurut adek, apakah yang adek inginkan agar mendapatkan perawatan yang lebih baik?
5. Apakah ada sesuatu yang ingin adek sampaikan kepada saya?

B. Anggota keluarga

1. Dapatkah Anda menjelaskan pengalaman Anda tentang bagaimana Anda memberikan perawatan untuk anak Anda di rumah?
2. Dapatkah Anda menjelaskan pengalaman tentang bagaimana anak Anda menerima perawatannya dan jenis perawatan apa yang telah terima?
3. Dapatkah anda menjelaskan bagaimana perawatan anak Anda mempengaruhi kehidupan Anda (misal., kehidupan keluarga, kehidupan masyarakat)?
4. Apakah dukungan, hambatan atau tantangan dalam memberikan perawatan untuk Anak Anda?
5. Bagaimana Anda membangun hubungan, berkomunikasi, dan berkolaborasi dengan dokter atau perawat dalam mencapai terapi kepatuhan anak Anda?
6. Sekarang setelah anak Anda tidak dalam kondisi sakit, bagaimana Anda mengelola penyakitnya setiap hari atau apakah Anda perlu pergi ke dokter dan kemana Anda pergi sekarang?
7. Menurut Anda, apakah perawatan harus harus diberikan kepada putra/i Anda agar lebih baik?
8. Apakah ada sesuatu yang ingin Anda tanyakan kepada saya?

Kesimpulan. Terima kasih banyak atas waktu dan berbagi pengalaman Anda.

Appendix 3.12 Interview guidelines for health professionals (Indonesian language)



PANDUAN WAWANCARA
(Untuk petugas kesehatan)

Pengantar

Informasikan yang Anda sampaikan disini hari ini akan bersifat rahasia. Wawancara akan berrlangsung kurang lebih satu jam. Jika Anda memerlukan istirahat,silahkan jangan ragu untuk menyampaikan kepada saya. Apakah Anda mempunyai pertanyaan yang ingin Anda sampaikan sebelum mulai?

Sebelumnya saya mengucapkan terima kasih banyak telah bergabung dengan saya hari ini dan berpartisipasi dalam wawancara ini. Seperti yang telah disebutkan sebelumnya, hari ini kita akan mendiskusikan pengalaman Anda terkait dengan perawatan untuk anak dengan HIV.

Pertanyaan wawancara.

1. Dapatkah Anda menjelaskan peran dan tanggung jawab Anda dalam perawatan anak dengan HIV (misal perawatan paliatif, perawatan psikososial)?
2. Dapatkah Anda menjelaskan tentang pengalaman atau pemikiran Anda tentang bagaimana Anda bekerja dengan yang lain dalam perawatan anak dengan HIV?
3. Bagaimana anda menerapkan pengetahuan atau pelatihan daalam praktik perawatan?
4. Bagaimana Anda membangun hubungan, komunikasi, dan berkolaborasi dengan anak-anak HIV beserta keluarganya dan dengan yang lain?
5. Bagaimana Anda memberdayakan anak dengan HIV serta keluarganya untuk mencapai kepatuhan terapi?
6. Bagaimana Anda memfasilitasi perawatan anak dengan HIV mulai dari klinik ke rumah (misal., proses rujukan)?
7. Apakah dukungan, hambatan atau tantangan dalam perawatan anak dengan HIV?
8. Menurut Anda, apakah yang Anda yakini terkait perawatan Anda yang dapat menjadi praktik terbaik?
9. Dapatkah Anda menjelaskan pemikiran Anda tentang bagaimana upaya meningkatkan perawatan anak dengan HIV di institusi Anda?
10. Adakah yang ingin Anda tanyakan kepada saya?

Kesimpulan. Terima kasih banyak atas waktu dan berbagi pengalaman Anda.

Appendix 3.13 Flyer (Children with HIV and their families)

College of Nursing and Health Sciences
Flinders University, South Australia

Flinders
UNIVERSITY
inspiring achievement

Does your child receive HIV care?

I am looking for volunteers to take part in a PhD study, on **"What factors influence the continuum of care for Indonesian children with HIV?"**

As a **participant in this study** you must be:

- A child living with HIV aged 8-18 years-old and family.
- The family of a child living with HIV aged 8-18 years-old.
- Being able to speak Indonesian.
- Having a willingness to participate in the study and willing to sign an informed consent and parental consent.

For more information, or to volunter for this study, please contact **Nuzul:**

Phone: (+62) 821 32439529 or
Email: Nuzul-q-a@fkp.unair.ac.id; qura0001@flinders.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number No.7818) and Health Research Ethics Committee (No. 506-KEPK) Faculty of Nursing, the University of Airlangga.

www.flinders.edu.au

Appendix 3.14 Flyer (health professionals)

College of Nursing and Health Sciences
Flinders University, South Australia

Flinders
UNIVERSITY
inspiring achievement

Do you provide care for children living with HIV?

I am looking for volunteers to take part in a PhD study, on **"What factors influence the continuum of care for Indonesian children with HIV?"**

As a **participant in this study** you must be:

- Managers and or/ policy-makers.
- Health professionals (e.g. registered nurses or doctors).
- Have one year experience dealing with people with HIV or providing care for children living with HIV.
- Being able to speak Indonesian.
- Having a willingness to participate in the study and willing to sign an in informed consent.

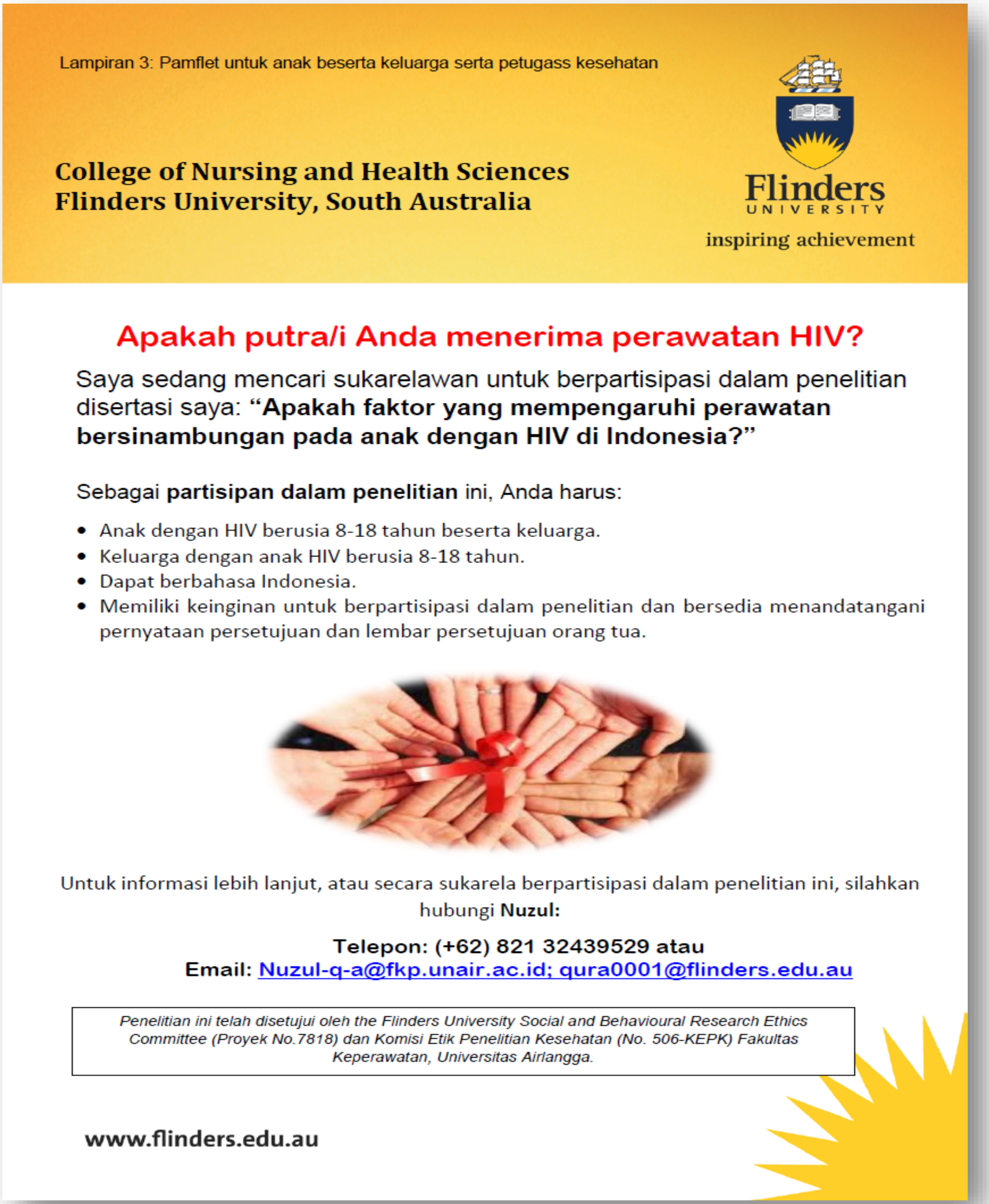
For more information, or to volunter for this study, please contact **Nuzul:**

Phone : (+62) 821 32439529 or
Email : Nuzul-q-a@fkp.unair.ac.id; qura0001@flinders.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number No.7818) and Health Research Ethics Committee (No. 506-KEPK) Faculty of Nursing, the University of Airlangga.

www.flinders.edu.au

Appendix 3.15 Flyer for children with HIV and their families (Indonesian language)



Lampiran 3: Pamflet untuk anak beserta keluarga serta petugass kesehatan

College of Nursing and Health Sciences
Flinders University, South Australia

Flinders
UNIVERSITY
inspiring achievement

Apakah putra/i Anda menerima perawatan HIV?

Saya sedang mencari sukarelawan untuk berpartisipasi dalam penelitian disertasi saya: **“Apakah faktor yang mempengaruhi perawatan bersinambungan pada anak dengan HIV di Indonesia?”**

Sebagai **partisipan dalam penelitian** ini, Anda harus:

- Anak dengan HIV berusia 8-18 tahun beserta keluarga.
- Keluarga dengan anak HIV berusia 8-18 tahun.
- Dapat berbahasa Indonesia.
- Memiliki keinginan untuk berpartisipasi dalam penelitian dan bersedia menandatangani pernyataan persetujuan dan lembar persetujuan orang tua.

Untuk informasi lebih lanjut, atau secara sukarela berpartisipasi dalam penelitian ini, silahkan hubungi **Nuzul:**

Telepon: (+62) 821 32439529 atau
Email: Nuzul-q-a@fkp.unair.ac.id; qura0001@flinders.edu.au

Penelitian ini telah disetujui oleh the Flinders University Social and Behavioural Research Ethics Committee (Proyek No.7818) dan Komisi Etik Penelitian Kesehatan (No. 506-KEPK) Fakultas Keperawatan, Universitas Airlangga.

www.flinders.edu.au

Appendix 3.16 Flyer for children with HIV and their families (Indonesian language)

College of Nursing and Health Sciences
Flinders University, South Australia

Apakah Anda memberikan perawatan pada anak dengan HIV?

Saya sedang mencari sukarelawan untuk berpartisipasi dalam penelitian disertasi saya: **"Apakah faktor yang mempengaruhi perawatan bersinambungan pada anak dengan HIV di Indonesia?"**

Sebagai partisipan dalam penelitian ini, Anda harus:

- Manajer atau pengambil kebijakan.
- Petugas kesehatan (misal dokter atau perawat).
- Mempunyai pengalaman sedikitnya satu tahun dalam menyediakan perawatan pada anak dengan HIV.
- Dapat berbahasa Indonesia.
- Memiliki keinginan untuk berpartisipasi dalam penelitian dan bersedia menandatangani pernyataan persetujuan dan lembar persetujuan orang tua.

Untuk informasi lebih lanjut, atau secara sukarela berpartisipasi dalam penelitian ini, silahkan hubungi **Nuzul:**

Telepon: (+62) 821 32439529 atau
Email: Nuzul-q-a@fkp.unair.ac.id; qura0001@flinders.edu.au

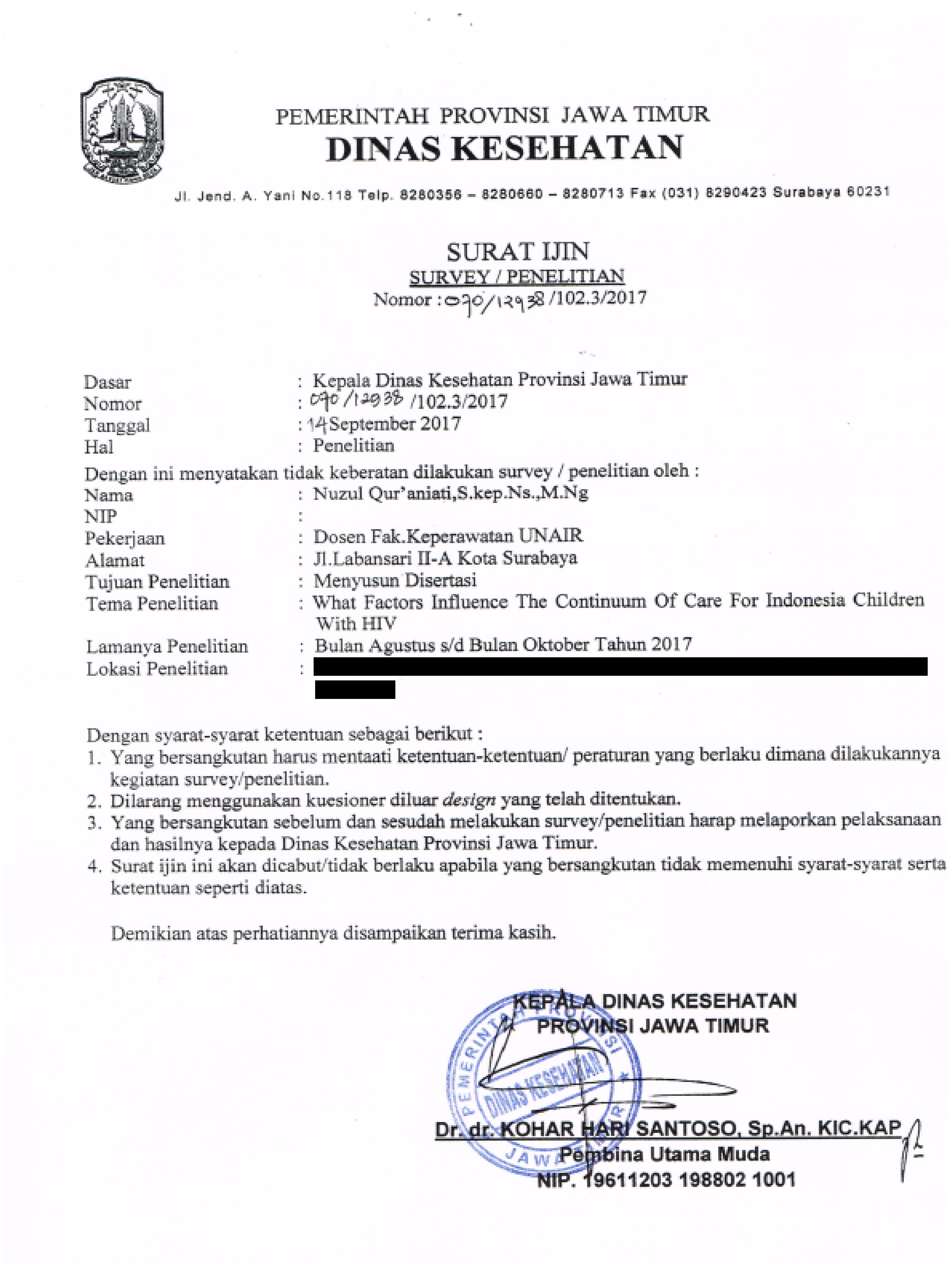
Penelitian ini telah disetujui oleh the Flinders University Social and Behavioural Research Ethics Committee (Proyek No.7518) dan Komisi Etik Penelitian Kesehatan (No. 506-KEPK) Fakultas Keperawatan, Universitas Airlangga.

www.flinders.edu.au

Appendix 4. Letters of permission

1) *Dinas Kesetahan Provinsi Jawa Timur*
2) *Dinas Kesehatan Kota Surabaya*
3) *Badan Kesatuan Bangsa, Politik and Perlindungan Masyarakat Kota Surabaya*
4) *Badan Kesatuan Bangsa, Politik and Perlindungan Masyarakat Propinsi Jawa Timur*

Appendix 4.1 Letter of permission from *Dinas Kesehatan Provinsi Jawa Timur*



PEMERINTAH PROVINSI JAWA TIMUR
DINAS KESEHATAN
Jl. Jend. A. Yani No.118 Telp. 8280356 – 8280660 – 8280713 Fax (031) 8290423 Surabaya 60231

SURAT IJIN
SURVEY / PENELITIAN
Nomor : 070/12938/102.3/2017

Dasar : Kepala Dinas Kesehatan Provinsi Jawa Timur
Nomor : 070/12938 /102.3/2017
Tanggal : 14 September 2017
Hal : Penelitian

Dengan ini menyatakan tidak keberatan dilakukan survey / penelitian oleh :
Nama : Nuzul Qur'aniati,S.kep.Ns.,M.Ng
NIP :
Pekerjaan : Dosen Fak.Keperawatan UNAIR
Alamat : Jl.Labansari II-A Kota Surabaya
Tujuan Penelitian : Menyusun Disertasi
Tema Penelitian : What Factors Influence The Continuum Of Care For Indonesia Children With HIV
Lamanya Penelitian : Bulan Agustus s/d Bulan Oktober Tahun 2017
Lokasi Penelitian : [redacted]

Dengan syarat-syarat ketentuan sebagai berikut :

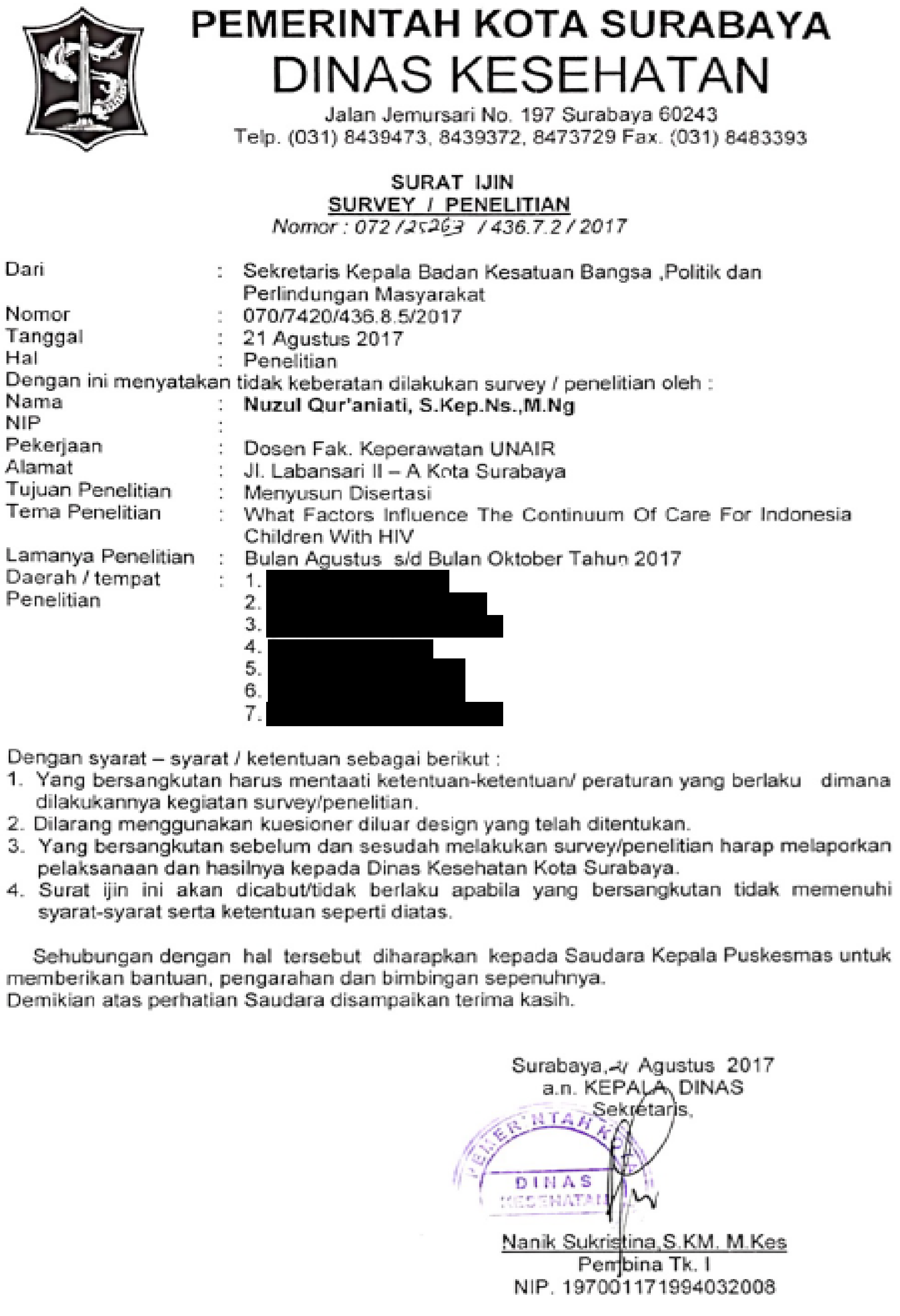
1. Yang bersangkutan harus mentaati ketentuan-ketentuan/ peraturan yang berlaku dimana dilakukannya kegiatan survey/penelitian.
2. Dilarang menggunakan kuesioner diluar *design* yang telah ditentukan.
3. Yang bersangkutan sebelum dan sesudah melakukan survey/penelitian harap melaporkan pelaksanaan dan hasilnya kepada Dinas Kesehatan Provinsi Jawa Timur.
4. Surat ijin ini akan dicabut/tidak berlaku apabila yang bersangkutan tidak memenuhi syarat-syarat serta ketentuan seperti diatas.

Demikian atas perhatiannya disampaikan terima kasih.

KEPALA DINAS KESEHATAN
PROVINSI JAWA TIMUR

Dr. dr. KOHAR HARI SANTOSO, Sp.An. KIC.KAP
Pembina Utama Muda
NIP. 19611203 198802 1001

Appendix 4.2 Letter of permission from *Dinas Kesehatan Kota Surabaya*



PEMERINTAH KOTA SURABAYA
DINAS KESEHATAN
Jalan Jemursari No. 197 Surabaya 60243
Telp. (031) 8439473, 8439372, 8473729 Fax. (031) 8483393

SURAT IJIN
SURVEY / PENELITIAN
Nomor : 072 / 25263 / 436.7.2 / 2017

Dari : Sekretaris Kepala Badan Kesatuan Bangsa ,Politik dan Perlindungan Masyarakat
Nomor : 070/7420/436.8.5/2017
Tanggal : 21 Agustus 2017
Hal : Penelitian

Dengan ini menyatakan tidak keberatan dilakukan survey / penelitian oleh :

Nama : **Nuzul Qur'aniati, S.Kep.Ns.,M.Ng**
NIP :
Pekerjaan : Dosen Fak. Keperawatan UNAIR
Alamat : Jl. Labansari II – A Kota Surabaya
Tujuan Penelitian : Menyusun Disertasi
Tema Penelitian : What Factors Influence The Continuum Of Care For Indonesia Children With HIV
Lamanya Penelitian : Bulan Agustus s/d Bulan Oktober Tahun 2017
Daerah / tempat Penelitian :
1. [redacted]
2. [redacted]
3. [redacted]
4. [redacted]
5. [redacted]
6. [redacted]
7. [redacted]

Dengan syarat – syarat / ketentuan sebagai berikut :

1. Yang bersangkutan harus mentaati ketentuan-ketentuan/ peraturan yang berlaku dimana dilakukannya kegiatan survey/penelitian.
2. Dilarang menggunakan kuesioner diluar design yang telah ditentukan.
3. Yang bersangkutan sebelum dan sesudah melakukan survey/penelitian harap melaporkan pelaksanaan dan hasilnya kepada Dinas Kesehatan Kota Surabaya.
4. Surat ijin ini akan dicabut/tidak berlaku apabila yang bersangkutan tidak memenuhi syarat-syarat serta ketentuan seperti diatas.

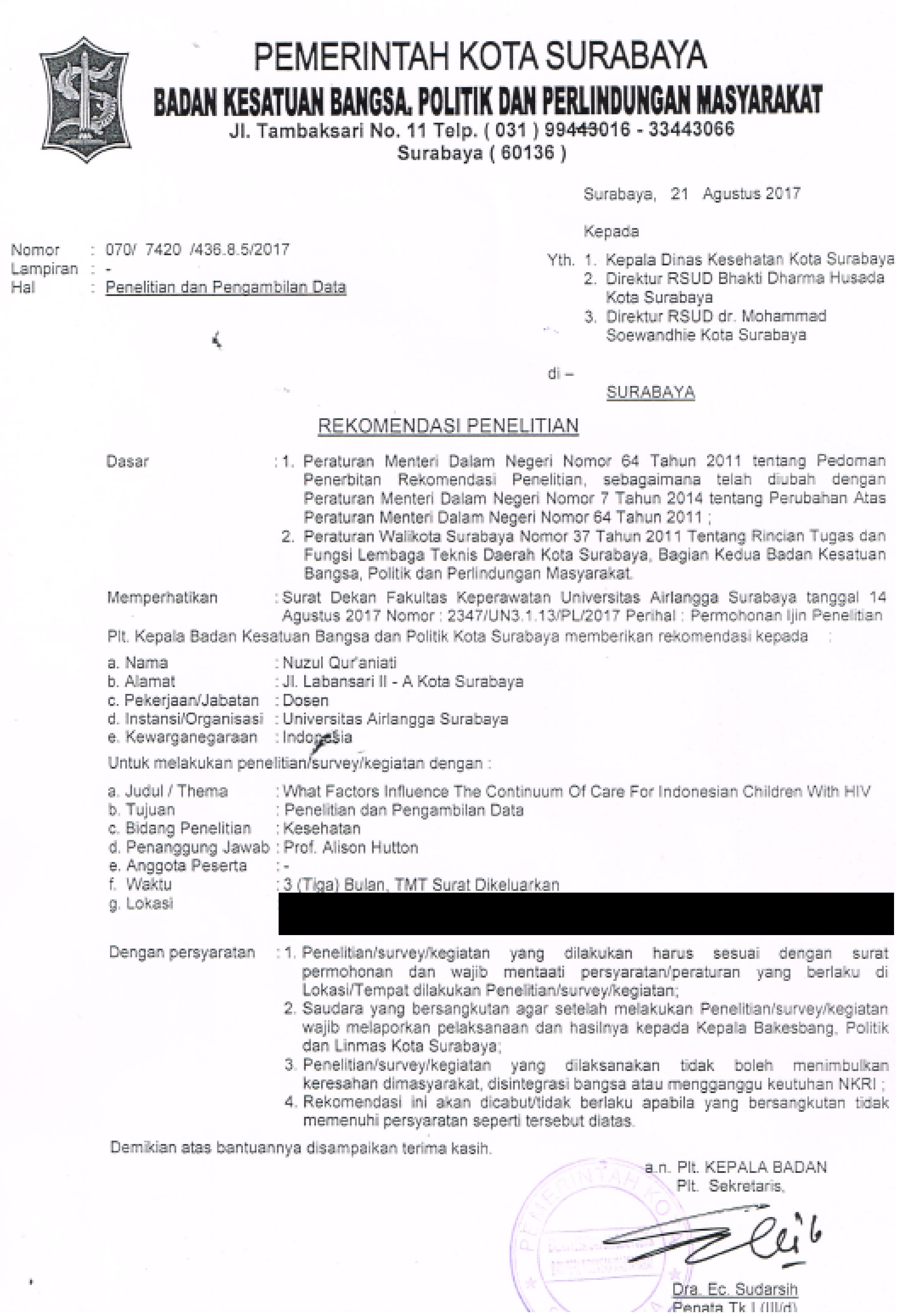
Sehubungan dengan hal tersebut diharapkan kepada Saudara Kepala Puskesmas untuk memberikan bantuan, pengarahan dan bimbingan sepenuhnya.
Demikian atas perhatian Saudara disampaikan terima kasih.

Surabaya, 21 Agustus 2017
a.n. KEPALA DINAS
Sekretaris,

Nanik Sukristina,S.KM. M.Kes
Pembina Tk. I
NIP. 197001171994032008

http://dinkes.surabaya.go.id, Email :dkk_surabaya@yahoo.com

Appendix 4.3 Letter of permission from *Badan Kesatuan Bangsa, Politik and Perlindungan Masyarakat Kota Surabaya*



PEMERINTAH KOTA SURABAYA
BADAN KESATUAN BANGSA, POLITIK DAN PERLINDUNGAN MASYARAKAT
Jl. Tambaksari No. 11 Telp. (031) 99443016 - 33443066
Surabaya (60136)

Surabaya, 21 Agustus 2017

Nomor : 070/ 7420 /436.8.5/2017
Lampiran : -
Hal : Penelitian dan Pengambilan Data

Kepada
Yth. 1. Kepala Dinas Kesehatan Kota Surabaya
2. Direktur RSUD Bhakti Dharma Husada Kota Surabaya
3. Direktur RSUD dr. Mohammad Soewandhie Kota Surabaya

di –
SURABAYA

REKOMENDASI PENELITIAN

Dasar : 1. Peraturan Menteri Dalam Negeri Nomor 64 Tahun 2011 tentang Pedoman Penerbitan Rekomendasi Penelitian, sebagaimana telah diubah dengan Peraturan Menteri Dalam Negeri Nomor 7 Tahun 2014 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 64 Tahun 2011 ;
2. Peraturan Walikota Surabaya Nomor 37 Tahun 2011 Tentang Rincian Tugas dan Fungsi Lembaga Teknis Daerah Kota Surabaya, Bagian Kedua Badan Kesatuan Bangsa, Politik dan Perlindungan Masyarakat.

Memperhatikan : Surat Dekan Fakultas Keperawatan Universitas Airlangga Surabaya tanggal 14 Agustus 2017 Nomor : 2347/UN3.1.13/PL/2017 Perihal : Permohonan Ijin Penelitian

Plt. Kepala Badan Kesatuan Bangsa dan Politik Kota Surabaya memberikan rekomendasi kepada :

a. Nama : Nuzul Qur'aniati
b. Alamat : Jl. Labansari II - A Kota Surabaya
c. Pekerjaan/Jabatan : Dosen
d. Instansi/Organisasi : Universitas Airlangga Surabaya
e. Kewarganegaraan : Indonesia

Untuk melakukan penelitian/survey/kegiatan dengan :

a. Judul / Thema : What Factors Influence The Continuum Of Care For Indonesian Children With HIV
b. Tujuan : Penelitian dan Pengambilan Data
c. Bidang Penelitian : Kesehatan
d. Penanggung Jawab : Prof. Alison Hutton
e. Anggota Peserta : -
f. Waktu : 3 (Tiga) Bulan, TMT Surat Dikeluarkan
g. Lokasi [redacted]

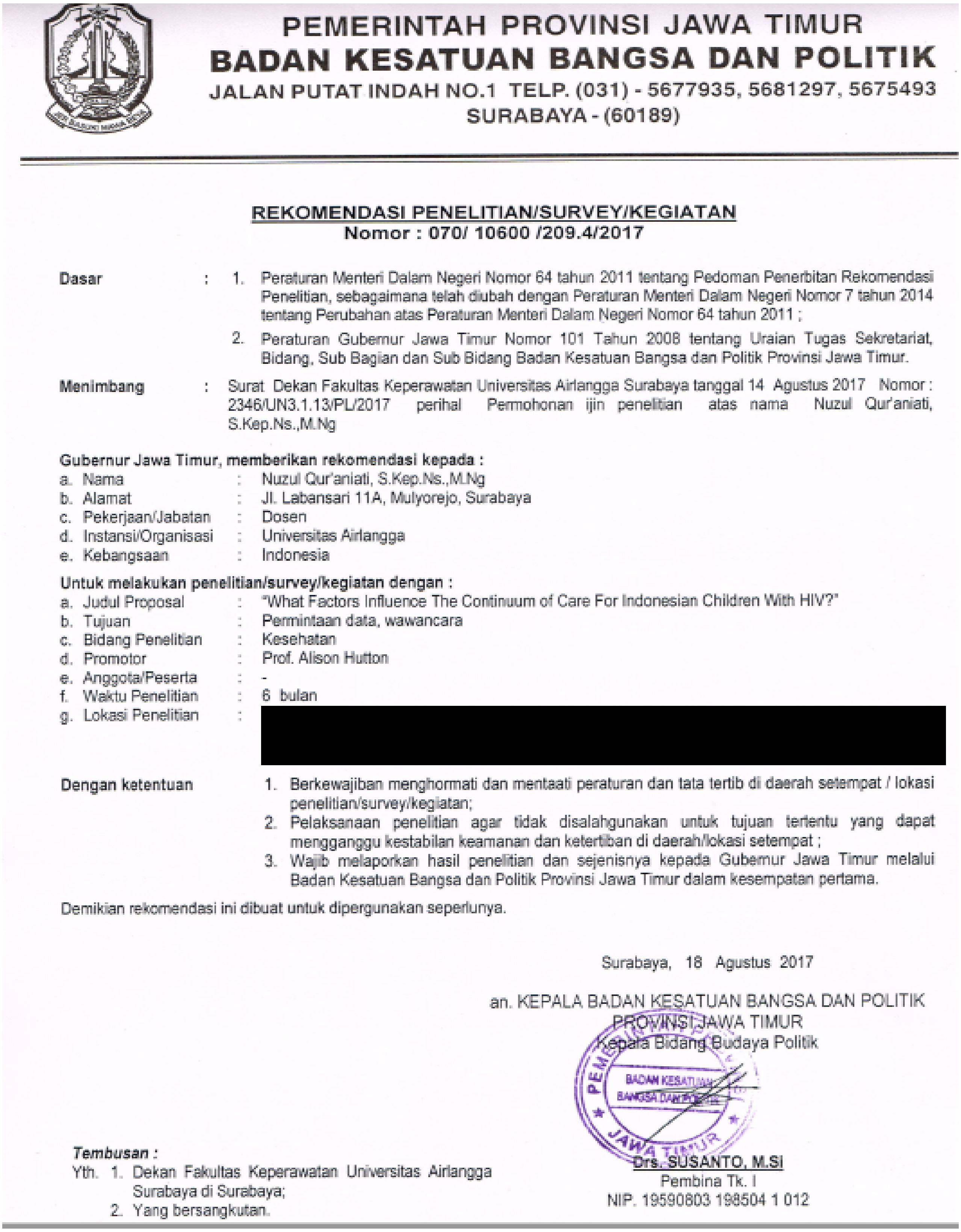
Dengan persyaratan : 1. Penelitian/survey/kegiatan yang dilakukan harus sesuai dengan surat permohonan dan wajib mentaati persyaratan/peraturan yang berlaku di Lokasi/Tempat dilakukan Penelitian/survey/kegiatan;
2. Saudara yang bersangkutan agar setelah melakukan Penelitian/survey/kegiatan wajib melaporkan pelaksanaan dan hasilnya kepada Kepala Bakesbang, Politik dan Linmas Kota Surabaya;
3. Penelitian/survey/kegiatan yang dilaksanakan tidak boleh menimbulkan keresahan dimasyarakat, disintegrasi bangsa atau mengganggu keutuhan NKRI ;
4. Rekomendasi ini akan dicabut/tidak berlaku apabila yang bersangkutan tidak memenuhi persyaratan seperti tersebut diatas.

Demikian atas bantuannya disampaikan terima kasih.

a.n. Plt. KEPALA BADAN
Plt. Sekretaris,

Dra. Ec. Sudarsih
Penata Tk I (III/d)

Appendix 4.4 Letter of permission from *Badan Kesatuan Bangsa, Politik and Perlindungan Masyarakat Propinsi Jawa Timur*



PEMERINTAH PROVINSI JAWA TIMUR
BADAN KESATUAN BANGSA DAN POLITIK
JALAN PUTAT INDAH NO.1 TELP. (031) - 5677935, 5681297, 5675493
SURABAYA - (60189)

REKOMENDASI PENELITIAN/SURVEY/KEGIATAN
Nomor : 070/ 10600 /209.4/2017

Dasar :
1. Peraturan Menteri Dalam Negeri Nomor 64 tahun 2011 tentang Pedoman Penerbitan Rekomendasi Penelitian, sebagaimana telah diubah dengan Peraturan Menteri Dalam Negeri Nomor 7 tahun 2014 tentang Perubahan atas Peraturan Menteri Dalam Negeri Nomor 64 tahun 2011 ;
2. Peraturan Gubernur Jawa Timur Nomor 101 Tahun 2008 tentang Uraian Tugas Sekretariat, Bidang, Sub Bagian dan Sub Bidang Badan Kesatuan Bangsa dan Politik Provinsi Jawa Timur.

Menimbang : Surat Dekan Fakultas Keperawatan Universitas Airlangga Surabaya tanggal 14 Agustus 2017 Nomor : 2346/UN3.1.13/PL/2017 perihal Permohonan ijin penelitian atas nama Nuzul Qur'aniati, S.Kep.Ns.,M.Ng

Gubernur Jawa Timur, memberikan rekomendasi kepada :
a. Nama : Nuzul Qur'aniati, S.Kep.Ns.,M.Ng
b. Alamat : Jl. Labansari 11A, Mulyorejo, Surabaya
c. Pekerjaan/Jabatan : Dosen
d. Instansi/Organisasi : Universitas Airlangga
e. Kebangsaan : Indonesia

Untuk melakukan penelitian/survey/kegiatan dengan :
a. Judul Proposal : "What Factors Influence The Continuum of Care For Indonesian Children With HIV?"
b. Tujuan : Permintaan data, wawancara
c. Bidang Penelitian : Kesehatan
d. Promotor : Prof. Alison Hutton
e. Anggota/Peserta : -
f. Waktu Penelitian : 6 bulan
g. Lokasi Penelitian : [redacted]

Dengan ketentuan
1. Berkewajiban menghormati dan mentaati peraturan dan tata tertib di daerah setempat / lokasi penelitian/survey/kegiatan;
2. Pelaksanaan penelitian agar tidak disalahgunakan untuk tujuan tertentu yang dapat mengganggu kestabilan keamanan dan ketertiban di daerah/lokasi setempat ;
3. Wajib melaporkan hasil penelitian dan sejenisnya kepada Gubernur Jawa Timur melalui Badan Kesatuan Bangsa dan Politik Provinsi Jawa Timur dalam kesempatan pertama.

Demikian rekomendasi ini dibuat untuk dipergunakan seperlunya.

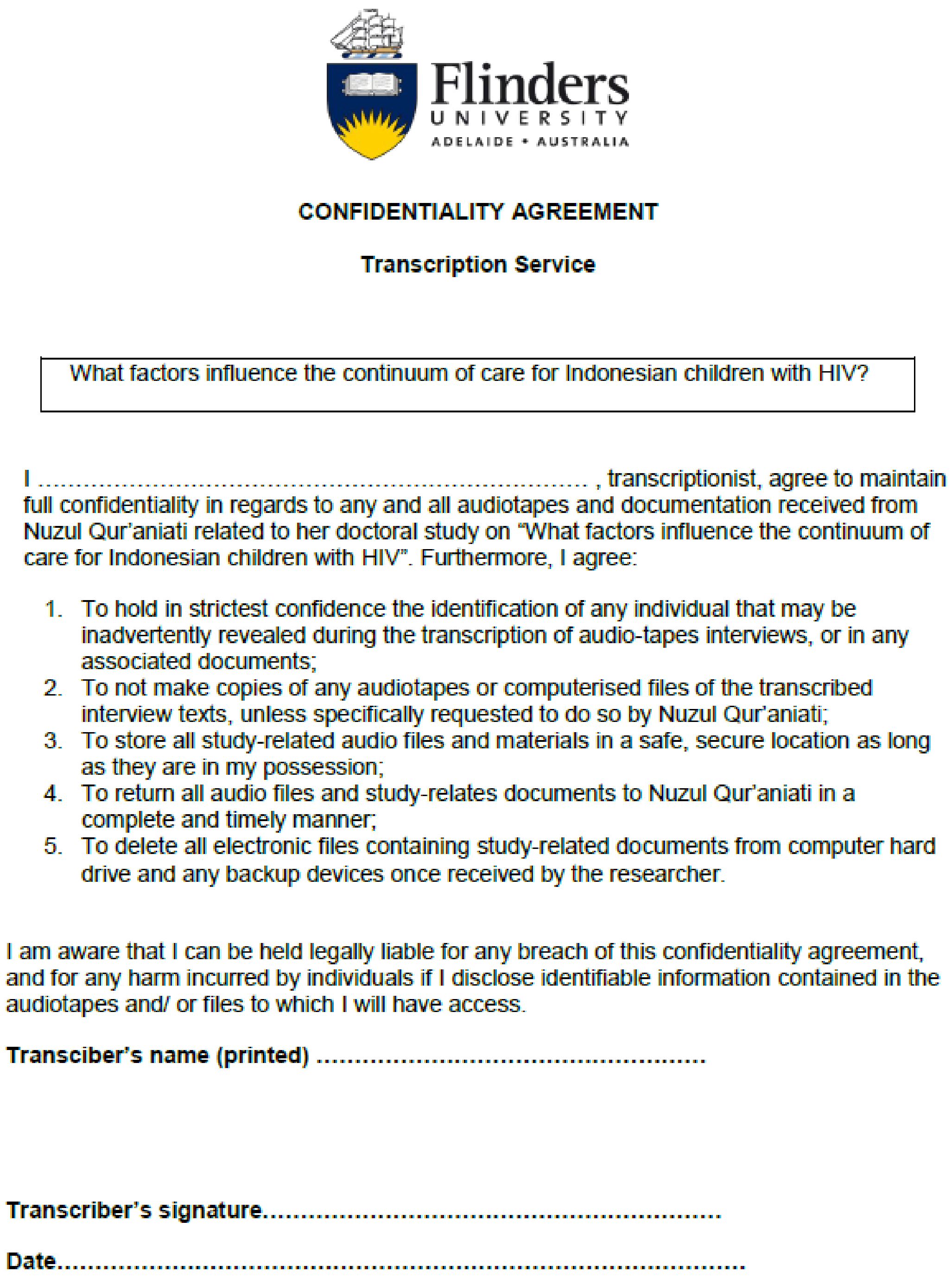
Surabaya, 18 Agustus 2017

an. KEPALA BADAN KESATUAN BANGSA DAN POLITIK
PROVINSI JAWA TIMUR
Kepala Bidang Budaya Politik

Drs. SUSANTO, M.SI
Pembina Tk. I
NIP. 19590803 198504 1 012

Tembusan :
Yth. 1. Dekan Fakultas Keperawatan Universitas Airlangga Surabaya di Surabaya;
2. Yang bersangkutan.

Appendix 5. Confidentiality agreement translation service



Flinders
UNIVERSITY
ADELAIDE • AUSTRALIA

CONFIDENTIALITY AGREEMENT

Transcription Service

What factors influence the continuum of care for Indonesian children with HIV?

I .... , transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documentation received from Nuzul Qur'aniati related to her doctoral study on "What factors influence the continuum of care for Indonesian children with HIV". Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-tapes interviews, or in any associated documents;
2. To not make copies of any audiotapes or computerised files of the transcribed interview texts, unless specifically requested to do so by Nuzul Qur'aniati;
3. To store all study-related audio files and materials in a safe, secure location as long as they are in my possession;
4. To return all audio files and study-relates documents to Nuzul Qur'aniati in a complete and timely manner;
5. To delete all electronic files containing study-related documents from computer hard drive and any backup devices once received by the researcher.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/ or files to which I will have access.

Transciber's name (printed) ....

Transcriber's signature...

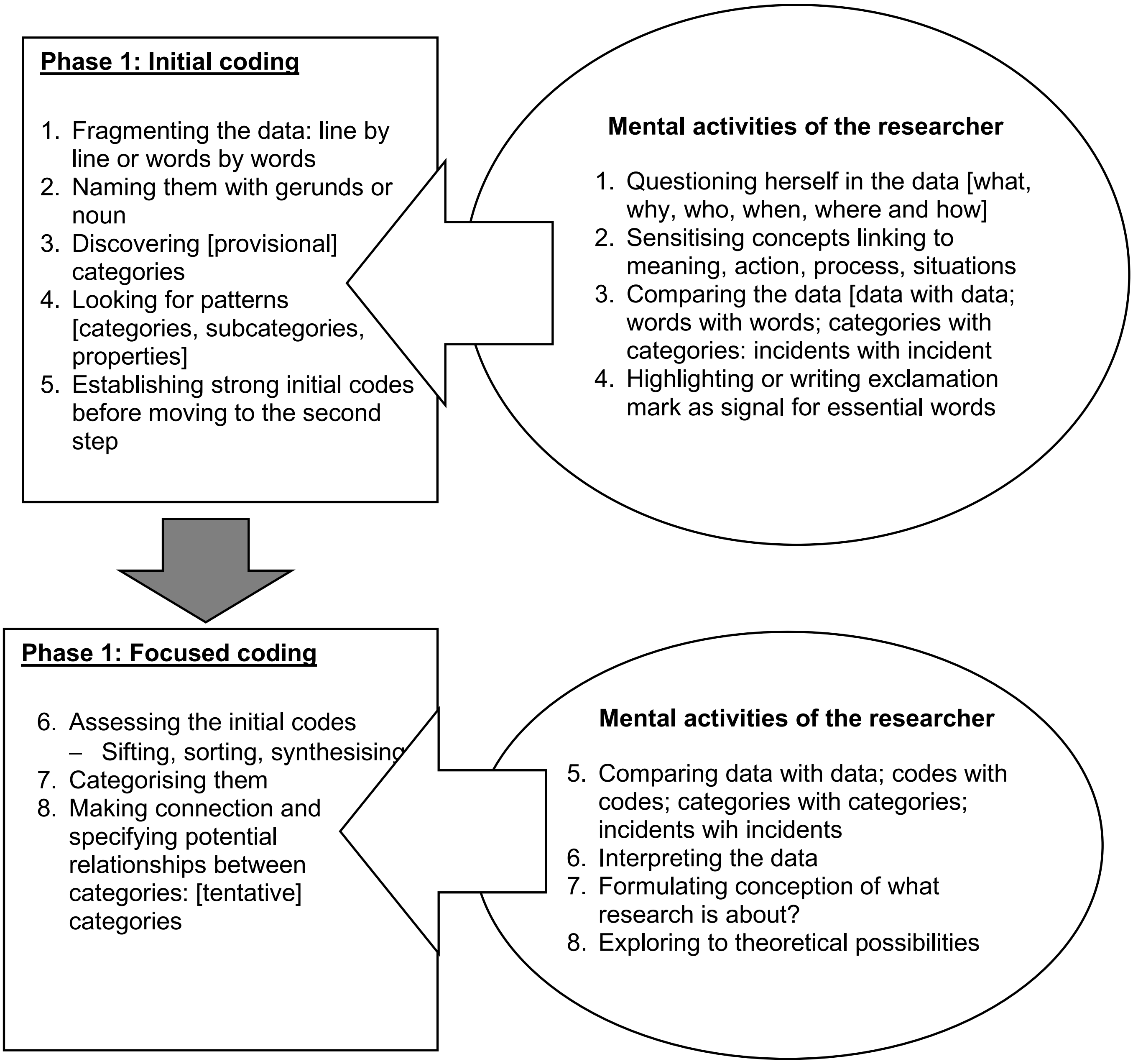
Date...

Appendix 6. Example of coding analysis and the constant comparison method

Figure 1 presented the two phases of the data analysis process, along with the mental activities of the researcher. The researcher in this study used initial coding and focused coding for the method of data analysis. The researcher constructed codes and named the codes as well as used a constant comparative method and theoretical sensitivity in a concurrent process.

The first phase of initial coding, the researcher fragmented the data with line by line coding, named each line of the data with gerund or noun. In the concurrent process, the researcher used the constant comparative method in several ways, such as comparing data with data, words with words, incidents with incidents to generate a range of ideas and information that helped to discover (provisional) categories. Additionally, consistent with theoretical sensitivity (Corbin & Strauss, 2008), the researcher in the study used the strategy of self-questioning [What? Who? When? Why? How?] to explore the data and to help to think analytically about the data. The researcher analysed of a word, sentence and looked for meaning, action, process and or situation to understand participants' views and actions from their perspectives. The researcher used signalling with exclamation marks and highlighting the word or sentence that helped to take a closer look for the essential words and or phrases of the participants. The researcher looked for a pattern, including categories, subcategories, or properties. Once, the researcher conducted a strong initial coding; the researcher moved to the second phase of data analysis.

The second phase of focused coding, the researcher brought all the categories, subcategories of the initial codes in this phase and assessed them. The researcher continued using the constant comparative method and theoretical sensitivity in the phase until the construction of a substantive theory. The researcher sifted, sorted, and synthesised the initial codes and made a connection between them into categories and subcategories. The researcher made sense of the data by comparing data with data of the same or different kind of experiences. Therefore, in the process of data analysis, the researcher used her abilities to construct the codes by asking questions and comparing the data that helped to think analytically and then looked for patterns. The process of each phase analysis is described:



Phase 1: Initial coding

1. Fragmenting the data: line by line or words by words
2. Naming them with gerunds or noun
3. Discovering [provisional] categories
4. Looking for patterns [categories, subcategories, properties]
5. Establishing strong initial codes before moving to the second step

Mental activities of the researcher

1. Questioning herself in the data [what, why, who, when, where and how]
2. Sensitising concepts linking to meaning, action, process, situations
3. Comparing the data [data with data; words with words; categories with categories: incidents with incident
4. Highlighting or writing exclamation mark as signal for essential words

Phase 1: Focused coding

6. Assessing the initial codes
   - Sifting, sorting, synthesising
7. Categorising them
8. Making connection and specifying potential relationships between categories: [tentative] categories

Mental activities of the researcher

5. Comparing data with data; codes with codes; categories with categories; incidents wih incidents
6. Interpreting the data
7. Formulating conception of what research is about?
8. Exploring to theoretical possibilities

Figure 1. The mental activities of the researcher in the phases of the data analysis process

Examples of initial coding and constant comparative method

1. The researcher fragmented the data line by line and words by words with gerunds or nouns to understand the meaning of the participant. For example:

Table 1 Coding line by line and words by words with gerunds

<table>
<tr><th>Excerpt 1: Bisma, a mother with HIV of a child with HIV</th><th></th></tr>
<tr><td>… **my son suffers from cough,**</td><td>**[a child] getting sick**</td></tr>
<tr><td>I will **immediately [!]**</td><td>**Level of importance**</td></tr>
<tr><td>**buy drugs from the drugstore.**</td><td>**Treating [non-prescription drug]**</td></tr>
<tr><td>If my son suffers is getting better, I stop giving him medicine.</td><td></td></tr>
<tr><td>**However, if the medicine does not work well, I will take him to the doctor**</td><td>**Seeking professional help [later]**</td></tr>
<tr><td>because **I am afraid his condition gets worse.**</td><td>**Anticipating “severe” condition**</td></tr>
<tr><td colspan="2">**During analysis, the researcher asked the data *What is going on in the above excerpt?* : the experience of the mother on how she gives care of a sick child: Caring for a sick child.**
The researcher highlighted ‘immediately,’ it shows timing that may relate to the level of importance. The researcher asked *What gives to a sick child?* And are drugs.
The researcher asked *How to get the drugs*: non-prescription at first then prescription later [sources of treatment].</td></tr>
</table>

2. The researcher used a constant comparative by comparing data with data in the same interview and then compared with the different interview. For example:

Table 2. Comparing data with data in the same interview

Excerpt 10: Sita, a teenaged with HIV	Coding	Excerpt 8: Bayu, an uncle of a child with HIV	Coding
In 2005, I felt sick, very sick until I was brought in **Hospital A.** I was checked. The doctor gave counselling…I feel like he is interrogating me. He said that I am not sure if you do not have a boyfriend. Then, he said, there is no way. I cannot believe that you do not have a boyfriend. And then the doctor asked me, “You know you have this disease, right? He assumed that I must have a boyfriend and had free sex so that I end up with this disease. I felt like intimidated. I did not do anything Finally, my grandmother explained that I got the disease from my parent. Both have passed away. She is an orphanage now [my grandma said]. The doctor finally recommended going to Hospital XX **At the hospital XX**, there were many nurses…I met the nurses, and they said ‘please, do not cry,’ we can help you and make you feel better**.** Even though you cannot be cure [HIV misconception], you are still able to do many activities. And then, they told me about medication that I need to take regularly. I cannot skip it	**Seeing unfriendly doctor** **Feeling intimidation** **Being referred** **seeing friendly nurses** **being supported**	… Bayu got infected because of posterity factor. Eventually, I kind of doubted Hospital 1, and I got him referenced to Hospital 2, the result was positive. Then, to hasten recovery, he was referred to Hospital XX so that his Tuberculosis could be firstly treated and after that his HIV. I was once told to have a primary treatment at Hospital XX. After his condition is stable, he could be referred back to Hospital 2. What is the problem in Hospital 2, we have lots of neighbours. I am afraid that they would know why he entered a red polyclinic. We call a room for HIV as red polyclinic. From what I have heard, a disease like Bayu is massive in the area of SMBT city. Well, they said that in Hospital 2, the medical staffs excommunicate the patients it is like they disrespect. It is like they are disgusted seeing of this kind of disease. That is why I prefer Hospital XX because the staff are kinder. The medical staff here [Hospital XX] re all nice, but for people who sick like Bayu in JBG city is considered to be disgusting, but it does not like in Hospital XX. It feels like a family	**misconception about HIV** **Being referred-HIV therapy access** **Being referred-HIV therapy access** **Fear of being found out** **labelling for HIV** **Hearing about unfriendly service** **Seeing friendly health professionals.** **Feeling discrimination** **receiving fairly treatment**

1. The researcher compared data with data in Sita's interview and found that health professionals (HPs) in different settings performed different practices throughout HIV care services, in particular, HPs in Hospital XX were friendlier than Hospital A. The researcher found the code of being referred for ARV refills access, showing that the access to ARV refills was centralised in the higher-level hospital.
2. The researcher continued comparing between Sita's interview and Bayu's interview. The researcher asked, *what is going on? And is ARV initiation can be accessed in Hospital XX.* The researcher continued asking what other reasons are? And are seeing friendly health professional, feeling comfortable, receiving fair treatment in Hospital XX, but fear of being found out, felt discrimination in Hospital B.

   From the above excerpt, the researcher developed questions?
   - *How is the care practice for children with HIV and their families according to health professional's perspectives*?
   - *How is access to ARV for children (based on the perspectives of children, families and HPs?*
   - *What supports that children and their families received and how?*
   - *How is about referral system?*

3. The researcher compared interview statements and incidents in different interviews to show the analytic distinction. For example:

Table 2. Comparing the interview statement and incidents in different interviews

Excerpt 1: Bisma, a mother with HIV of a child with HIV		**Excerpt 3: Kunti, a mother with HIV of a child with HIV**	
	Coding		**Coding**
My neighbour does not know my status and my child status except for my families. From my family's side, they are still uncomfortable and afraid of my son and me. For example, if we have a family gathering or family activities, my son will need to isolate his glass from others, must remember where he puts his glass. His glass should not be placed everywhere carelessly. If he finished drinking, he had to wash his glass by himself.	Keeping secret Disclosing [to family] [Family] Fear of HIV transmission Isolating food utensils	…people tell there is no cure to the disease, …because this kind of disease has no cure so far, miss. All family do not want to touch my children My family usually share a banquet for the Javanese ritual, but when I wanted to blend in, I was scolded. They told me to eat it on my own plate.	Misconception about HIV Being ignored [by family] Being scolded [by family] Being inferior Rudeness [by nurse]

Another example, if my child is sweating, he should not come closer to his relatives. That hurts me. They are my families and did that to me. I have explained to them if the transmission of the disease is not easy, but my family is hard to tell. Perhaps they do not clearly understand this disease and its transmission process. Therefore, if it happens, I will accept it. I have just accepted what they think of me.	Being isolated Feeling powerless	Then, I got home I Cried; I am carrying a disease.…the nurses, they said my child is contagious, oh no, you are again	
From the above excerpts, the researcher asked *what process was at here?* And was **disclosure and impact**. The researcher found that mothers with HIV disclosed their HIV diagnosis to their families and health professionals (HPs) and experienced *Isolating food utensils, being isolated, feeling powerless, being ignored [by family], being scolded [by family],* *Being inferior, rudeness [by nurse].* The researcher found the participants disclosed their status and their child's diagnosis to *families* and *HPs and had negative treatment from them* The researcher asked *what the adverse treatment or the consequence of the disclosure process were?* From the participants' coding, the discovered **discrimination** (derived from *Isolating food utensils, being isolated, being ignored [by family], being scolded [by family], rudeness [by nurse],* and **marginalisation** (derived from *feeling powerless, Being inferior)*			

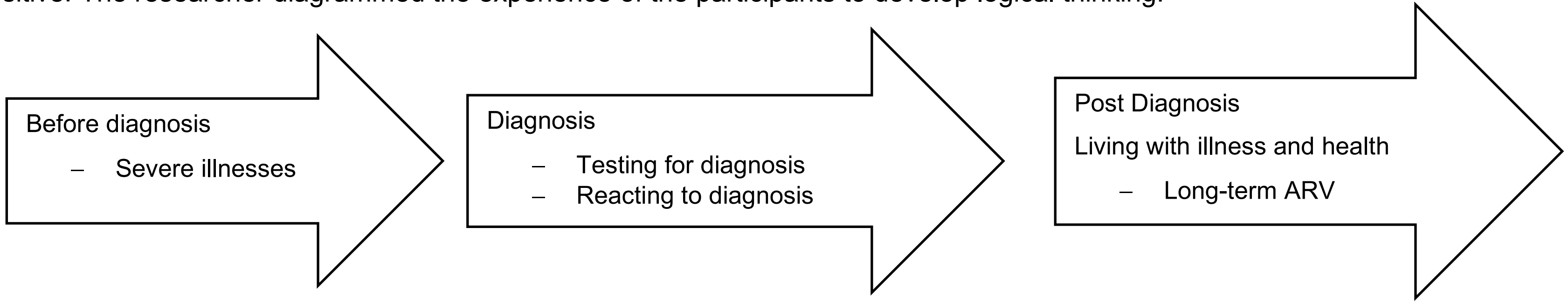
4. The researcher compared incidents with incidents in different interviews and used red highlighted to sensitise within the data that helped to generate ideas, for example:

Table 4. Comparing incidents with incidents in different interviews

Excerpt 2: Arjuna, a sister with a child with HIV	**Excerpt 10: Sita, a teenage with HIV**	**Excerpt 12: Barata, Foster Mother**	**Excerpt 9: Samba, an aunt with a child with HIV**
Before receiving medication, he frequently admitted to the hospital. His condition was deteriorated, and his body	When I was a child, I have a health issue; I felt sick until I have a problem at school because I had to stay at the	When he reached 1 year of age, I was wondering why he got a fever, diarrhoea. I took him to Hospital A. There he was hospitalised. If my child was sick,	[A child said] I take medication for a long time, forever. [an aunt said] For the future I am afraid if the ARV medicine is late in the hospital. I hope she can grow into an adult, get

was thin. He often admitted to the hospital for almost a month or over. God be praised, now my brother is not admitted to the hospital anymore. He has not relapse	hospital for one month and after that the disease kept recurring. Now, I take medicine in the adult section. Schedule for adults on Wednesday and children is on Tuesday. The service is the same; the daily schedule is different. The just told me that from now on I must take medicine in the adult section, the schedule is on Wednesday and Monday and for children is on Tuesday.	I always took him to the paediatrician. At first, I took him to Hospital B. He always felt ill every month. Reaching the age of 2, he felt sick again; I took him to a hospital C then I took him to a professor. He was skinny like Ethiopian the first time of the counselling I cried. I was bathed in tears… this is a disgrace. The husband is to… how to say it, it does not matter then the important thing is that my son has medical attention. I said you have to take your medicine regularly every day; you can't skip it here is your vitamin. If you do not do that your condition might drop, skinny, I tell you now, if you don't eat your growth could be hampered	married to the person who loves her, who can accept as she is. I hope she will live a long life.

By comparing incidents in different interviews, the researcher used theoretical sensitivity to sensitise with the data and highlighted that the participants have collective experience in the past; children suffered from severe illness before commencing ARV therapy, getting tested for HIV, reacting to diagnosis, starting access to ARV, children were no longer severe illness, living with the diagnosis and taking ARV in the rest of life, the researcher asked *What is going on?* And that is **Illness Trajectory linked** to the experience of being HIV positive. The researcher diagrammed the experience of the participants to develop logical thinking:



Before diagnosis

- Severe illnesses

Diagnosis

- Testing for diagnosis
- Reacting to diagnosis

Post Diagnosis

Living with illness and health

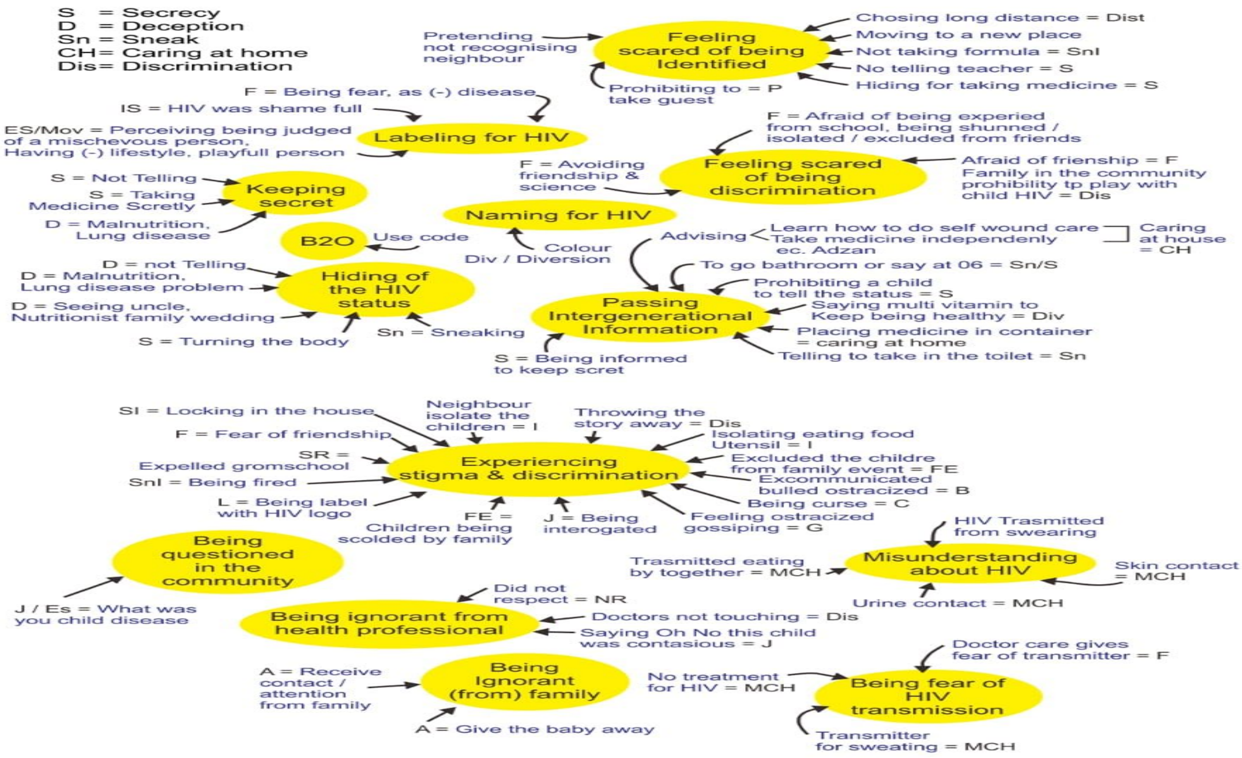
- Long-term ARV

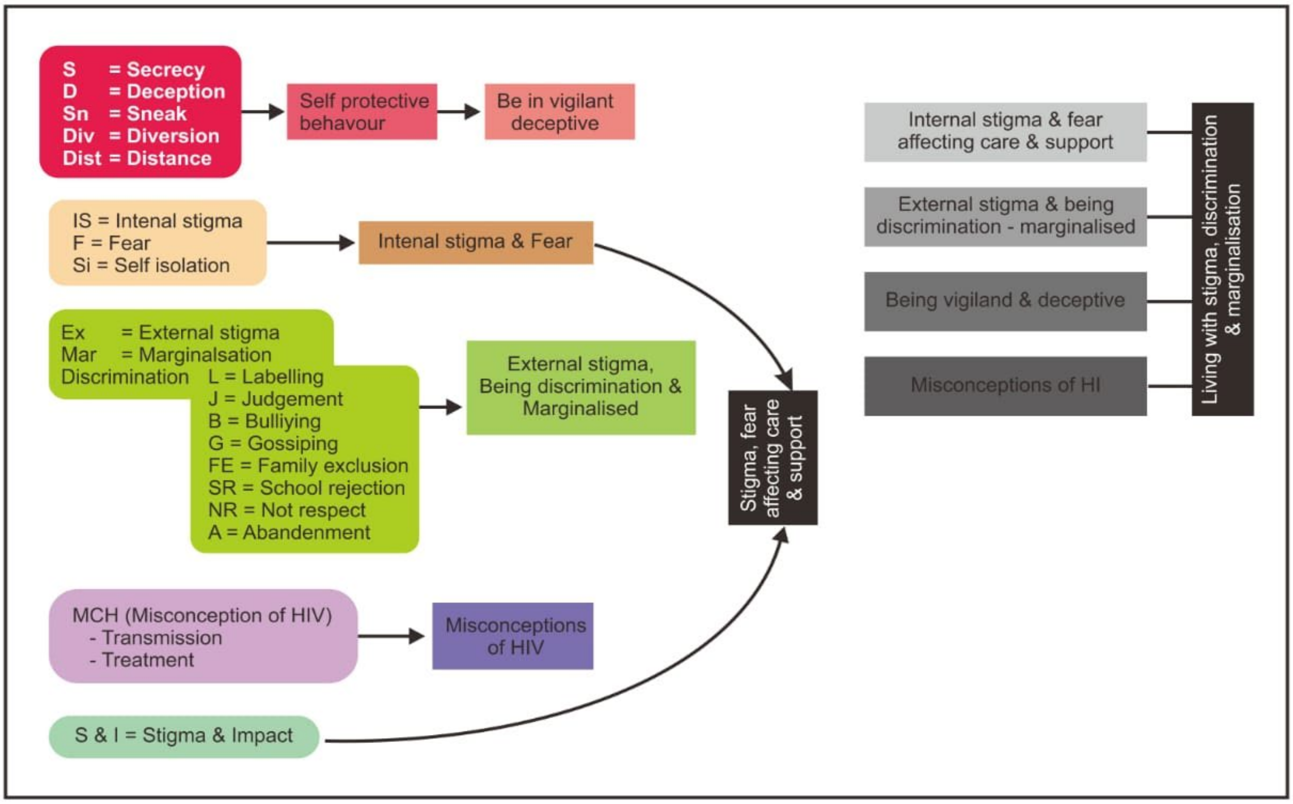
5. The researcher compared different incidents in the same interview, for example:

Table 5. the comparison of different incidents in the same interview

Excerpt 5 **Experience of the mother access to her ARV in PHC and access to his son’s ARV in hospital**	
I have to be punctual when it comes to the check-up; the medicine has to be taken regularly. Sometimes I take him. I am afraid of his teacher. If he did not go to school, he would be questioned by his teacher. I told his teacher that he is going to a medical check=up. I told my son has a lung infection. I collect his medicine by taking public transport; I collect it by myself. I collect it at Hospital XX. I do not wish, but if my son condition’s relapse, it would be easier for us to be taken by the doctors. I wanted to take here [PHC], so it would not be far away, but I do not know whether PHC provides HIV drugs for medicine or not. I heard that people say there is HIV medicine in PHC for the mother but not for the child. That is what I know. Sometimes, he is late taking medicine just like me. **[in PHC]** I was warned by the nurse. I am supposed to collect the medicine at a certain date. For example, on the 10 days of the month, but I collected it on the 12, I will get warned by Nurse in PHC by saying you cannot do that. I felt sad and felt sorry for her. Well, because I had a headache, tired that made me do not want to go. If I took my son’s medicine **[in Hospital]** over there, even I was late; they did not ask. They did not. I collected the medicine; the doctor wrote a prescription, that is all. I was not asked.	Making a priority Fear of being identified Telling a lie Access to ARV Wanting access to ARV in PHC- a short distance Not available of ARV for children [in PHC] Late taking ARV Being warned if late access Late access to ARV refills Not being asked why is late Focusing in writing a prescription
The researcher asked *What is going on?* And that is **ARV refills access, a hospital based.** The researcher coded late taking ARV and late access to ARV, it shows **cause** that may relate to being risk of adherence to therapy. The researcher identified being warned if late access (in PHC) and not being asked why is late (in Hospital). The researcher asked what is about? And **being monitored (between PHC and Hospital)**	

6. Consistent with the constant comparative method, after the researcher coded all the data, the researcher continued comparing data with data and found similarities and differences for the same phenomena. The researcher began an initial pattern to name a phenomenon and connected various codes and mapped them using a diagram. The researcher used a diagram to help to discover properties, dimensions and subcategories (Birks & Mills, 2011). The researcher continued interrogating herself about the early analytical decision by identifying conceptual possibilities. The researcher grouped all similar codes into a table that helped to provide a clear and complete description of the concept. For example:


S = Secrecy
D = Deception
Sn = Sneak
CH= Caring at home
Dis= Discrimination
Pretending not recognising neighbour
Feeling scared of being Identified
Prohibiting to = P take guest
Chosing long distance = Dist
Moving to a new place
Not taking formula = SnI
No telling teacher = S
Hiding for taking medicine = S
F = Being fear, as (-) disease
IS = HIV was shame full
ES/Mov = Perceiving being judged of a mischevous person, Having (-) lifestyle, playfull person
Labeling for HIV
F = Afraid of being experied from school, being shunned / isolated / excluded from friends
F = Avoiding friendship & science
Feeling scared of being discrimination
Afraid of frienship = F
Family in the community prohibility tp play with child HIV = Dis
S = Not Telling
S = Taking Medicine Scretly
D = Malnutrition, Lung disease
Keeping secret
Naming for HIV
B2O
Use code
Colour
Div / Diversion
Advising
Learn how to do self wound care
Take medicine independenly ec. Adzan
Caring at house = CH
To go bathroom or say at 06 = Sn/S
Prohibiting a child to tell the status = S
Saying multi vitamin to Keep being healthy = Div
Placing medicine in container = caring at home
Telling to take in the toilet = Sn
Passing Intergenerational Information
S = Being informed to keep scret
D = not Telling
D = Malnutrition, Lung disease problem
D = Seeing uncle, Nutritionist family wedding
Hiding of the HIV status
S = Turning the body
Sn = Sneaking
SI = Locking in the house
F = Fear of friendship
SR = Expelled gromschool
SnI = Being fired
L = Being label with HIV logo
Neighbour isolate the children = I
Throwing the story away = Dis
Isolating eating food Utensil = I
Excluded the childre from family event = FE
Excommunicated bulled ostracized = B
Being curse = C
Feeling ostracized gossiping = G
Experiencing stigma & discrimination
FE = Children being scolded by family
J = Being interogated
Being questioned in the community
J / Es = What was you child disease
HIV Trasmitted from swearing
Trasmitted eating by together = MCH
Misunderstanding about HIV
Skin contact = MCH
Urine contact = MCH
Did not respect = NR
Being ignorant from health professional
Doctors not touching = Dis
Saying Oh No this child was contasious = J
A = Receive contact / attention from family
Being Ignorant (from) family
A = Give the baby away
No treatment for HIV = MCH
Doctor care gives fear of transmitter = F
Being fear of HIV transmission
Transmitter for sweating = MCH


S = Secrecy
D = Deception
Sn = Sneak
Div = Diversion
Dist = Distance
Self protective behavour
Be in vigilant deceptive
IS = Intenal stigma
F = Fear
Si = Self isolation
Intenal stigma & Fear
Ex = External stigma
Mar = Marginalsation
Discrimination
L = Labelling
J = Judgement
B = Bulliying
G = Gossiping
FE = Family exclusion
SR = School rejection
NR = Not respect
A = Abandenment
External stigma, Being discrimination & Marginalised
MCH (Misconception of HIV)
- Transmission
- Treatment
Misconceptions of HIV
S & I = Stigma & Impact
Stigma, fear affecting care & support
Internal stigma & fear affecting care & support
External stigma & being discrimination - marginalised
Being vigiland & deceptive
Misconceptions of HI
Living with stigma, discrimination & marginalisation

Example of grouping similar codes and construction dimensions, properties within provisional categories

Grouping Similar Codes	Dimensions and or Properties	[Provisional] Categories
1. Keeping secret 2. Not telling status 3. Prohibiting to tell the status 4. Telling a lie [i.e., Malnutrition, lung diseases, visiting families, attending family's wedding] 5. Fall excuses 6. Keeping distance for friendship 7. Hiding 8. Sneaking [taking ARV in the bathroom, toilet] 9. Playtime restriction 10. Pretending not to know 11. Outside appointment 12. Being told [by HPs] to keep secret 13. Long-distance 14. Self-isolation [from neighbour] 15. Protecting the status 16. Self-defend	Protective Strategies – Secrecy – Prohibition on disclosure – Deception – Hide – Sneak – Playtime restriction vs overprotective – Pretending/ acting – Distance – Self-isolation	Being vigilant and deceptive
17. Non-Disclosure to a child – Telling a lie [i.e., multivitamin, keeping healthy]	Protecting	
18. Disclosure Age of disclosure – 12 years old/ [unintentional] disclosure	Disclosure	Disclosure and Discrimination
19. Impact of disclosure: – Family exclusion – Family isolation – Feeling inferior 20. Family disharmony 21. Being excluded [of families] 22. Being isolated [of families] 23. Being avoided [by neighbour] 24. Being bullied [by neighbour] 25. The community believed about being cursed 26. Play prohibition [from the community] 27. Being isolation [in the community] 28. Being ostracised [by the community] 29. Gossiping 30. Being interrogated [by the community] 31. Being cornered 32. Being judged	Discrimination – From Family [Family exclusion, family isolation, feeling inferior, family disharmony – From communities [bullying, social avoidance, prohibition	

33. Being told to move the school		
34. Disclosing and School Rejection	– School rejection	

Grouping Similar Codes	Dimensions and or Properties	[Provisional] Categories
35. Keeping secret 36. Not telling status 37. Prohibiting to tell the status 38. Telling a lie [i.e., Malnutrition, lung diseases, visiting families, attending family's wedding] 39. Fall excuses 40. Keeping distance for friendship 41. Hiding 42. Sneaking [taking ARV in the bathroom, toilet] 43. Playtime restriction 44. Pretending not to know 45. Outside appointment 46. Being told [by HPs] to keep secret 47. Long-distance 48. Self-isolation [from neighbour] 49. Protecting the status 50. Self-defend	Protective Strategies – Secrecy – Prohibition on disclosure – Deception – Hide – Sneak – Playtime restriction vs overprotective – Pretending/ acting – Distance – Self-isolation	Being vigilant and deceptive
51. Non-Disclosure to a child – Telling a lie [i.e., multivitamin, keeping healthy]	Protecting	
52. Disclosure Age of disclosure – 12 years old/ [unintentional] disclosure	Disclosure	Disclosure and Discrimination
53. Impact of disclosure: – Family exclusion – Family isolation – Feeling inferior 54. Family disharmony 55. Being excluded [of families] 56. Being isolated [of families] 57. Being avoided [by neighbour] 58. Being bullied [by neighbour] 59. The community believed about being cursed 60. Play prohibition [from the community] 61. Being isolation [in the community] 62. Being ostracised [by the community] 63. Gossiping 64. Being interrogated [by the community] 65. Being cornered 66. Being judged 67. Being told to move the school	Discrimination – From Family [Family exclusion, family isolation, feeling inferior, family disharmony – From communities [bullying, social avoidance, prohibition	
68. Disclosing and School Rejection	– School rejection	
69. [a family] Fear [of HIV transmission] 70. [family] lack of HIV transmission	Cause of discrimination	

71. [a community] fear of HIV transmission	– Fear of HIV transmission – Lack of HIV transmission knowledge	
72. Reacting to disclosure – Being on denial – Feeling powerless – Feeling shocked – Thinking of death – Thinking as testing for good – Feeling desperate – Crying	Reacting to disclosure	
73. [unintentional] disclosure; from socialisation at school 74. [planned] disclosure – Informed slowly about HIV, HIV prevention – Waiting for a child to get older [15/16 years old]; 13 years; junior high school, 17 years – Why: older children would have a better understanding, if too young, fear of not keeping the disease a secret – How: avoid saying you have or suffered from HIV, use open-ended questions [i.e. what do you know? What do you think? Continued with the explanation HIV sign, symptoms and prevention to minimise emotional distress, give the – motivation and or reinforcement [i.e., is not the end of the world] – Who disclosed Uncle, father, grandmother, a psychiatrist – Self-disclosure but afraid of [moral dilemma] – Planning to visit a psychologist – Planning to visit a doctor, NGO, counselling	Types of disclosure – Planned [intentional] disclosure – Unplanned [unintentional] disclosure	
75. Being inferior	Being Marginalised – Inferiority	
76. A feeling of being isolated	Fear, Shameful and Negative Perception	Fear and Stigma
77. The negative perception of HIV 78. Feeling shame and fear 79. Perceived HIV brought a negative label		

80. Being judged if HIV is caused by negative lifestyles of behaviour 81. Fear [of being] excluded from schools or friends 82. Fear [of being] isolated 83. Fear of being shunned 84. Fear of being identified 85. Fear of being found out 86. Fear of being discriminated 87. Fear of being judged [by the doctor] 88. Fear of making friendship 89. Fear of being rejected 90. Felling of being marginalised 91. Fear of being asked 92. Embarrassment 93. Negative perception of revenge 94. Being expelled from school		
95. Misconception about HIV – Having a short live – Closing to death – No cure for HIV – The community believed that HIV causes die or closes to die – The community believe that HIV is transmitted from sweat, touch, and change clothes – HIV is caused by posterity factor – HIV is caused by being cursed, a supra-natural thing		Misconception about HIV
96. Ignorance [from HPs] – Less empathy – Rudeness		External Stigma and Discrimination
97. Being banned [HPs] to go to the hospital		
98. Being interrogated [by doctors] during HIV consultation 99. Feeling intimidation 100. Being separated [for blood test specimen]		
The researcher changed from the [provisional] categories of being vigilant, fear and stigma, misconceptions about HIV, misconceptions about HIV, Disclosure and Discrimination, and External Stigma and Discrimination to the category of **fear, stigma and disclosure.** By comparing all the data with different interviews, fear, stigma and disclosure hampered effective care. Because of this, the researcher changed it as one of the dimensions of the [provisional] category of determinants of health		

Example of sifting, sorting and sintesising the codes

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	**Subcategory/ Properties**	**Potential Category**
1. Being sickly child	- Acute physical health problems - Hospitalization	Life-threatening & hospitalisation	Reacting to diagnosis
2. Not knowing about the illness			
3. STD testing	STD testing	HIV Counselling, Testing and Coping with the diagnosis	
4. Describing STDs			
5. HIV testing	HIV testing		
6. Doing VCT and PITC	HIV counselling process: counselling and consent		
7. Explaining HIV stadium, its treatment and side effect			
8. Talking about ethical concerns			
9. Concerning confidentiality			
10. Believing the culture	Psychological response - Initial crisis: shock- disbelief/ denial- hopelessness - Family transitioning - Fears - Losses - Acceptance		
11. Feeling surprised/ shocked (of) being HIV positive			
12. Being orphans			
13. Being acceptance			
14. Being denial			
15. Thinking & preparing death			
16. Death of HIV-AIDS			
17. Being HIV positive child			
18. Misunderstanding about HIV			

NOTES

Children and their families are physically ill and are often hospitalised before the status of their HIV are identified. When the children first were diagnosed as HIV positive client, the families of HIV positive children experience different responses. The responses include shock, disbelief or denial, hopelessness, and acceptance.

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	**Subcategory/ Properties**	**Potential Category**
1. Keeping secret	Developing active strategies: being silence & hiding	Strategies to prevent social stigma and discrimination	Being vigilant HIV-related stigma & discrimination
2. Hiding of the HIV status			
3. B20	Changing the term of HIV in the care practice		
4. Naming for HIV			
5. Passing intergenerational information	Not telling the truth about HIV medication: - Parents say vitamin instead of HIV therapy - Parents told to go to the bathroom for taking HIV therapy - Parents tell children for not telling their disease to other people		
6. Labelling for HIV	Self-stigmatisation	Internalised Stigma	
7. Feeling scared of being identified			
8. Feeling scared of being discriminated			
9. Experiencing stigma & discrimination	Being stigmatised and discriminated	Social stigma & discrimination	
10. Being questioned in the community	Being stigmatised		
11. Being ignorant (from doctor, nurse & health professionals	Not being respected		
12. Being ignorant (from family)	Being marginalised		
13. Being fear of HIV transmission			

NOTES

HIV positive children and their families are aware of stigma and discrimination. HIV positive children and their families experience internal or self-stigma and external stigma from health professionals, their families, and communities. HIV positive children and their families were also discriminated from health professionals and the communities. Due to stigma and discrimination, HIV positive children and their families are silent, hide or tell a lie to keep their status secretly. Additionally, they use the code of B20 instead of the term of HIV.

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	Subcategory/ Properties	Potential Category
1. Medication (caring practices at home)	Providing care and support for their children at home - Managing children 's therapy at home - Providing children needs and first aid medication in their daily life - Developing strategies to build children independence in taking the medication - Practising spiritual care with positive thinking - Participating in some activities in the community (school, play) like a healthy child	(Families) providing home-based care	Experiencing the risk of care fragmentation
2. Receiving) Medicines			
3. Self-empowering			
4. Being an independent child			
5. Believing in religion			
6. Participating child			
7. Experiencing care within health care services	Describing the service in an outpatient clinic during monthly regular visit ART: - Short anamnesis - Anthropometric measurement if the child visits - Having a consultation - receiving ART - speaking to different doctors during a family visit	The centralisation of service for pediatric HIV treatment and boundaries	
8. ARV Care service in XX hospital	- Hospitalized HIV positive children receiving care based on standard		

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	Subcategory/ Properties	Potential Category
	operating procedures in XX hospital - Continuing access ART refill in the XX-outpatient clinic		
9. Accessing pediatric ART in a certain hospital	- Seeing a different doctor in the hospital - Receiving care based on standard operating procedures (SOP)		
10. Medication (caring practices of health professionals)			
11. Challenging in the care of HIV for health professionals	- High workload - Stigma - Financial and demographic factors of the clients - Health professional capacities - Pill burden - Ethics - Complex problems of HIV positive children		
12. Being referred	- Referring to XX hospital - Lacking coordination of referral back from the hospital to PHC - Providing the referral documents of the clients		
13. Making a referral for HIV clients			
14. Preparing health documents administration			
15. Anything about health insurances	- Having a long queue for the use of BPJS or JKN insurance Requiring a reference letter from PHC to visit the hospital		

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	Subcategory/ Properties	Potential Category
	- Simplifying the procedure of government insurance		
16. Establishing partnership and networking	- Working multidisciplinary is widely implemented in adults' HIV clients to children		
17. Working for an intra-inter-multidisciplinary team			
18. Describing HIV-AIDS program activities	HIV activities are more focus on adults than children's clients. In PHC - HIV counselling and testing - Milk formula support In the hospital - HIV counselling and testing - Accessing ART refills - Care and treatment for opportunistic infections - PMTCT - Home visit - Health education: safe sexual behaviour with a free condom for LGBT		
19. Describing PMTCT interventions	Health professionals provide care prevention from mother to child transmission, including: - Providing education about safe sexual behaviour - Screening HIV for a future bride - Providing ART for pregnant women - Monitoring and or referring to their pregnancy		

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	Subcategory/ Properties	Potential Category
20. Explaining HIV-AIDS policy	- Public policy (Local/Regional/ National)		
21. Reporting and recording on HIV	HIV clients receiving care support are reported and recorded every month by health professionals with the use of a manual record or government electronic documentation.		
22. Factors contributing to ART adherence	- Internal factor: socioeconomic factors, - External factors: geographical location, and health professional capacity	Facilitating factors to adherence therapy	
23. Having a side effect of taking HIV drugs	- Cardiovascular systems: anemia dizziness, seeing blurred - Integument system: itchy, black skin spot - Gastrointestinal system: nausea		
24. Maintaining adherence to therapy	- Describing additional health professionals’ intervention to support adherence of ART		
25. Being supported (by governments)	Receiving 1. different types of support that are: - food support - informational support - social support - financial support/ charity	Receiving inadequate support and facilities	
26. Being supported (by the community)			
27. (Family) adopting HIV positive child			
28. Being supported (by family)			
29. Protecting child			
30. (A family) providing sympathy			
31. Being supported (by governments)			

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	**Subcategory/ Properties**	**Potential Category**
32. Being supported (by health professionals)	2. Various sources of support from government and private		
33. Understanding (from doctors or nurses)			
34. Lacking resources facilities	- Having limited facilities for pediatric HIV services - Lacking the delivery model of care for HIV positive children		
35. Receiving discontinuity of care and support			
36. Disclosing of HIV positive status	When and how the process of the disclosure		
NOTES Families of HIV positive children have committed the care and support for their children at home and in the health institution. However, they potentially experience the risk of care fragmentation regarding adherence to antiretroviral therapy (ART), inconsistent supports, or centralisation of ART access with inadequate children-friendly facilities.			

Initial Coding	**Focused Coding**		
	Sift/ sort/ synthesise the data	**Subcategory/ Properties**	**Potential Category**
1. Communicating approaches with clients & families or caregivers	The interaction process between health professionals, clients, and families. - Building trust - Understanding the socioeconomic status of the clients	The ongoing relationship between children- families and health professionals	
2. Discharge planning			
3. Having consultation	Accessing health information and therapy from health professionals: - Talking with doctor - Learning/ gaining the information - Learning/ gaining the information - Seeking health care support		
4. Gaining the information (about HIV & STDs)			
5. Understanding HIV care and prevention			
6. Getting care & support for STDs			

NOTES

Interpersonal communication is two-way communication between health professionals, HIV positive children, and their families. Families with HIV positive children experience ongoing interpersonal communication with health professionals during the delivery of care, such as through consultation or discharge planning. On the other hand, health professionals use different approaches in the process of communication with families.

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	Subcategory/ Properties	Potential Category
1. Sharing hope (children and family)	Care and Treatment Service - Child-friendly counselling - Improvement of friendly pediatric hospital infrastructure (playground, corner library, educational toys) - Simplifying the procedure of the use of BPJS insurances - Sexual and reproduction information for a teenager - Single payment of BPJS for the child only - Disclosure support - Advocation - Providing and differentiating ART care access between children and adults HIV? - The availability of Antiretroviral Therapy and free - Health professional practice: no judging and discrimination Support - Nutrition: milk-formula, food support - Education: school fee - Health insurance: free-BPJS	Hope for the availability of HIV prevention, care, support, treatment, and rehabilitation, from children and families perspectives	

<table>
<tr><th rowspan="2">Initial Coding</th><th colspan="3">Focused Coding</th></tr>
<tr><th>Sift/ sort/ synthesise the data</th><th>Subcategory/ Properties</th><th>Potential Category</th></tr>
<tr><td></td><td>- Psychosocial support
- Children and family peer support activities
- Friendly school transport facilities
- Financial support
- Encouraging stepfamilies or orphanage or HIV foundation to adopt an orphan with HIV positive
- Life planning: continue studying, marriage
- Financial aid for entrepreneurship
- Socialization or health education on HIV through social media</td><td></td><td></td></tr>
<tr><td>2. (Health professionals) sharing hopes & thought</td><td>1. Care and Treatment
- Pill burden management
- ART management
- Disclosure management
- Patient-centred care and continuity
- Home-based care
2. Support
- psychological support
- social protection support
- family empowerment
3. Effective and Accurate Information System
4. Policy Commitment
5. Professional Practice</td><td>from health professionals perspectives</td><td></td></tr>
</table>

Initial Coding	Focused Coding		
	Sift/ sort/ synthesise the data	Subcategory/ Properties	Potential Category
	6. Continuing professional education 7. HIV Promotion, Prevention, and Surveillance 8. Communication and Coordination System		

NOTES

HIV positive children and their families need comprehensive and supportive care service. The service does cover not only care and treatment, but also the availability and sustainability of prevention, support, and rehabilitation of HIV. The families with HIV positive children may require that the care for HIV positive children should be widely covered comprehensively and consistently so that HIV positive children can live like other healthy children, so their quality of life could improve. Comprehensive and supportive care may consist of treatment, informational, psychosocial, spiritual supports, or life-planning. Additionally, health professionals also explain the need for coordinated system thinking on HIV children care service.

Initial Coding	Focused Coding		
	Sift/ short/ synthesise the data	**Subcategory/ Properties**	**Potential category**
1. Understanding the client family's characteristics & circumstances	Living in poverty	The impact of HIV on poverty and education	Family living in the hardships and worries
2. Failing at school	Not continue taking the school		
3. Facing financial challenges	Affecting financial and psychological problems in the family	Having psychosocial & financial problems	
4. Gaining conflict within a family			
5. Depending on the family or friend			
6. (A child) getting violence / abuse	Experiencing: - Domestic violence - Verbal abuse - Sexual abuse (for transgender)	Parent-child interactions	
7. Understanding the child's characteristics	Characteristic of children - Talking less formal - Being Stubborn - Depending on gadget - Delaying eating		
8. Being relationships between mother & child	Parenting styles		
9. Telling family concerns/ worrying	Worrying about children's marriage and the children turn to the bad condition	Family Concerns/ Worries	

NOTES

Family living in the hardships and worries explains the experience of HIV positive children and their families live in a situation with HIV. HIV positive children and their families live with low socioeconomic status, causing other negative impacts for them, such as domestic violence, school problems, or other psychosocial issues.

Appendix 7. The description of children with HIV and their families

The Description of Children and their families
PK 1 Bisma (A child and mother) A child Bisma is a male, aged 14 years old male, acquired HIV through perinatal transmission from mother to child. He has been diagnosed as HIV positive in 2009 at XX Hospital and has received ARV medicines, namely Nevirapine and Duviral. He experienced lung disease prior to diagnosis. His mother disclosed his HIV status in 2018. He is a Junior High School student. Mother HIV positive mother aged 36 years old. And her husband died of HIV-AIDS.
PK 2 Arjuna (A child and the oldest Sister) A child Arjuna is a male, aged 15 years old, acquired HIV through perinatal transmission from mother to child. His mother died of HIV. He used to experience recurrent hospitalisation prior to diagnosis. He has been diagnosed as HIV positive in May or June 2012 when he was at year four primary school and has received his ARV medicines since December 2012 in XX Hospital. In the year six of primary school, He suffered from tuberculosis. He consumed efavirenz and duviral. The family disclosed his status when he was in year six primary school. Now, he lives with her sister, who looks after him. The oldest sister The oldest sister who takes responsibility for his brother daily care. As well, the one who supports the access to ARV refills in XXX hospital for both his father and brother.
PK 3.1 Kunti (A mother) Kunti who is a woman with HIV, aged 50 years old HIV. She acquired HIV through sexually transmitted from her husband who died of HIV positive. Kunti has two twin daughters aged 12 years. The children experienced malnutrition, diarrhoea and oral candidiasis that required frequent hospitalisation prior to diagnosis. The children have been diagnosed as HIV positive since 2006 in XX Hospital due to perinatal transmission from mother to child. The first child received Neviral and Duviral, and another child received Lamivudin and Abacavir. The mother has not disclosed their HIV status yet to her children Kunti lives out of her sister in 1.25 square metre two floors house with her children. She works as a laundry worker to fulfil daily needs. Kunti received support from her sister in the care of the children.
PK 4 Arimbil (A child) Arimbi is a girl, aged 18 years old is an HIV positive girl, acquired HIV through perinatal transmission from mother to child. She experienced tuberculosis prior to diagnosis. She was diagnosed as HIV positive when she was four years old in XX hospital. She lives with her grandmother in the city of SS, separated from her mother who lives in a different province. Her father died of HIV positive. She knows her HIV status when she was 17 years old. She takes Duviral and Neviral and accesses her monthly ART refills independently in XX hospital.
PK 5 Barata (A child and mother) A child

Barata is a boy aged nine years old. He acquired HIV perinatal transmission from mother to child. He was first diagnosed in PHC-DK in 2012 and was referred to XX Hospital to receive ARV medicines. He receives Neviral and Duviral in XX Hospital.

Mother
A mother with HIV positive, aged 30 years old. She acquired HIV through sexual transmission from her husband who died of HIV. She is a housewife with her educational background was graduated from Primary School.

PK 6 Wisnu (A child)

Wisnu is a male aged 17 years old and transgender. He has experienced as a sex worker. He has not experienced suffering from sickness prior to diagnosis. He was first diagnosed as HIV positive in 2016 due to sexual transmission. He receives FDC therapy and accesses his medicine independently. He did not disclose his HIV status for his family members. He did not finish his Junior High Scholl and plans to continue his study through Kejar Paket. He starts setting a small business by selling merchandise in an online shop.

PK 7 Subali (A child)

Subali is a male aged 17 years old and transgender. He suffered from condyloma prior to diagnosis. He has been diagnosed as HIV positive in 2016 due to sexual transmission and has received FDC therapy. His parents knew about his HIV status. He experienced school rejection due to HIV-stigma and continued his study through Kejar Paket. Now, he is active in joining some activities with Youth Focus, NGO relating HIV.

PK 8 Bayu (A child and an uncle)

A child
Bayu is a boy aged 11 years old boy. He acquired HIV through perinatal transmission from mother to child. He was diagnosed as HIV positive when he was nine years old, in 2016. He suffered from tuberculosis and malnutrition as his opportunistic infections prior to diagnosis. Both of his parents died of HIV positive when he was 1,5 years old. His uncle has disclosed his HIV status.

An uncle
His uncle continues providing the care for a child due to being orphan. He is 39 years old, married and has not had a child yet. He works as an entrepreneur, and his educational background was graduated from Junior High School. He provides daily needs and access to monthly ART-refills for the child in XX Hospital.

PK 9 Samba (A child and an aunt)

A child
Samba is a female child, grade 4 primary school (12 years old). She acquired HIV perinatal transmission from mother to child. Both of her parents died of HIV positive when they were hospitalised in XXX Hospital. She has been diagnosed as HIV positive when she was two years old (in 2010). She used to live with her grandmother and now is living with her aunt. She did not know her HIV status yet.

An Aunt
She was a widow aged 43 years old. She provides the child's daily needs, supported by her older son. She accesses ARV refills in BB hospital after asking referral letter from PHC SMI

PK 10 Sita (A child)

Sita is a girl, aged18 years old. She had HIV counselling test and was diagnosed as HIV positive in 2015 in BB Hospitals. She experienced tuberculosis prior to diagnosis. She acquired HIV through perinatal transmission from mother to child caused. Both of her parents died of HIV.

Now, she is living with her grandmother. She accesses her therapy in XX hospital independently and receives Duviral and Evavirens. She is a high school student.

PK 11 Surya (A child and foster parents)

A child
Surya is a boy aged nine years old. He is a primary year student He acquired HIV through perinatal transmission from mother to child. A family adopted him since he was a baby. He experienced recurrent hospitalisation prior to diagnosis. He has been diagnosed as HIV positive since 2012 in XX Hospital and receives Aluvia, Duviral, and Abacavir for his HIV therapy. He still does not know about his HIV status yet. His family tells the neighbourhood if he suffers from a lack of nutrition.

Foster parents
A married couple without having a baby who adopted the child. Both work as an entrepreneur.

PK 12 Indra (A child and foster mother)

Indra is a boy aged 13 years old. He experienced diarrhoea, oral candidiasis, malnutrition that required recurrent hospitalisation prior to diagnosis. He was diagnosed as HIV positive in 2006 in XXX Hospital and has received Lamivudine and Zidovudine for his HIV therapy. He has a growth and development problem that required him to follow in an inclusion program for his school.

Foster mother
A married couple without having a baby adopted the child since he was a baby. The child lives with his mother in everyday life because his father works as a salesman in a different province.

Appendix 8. The description of health professionals

The Description of health professionals
Dr 1/ Sukesi/ The head of PHC-DK from 2005 to present, female, aged 49 years old. She manages how the PHC can deliver the healthcare service according to the standards made by the Ministry of Health for the health of individuals living in the area of this PHC. As a manager of the PHC-DK, her task starts with planning. She planned based on the analysis of community needs, and the community satisfaction survey, such as population data, economic status. Then, she makes the proposed action plan with the use of a standard form from the department of health. Furthermore, she explained that PHC has two functions, delivering individual health *(UKP)* and public health *(UKM).* The portion for public health service is higher than individual health service, which *UKM* is 60%, while *UKP* is 40%. She initially worked with sex workers. In the area of PHC-DK has two prostitution areas, which had almost 1500 commercial sex workers. She established a reproductive clinic service in 2006 and started delivering the service in 2017 after she and other five health professional of PHC-DK received training. She explained that in 2005, she had a case of a malnourished toddler and deteriorated. She referred him first to the Surabaya city government hospital and turned out to be referred directly to XX Hospital, and then the child was diagnosed as HIV positive. She explained some other activities on HIV, such as: - Collaborating with NGO HOTLINE to screen parents suspected with HIV signs and symptoms - She was collaborating with the leader in the community to screen on sexually transmitted disease testing for commercial sex workers in PHC-DK, or a hidden sexual worker in the house. - Providing HIV Counselling and testing for sexual workers since 2009 and started supplying ARV service for adults in 2012. Before in 2012, the clients with HIV positive were referred to XX Hospital, which was the only hospital that receives referral clients and provides ARV treatment. - She was collaborating with NGO to provide a reading corner for children, who live in the area of prostitution. She attended several HIV training, including PITC, PMTCT, ARV, HIV & STI Screening and Treatment, CST, VCT.
Dr 2/ Agni/ HIV coordinator, PHC-DK since 2011, female, aged 41 years old She is responsible for the control program of HIV-AIDS, especially for public and individual healthcare services (*UKM* and *UKP)*. Furthermore, she coordinates services, such as PMTCT and PITC programmes. PMTCT program is a program to prevent the transmission of the disease from the mother to the child. PITC is a program to deliver HIV counselling and testing initiated by health providers for a patient suspected of having HIV signs and symptoms. In 2012, PHC-DK became the pilot project of the health ministry to do PMTCT on all pregnant woman. She ensures if the mother cannot do the test, she looks for the cause. She would monitor her until the mother is willing to take HIV testing. If the test result is positive, the mother will be informed and planned for her caring. She also supervises the patients that she takes care of, monitors what the patient needs and what and where the problem lies. PHC programmes are made by the district health office department and usually receives socialization from the department. She attended several HIV training, including VCT, PITC and PMTCT.
Dr3/ Utari/ HIV Coordinator PHC-KR, female, aged 32 years old She has worked in PHC-KR for six years with her employment status as a contract doctor of The Health District Officer. As a contract doctor, her job is working in *Puskesmas Keliling. Puskesmas Keliling* is a mobile health centre that supports primary *Puskesmas* to improve health services especially those related to promotive and curative in remote areas far from the reach of health facilities and to monitor PHC activities in the local area. Her jobs should be more focus on the community. There are two *puskesmas keliling* available that under managed PHC-KR. However, the head of PHC-KR gives her more works not only as a doctor of

puskesmas keliling but also concurrently provides health service in the PHC. Furthermore, since 2007 she has been a coordinator of the control and prevention program of infectious and non-infectious disease *(is called Pengendalian dan Pencegahan Penyakit Menular dan Tidak Menular/ P2PM and PTM).* The contagious diseases programmes include HIV, tuberculosis, leprosy, haemorrhagic dengue fever, diarrhoea, typhoid and the non-infectious diseases programmes cover hypertension and diabetes mellitus diseases.

In terms of HIV, she involves in HIV care service after receiving counsellor training. She serves counselling and VCT examination. PHC-KR provides services inside the building that is VCT and outside the building that is mobile VCT. The consideration of mobile VCT is because the PHC is located in the central business district in Surabaya, which has many entertainment facilities. Additionally, she delivers PITC examination that is HIV testing, initiated by health care provider due to the availability of HIV signs and symptoms for patients, including children. However, she claimed that she has limited experience in children because PHC does not provide service for paediatric HIV treatment. She attended several HIV training, including VCT, CST, PMTCT.

Dr4/ Gandawati/ The head of PHC-KR from 2007 to present, female, aged 50 years old

She provided an IVA test for female sex workers in the sexually transmitted infections (STIs) service. She explained that the guidance of PHC-PT, she and her team in PHC-R could do HIV testing for those patients. Since then, PHC KR has delivered HIV testing, but the knowledge of HIV management of health professionals was still limited. As a result, a case of lost follow-up for mothers with HIV positive and children with HIV occurred.

In term of HIV care service, PHC-KR has the same HIV program as other PHCs. PHC-KR has HIV team which provide HIV testing service and mobile clinic, STI-HIV examination, home visit, and counselling. The counselling is conducted both inside and outside the building. PHC-KR provide care, support and treatment, which was more focused on adults with HIV without opportunistic infections than children with HIV as HIV treatment for children are available in XX Hospital. Health education programs for teenagers was also available, such as education about HIV prevention and healthy lifestyle. PHC-KR also establishes cooperation with cross sectors, sub-districts, and HIV-AIDS commissions. She attended HIV & STI screening and treatment training.

Dr5/ Uma, an HIV coordinator in PHC-SMI, female, aged 36 years old

She is responsible for the reproduction clinic service, and one of the tasks is dealing with STIs clients in PHC-SMI. Additionally, she also handles medical service for patients. For example, if there is HIV client, she will be consulted. The PHC provides ARV service, but it focuses on adult clients only and is not authorised to provide paediatric ARV. She has referred most of HIV positive children, followed by accompaniment from cadre and/ or health professionals. She attended HIV & STI screening and treatment, PITC, and PMTCT training.

Dr6/ Gendari/ HV coordinator in PHC-PJY, female, aged 38 years old

She has been responsible for the health of mother and children service, STI and HIV services since 2010. PHC-PJY has provided the STI services since 2005 where the prostitution area was available. Although the prostitution area was closed in 2014, the STI service is still available in PHC. Then in early 2017, PHC has begun the provision of ARV satellite service for adults with HIV. She attended VCT and CST training.

Dr7/ Larasatl/ HIV Counsellor PHC-PA from 2009, female, aged 40 years old

She is an HIV coordinator and provides HIV examination, and medication, PITC, CST, HIV counselling and testing, HIV report to health district office department, and referral to the hospital. She attended several HIV training, including PITC, PMTCT, HIV & STI screening and treatment.

Dr8/ Srikandi/ The head of PHC-PT from 2002 to present, female, aged 49 years old.

She provides individual health care service (UKP, *Upaya Kesehatan Perorangan*). For example, as a functional doctor, she provides patient care service and counselling. PHC has programmes inside and outside the building, called UKM in which PHC-PT has cooperated with society, cadres, cross-sector, and stakeholder in taking care of the health problems that exist within its region. Infectious diseases are the highest case in PHC-PT, and the number of non-infectious diseases is also increasing. She has handled HIV AIDS through Sexually Transmitted Infections service since the year of 2003 to present. At that time, STI service handles the port region, and there was one the localization area. Entering the port is not as easy as entering our village, so the process of the permit goes through several stages, and NGO assisted it. Then, two years later, PHC-SI provided HIV testing in a high-risk population. At that time, offering a blood check for HIV testing was hard because HIV was still considered as a scary disease. She attended HIV training, namely VCT, PITC, and PMTC.

Dr9/ Suhita/ The head of PHC-SI from 2007 to present, female, aged 50 years old

As the head of PHC, she provides coordination and advocacy across the sector, such as arranging the disadvantaged letter for disadvantage patients or patients from outside of Surabaya who require treatments. Regarding the implementation of PHC program, PHC-SI socialises the program to across sectors, and then we will form an association of cadres as our extended arms in community. PHC-SI will also work with cross-sector related to health insurance, whether it is ready or not for patients. I have conducted routine cross-sectoral meetings every 3 months.

PHC-SI has been running the prevention of transmission from pregnant women to their children with the use of five prongs. PHC-SI starts it with socialisation, counselling, and a PITC examination. For example, pregnant mothers who are detected with HIV, children who have been indicated with HIV, or children from mothers who are suspected of HIV would have STI and HIV examination, VCT, and ARV therapy for adults. She attended HIV & STI screening and treatment and HIV/AIDS Case Management training.

Dr10/ Anjani, a paediatric specialist in the XX Hospital, female, aged 42 years old

In the XX hospital, her roles are a team member in infection and tropical illness division, works in Care Unit for Intermediate and Infectious Disease, which is a poly that provides care for patients diagnosed with HIV, including HIV cases on children. Additionally, she is also a part of the HIV AIDS team of XX hospital. Furthermore, she with her team also provide the training. I collaborated with the public health office, the public health ministry, and the committee for the prevention of HIV AIDS or *KPA*. She attended several HIV training, including CST, PMTCT, PITC, and HIV Therapy Paediatric.

Dr11/Dewi, a paediatric specialist in the XX hospital, female, aged 43 years old

In the XX hospital, she is as staff at the division of infectious diseases and tropical paediatrics. She is responsible for patient services and professional program of a specialist doctor. She is also as the secretary for specialization in tropical and infection. In term of HIV, she involves in HIV CST team. As a paediatrician, she experienced dealing with both medical and non-medical issues of children with HIV. For example, from the medical side, the problem is adherence to taking medication, opportunistic infections, and other diseases faced by patients. Then, from the non-medical side is non-disclosure. The challenge for the children themselves is more complicated compared when their parents are the one who was taking care of. She attended PMTCT and HIV Therapy Paediatric training.

Dr13/Krisna, paediatric infectious consultant in the XX hospital, male, aged 51 years old

In the XX hospital, he is a team member of child infection and tropical diseases division and handles infectious diseases. He handles infections that are systemic, such as typhoid, measles, tetanus, and HIV. As a consultant, he does not just delivery treatment in the hospital but also has the responsibility for providing educational matter, such as lecturing for the specialist medical students 1 and 2. His role is also as a researcher in the hospital. As a consultant, he also involved activities outside the hospital, such as the public health service of East Java, and public health services in the cities. He attended several HIV training, including CST, PMTCT, PITC, and HIV Therapy Paediatric.

N1/Uma, nurse unit manager in HIV outpatient clinic, female, aged 54 years old

She is in charge of the child outpatient clinic and serves patients with HIV who need regular check-ups and require medical prescription. She had routine activities; for example, every day she would do some cleaning. Then, if a patient comes, she will point out incomplete forms. If the document is complete, she would ask the patient to queue up a line to see the doctor. Interaction with the patient would usually only be around 5 minutes; getting the documents ready is what makes it take so long. The other kind of treatment usually done is the Nebulizer and usually done if suggested by the doctor. Aside from that, there is no other treatment. She attended CST training.

N2/ Sri/ nurse coordinator in the PHC-DK, female, aged 40 years old

She has taken part in the HIV-AIDS program since 2012 and is also responsible for the palliative, leprosy, and HIV. Her roles are monitoring medication compliance for patients, arranging documents for patients with low economic who need referral care to the hospital and providing home care visit. Furthermore, she involves HIV counselling and testing for mostly the key population. She attended CST training.

N3/ Pandu, nurse unit manager in inpatient ward for patients with HIV in the XX hospital, male, aged 52 years old.

As the head of the inpatient room, his first roles are to manage the ward, including arranging the service schedule and administration. He also involves HIV counselling and care in the ward. He attended several HIV trainings, including CST, Standards for HIV and Education Service, HIV/AIDS Case Management, Monitoring and Evaluation of HIV.

N4/ Ratri, nurse unit manager in the paediatric ward specifically for tropical and infectious diseases in the XX hospital, female, aged 47 years old.

As NUM, she makes sure the patient's privacy in which patient's information will not spread outside the hospital manages the children's care in the ward, such as monitoring the care based on the standard operating procedures (SOP). In terms of HIV care, she thinks that the ward does not have a special SOP for children with HIV but follows the rules of protection. In addition, there are many HIV AIDS cases here and most of the patients do not have parents or maybe children of the prostitutes or poor family. She does advocacy to NGO to help the children's patients to get formula support. She attended CST training

N5/ Ratih, community nurse in PHC-PJ, female, aged 30 years old

She is in charge in the STI policlinic. Her previous experience was she did not have knowledge about HIV knowledge and skills and felt fear because she had not been trained yet. However, after being trained, if she met patients with HIV, she felt like the usual disease. Her roles provide caring of STI patients, HIV counselling and testing for patients suspected with HIV signs and symptoms, including mother and children, and mobile HIV counselling and testing for key population. She is also community health nursing coordinator in the PHC and some of her tasks sometimes are providing home visit for patients with palliative condition and managing referral for patients who need hospital care. She attended ARV and VCT trainings

N6/ Gangga, female, aged 50 years old

She is a nurse coordinator for gastrointestinal room in the paediatric ward, XX hospital. Her roles are making nursing care plan, implementing and evaluating the care. Furthermore, she makes sure that the room is clean, and the patients' medical record were well-documented. She experienced providing care for children with HIV with their opportunistic infection of diarrhea and malnutrition. She attended VCT training.

N7/ Prita, female, aged 50 years old She is a nurse coordinator for respiratory room in the paediatric ward, XX hospital. Her roles are implementing treatment based on doctor’s advise and monitoring the intake of nutrition and medication compliance. In term of dealing with children with HIV, she experienced a rapid blood test, checked CD4 testing, and referred the children with HIV positive result to an HIV outpatient clinic. She attended PITC training.
M1/ Tara, female, aged 45 years old She is responsible for STI service. Her duties are providing STI testing, HIV counselling, arranging referral for patients who need hospital care, and coordinating peer support activities for adults with HIV in PHC. She attended several HIV trainings, including CST, HIV/AIDS Case Management, HIV & STI screening and Treatment.
Nutritionist 1/ Gayatri, female, aged 37 years old As a nutritional officer, her roles are delivering nutritional counselling and care for children and mother with non-communicable and communicable diseases, including HIV. She attended nutritional management of HIV and malnutrition training.
N9/ Rama, male, aged 40 years old He is as team coordinator in the reproductive service. His roles are providing service related to HIV-AIDS and STI. For example, he did HIV counselling and testing inside PHC building and outside building, such as mobile clinic in collaboration with NGOs and STI testing. Furthermore, he facilitated peer group meeting with patients with HIV once a month. She attended CST training.
N12/Brahma, male, aged 51 years old He is a CST coordinator in the outpatient clinic of A Hospital and also responsible HIV recording and reporting. His roles are providing HIV counselling, collaborating with NGO, arranging referral to the XX hospital for young children with HIV to access ARV treatment, and reporting and recording the data of patients with HIV in the SIHA system. He attended several HIV trainings, including VCT, CST, HIV Recording and Reporting, PMTCT.

Appendix 9. Bibliographic details of the existing studies from chapter seven

Component of Review	No. of Studies (N=98 studies)	Sources
Patient [child] cantered care, N=32 studies		
– ARV treatment and adherence	N= 11 studies	Almeida-Brasil, et. Al., 2018; Coetzee, B, Kagee, A & Bland, R 2015; Kheswa et al 2017; Mehta et al., 2016; Nabukeera-Barungi., et al, 2015; Naidoo et al., 2015; Nyogea et. Al., 2015; Okawa et al., 2018; Olds et al., 2015; Schlatter et al., 2016; Vreeman et al., 2015.
– Disclosure of HIV status	N= 10 studies	Arrive et al., 2018; Brown et al., 2011; Ekstrand, et al., 2018; Elsland, SLv, et al., 2019; Kalembo et al., 2019; Lencha et al., 2018; Lowenthal et al., 2014; Nichols et al., 2017; Verma, A & Sahay., S 2019; World Health Organization, 2011
– Adolescent sexual and reproductive health	N= 11 studies	Vujovic et al., 2014
– Transition care		Fair et al., 2011; Kovacs & McCrindle, 2018; Lee & Hazra, 2015; Sharma, et al., 2014, Tulloch et al, 2014, Verma & Sahay, 2019
– Psychosocial care		Amzel et al., 2013; Barenbaum & Smith, 2016; Chenneville, 2017; Lang et al., 2014; McCleary et al, 2013
Integration and coordination of care, N= 16 studies		
– Integration and coordination of care	N= 7 studies	Borgermans et al, 2017; Kuramoto, 2014; Oldfield et al., 2019; Stadnick et al., 2019; Swanson et al., 2015; The USAIDS, 2015; Van der Heide et al., 2018
– Coordination of care	N= 9 studies	Bower, 2016; Kilbourne et al., 2018; Kuo et al., 2017; Miguélez-Chamorro et al, 2019; Ramelso et al., 2018; Sawe etal., 2016; The UNICEF, 2015; Van de Heide et al., 2018; Wang et al 2016
The context of social determinants of health, N=50 studies		
– SES	N= 18 studies	Abgrall & Del Amo, 2016; Basset et al., 2015; de Andrade et al., 2015; Diniz et al, 2019; Healthy People 2020, 2019; Heise at al., 2013; Krnzer et al., 2018; Kuo et al., 2017; LaBrec et al., 2017; Matune et al., 2017; Merten et al., 2016; Njuguna et al., 2018; Osafo et al., 2017; Pettifor et al 2019; Rachlis

		et al., 2016; The Global Fund, 2019; The UNICEF, 2019; Wilson, 2019
– Stigma and discrimination	N= 16 studies	Adi, 2019; Busza et al., 2018; Delany-Moretlwe et al, 2015; French et al, 2015; Geibel et al 2017; Gyamfi et al., 2017; Handayani et al., 2017; Kerr et al., 2015; Kerrigan et al., 2017; Lang et al. 2014; Lestari, 2019; Prabandari et al., 2018; Sangowawa & Owoaje., 2012; Sarma & Oliveras., 2013; Shankar et al., 2013; The Global Fund et al., 2015; The UNICEF, 2019
– Social support	N= 9 studies	Achmat & Pramono, 2015; Almeida-Brasil et al., 2018; Amico et al., 2019; Amzel et al 2013; Ford et al., 2017; Mehta et al 2016; Raghavendra & Viveki 2019; Rice et al 2019; WHO, 2017
– Policies	N= 7 studies	Dartanto, 2017; Jackson, 2017; Minkman, 2012; Miranti et al., 2013; Pramono et al, 2018; Uebel et al., 2013; Umukoro, 2013

Appendix 10. Conferences

Nuzul Qur’aniati, Anita de Bellis, Linda Sweet, Alison Hutton, “Discovering the Continuity of Care for Indonesian Children with HIV: Using Grounded Theory”, Mid Candidature Review, Annual College Higher Degree Research Student Conference Flinders University, South Australia, 5-7 November 2018.

Nuzul Qur’aniati, Linda Sweet, Dean Whitehead, Alison Hutton, ‘Understanding Paediatric HIV Care Management to Improve Quality of Care for Children Infected with HIV in Indonesia’, International Nursing Conference, Indonesia, 7-8 April 2018.

Nuzul Qur’aniati, Linda Sweet, Dean Whitehead, Alison Hutton, ‘Developing Social Protection Program for Children Infected with HIV in Indonesia: best practices from Sub-Saharan Africa, Indonesian Council Open Conference’, South Australia, 3 July 2017.

Nuzul Qur’aniati, Linda Sweet, Dean Whitehead, Alison Hutton, ‘Understanding the Nurses Role in The Continuity of Care For Children Infected With HIV in Indonesia’, Research Week, SONM Higher Degrees Research Week, Flinders University, South Australia, 26-29 June 2017

Nuzul Qur’aniati, Linda Sweet, Dean Whitehead, Alison Hutton, ‘Best practice on the integration between patient family centred care and collaborative practice to improve quality of care for children with HIV in Indonesia’, Indonesia Research Day, The University of Adelaide, South Australia, 8 April 2017.