THESIS

‘The forgotten homeless children’

Health worker perceptions of the needs of children living with HIV AIDS in Arusha, Tanzania

Winfrida Mwashala,RN.

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DECLARATION OF AUTHORSHIP

I certify that this thesis does not include without my acknowledgement, any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where reference is made to it in the text.

ABSTRACT

Reference to homeless children living with HIV/AIDS is absent in the Tanzanian government national costed plan of action (NACPA) for Most Vulnerable Children (MVC). The NACPA plan aims to enhance the lives of the most vulnerable children in the areas of shelter, nutrition, education, psychosocial support, and health. Lack of inclusion in the plan has had detrimental effects on children living with HIV/AIDS and has resulted in them facing challenges including abuse and maltreatment, poor adherence to clinical care for treatment, and failure to meet clinical and psychosocial needs resulting in premature death. Furthermore, there is significant risk of abandoned children infecting other street children with whom they engage in unprotected sexual activity. Previous studies have shown that the government is significantly challenged in how to care for these homeless children. In order to bridge the gap in the literature on what care is available for these children, this study aims to explore how healthcare professionals manage the care and health needs of abandoned and homeless children living with HIV/AIDS in Tanzania.

This study employs a qualitative, descriptive approach to obtain an in-depth understanding of the experiences of healthcare professionals working in the Care and Treatment Centre (CTC), a hospital department which provides care for people living with HIV/AIDS. Data were collected through semi-structured interviews from seven healthcare professionals (HCPs) working in Arusha Tanzania. The data were analysed through the thematic analysis approach of Braun and Clark's (2013) six step method.

Five themes and eight sub-themes emerged from the data, representing the selected healthcare professionals' experiences in managing the health needs of homeless children living with HIV/AIDS. The themes are outlined below.

The lived experience of homeless children living with HIV/AIDS presents explanations of why children escape to live on the street as well as an overview of the complexity of their lives as their day unfolds on the street. *HIV/AIDS treatment, care, and support services offered in CTC centres* presents the experiences of HCPs in the provision of

care for children living with HIV/AIDS and the challenges they face as service providers. *Community mobilization and networking* demonstrates the share of responsibilities and resources among community members. *Health promotion and primary prevention health services for HIV/AIDS among homeless children living with HIV/AIDS* presents the range of public health preventative measures available on the street. Finally, *Utilization of policy and guidelines in the care of homeless children living with HIV/AIDS* presents the current community awareness of available policies, which aim to protect children, and of guidelines for ensuring local implementation of these policies.

The findings contribute to knowledge about healthcare professionals' experiences in the management of the health needs of homeless children living with HIV/AIDS. The findings of this research indicate that the lives of HIV positive children on the street is very difficult, often leading to premature death. Therefore, this study suggests a need for greater public awareness about the policies, which support and protect children, and also recommends that the development of practice guidelines is crucial in order to implement health guidelines in Tanzania. Finally, strategies to restore HIV/AIDS preventative services for the community, and particularly for homeless children, need to be implemented. Further research on end-of-life needs for homeless children should be explored along with innovative interventions to reduce child abuse and neglect.

CHAPTER ONE: INTRODUCTION

1.0 Introduction

This study was designed to explore how healthcare professionals at hospital, in Arusha Tanzania, manage the health needs of homeless children living with HIV/AIDS. The idea of exploring this topic emerged from the interests of the researcher as a community health nurse in the care of people living with life-threatening illnesses, including Human Immunodeficiency Virus/Acquired Immune Deficiency (HIV/AIDS). As a community care nurse working in a rural and urban home-based care program for people living with HIV/AIDS in Arusha Tanzania, I have witnessed the tragically adverse circumstances faced by abandoned children living with life threatening illness including HIV/AIDS. During my daily engagement with these abandoned children, questions arose about how I, as a healthcare professional, could contribute to addressing their urgent healthcare needs in order to enhance their lives. There appeared to be so little that I alone could achieve. To become informed, and to potentially formulate solutions to this vexing, heartbreaking problem, it was viewed as crucial to interview the healthcare professionals (HCP) who work with these children in the local hospital's Care and Treatment Centre (CTC) for people living with HIV/AIDS, and to pose questions about how they meet the healthcare needs of abandoned children living with HIV.

This chapter firstly explains, the scope of the problem facing children living with HIV in Tanzania is introduced. This is followed by a detailed explanation of the impediments facing vulnerable children in Tanzania in order to reach the planned United Nations Sustainable Development Goals (SDGs). Finally, an account of the national efforts to support the most vulnerable children through the implementation of the National Costed Plan of Action (NCPA) is offered. This plan was implemented in two phases; phase 1 was implemented from 2007-2010, while phase II has been taking place from

2013-2017. Core gaps that have occurred during the implementation of the NCPA I-II will be explored as the foundation of this study.

1.2 Significance of the study

Abandonment and neglect of children living with HIV/AIDS has become an increasing problem in Tanzania (Machine, Gillespie et al. 2016). Abandoned children in Tanzania are defined as those who are under 18 years of age and who live on the street. According to UNICEF, as quoted by Panter-Brick, they are "boys and girls who the street has become their home and/or source of livelihood and who are inadequately protected or supervised by responsible adults. They are temporarily, partially or totally estranged from their families and society" (Panter-Brick 2002).

In Tanzania, the abandonment and neglect of children living with HIV/AIDS is evident (Cruz, Bastos et al. 2015). This situation has left children with no option other than to live on the street (Kacholi 2012; Lugalla & Mbwambo 1999). This problem occurs due to a range of factors such as poverty, poor access to healthcare services, caregiver negligence, and the stigma associated with the HIV/AIDS illness (Beck 2016). Abandonment usually occurs when the child's parent dies due to AIDS (Cruz, Bastos et al. 2015).

Despite the urgency of the problem, little is known about how to manage and address the challenges faced by homeless children living with HIV/AIDS. This is of concern given the known consequences of abandonment of children living with HIV. Firstly, these children often miss their follow-up care for HIV/AIDS treatment (Fournier, 2014). The lack of continuity of HIV treatment may result in a dwindling illness trajectory, and ultimately, death (Azzopardi, Wade et al. 2014). Secondly, abandoned children living with HIV engage in sexual activity which may lead to the spread of HIV infections (Waziri 2013). This is particularly concerning as most children living with HIV are not aware of their HIV status (Emmet et al 2013). Thirdly, there is debate over who is responsible for HIV disclosure to children living with HIV between HCPs and

caregivers (Pegguril et al 2015). This delays the child's awareness of their health status, and therefore, their capacity to be responsible for their illness and to adhere to the HIV treatment that is available to them (Fauk et al. 2017; Machine et al. 2016).

Children living with HIV/AIDS usually remain orphaned after the death of their parents due to the HIV/AIDS illness (Fauk et al. 2017). This situation increases their vulnerability due to abandonment and homelessness. They also suffer emotional and physical trauma, and have poor adherence to their HIV/AIDS medication, which results in a high mortality rate (Azzopardi et al. 2014). This study will provide information on how healthcare professionals meet the healthcare needs of these children. Additionally, the findings of this study will provide evidence to create awareness among core stakeholders about the needs of abandoned children living with HIV/AIDS. It will also encourage sustainability of the interventions geared to support and protect children through community mobilisation and the use of readily available local resources. Finally, the findings will contribute to improved practice guidelines, which, in turn, will enhance the lives of the children and increase collaboration and networks among health service providers to support the population of abandoned children living with HIV/AIDS in Arusha Tanzania.

1.3 Background

The research question arose from the evidence that globally, 2.1 million children are currently living with the Human Immunodeficiency Virus/Acquired Immune Deficiency (HIV/AIDS) (Azzopardi et al. 2014). HIV/AIDS is the leading cause of childhood death for children aged from 10-19 years in Sub-Saharan Africa, and the second highest cause of death globally (UNICEF 2015). In Tanzania, despite being the leading cause of death, there has been a significant decrease in HIV/AIDS prevalence of the total infected population from 8% in 1995 to 5.1% in 2012 (TACAIDS 2015). It has been estimated that there are approximately 1.4 million people living with HIV/AIDS in Tanzania (TACAIDS 2015), and children aged from 0-7 years account for 11% of the total

infected population (WHO 2015). This is a very high percentage given that children account for 50% of the total population of Tanzania, according to the Tanzania Total Population and Housing Census 2012 (TPHC 2012).

The Sustainable Development Goals (SDGs), and in particular SDG 3, aim to ensure healthy living and the well-being of people in developing countries. Despite these well-established goals, the HIV/AIDS illness has left adverse impacts upon children, families, and communities (UNICEF 2016). A major negative impact of HIV/AIDS is the increase in the amount of orphans, children living with HIV who have been perinatally infected, and affected and vulnerable children (Fauk et al. 2017). For example, according to UNICEF (2016), the number of children that are estimated to have lost one parent or both due to HIV/AIDS was around 13.3 million by the end of 2014, and 80% of these children live in Sub-Saharan Africa. In Tanzania, it has been estimated that there were 1.3 million orphans by the end of 2014, and most of these were HIV-positive (Fauk et al. 2017).

Due to improved social support services and supplies of antiretroviral therapy (ART), the life expectancy of children living with HIV/AIDS has increased and has enabled many to live longer, even into adulthood (Dieffenbach & Fauci 2011). In Tanzania, however, this has not happened for abandoned children living with HIV/AIDS. They typically suffer social deprivation, neglect, and a range of physical impediments (Phuma-Ngaiyaye & Dartey 2015).

While child abandonment is a serious problem in Tanzania, there is very little understanding of the causative factors. There is also a lack of awareness about the provision of effective care to the affected children to help them live a normal, or a near normal, life (Fauk et al. 2017). Waziri (2013) examined the problem of abandoned children in Tanzania and reported that there were no established reasons why these children were not provided with services by the government of Tanzania to the extent that they have become homeless. Furthermore, he stated that there is a belief that

poverty is considered to be a contributing factor to abandonment, but that there is no evidence to support this concept (Vreeman et al. 2015; Waziri 2013). This is similar to a study conducted in South Africa exploring the abandonment of children (Blackie 2015). This study also relates to issues of abandoned children in Tanzania because the prevalence of HIV infection and psychosocial issues facing children are similar across many Sub-Saharan countries. As with Waziri's study, Blackie's research also suggested that it is unclear why children in general are abandoned (Blackie 2015).

The concept of street children and the abandonment of children are well-known phenomena and have been discussed across the globe. Some countries, for example the United Kingdom, have established good interventions for homeless children (Kazungu & Cheyo 2014; Waziri 2013; Wei et al. 2016). In Tanzania, however, very little is known about abandoned children, and essentially, nothing is known about street children who are living with HIV/AIDS.

In order to achieve the objectives of Millennium Development Goal 6 (MDG 6), which aims to combat HIV/AIDS, Tanzania initiated preventative HIV/AIDS services from mother to child before, during, and after the delivery of a child, known as Prevention of Mother to Child Transmission (PMTCT) (CIS & CIS 2006). The PMTCT services in Tanzania were developed in the year 2000 (Akarro, Deonisia & Sichona 2011). The program aimed to reduce the number of children born with HIV/AIDS from antenatal infected mothers through the provision of an antiretroviral drug called Nevirapine before and after delivery of the babies (Semali, Damian et al. 2014). In Tanzania, 43,050 new-born children are infected with HIV annually through mother-to-child transmission (Nuwagaba-Biribonwoha et al. 2010).

The treatment of Highly Active Antiretroviral Therapy (HAART) is the regimen of choice recommended by the WHO for the treatment of HIV/AIDS and as a preventative for PMTCT services. An antiretroviral tablet of the drug Nevirapine (which is HAART), if given at the beginning of the 28th week of pregnancy to women who are HIV+, will

prevent the transmission of HIV/AIDS to their unborn offspring (Semali et al. 2014). The PMTCT services are available for free in antenatal care services and CTC centres across Tanzania; however, many antenatal mothers do not access these services, which results in the birth of HIV+ children. The major reason for the occurrence of HIV+ children, despite the availability of free preventative PMTCT health services, is the fear that pregnant women have of learning about their HIV status due to the stigma associated with the illness, and thus, they often choose to remain undiagnosed (Azzopardi, Wade et al. 2014). This fear and shame causes them to avoid accessing HIV treatment (Paudel 2015).

Children infected with HIV/AIDS are often abandoned by their extended family members after the death of their parents due to the AIDS illness (Cohen 2010). When their vulnerability increases, orphans frequently become homeless (Fauk, et al. 2017). This forces them to live on the street, suffering emotional and physical trauma, adhering poorly to HIV/AIDS medication (antiretroviral therapy), and ultimately, resulting in a high mortality rate (Beck 2016). The care and support of orphans typically depends on elderly grandparents who cannot provide for the increasing needs of sick children (Demmer 2011). Other stakeholders, such as non-profit organisations including orphanages, have shown a reluctance to care for children who are living with HIV/AIDS (Fournier, Bridge et al. 2014). This is partly due to the increased demands of children who are living with HIV/AIDS and whose specific healthcare needs require significant use of the scarce resources available in these institutions (Chauhan, Rai et al. 2016). Secondly, due to the lack of availability of sufficient knowledgeable, well-trained healthcare staff working in the orphanages, there is genuine concern about the co-housing of HIV/AIDS children and uninfected children for fear of cross-infection (Chauhan et al. 2016). There are actual risks which need to be taken into account when raising young children in the same facility; for example, unrecognised bruises and open wounds which can occur during normal play activities (Wiener, Fair et al. 1993). In addition, most orphanage infrastructure has been created to address the needs of

healthy children; therefore, these facilities lack the resources required to manage the needs of sick children in their care (Fournier, Bridge et al. 2014).

The Tanzanian government has taken positive steps in the fight against HIV/AIDS in line with global efforts such as the UN Millennium and Sustainable Development Goals. The Ministry of Health and Social Affairs of the Tanzanian government developed a National Costed Plan of Action (NCPA). This plan aimed to implement programs that would minimise the negative impacts of HIV/AIDS on the community, and especially, on the most vulnerable children (MVC). These projects were supported by the Global Fund for HIV/AIDS and Malaria and were run in phase I of the program in eight districts of the Tanzanian mainland. These districts had been reported to have a high number of MVC. The districts were: Arusha urban, Mufindi, Kigoma, Singida, Kagera, Tanga, Handeni, and Morogoro (Kacholi 2012).

1.3.1 United Nations Sustainable Development Goals 2015-2030

The initiation of the UN Millennium Development Goals (MDGs) by 2015, which was followed by the establishment of the Sustainable Development Goals, has aimed for quantitative outcomes by 2030 (Paudel 2015). The goals were intended to: eradicate poverty for 500 million people; adequately feed 250 million people; and enhance the survival of 30 million children less than five years of age (UNICEF 2015). The overarching strategy of the global MDGs aimed to enhance the growth and development of children, the future of each nation. However, the strategies were hindered in reaching the targeted goals due to the lack of focus in the targeting of large numbers of children in the national strategy. This gap was due to a variety of reasons such as a lack of strategic policies within nations aimed at supporting vulnerable children; research gaps that did not target children; poor financial stability; and poor law enforcement at the country level to implement established policies (Paudel 2015).

The key questions to ask are: Where is Tanzania in the fight against the negative impacts of HIV/AIDS on children? What are the current national efforts in addressing these

impacts? In addition, how do these efforts fit in the Millennium and Sustainable Development goals? According to national reports in relation to the Millennium Development goals, Tanzania has made significant progress on MDG 6, which aims to combat the spread of HIV/AIDS (UNICEF 2015). There has been a lag in relation to addressing the socio-economic effects of HIV/AIDS on children and their families. The development of the NCPA in Tanzania was intended to carry forward the gaps identified during the implementation of MDG 6, and reinforced Sustainable Development Goal Number 3 (SDG3) which aimed to improve health and well-being for all ages.

Members of the United Nations were expected to act on the Millennium Development Goals by adhering to the Convention of the Rights of Children (CRC 1989). Supporting children within their own nation was not viewed as an act of compassion, but rather, as a legal duty of a responsible government to its own children. The government of each member nation has the responsibility to report to the Committee on the International Rights of Children to ensure that there are continuous, deliberately established plans to protect children and to enhance their survival. Tanzania, under the established National Costed Plan of Action (NCPA) phases I & II, has the overall objectives of ensuring that the rights of the most vulnerable children are protected, and that children are protected from risks and harm (Ng'ondi 2015).

1.3.2 Tanzanian efforts to support the Most Vulnerable Children (MVC) through the National Costed Plan of Action (NCPA)

The Tanzanian NCPA phase I, which was implemented in the years 2007-2010, and phase II, which is being implemented from 2012-2017, have been developed in order to align with the Global Millennium Development Goals and the Sustainable Development Goals, as well as to adhere to the Convention on Children's Rights (CRC 1998; TACAIDS 2015). In Tanzania, this responsibility has been vested in the Department of the Ministry of Health and Social Welfare, which intends to overcome the negative impacts of the

HIV/AIDS pandemic on MVC. The specific aims of the NCPA have been to improve the lives of children through social support services such as shelter, nutrition, health, psychosocial support, and education (TACAIDS 2015). The NCPA was established to work hand-in-hand with the National Strategy for Growth and Eradication of Poverty (NSGPR), VISION 2025, and the National HIV/AIDS Policy (Kazungu & Cheyo 2014). According to the NCPA phase I, the most vulnerable children (MVC) were defined as those who were less than 18 years of age and were in the following situations: living in child-headed households; living with elderly grandparents or an adult older than 59 years of age; disabled and living in a house of mud and grass with one surviving parent; and living in urban settings in poor housing with poor roofs and walls with one surviving parent.

According to the NCPA I in Tanzania, child neglect and abandonment were considered among the factors that increased vulnerability (Mbangwa 2013; Olsson 2017). However, the implementation plan strategy document did not indicate abandoned children living with HIV/AIDS as a specific category of children to be considered as vulnerable, and there were no specifically-targeted efforts to address the uniquely demanding needs of abandoned children living with HIV/AIDS. There was an urgent need for the government of Tanzania to initiate deliberate efforts. The rolling out of the implementation of the NCPA-initiated partnerships between communities, key stakeholders such as non-profit organisations, core influential people, and the government was one such initiative (Guga, Parry-Williams et al. 2009).

1.3.3 Rolling out of the NCPA to support MVC through community engagement

Innovative multi-sectored interventions through public-private policy partnerships have gained popularity in the implementation of public health activities and have also found interest from donor funding (Benner, Reinicke et al. 2004). Tanzania used this approach in implementing the national MVC program. Local non-government organisations, and the government through the Ministry of Health and Social Work, partnered with local

communities by working with Most Vulnerable Children Committees (MVCC) who, at the local level, were delegated the custody of the MVC. The rolling out of the program relied on communities working together through community-based organisations. Of the 119 councils in Tanzania, only 35 had a trained social worker to address the needs of the 999,000 identified most vulnerable children within the country. Due to the severe shortage of trained social workers, it fell to the MVCCs to identify the MVC through door-to-door home visits using a checklist tool developed by the government. Likewise, the actual provision and distribution of services was primarily accomplished on a door-to-door basis by the MVCC and other core stakeholders (Kacholi 2012).

1.3.4 The challenges faced by Tanzania in the implementation of the NCPA to support MVC

In order to continue to address the needs of the MVC in Tanzania, all children with vulnerabilities need to be considered. However, this is very challenging because abandoned children living with HIV in Tanzania exist 'invisibly' (Waziri 2013). The identification process for MVC, supported by Global Funds for HIV/AIDS, Tuberculosis, and Malaria, and organised by the Tanzanian Ministry of Health and Social Welfare, did not identify homeless children (Kacholi 2012). As a result, homeless children living with HIV/AIDS were excluded from care and support services. It is against these backgrounds, that this study seeks to understand the experiences of healthcare professionals working in the Care and Treatment Centre in order to gain an insight that can inform policies and programs to improve care and support needed for homeless children living with HIV/AIDS.

1.4 Purpose of the study

The purpose of this qualitative descriptive study is to explore the perspectives of healthcare professionals working at CTC on how they meet the health needs of homeless children living with HIV/AIDS, in order to establish what support is needed to improve

the children's quality of life. As will be demonstrated later in this thesis, this purpose has been accomplished through interviews with HCPs who work in the Care and Treatment Centre for patients and children living with HIV/AIDS.

1.5 Objectives of the study

The objectives of the study are:

1) To explore how healthcare professionals identify and track abandoned children living with HIV/AIDS;

2) To find out how healthcare professionals disclose HIV/AIDS diagnostic status to children living with HIV;

3) To find out what medical and psychosocial supports healthcare professionals provide for abandoned children living with HIV/AIDS; and

4) To find out how HIV is prevented among abandoned children in Arusha, Tanzania.

1.6 Thesis overview

This thesis presents a qualitative descriptive study that has explored the experiences of HCPs working at the Care and Treatment Centre in Arusha region, Tanzania. The participants for the study were interviewed and asked to provide their perspectives on how they manage homeless children living with HIV/AIDS.

This thesis has been organised into six chapters. The first chapter introduces the research topic, the background to the problem, and a statement of the research question. Chapter Two will explore the literature on the problem of abandoned children living with HIV/AIDS. This integrated chapter illustrates the gaps in the existing research which lead to the research question. Chapter Three explains the process and steps that were followed in conducting the study, the method and the methodological approach used, an overview of the processes used to ensure rigour, and the ethical considerations.

The findings are presented in Chapter Four, including a demographic overview of the participants, followed by a discussion of the themes that were developed from the thematic analysis of the data.Chapter Five presents a discussion of the findings in relation to the current existing literature. Finally, Chapter Six presents the conclusion of the thesis, the contribution of the study, the limitations, and a number of recommendations for practice, policy and future research.

1.7 Conclusion

Homeless children living with HIV/AIDS are living in a difficult situation. In order to enhance their lives and enable them to live a good quality life, it is important to understand how healthcare professionals meet their health needs. Previous studies have shown that homeless children face adverse circumstances on the street; however, there is little known about these homeless children living with life-threatening illnesses, including HIV/AIDS. In response, this qualitative descriptive study bridges this gap in the literature.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter provides a review of the literature exploring why children living with HIV are abandoned in Tanzania. A comprehensive outline of the subject will be analyzed and presented in a broader context. The focus will be on why children are being abandoned .Following an introduction that describes the aim of the review, an overview of the systematic search is provided. The second section critically analyses the included studies, and describes the findings of the review, after which the major findings are outlined. Finally, a conclusion of the overall review is provided which identifies the gaps in the existing knowledge and the need for further research.

2.1 Search Strategy

A systematic search of the CINAHL, Scopus, Psych Info, and Ovid databases was conducted to identify why children living with HIV/AIDS are abandoned. The formula based on the specified data engine, the key search terms, and the synonyms used was "child* or adolescent* or infant* or baby* or babies* or teen* and abandon* or neglect* or stigma* or desertion* or reject* and hiv or aids or acquired human immunodeficiency syndrome" (Appendix 1).

A preliminary search was conducted of the literature published during the period January 2006 to August 2016. However, due to the limited number of studies directly undertaken in Tanzania, the search was widened to a period of 20 years (1996-2016), and also to include surrounding countries with similar economic and cultural issues. One country which had similar problems, but did not have the same economic and cultural context was included in order to compare the reasons for the abandonment of children living with HIV in different economic and cultural contexts. The search period includes the 10 years after which the HIV/AIDS pandemic was prevalent and the impact of HIV

was extensive. The articles included were those written in English, and which reported on primary research.

2.2 Screening of articles

Initially, 69 articles were retrieved from the CINAHL database, 214 from Scopus, 175 from Ovid Medline, and 145 from Psych Info, which resulted in a total of 603 articles. A review of the abstracts was undertaken and those which were not relevant were removed from the review. The final numbers of articles considered for review were re-read to gain a full understanding of their meaning for further analysis. Of the 603 articles in total, 13 were removed due to duplication, and 565 were removed because they did not answer the research question. Twenty-five (25) articles remained that were relevant to the subject after the initial review. A subsequent manual search was conducted whereby 3 articles were added which were retrieved through the Flinders University link to Google Scholar, and a further 3 articles retrieved by manual search (Table 1 - PRISMA chart). This resulted in a total of 31 articles, which were used in this review (Appendix 2).

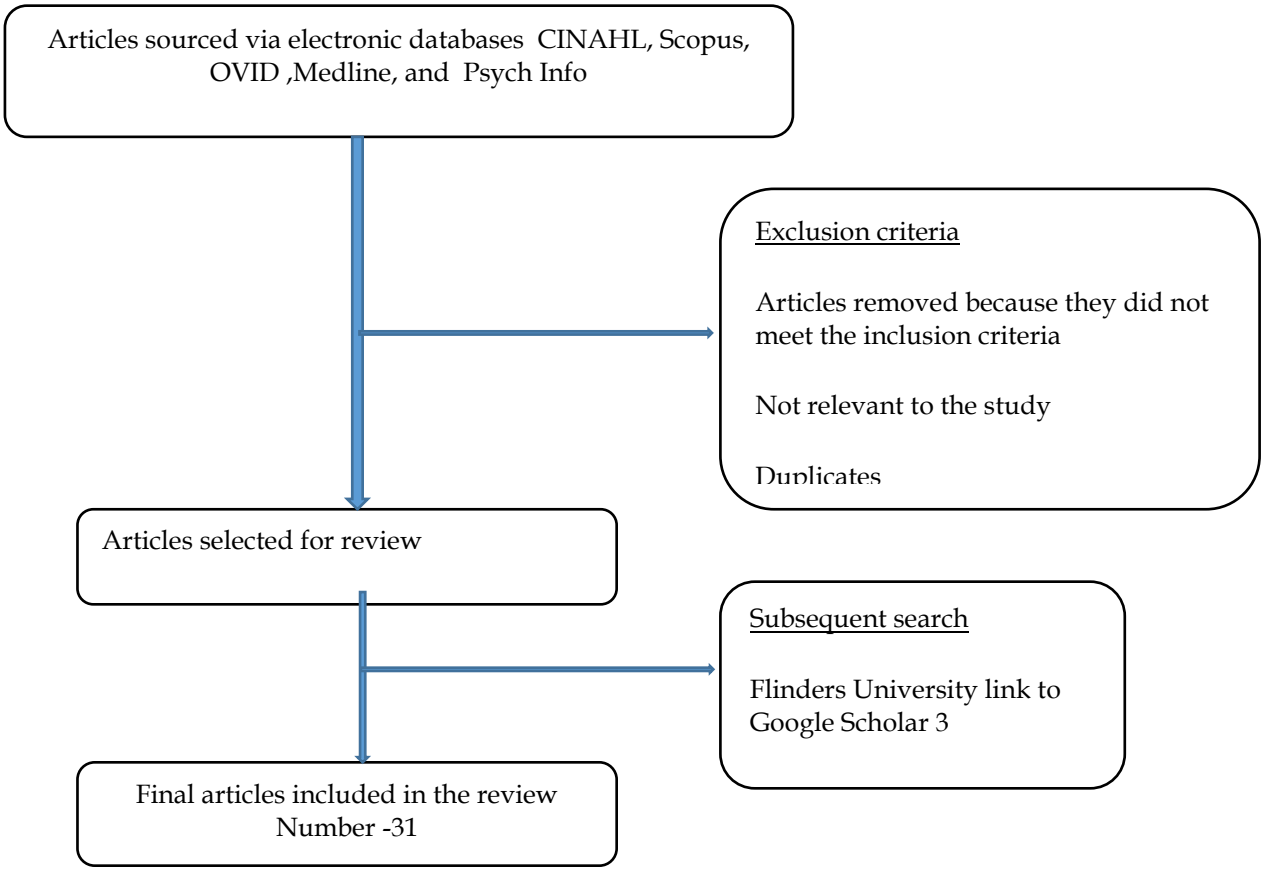
The methodological approaches identified in the selected literature were as follows: 15 studies used a qualitative approach, 4 studies used mixed methods, and 12 studies used a quantitative approach. Children, caregivers, and healthcare professionals, who were nurses and doctors, were examined in these studies. The location of the studies are from South Africa (7), Canada (1), Ethiopia (1), Tanzania (5), Zimbabwe (2), Romania (1), the UK (1), India (1), the Ukraine (1), Kenya (1), Malawi (1), Brazil (1), the USA (5), Sweden (1), Nigeria (1), Uganda (1), and Russia (1). One of the studies, which used mixed methods, was conducted in 2 countries.

In order to ensure rigour, the articles were scrutinised using appraisal tools that were appropriate for the research methodology of each study (Polit, D & Beck 2012). The CASP checklist tool was used to analyse the articles using the 10 provided questions (Attride-Stirling 2001). The mixed methods study was critically appraised through an

evaluation tool for mixed methods (Long et al. 2002). The rigour of each study was classified into high, medium, and low based on the developed checklist tool (Appendix 3, 4, 5).

Issues identified were primarily related to sample selection, ethics approvals, and data collection. For example, two studies (Campbell et al, 2012; Machine et al 2016) showed limitations in relation to small sample sizes for quantitative research. To reconcile this, they used mixed methods to triangulate the data. Zabina et al (2009) initially explained that they used a random sample for participant identification across a population; however, the participants appeared to be purposefully selected as women who attended a healthcare centre for HIV services in one specific area. Ethics concerns were raised in a study by Fournier, B. Bridge, Pritchard Kennedy, and Sanjeeva et al (2015), with images identifying participant details being shown in their publication without explicit consent to use these images (HRECS 2015). Overall, 31 studies were found to have acceptable rigour to include in this review.

Table 1 PRISMA chart



2.3 Key findings

The process of qualitative thematic analysis, as described by Braun and Clarke, was used to synthesise the findings and to develop themes and common patterns (Braun & Clarke 2006). The patterns that were identified formed six major themes, including the factors associated with abandonment, the stigma associated with HIV illness, poverty, caregiver roles, access to healthcare settings, and gaps in policy and law. The themes

emerged from the literature review and are discussed in the following section (Appendix 6).

2.4 The factors associated with the abandonment of children living with HIV were:

2.4.1 Stigma associated with HIV/AIDS illness

One of the major factors associated with the abandonment of children living with HIV/AIDS, as experienced in the South African study, is that of stigma (Demmer, C. 2011; Dowshen & D'Angelo 2011). In this study, stigma among youth and children was identified as a chronic factor that has not been well researched and which interferes with the positive outcomes of programs for children affected with HIV/AIDS. Demmler et al (2011) identified that there is a need to look for culturally appropriate solutions because caregivers are overwhelmed in caring for children with HIV/AIDS due to stigma. The needs of children with HIV/AIDS were neglected, and most of them delayed their treatment and only attended hospital when their symptoms were fatal (Campbell et al. 2012a; Chauhan et al. 2016). One study conducted in Cambodia, which has a similar socio-economic background to Tanzania, found that 53% of 113 children aged 6-15 years had experienced stigma. They explained that they had experienced it in their social life in their communities, particularly in the school setting and in other public settings such as in the care and treatment center(Barennes et al. 2014). Some children in Uganda, who had been raised by their caregivers, reported being stigmatised by extended family members and isolated from some family events (Fauk et al. 2017; Fournier, Bonnie, Bridge, Andrea, Kennedy, Andrea Pritchard, et al. 2014). The consequences of stigma prevented them from accessing care and treatment services (Barennes et al. 2014; Coombes 2000).

This is a similar situation to Tanzania as demonstrated in a study which showed that children were neglected and decided to live on the street to cater for their material needs (Lugalla & Mbwambo 1999). In a descriptive cross-sectional study, the researchers

interviewed community leaders, with 80% of the respondents confirming that the stigmatisation of children with HIV contributed to their move from living in extended families to living on the street (Waziri 2013). Furthermore, in Kwazulu-Natal, a case study was conducted confirming that children living with HIV demonstrated an increased mortality rate when their needs were not met (Bateman 2003; Cruz, Maria Leticia Santos et al. 2015). Stigma was evident within the families of children living with HIV/AIDS at the community level and in other public settings such as schools and healthcare settings (Campbell et al. 2012b). For example, in a study of "HIV infected children in Brazil, children were interviewed to see how stigma affected their use of healthcare settings, drug adherence, and engagement with social activities (Fauk et al. 2017; Semali et al. 2014). Self-stigma and neglect of treatment were also shown to be amplified by a lack of HIV disclosure. For instance, as indicated in the following case scenario:

> Teresa was diagnosed as HIV+ when she was one and has a step-mother who did not accept disclosure that she was adopted and or HIV. When Teresa was 16, HIV disclosure occurred incidentally and the family disclosed she was adopted. Two years after disclosure, Teresa still does not accept her new identity, stop taking her medicines and is scared by the new reality (Cruz, Maria Letícia Santos et al. 2015).

Studies have shown that abandoned children living with HIV in low resource settings were abandoned because their parents died and the children were left in the care of older grandparents who abandoned these children due to the shame associated with the HIV illness (Fair & Brackett 2008; Machine et al. 2016). Although there were similarities in the reasons for abandonment between developed countries and less developed countries, the difference was that in developed countries, women infected with HIV abandoned their children, whereas it was extended family caregivers in less developed countries who abandoned children living with HIV/AIDS after the death of the children's parents (Foster, Waelbrouck & Peltier 2007). In both scenarios, it was stigma that influenced the motives behind abandonment (Zabina et al. 2009). The studies

conducted in the Ukraine, the United Kingdom, and Brazil reported that women living with HIV left their infants in the hospital setting for fear of being left by their partners if they found out about their HIV status, or for fear that community and family members would not support them when their condition deteriorated due to stigma and the shame associated with the illness (Abadía-Barrero & Castro 2006; Bailey et al. 2010b; Coombes 2000).

2.4.2 Poverty

The 2010 World Bank report on confronting AIDS explained that "widespread poverty and unequal distribution of income that typify underdevelopment appear to stimulate the spread of HIV" (Parkhurst 2010). This report is similar to the findings of a WHO (2010) report which found a correlation between HIV/AIDS illness and poverty. Poverty is the factor which has driven the pandemic and it makes the infected people suffer after contracting the illness due to a lack of resources (Parkhurst 2010).

The lack of resources has also fueled the problem of abandonment. For instance, a study conducted in Tanzania found that poverty contributed to children living with HIV becoming homeless due to the lack of family resources (Waziri 2013). A further study in Tanzania established that one of the reasons for an increase in the number of children living on the street is family poverty (Lugalla & Mbwambo 1999). The relationship between poverty and abandonment are high (Campbell et al. 2012b). In another example, this time from Russia, Zabina et al (2009) found that women with HIV/AIDS were more likely to abandon their children with HIV because of a lack of family support in raising the sick child(ren), and also due to the requirement for expensive resources such as medical treatment (Demmer, Craig 2011). These children could have benefitted if they had been kept in long-term care. For example, another Russian study found that infected children with HIV/AIDS who were abandoned and kept in children's homes had higher survival rates than those who were not in children's homes (Kline 1998). In a Ugandan study, long-term facilities such as orphanages and children's rehabilitation

homes that adopt orphans and vulnerable children, could not take abandoned children who are HIV-positive due to the fact that it requires costly resources to keep the children in long-term care, particularly those who are infected with HIV (Fournier, B. et al. 2014). Uganda and Tanzania have similar economic backgrounds with a similar prevalence of HIV/AIDS and also of abandonment of children living with HIV (Malamud 1995). The major concern is the pain and suffering of the abandoned children living with HIV/AIDS, who are forced to live on the street to cater for their basic material needs, and this will not end unless holistic measures are taken to change this situation (Waziri 2013).

2.4.3 Caregivers' roles

Kinship models of care have been embraced culturally in a range of African contexts over many years (Okagbue-Reaves 2005). This type of model traditionally creates a safety net through which children can be raised with their extended family members. However, since the emergence of HIV/AIDS over 30 years ago, this tradition has been disappearing slowly due to family displacement, socio-economic factors, and the death of bread-winners due to HIV/AIDS (Dieffenbach & Fauci 2011). The lack of kinship has been a major factor in fueling the abandonment of children living with HIV after the death of their parents due to AIDS (Cruz et al 2015). Older grandparents are forced to care for their grandchildren; consequently, they are overwhelmed due to their old age and associated illness, and the dwindling economy (Luggalla & Mbwambo 1999). In these families, in some cases, caregivers are also suffering from HIV and some face family breakdown (Sherr et al. 2016). When this occurs, the care provided by the grandparents results in disadvantage to a child living with HIV within the household (Clemo 1992). In other cases, due to perceived neglect, children living with HIV move to living on the street to attempt to cater for their own material and basic needs (Waziri 2013). Their needs remain unrecognised and unmet (Demmer, Craig 2011). In Romania, Ferris et al. (2007) found that children living with HIV who were left in the care of extended family were more likely to suffer a decline in their Cd4 count and death due to

social and economic factors. As a result, most of the children abandoned by their families in Romania were therefore cared for in special homes for children (Bohlen 1990; Ferris, M. et al. 2007).

2.4.4 Access to healthcare settings

In developing countries, access to healthcare is a challenge due to factors such as lack of transportation to care and treatment centres and the stigma associated with HIV/AIDS (Sherr et al. 2016). However, in the context of the abandonment of children with HIV, these issues are augmented by factors such as the delivery of babies in the home, and the lack of follow-up of healthcare professionals (HCP) to antenatal mothers when they are attending prevention of mother-to-child transmission clinics (PMTCT) before and after delivery (Bailey et al. 2010a; Machine et al. 2016). This results in the delivery of babies who are HIV-positive (Sanjeeva et al. 2016). Consequently, they grow up without knowing their HIV status (Myer et al. 2006).

There is a huge problem of disclosure of HIV status to children. Healthcare professionals assume that caregivers will disclose the status; however, most of the time, they do not due to emotional fear that disclosing the status will reflect their own immoral behaviors and feelings of guilt about causing the infection in their children. In addition, some parents remember their own experience when they found out about being HIV-positive and fear how their children will react to the information (Cruz, M. L. S. et al. 2015). This problem contributes to abandonment because of the lack of follow-up care for HIV medicine (Azzopardi et al. 2014). When this is the case and the child's condition worsens, extended families abandon them due to the lack of resources to support their care and treatment, and other social issues such as stigma (Jemmot et al 2014).

2.4.5 Gaps in law and policy

There are sound international laws and policies in place, such as Article 22 of the UN Convention on the Rights of the Child emphasising child protection, and Tanzania is a member UN state and a signatory to the convention (Rwezaura 2000). However, the child protection policies are still not well known with the stakeholders and there is a gap in following-up of children's rights due to poor infrastructure, and lack of practice guidelines and awareness in Tanzania and in neighboring countries such as Uganda (Akani & Erhabor 2006; Sherr et al. 2016). In Uganda, Fournier et al (2014) recommended that policy-makers provide guidelines to enhance the lives of children with HIV infection (Rydström et al. 2016). Unfortunately, this has not happened in Tanzania (Fournier, Bonnie, Bridge, Andrea, Kennedy, Andrea Pritchard, et al. 2014).

2.5 Discussion

This literature review has sought to discover why children living with HIV in Tanzania are abandoned. The major factors that appeared as a cause of abandonment in all countries where studies have been conducted were stigma, socio-economic factors, gaps in law and policy, poor access to health facilities, family disintegration, and illness. The abandonment of children living with HIV results in the following two consequences: they miss care opportunities and are prone to infecting other children with HIV/AIDS in the community.

Children living with HIV/AIDS miss out on follow-up care of recommended HIV treatment (Fournier, 2014). This is a problem because the lack of continuity of HIV treatment may result in a poor illness trajectory, and eventually, death (Azzopardi et al. 2014). For instance, there is a correlation between children missing out on care in treatment centres (CTC) for HIV medication and the abandonment of children living with HIV who become homeless and drop out of their HIV treatment regime, which is provided for free in hospital CTCs (Pegurri et al. 2015). In particular, one study conducted in Tanzania predicted virology failure due to poor adherence to HIV/AIDS

medication drugs, because HIV-positive children do not attend the follow-up clinic (Emmet et al 2013). This problem is similar to a study conducted in Ethiopia which found that the lack of follow-up for children living with HIV in the CTCs was due to caregiver negligence (Pegurri et al. 2015).

Secondly, children living with HIV who are abandoned engage in sexual activities which may lead to the spread of HIV infections among homeless children in general (Waziri 2013). This is because most children living with HIV do not know about their HIV status. They may engage in un- protected sex which makes them prone to multiple infections of HIV, and they might also spread the disease to other homeless children who are not infected with HIV (Emmet et al 2013; Fournier et al, 2014; Waziri 2013). Furthermore, another important matter which raises concern in the findings and which could be important for children living with HIV is disclosure about their HIV status. Discussing the prognosis of patients suffering from a life-threatening illness is a key aspect for healthcare professionals in attending to patients and their families (Clayton et al. 2007). This is because the provision of information increases autonomy for patients and their families (Clayton et al. 2007). However, the communication of a diagnosis for children living with HIV is currently expected to be conducted by either healthcare professionals or the caregivers, which has resulted in no-one performing this task effectively (Pegguril et al 2015). This situation results in the delay of children living with HIV to learn about their HIV status, and to adequately follow the recommended treatment and supportive services available for people living with HIV/AIDS (Jemmott III et al. 2014; Machine et al. 2016)

Finally, orphanages could have served the purpose of taking care of abandoned children living with HIV/AIDS; however, the UNCRC 1989 stipulated that institutionalised care for vulnerable children should be considered as a last resort. Nevertheless, for the reasons stipulated in this review, family care has several gaps in providing care for sick children (Lugalla & Mbwambo 1999). Furthermore, the available institutional care, such as orphanages, were created to cater for orphans who are HIV-negative to prevent the

transmission of the disease (Ferris, M. et al. 2007). The stigma of HIV also contributes to these children not being accepted in the available orphanages for fear of cross-infection when they are kept together with non-HIV infected children (Fournier, Bonnie, Bridge, Andrea, Pritchard Kennedy, Andrea, et al. 2014). Most of the orphanages are too under-resourced in both infrastructure and skilled human resources to provide support for children who are sick (Ferris, Margaret et al. 2007).

The question which remains is what can be done to identify and support these children who are invisible in the Tanzanian community, and who are living with HIV, abandoned, and on the street. There is an emerging global awareness of homeless children (Waziri 2013). However, there is a paucity of evidence relating to homeless children who are HIV-positive who live on the street. According to Emmet et al's (2011) study, children could not comply with their drug regime because of their caregivers' economic and social challenges. It is crucial for policy-makers, healthcare professionals, and other like-minded stakeholders to find holistic ways to address issues pertaining to children living with HIV who have been abandoned (Fournier, Bonnie, Bridge, Andrea, Pritchard Kennedy, Andrea, et al. 2014).

2.6 Conclusions

This chapter provides a systematic selection of articles for a review of the literature. The major findings on why children living with HIV are abandoned were analysed and the findings were discussed to reflect the research question. The varied reasons for the abandonment of children, such as poverty, poor access to healthcare settings, gaps in the law, and the stigma associated with HIV illness show the complex situation of abandoned children living with HIV/AIDS. Their voices go unheard, and their suffering is evident. There is a need to take deliberate steps to inform leaders of their presence on the street, and policy-makers about their unmet challenges, to enable these children to thrive. In addition, there is an urgent need to conduct research to explore how healthcare professionals can manage abandoned children living with HIV/AIDS. This

will enable the identification of gaps in HIV disclosure for children living with HIV, particularly in identifying who is responsible for disclosing the diagnosis to these children between caregivers and healthcare professionals, and to find ways to develop guidelines which will offer help to support healthcare professionals to deliver an HIV diagnosis to children, which is an important part of their skills.

CHAPTER THREE: METHODOLOGY AND METHODS

3.0 Introduction

The aim of this study is to explore how healthcare professionals in the Care and Treatment Centres (CTC) manage abandoned children living with HIV/AIDS in Arusha municipality. In chapter two the literature relating to why children living with HIV/AIDS are abandoned in Tanzania was presented and discussed. This chapter presents the methodology used and the process that was followed to answer the research question. It describes the research paradigm, research methods, the participant's characteristics and recruitment, data collection, and data analysis. The rigour of the study and the ethical considerations are also explained before concluding the chapter.

3.1 Settings

The study was conducted in Arusha which is one of the districts in Arusha region in the northern part of Tanzania. The Arusha region covers an area of 37,576 square km and has a population of 1,694,310 people, according to the 2012 national census. Arusha City is the capital of the Arusha region and had a population of 516,000 in 2012, making up approximately 47% of the Arusha region (TPHC 2012). The participants were from hospital in Arusha District. The hospital is a government-administered public tertiary-level hospital, which provides a free CTC for people living with HIV/AIDS from the Arusha district. Approximately 1,500 patients and children attend this clinic each year (TACAIDS 2015). The hospital was selected because of its location in the middle of the city centre, making it easily accessible for inhabitants from both the urban and rural parts of Arusha district. Informal settlements are growing rapidly in Arusha City. Only about 16 per cent of the total population of Arusha has a reliable income, and 50% of the total city population are children. Urbanisation has fuelled the growth of new HIV infections and left many children living in poverty and hunger (UNICEF 2012).

The Tanzanian Commission for AIDS and the National AIDS Control Programs (NACP) coordinates the national response to HIV/AIDS in Tanzania. The major role of the NACP is to provide prevention, care, and treatment services through the establishment of CTC centres across all Tanzanian healthcare systems. These efforts are coordinated by the NACP and supported by local and international donor funding. In Arusha region, there are 53 CTCs, and this hospital has been established as a referral hospital within the region (TACAIDS 2015).

3.2 Paradigm

A paradigm in research is a shared worldview, or a set of beliefs, values, and practices in the rigorous process of theory generation (Weaver & Olson 2006). Nursing research is underpinned by two paradigms of qualitative and quantitative inquiry in order to develop evidence (Polit, DF & Beck 2008). These two paradigms are key in conducting research and generating knowledge. However, they are two distinctive sets of methods. The distinction between them is based on their structuring of research based on the research question and the methods in synthesizing information from the respondents (Schneider & Whitehead 2013; Tuckett 2005). Compared to qualitative research, quantitative studies are rigid in their nature and follow strict procedures in identifying whether an intervention is useful for people (Morse 1990). On the other hand, qualitative research offers more flexible ways of collecting information suitable for understanding the human experience based on the research questions being posed (Schneider & Whitehead 2013; Tuckett 2005). Qualitative research can be used to identify the underlying cause of a problem and can generate ideas that can then be used in conducting quantitative studies (Munhall 2012; Polit, DF & Beck 2004).

The chosen paradigm for this research is the qualitative approach. This approach is appropriate for this study as it aims to generate meaning about phenomena under investigation by understanding the perspectives of the participants which lead to the construction of knowledge (Weaver & Olson 2006). This study aims to understand how

healthcare professionals manage abandoned children living with HIV/AIDS who live on the street; therefore, a qualitative approach is appropriate as it aims to develop theory from the data and to generate new knowledge (Polit, DF & Beck 2004). It is also an appropriate paradigm for this study as it enables the researcher to understand the perspectives of the participants, particularly their experiences in the management of homeless children living with HIV/AIDS (Polit, DF & Beck 2004). Qualitative research enables the researcher to construct reality directly from the participants' information (Munhall 2012). This reflective process enables the participants to be involved in the process of constructing and generating knowledge (Munhall 2012). Also, qualitative research enables the researcher to collect meaningful data from a small sample size (Whitehead & Whitehead 2016). For example, in this study, the interviewing of seven healthcare professionals (HCPs) was enough to achieve data saturation. This was an advantage due to the lack of availability and fewer number of HCPs working in the care and treatment centres (CTC) due to their busy schedules. Unlike in quantitative research where statistical information from a large sample size can be generalised to larger populations, human experience evolves over time and through naturally occurring experiences, which means that qualitative studies are not suitable for generalisation.

A qualitative descriptive approach is used to explain difficult events facing healthcare professionals, or to develop theories about the experiences facing the recipients of care and their families, which are the core aims of this study (Whitehead & Whitehead 2016).

3.2.1 Methodological Approach

Qualitative descriptive research, is a broad approach due to its foundational basis of implementing the common components of a range of qualitative approaches (Schneider & Whitehead 2013; Thorne 2009). These approaches can include ethnography, action research, phenomenology, and grounded theory (Thorne 2009). Qualitative descriptive approaches are based on constructive research principles and can be used to construct theory (Sandelowski 2010). According to Thorne (2009), this approach was established

to give researchers a liberal way of communicating and reporting findings, freeing them from the obligations of more traditional methodological approaches (Sandelowski 2010). This methodological approach enables the researcher to become a key factor in the smooth facilitation of the research and to act as a tool for data collection (Schneider & Whitehead 2013).

A reflexive approach was taken by the researcher to identify any potential preconceptions which might influence the findings of the study (Malterud 2001). Being a nurse herself working with abandoned children living with HIV/AIDS in Arusha Tanzania, the previous work experience and personal values of the researcher were acknowledged in order to realise the HCPs' full potential in being the 'knowers' of the subject matter (Malterud 2001). This approach has been recommended by Elliot and Timulak (2005) in that it is very important for the qualitative descriptive researcher to identify preconceived ideas during the data collection process. The previous experience of the researcher enhanced the study by enabling probing participant responses to gain their deeper meanings and understandings of their management of homeless children living with HIV/AIDS. Knowledge building, which is core to this study, is the underlying philosophy behind the descriptive-qualitative approach. The findings of the study will create awareness of abandoned children living with HIV in Tanzania.

3.3 Rigour

Rigour in qualitative research defines the processes undertaken to ensure trustworthiness, validity, and reliability (Sandelowski 2010). Rigorous qualitative research occurs when a researcher remains focused on the phenomena of interest and its interpretation which can be viewed as trustfully to others (Thomas & Magilvy 2011). Maintaining rigour during research is key to ensuring the reliability of the findings (Morse et al. 2002). Polit and Beck (2013) explained that reliability and validity are characteristics explored in qualitative research, because all research must be constructed upon a foundation of trustworthiness and integrity in order to generate knowledge

(Liamputtong 2011). Even though the concept of rigour has been debated in qualitative research, it is a crucial process for generating reliable and transferable knowledge (Liamputtong 2013; Munhall 2012).

There are a number of important techniques in qualitative research to ensure that rigour is achieved. This includes theoretical rigour, triangulation rigour, methodological rigour, evaluative rigour, interpretive rigour, and reflexivity (Thomas & Magilvy 2011). This study employs methodological and theoretical rigour to answer the research questions. Methodological rigour is demonstrated in the way the study has been conducted in relation to the inclusion criteria, recruitment, data collection, and data analysis (Liamputtong 2013; Mateo & Kirchhoff 1999). Documenting of the process is crucial to ensuring an audit trail and to enhance rigour (Mays & Pope 1995). In this study methodological rigor was enhanced through listening to audio recordings many times. Frequent listening of tapes enabled the researcher to gain deeper understanding of the participant's perceptions of their experiences which enhanced in the interpretation of meaning (Liamputtong 2013; Weaver & Olson 2006).

Theoretical rigour was demonstrated through Guba and Lincoln's (2011) framework to ensure that trustworthiness was adhered to following the four criteria of credibility, transferability, dependability, and conformability, which are key values in this study. These criteria emphasise the following points:

i) Credibility is key and can be achieved by having a clear explanation of the methodology and the approach taken to conduct the data collection and analysis for the reader. In this study, credibility has been ensured through working in collaboration with the supervisors. Firstly, the telephone Skype interviews were recorded to ensure that all the subjective data was clearly collected from the participants. Recording of the data collection served to reduce researcher bias. Secondly, the study findings, and the researcher's interpretation of those findings, were supported by the participants' quotes from the interviews. This enhanced the credibility of the information. Finally, there were

scheduled supervisory meetings to discuss the findings with the supervisors, who have experience in qualitative research, and who therefore, were able to ensure that the coding process was aligned to, and consistent with, the chosen themes.

ii) Dependability can be achieved through a transparent explanation of how the themes and concepts were developed. Documentation is the key to ensuring that the findings are dependable. In this study, there was a consistent and systematic process for collecting and developing the themes. Appendix three illustrates how the themes were developed out of the coding process.

iii) Transferability is the capacity for the findings to be used in different settings. For this study, there is a detailed description of the sample population and the settings for this study. However, as the participants in this study provided a deep perspective based on their own experiences in their own local context, replication cannot be guaranteed to another setting or sample. This is because qualitative research findings cannot normally be generalised (Liamputtong 2013; Patton 2005).

iv) Conformability has been achieved in this study by ensuring that the respondent information was recorded and that there was a detailed audit trail of the data (Liamputtong 2013). Guba and Lincoln's (2013) framework opens the opportunity to be reviewed by others on how the research process was conducted and how the findings were established. In order to achieve this, the rigour of this study ensured that all the necessary processes were reviewed by the supervisors, and then documented in the thesis as appendices, including an information pack for the potential participants, correspondence emails and letters, ethics approval letters, interview guides, the transcript analysis, the coding process, transcripts of the interviews, and the thematic analysis (Liamputtong 2013).

3.4 Ethical considerations

This study has adhered to the requirements of the Tanzanian National Health Research Ethics Review Council (NHRECC) and the Australian National Health and Medical Research Council (**NMHRC 2007**). Both ethical bodies adhered to ethical components related to this study in order to ensure no harm between the researcher and the participants. This includes anonymity, confidentiality and beneficence, autonomy and voluntary. Ethics approval to conduct the study was obtained from the Flinders University Social and Behavioural Science Ethics Committee (Approval Number 7577) (Appendix 7).

The study also obtained formal approval from the Arusha region director office. A letter granting permission to conduct the study at hospital was issued by Arusha regional administrative secretary on 17 March with reference number FA 80 /251/ 01/12 (Appendix 8). The hospital management required the researcher to provide a letter from the regional office for approval to conduct the study within their facility. The permission from Arusha regional administrative secretary to conduct a study was a requirement by the Social and Behavioral Science Research Ethics Committee Flinders University

The potential participants were provided with an information pack which included a letter of introduction (Appendix 9), an information sheet (Appendix 10), and a consent form (Appendix 11). The information pack provided potential participants with the benefits of informed consent, so that they could choose to participate in the study or not.

This research is a low risk research and researcher did not foresee any risk to participants. However, according to Minichielo (2013) collecting data through interviews, participants may feel distressed if some questions induce fear, guilty, sadness and anxiety. In view of this, participants were asked to contact local counseling department at Selian hospital which were prior organized by researcher in case they were distressed during interviews (Munhall 2012; Polit, DF & Beck 2008).In addition,

participant were given the contacts of the researcher. Before conducting each interview, the researcher went through the detailed information in the information pack with the potential participant. They were also told that participating in the study was voluntary and that they could withdraw at any time without consequence (Polit, DF & Beck 2008). Also they were reminded that, they were free to choose not to answer any particular question. Following this process, informed written consent to participate was gained, and consent was also sought on whether the interview could be recorded or not (Minichiello, Aroni & Hays 2008; Patton 2005).

Privacy and confidentiality were strictly maintained by the researcher. This involved using a 'safe office' agreed to by the participants, which was provided without cost by the hospital management. The identity of the participants was protected through the use of pseudonyms in all written information, and in the final thesis, to ensure confidentiality (Minichiello, Aroni et al. 2008).

A potential conflict of interest was declared due to the researcher being a healthcare provider in a district where she may have worked with the potential participants. Coercion was avoided by involving a local key contact person during the recruitment process.

Data was stored in a secure locked cabinet, which was only accessible to the researcher. It was stored electronically on a laptop, which is password-protected and only known by the researcher during the study, and will be stored on a Flinders University computer with a special locked password for five years after examination of the thesis.

3.5 Sampling and recruitment

A sound sampling strategy for the recruitment of research participants is crucial for identifying suitable participants for data collection, to obtain rich information about the phenomena of particular interest.

A qualitative research uses a non-probability sampling technique. A purposive sampling was employed in this study. A purposive sampling gives a deliberate option to a researcher to choose the number of study participant and the characteristics they poses who would reach saturation especially when the number of participants to choose from are too small and the characteristics they poses (Schneider & Whitehead 2013).

Purposive sampling was the primary strategy for obtaining potential respondents for the study. Healthcare professionals (HCP) in this study were chosen due to their experience in working at the hospital Care and Treatment Clinic (CTC), which is dedicated to the care of people living with HIV/AIDS. The CTC has great expertise in the care of homeless children living with HIV/AIDS. In addition, purposive sampling was useful for this study due to its cost and time benefits.

The purposive sampling for this study was augmented by snowball sampling. According to Polit and Beck (2012), snowball sampling can enhance purposive sampling in cases where the participants are difficult to access. The initial HCPs involved in the study were asked to refer other participants and to contact the researcher if they were interested in participating. From the above process, seven HCPs were selected from a pool of 37 HCPs.

The setting of the inclusion criteria is one of the key factors in the effective recruitment of participants (Schneider & Whitehead 2013). This process ensures that participants who are able to share their in-depth views based on their experiences would be selected. Healthcare professionals were eligible to participate in this study if they were over 18 years of age, worked in the hospital Care and Treatment Centre could read and understand English and speak Swahili. The recruitment and data collection processes were conducted simultaneously.

Following the ethics approval, a local key contact person provided the hospital management a letter from the regional director officer granting permission to conduct the study. The hospital management and the local key contact person both created

awareness about the study throughout the hospital. Awareness was created by displaying the information sheet, and fliers on the hospital and CTC notice boards. In addition, fliers were also placed in the CTC staff pigeonholes. Interested participants contacted the researcher voluntarily through an email to confirm their participation in the study. Upon receipt of the email from potential participants, the researcher planned for the interview date through local key contact person and the participants were asked to sign consent form before the interview.

3.5.1 Participants' demographic characteristics

Seven healthcare professionals working at the hospital Care and Treatment Centre were interviewed for the study. Of these, three were nurses, while the others were three doctors and one community healthcare worker (CHWs). The age of the participants ranged from 32-55 years, while the length of experience in working at the hospital CTC was between two and ten years. The gender spread was four males and three females. Table 2 presents the demographic characteristics of the research participants.

Table 2. Demographic characteristics of the participants

Participants	Age	Gender	Years of experience working in the CTC	Professional background
1	39	Female	7	Nurse
2	26	Female	2	Nurse
3	35	Male	3	Doctor
4	32	Female	3	Nurse
5	42	Male	5	Doctor
6	55	Male	10	Doctor
7	49	Male	9	CHW

3.6 Data Collection Method

Selection of an appropriate method is a key quality factor in conducting research in order to achieve the aims and objectives of the research (Polit, DF & Beck 2008). The most common qualitative methods include in-depth interviews, focus groups, case studies, ethnography, and action research (Liamputtong 2013).

Interviews are defined as encounters between the respondent and the researcher with the aim of collecting spoken information based on the life experiences of the participants (Minichiello, Aroni & Hays 2008). They also aim to find ways to understand and generate new knowledge about the participants' lived experiences in a particular area of interest (Elliott & Timulak 2005). Interviews can be identified in three ways, structured, semi-structured, and unstructured. In-depth semi-structured interviews were used to collect data from the HCPs involved in this study. Sandlewoski and Margareta (2000) explained that in descriptive studies, the researcher is expected to gather valuable information by asking questions about the participants' feelings and attitudes about the issue being explored. Semi-structured interviews encourage openness through the use of open-ended questions as well as enabling discussion of difficult topics (Polit & Beck 2012; Schneider & Whitehead 2012). Interviews enable flexibility during the collection of information through the process of probing, which can bring valued meaning to the topic under investigation, thereby providing authentic information. Furthermore, the use of open-ended questions enabled a focus on the individual being interviewed, which enhances their specific viewpoint (Thorne 20008; Munhall 2012). This is the key to ensuring autonomy and gathering rich subjective data to generate theory as an outcome of this study (Sandelowski 2010; Thorne 2009).This study used Skype telephone application, in -depth interviews to collect data**.**

3.6.1 Data Collection Process

Interviews provided the researcher with the opportunity to understand the in-depth experiences of the interviewees about the phenomena being explored, which then

contributed to the generation of knowledge (Morse 1990; Thorne 2009). Interviews are generally flexible and allowed the use of open-ended questions which encouraged participants to freely express their insights which, in turn, supported the researcher to construct knowledge(Minichiello, Aroni & Hays 2008). An in-depth semi-structured interview guide was used to collect the data in this study (Appendix 12). Thorne (2000) and Rattray et al (2007) support this method of collecting data. They emphasised that in order to maximize potential use of the study from local context to be adapted in different similar context there should be a pre-planned, standardized interview guide for the intended study.Healthcare professionals (HCP) were established as the key informants, because they were able to provide rich, in-depth meaning and experience on how they managed abandoned children living with HIV/AIDS (Polit, D & Beck 2012).

The researcher conducted a mock interview prior to conducting the research to ensure that she could gain confidence in the interview process and could explore any potential challenges of interviewing and find ways to enhance the process prior to conducting the research (Minichiello, Aroni & Hays 2008; Thorne 2009). The mock interview was conducted under supervision and reviewed by the supervisors. It enhanced the interviewing skills of the researcher and identified several challenges, which could have occurred during the actual interviews. As a result, there were a number of alterations to the interview technique, and modifications of the interview guide as recommended by the supervisors. Among the modifications, probing questions were included which were initially absent from the interview guide. As well, the researcher learned about more flexible ways of asking questions in response to the participants' explanations, rather than strictly following the question order in the interview guide. This process enabled the researcher to undertake reflection after each interview to write-up the process and to improve the approach in the subsequent interviews.

The interviews ranged between 30-45 minutes. The participants were asked for their written consent to take part in the study and to record the interviews prior to the data collection process. All the interviews were conducted using the Skype telephone

application. They were then recorded and translated verbatim into English by the researcher.

The interviews were conducted in the office of the hospital which was provided by the hospital management. It was observed by the hospital management that this office was private and convenient for the HCPs to access during their free time; for instance, during their work-breaks or after finishing work. This enabled the participants to feel relaxed so that they could focus on the interviews. The interviews were audio-recorded on a recording device borrowed from the Flinders University library. Later, the data were transferred to a password-protected laptop. There were two main advantages of recording the interviews. Firstly, this enabled the researcher to be able to listen closely and to focus on asking questions. This also allowed the researcher to take notes whenever necessary to capture sensitive discussions for future reference. It also meant that the participants had ample opportunity to express their experiences without being interrupted. Finally, recording enabled the capture of each entire discussion, which facilitated accurate transcription of the data.

The audio Skype interviews were transcribed verbatim by the researcher. This process helped the researcher to familiarise herself with the data, which also helped the process of data analysis, based on the thematic analysis method of Braun and Clarke (2013). The transcripts were double-checked for accuracy by re-listening and reading the transcripts, and later, being reviewed by the researcher's supervisor.

3.6.2 Data Analysis

Data analysis in qualitative research is defined as the process of transforming the raw data from the respondents to generate knowledge following a rigorous process of understanding and interpreting the data (Schneider & Whitehead 2013). The analysis of the data in this study aimed to analyse the raw data from the HCPs on how they manage abandoned children living with HIV/AIDS (Thorne 2009). The analytical process adopted from Braun and Clarke (2013), which is commonly used for analysing

narrative data, was used to analyse the common patterns and themes arising from the interviews in order to produce the findings.

Thematic analysis has become an increasingly popular method for analysing qualitative data due to its flexibility and easy accessibility (Braun & Clarke 2013). Thematic analysis is defined as a logical method that enables the identification and organisation of ideas and information into related patterns known as themes (Braun & Clarke 2013). Braun and Clarke (2013) claimed that thematic analysis gives researchers the coding opportunities that help them to systematically analyse research data. The six steps of thematic analysis, as developed by Braun and Clarke (2013), were used to interpret the findings of this study. The first step in the process was for the researcher to familiarise herself with the audio-taped data which was transcribed after a meticulous listening process which was repeated three times. Important notes were recorded, particularly those which had occurred in many of the interviews for the possible formulation of codes. The transcripts were shared with the researcher's supervisor for review. This was a crucial step in order to ensure rigour. Interpretation was the second phase of the process. This involved development of the codes to better understand the participants' meanings in relation to the research question.

The third phase was the establishment of themes from the developed codes. Five themes were developed from coding, based on the experiences of the HCPs in managing abandoned children living with HIV/AIDS. A quality check was conducted as the fourth phase. This step ensured that the themes correlated with the data and were answering the research questions and objectives. All five themes were included as they contained rich descriptions which translated the respondents' experiences and answered the research question. They were also coherent and related directly to the stories provided by the HCPs. The final stage was to describe the findings and write up the report. This included comparisons to the current evidence.

3.7 Conclusion

This chapter includes a description of the methodological approach used in this research together with an exploration of the rigour of the study. Ethics approval was obtained before the data were collected and ethical considerations were adhered to throughout the study. This included maintaining the privacy, confidentiality, and anonymity of the participants in order to ensure their autonomy by informed consent. The study adhered to a qualitative methodological approach using in-depth interviews to collect the data, which were then analysed.

CHAPTER FOUR: FINDINGS

4.0 Introduction

Chapter three discussed the methodology and the rigorous process used to conduct the research. This chapter presents a summary of the findings and interpretation of the data analysis based on the spoken information from the participant's experiences in the care of homeless children living with HIV/AIDS. The findings have been structured through themes and sub-themes that arose from the thematic analysis of the data.

4.1 Presentation of the findings

4.1.1 The lived experience of homeless children living with HIV/AIDS

Living on the street has been explained as being caused by poverty (Chauhan et al. 2016). In this study, Health Care Professionals (HCP) identified poverty as a challenge facing homeless children on the street. HCPs explained that living on the street is not an easy life for a sick child. The participants explained that the first major challenge for these children is a lack of basic needs. They also mentioned that these children lack love and affection in general.

The experience of homeless children living with HIV/AIDS on the street was explained by the HCPs as facing a variety of problems, including barriers to accessing basic needs and healthcare services, and also facing social exclusion. This situation leads to a range of mental, physical, and psychosocial problems. In this study, the interview data from the HCPs about the lived experience of homeless children has been divided into three categories, such as , The reasons for living on the street; Child abuse and neglect; and Death and dying for homeless children living with HIV/AIDS on the street.

4.1.2 Reasons for living on the street for children with HIV/AIDS

The HCPs had their own perspective on why these children are homeless. They all explained that the major reasons for the homelessness were that children were not welcomed by their extended family after the death of their parents due to their HIV-positive status. Families were overwhelmed with a lack of resources due to poverty which hindered them in supporting their sick child. Extended families were reported to be inundated due to the increased demands and needs associated with the HIV illness. They showed resentment towards these children which led them to feel unwelcome in their own extended families. In addition, unresolved family matters, particularly parental conflict resulting in divorce and separation, was explained as a contributing factor for children living on the street. Other factors discussed by the participants were a lack of community awareness about the issues facing children living with HIV/AIDS, unexpected pregnancies, peer pressure, and a lack of commitment to and neglect of orphans by caregivers and relatives. For example, one participant discussed the possible causes of homelessness for these children which the participants associated with issues related to poverty, family conflict, and the stigma of HIV illness. Participant 7 explained that:

> *It may be caused of life hardships some woman reaching a point of abandoning their own children. There is a group of woman left by their husbands leading to a huge burden left to them which also leads to the abandonment. Sometimes, internal conflicts between parents may lead to this; for example, a mother may decide to run away with children then later she fails economically to take care by herself. These children may end up in the streets. So, there is a lot of factors things in between. Also, we have seen many being abandoned by their caregivers due to stigma of their HIV status, or after their parents died of AIDS, extended family fails to take care for them and they end up abandoning their children's (Participant 7).*

Another participant stated that:

> *… another challenge is lack of awareness within our society about the presence of these children who are living and in the street and are sick. The community member has experienced the presence of homeless children however less is known about those who are in the street and are living with HIV disease. Also the HCP noted that these HCP they also face challenges such as, the challenges such as lack of shelter and parental care despite their ill health status (Participant 6).*

He continued explaining some of the other factors in relation to children living on the street, being the poor economy and unwanted pregnancies:

> *Under my personally investigation, I have realized that most of these scenarios are cause by those who have been facing life hardships. The moments they want to abort the pregnancy someone may have no financial backup to do so, so when a child is born she will abandon a child since she had the same thoughts before. All in all, when the situation may be contributed by lack of financial to provide for a child's needs, she may be tempted to abandon a child anywhere. For example, the child of mine who I adopted, I found him on a crossroad heading to my house. Some of them are abandoning babies in many different places. My investigation tells me that most of those who fail the abortion of the particular pregnancy are the ones responsible to the abandonment (Participant 6).*

Another participant thought that poor commitment and the lack of skills of the caregivers in caring for orphans also resulted in child homelessness. She explained that:"

> *Caregivers living and taking care of orphans, they need to know how to live with them and how to handle difficult situations when raising orphan child. I recommend mass education to reduce or even eradicate*

> *this problem of street children. Some of these children are coming from villages and move to big cities without having anyone they know after escaping from their extended families (Participant 2).*

Finally, the stigma of HIV/AIDS-related illness results in the extended family abandoning the children after the death of their parents. For example, Participant 1 expressed the view that these children were being stigmatized: "*These children are the victims of stigma and discrimination of AIDS" (Participant 1).* She continued to explain that *"stigmatization is stimulating the number of street children to increase. After parents died due to HIV/AIDS, children will end up being segregated by his/her own family members or caregivers" (Participant 1).*

4.1.3 Child Abuse and Neglect

The maltreatment of children was cited as a recurring problem facing homeless children living on the street. They often face physical, social, and psychological abuse in their daily life on the street, particularly after they start showing symptoms due to opportunistic infections, such as weight loss, and coughing. The environment is not conducive for the growth and development of the child and their well-being. Abuse such as the rape of girls and sodomy of boys was explained by four participants as normal incidents occurring on the street. They explained that these children are victims of sexual exploitation and childhood labour. Participant 3 explained how homeless children are sexually exploited:

> *She began to live with adult man on the street despite of young age till the time I met her. After getting to know about all that, I advised her mother a girl to be HIV-tested together with other diseases and pregnancy. At the hospital, we discovered that she was raped in both sides. I took this matter to the police force, unfortunately, before they went to capture those man, they had already left that area (Participant 3).*

Another participant stated that:

> *For cases where abuse has been conducted to a child, we have been informing government forces dealing with crimes to take more actions to those responsible; however, the following-up is too slow (Participant 5).*

Abuse and neglect contributed to many other negative issues which were considered as major challenges to the thriving of homeless children living with HIV/AIDS. The biggest challenge was how these children meet their basic daily needs such as nutrition, shelter, and healthcare while living on the street. It was believed that the lack of proper shelter and nutrition, and poor access to healthcare has led to them becoming very ill during their first visit to the hospital. Nutrition is a crucial aspect of life for a person living with HIV/AIDS in order to maintain a healthy immune system to fight against the HIV virus. It is also a requirement to take the ART medication before meals. However, the HCPs explained that these children do not have proper access to basic meals as they depend on leftovers from restaurants, which has a detrimental effect on their health. The majority of participants showed major concern towards the lack of nutrition of homeless children living with HIV/AIDS and how this has led them to fail to adhere to the ART drugs. For example, HCP 4 explained how difficult it is to prescribe an ART dosage to a patient who is going to take it on an empty stomach.

> *It is a challenge to encourage a patient to take an ART medication when they tell you that they don't have food at home (Participant 4).*

The issue of meeting their basic needs and how these issues affected their drug adherence was clearly explained by Participant 3:

> *Homeless children live in the streets and sleep in front of Indians shops during the night. They depend on food from hotel leftovers and various dumping sites around the Arusha city (Participant 3).*

4.1.4 The experience of death and dying for homeless children living with HIV/AIDS on the street

The place of death for homeless children emerged as a major concern for many of the participants. They discussed the challenges facing children as their day unfolds as being the cause of premature death for homeless children living with HIV/AIDS. Maintaining one's health and adhering to the required lifestyle of a patient with a chronic illness is hard to achieve on the street. Children living with HIV/AIDS who live on the street found it difficult to prevent opportunistic infections. Despite the fact that HIV medication is available for free, homeless children find it difficult to access as there are costs associated with transport and, most of the time, cotri-moxazole tablets, the drug required for the prevention of opportunistic infections, is usually out of stock in the hospital pharmacies and this requires a patient to buy it in a private pharmacy. It is very difficult for homeless children to buy cotri-moxazole tablets as a prophylactic treatment. This results in worsening health, and death which may occur at any stage. The HCPs stated that the street is a difficult and lonely place to die for a child. HCP 3 explained that:

> *When it happens that these children's health deteriorates dying in the streets is very difficult for a young child. They don't possess valuable beddings or comfortable shelter. Most of their end of life is due to opportunistic infections related to chest infections and Tuberculosis. This is due to cold weather and dust they have to live with on daily basis (Participant 3).*

> *The future and well-being of homeless children living with HIV is in crisis. Their needs and future plans and admiration need to be considered and supported. They also wish to be doctors and engineers and support the mankind (Participant 2).*

4.2 HIV/AIDS treatment care and support services offered in the CTCs

In the current study, the theme of HIV/AIDS treatment, care, and support services offered in the CTC centres was considered to be critically important by the HCPs. The HCPs explained their perceptions in relation to the CTCs' work of tracking homeless children so that they adhere to the treatment, their service provision, and the challenges facing the CTC centres. This is important in ensuring that they can offer quality services to people living with HIV/AIDS in working towards the UNAIDS 2011-2015 strategy. The sub-themes which arose around this theme were as follows: i) Monitoring and tracking of homeless children living with HIV/AIDS for ART drug adherence; ii) Disclosure of HIV/AIDS diagnosis to homeless children living with HIV/AIDS; and iii) Management of homeless children living with HIV/AIDS and the challenges facing the CTCs.

4.2.1 Monitoring and tracking of homeless children living with HIV/AIDS for ART drug adherence

The HCPs stated that the process of ensuring that homeless children access and adhere to HIV treatment services is very difficult. Despite this, the HCPs had a good tracking mechanism and good tracking tools, such as tracking resources and attendance records on a monthly basis; however, ensuring that homeless children attend the clinic posed a challenge in the CTCs. The HCPs explained that this was due to the nature of homeless children relocating from one place to another which created difficulties in tracking them. Participant 1 explained how they track the children:

> *Tracking of homeless children to attend CTC is a very big challenge, what we do first to help them is by using our Home Based Care (HBC) for those children identified at Mt. Meru clinic and are living around. For those living in other streets, we refer their cases to Home Based Care (HBC) of Kaloleni and Levolosi health center for closer follow ups. It is difficult to use Home Based Care (HBC) to some of street children; this is*

because some of them do not agree to come to the clinic or being identified by others that they have HIV infections. Some children's need their privacy while coming to get their HIV medications (Participant 1).

Participant 2 had the following view which was based on the lack of enough active home-based care volunteers and the nature of volunteerism in home-based care roles:

Some other streets they don't have active home-based care providers and this make the situations worse in allocating the children's. These home-based care providers are also just volunteers, are not paid staff, so it is difficult to make them accountable in the monthly basis follow-up and tracking of identified children who have stated that they live in the streets (Participant 2).

Participant 1 also explained the services offered in the CTCs to address the clinical and psychosocial well-being of the children:

The most important thing we do in psychosocial aspects is by combining them into clubs, from there they get to know each other and share different kinds of knowledge. Those with high capacity of understanding of how to live with HIV/AIDS become educators especially to motivate others the importance of using HIV drugs accordingly. In medical perspectives, they receive monthly routine checkup, being their cd4 count, viral load, laboratory check-up and control x-rays to follow up tuberculosis episodes. They also receive monthly drug regime for ART (Participant 1).

Participant 4 stated that:

Most of these homeless children tend to be forgotten. It is very difficult to track homeless children due to the nature that they don't have stable locations. Even our home-based care providers work in the street however, not for the street/homeless children, but works with children at

community level who live with the family social support system (Participant 4).

Participant 1 discussed the reasons why children living on the street are difficult to locate due to their lifestyle:

Children in the streets also makes a lot of crimes, so they don't like to make themselves known as to where they are permanently located, they therefore move from one place to another in order to camouflage their illegal status. This makes it harder for healthcare professional to track them … As we work as institution base that patients access our services but we don't have following mechanism at community level rather than established home-based care organizations, community leaders who only works at their convenient not as their permanent responsibility.

The HCPs showed that tracking homeless children so that they adhere to HIV/AIDS services is a challenging issue. The reasons for this were relocation of the homeless children due to their lifestyle, and sometimes, homeless children commit crimes on the street which leads them to lack confidence in showing up in public settings for fear of being arrested by the police. Moreover, the participants explained that the available tracking mechanisms involving community outreach programs usually fail because they are geared to creating HIV awareness interventions in public which usually target adults. As a result, children are left out, particularly those who live on the street without parental guidance. The HCPs also showed concern about home-based care activities being left to community health volunteers who are not paid staff and simply act in the role of Good Samaritans who choose to work based on their conscience.

4.2.2 Disclosure of HIV/AIDS diagnosis to homeless children living with HIV/AIDS

The disclosure of a HIV diagnosis to a HIV-infected child was explained by one HCP as a very important intervention in order to ensure drug adherence and for a child to be responsible for his/her own health. However, communicating and delivering a HIV

diagnosis to children raised concern for many of the participants, as a significant ethical dilemma. The particular HCP discussed the factors which create uncertainty about when and how to inform a child about their HIV diagnosis. Among the factors that hindered effective communication to a child about their diagnosis was firstly the uncertainty about what is an appropriate age for the child to be informed about their diagnosis. Secondly, the mental and physical health of a child so that they can comprehend the information given about their HIV status. Finally, there is the issue of cultural appropriateness as some people do not like to involve children in matters which create psychological trauma for them. The HCP stated that they have been using their own experience to determine which child is eligible for HIV disclosure and whether the child can assimilate the information. A lack of practice guidelines from the Ministry of Health about which age is appropriate for HIV diagnosis disclosure to children, and the counseling process of conducting disclosure was explained as a contributing factor to the uncertainty. For instance, HCP 1 explained the consequences of late diagnosis and disclosure for homeless children.

> *Most of these children get to know about their health status later in late stage. It happens when they are in the streets they think they are just normal as other children and suddenly things change and become very ill. At this stage is when we see them at the clinic. It is at this situation even their mortality rate becomes high (Participant 5).*

Other participants explained why parents do not disclose their HIV status to their children.

> *Parents feel guilty most of the time for infecting their children, and then they choose to protect them by hiding the information (Participant 4).*

Participant 7 explained the challenge of not having proper guidelines from the Ministry of Health on the disclosure of HIV/AIDS and how it affects the process and its effectiveness.

> *We have not received from the Ministry of Health a guideline on when a child should be informed of the HIV status, so it depends with healthcare professionals' perception and experience on when and how to disclose the HIV diagnosis to a child (Participant 7).*

Participant 2 explained that HIV disclosure creates challenges in the CTCs for the following reasons:

> *There are lots of challenges. First of all, some of these children were left without being told anything about their HIV health status when their parents died. It makes it very difficult for them to understand the situation since they do not know how did they got HIV infections. Once they are told by healthcare professional that they are HIV-positive, eventually, it takes so much time to heal on the pain of bearing HIV diagnosis (Participant 2).*

Parental protectiveness of their child's diagnosis, along with the lack of practice guidelines for HCPs, results in serious gaps in disclosure and management of children living with HIV/AIDS.

4.2.3 Management and Challenges facing CTC centres

The establishment of trust and friendliness was perceived by HCPs as a useful strategy in reaching and providing care to homeless children with HIV/AIDS. This is because most homeless children have suffered cruelty and abuse on the street, and in the community at large, which has led them to have trust issues. As well, they are often hiding from the legal authorities due to their misconduct; therefore, it is difficult to convince them to publicly attend healthcare services for fear of being caught. The participants stated that their collaboration with home-based care (HBC) volunteers has enhanced their work. They explained that HBC volunteers served as a link between them and the CTC centres at the community level. They would identify children on the street and refer them to the CTC centres for ART treatment and care.

The healthcare professionals also had concerns about the challenges they faced in the CTC centres in delivering effective care. These concerns were as follows:

1) Lack of skilled staff for interventions with particular specialties. For example, most of the children had a mental illness such as depression, which can be one of the side-effects of HIV/AIDS, and post-traumatic stress from the stigma and abuse they face on the street. However, such expertise was missing in the CTC centres and other HCPs lacked the confidence to support children in the areas they were not trained for. For example, Participant 4 explained that the need for certain expertise is crucial in CTC centres.

> *Some of these children are mentally disturbed due to HIV illness making it so difficult to understand when we explain to them about their conditions. It is very challenging for me as a nurse to take a role of a psychologist and try to intervene with these children on daily basis. I lack confidence (Participant 4).*

2) Internal relocations of staff were another challenge for the provision of quality care in the CTC centres, which were always constrained by the low number of staff compared to the high demand of the children seeking support. For example, Participant 7 stated that:

> *A big challenge I have notice in our CTC centers is when a child meets a healthcare professional with less experience in this criteria. We have experienced healthcare professionals being exchanged from one health center to another, so making less variety for those with a longtime experience. A child or adult patient may need to get specialized care and advices from healthcare professionals while at the same time you may find a clinic to lack those experts such as nutrition and child psychology or mental health (Participant 7).*

3) Lack of infrastructure to support children through psychological activities and other improvements also hindered their services.

4) Finally, the HCPs were overwhelmed with the children's psychosocial needs which required urgent intervention. These were issues such as access to food, and the issues of rape and abandonment, which were a challenge as the CTC centres could offer only limited support for psychosocial interventions. For example, sometimes the HCPs volunteered to use their own resources to support the children's needs or to initiate communication to a Good Samaritan and ask for support. As an example, Participant 6 explained that:

> A *major percent of complains from patients is lack of enough food, you may be asked by patient such question when prescribing ARVs to him/her. As a healthcare professional you are caught in ethical dilemma to know that you are providing a drug without a meal. We most of the time contact other good samaritans to ask for food donation to support these patients (Participant 6).*

The CTCs are an integral part of the healthcare system in Tanzania. Engaging the community in tracking and monitoring children living with HIV who are on ART drugs is crucial through the involvement of other like-minded stakeholders within the community, such as home-based care volunteers, non-government organisations, faith-based organisations, and a range of individuals. The participants expressed their concerns about the challenges confronting the CTCs which hindered equality in access to ART, and care and support services, particularly for those in adverse and vulnerable situations such as homeless children living with HIV/AIDS.

4.3 Community mobilization and networking

In this study, the HCPs discussed what was helpful in managing children living with HIV/AIDS on the street through community engagement. In addition, they provided innovative ideas and advocacy in relation to the issues affecting street children living with HIV/AIDS. This theme was divided into the following two sub-themes: i) The role of community home-based care in home-based care programs; and ii) Orphanages.

4.3.1The role of community home-based care volunteers in home-based care programs

The HCPs explained that working with home-based care volunteers, usually known as CHWS, has enhanced the effectiveness of care and improved the links between the hospitals and the community setting.

The HCPs explained that the CHWS had helped with the problem of lost and missing children in the CTC tracking book. As well, they explained that one of the roles of CHWS was to ensure that children enrolled in care adhered to treatment and that they followed-up with them when they missed a session at the clinic. In addition, all the participants explained that home-based care volunteers had a positive impact on the care of vulnerable children. Participant 6 explained the strategy they used to ensure that people living with HIV/AIDS were accessing CTC support and services:

> *We are working by ensuring that an access to care strategy of 90-90-90 is adhered. This strategy intends to ensure that. The first 90 is to identify a child, the second 90 is to make sure a child begin medication (services) and the last 90 is to make sure that a child remains under medication (services) for his/her entire life time. All these makes what we call 90-90-90 strategy (Participant 6).*

On the other hand, another participant who is a home-based care volunteer himself explained how the home-based care volunteers faced challenges in their work. He stated that despite this job being considered as a volunteer position, it was very demanding in terms of the time spent on the patients at the community level and then linking the patients with the required and available resources. Participant stated that:

> *Our main challenge is on how to get these children to the hospital. Most of the time we lack transport fees. Particularly when a child is abandoned, she/he has no relative to look after, and then there is no-one who is responsible to pay for their cost. We have to take a very long walk*

with a child to access ART care services. Considering this is not a paid job, a home-based care volunteer needs a kind-hearted spirit (Participant 5).

Many of the participants remarked that through the help of HBC volunteers, there was a good link to community-based organisations and other authorities.

Home-based care volunteers are very helpfully. Through working with them helps create a good relationship with local government leaders. We have been conducting mass education through community meetings arranged by local government leaders. We use this opportunity to provide health education in general including HIV/AIDS. Local Government leaders and councilors have tried to encourage these abandoned and homeless children to go to schools without having to contribute anything (Participant 3).

Another participant shared how they link and network with other supportive groups in the community, such as teachers, youth groups, and Samaritans to mobilise support and create awareness for HIV services among youth and children. In relation to this, Participant 4 stated:

In order to get street children to be involved in our care, we also co-operate with volunteers within those streets with a number of street children. Also, there are programs known as adolescence and youth teams established by individual volunteers within different streets aiming to gather youth at one place, whereby, we health providers attends in such teams to provide HIV education to the youth. Later, after agreements with these children, we conduct HIV test (Participant 3).

Participant 3 went on to point out that:

We also get support from teachers in schools. Teachers' are told about those children living with HIV and their clinical dates of attendance.

> *They also help us to remind children about coming to the clinic, they give them permission to attend and sometimes they make follow-up on the uses of medicine (Participant 3).*

A few HCPs made suggestions on how other stakeholders could have invested more commitment and resources in the care of street children in order to improve their well-being. Participant 7 stated:

> *There are many NGO in Arusha who could have tackled the problem of street children. These organizations need more commitment in a distribution of resources to reflect children's needs (Participant 7).*

Participant 2 also offered the following suggestion:

> *My suggestion about what are the important things to be done includes empowering volunteers and adolescence teams within our societies so that they reach out more children in need. In doing so, eventually it will lead us to our targeted goal (Participant 2).*

4.3.2 Orphanages

The participants had the perception that homeless children did not have protection and guidance in comparison to those who lived with their families. They stated that referring homeless children to rehabilitation centres and orphanages was a good way to support homeless children by teaching them life skills and protecting them from HIV infections. However, the participants were aware of the challenges facing many orphanages in terms of the lack of infrastructure, and they also perceived that keeping HIV-positive children in one place might result in stigma. The participants had the following positive reaction on how orphanages might provide solutions for homeless children on the street. Participant 5 stated:

> *After providing health education to these street children, we need to create an environment of a promising future for these children because it can be very possible that same children are complete orphans. Some of them have parents/relatives who participated on their injuries which has led them to become homeless, so if you want to send them back to their families they won't agree at all. For such cases, we have been informing forces dealing with crimes to take more actions to those responsible (Participant 5).*

Advocacy and community awareness on the issues affecting homeless children is crucial in order to ensure that the community is sensitised to providing support. Mapping of the available resources is the key, as the use of readily available resources, such as the orphanage in Arusha as a drop-in centre, is crucial in enhancing the lives of homeless children living with HIV/AIDS, despite the fact that these orphanages were reported to have a lack of infrastructure. Participants stated that all stakeholders should collaborate in finding innovative interventions to find solutions to the problem. In addition, participants suggested that donor's funding priorities should be harmonised with the needs of the community in the local context and should be culturally appropriate.

4.4 Health promotion and primary prevention health services among homeless children living with HIV/AIDS

The prevention of HIV-infection and health promotion services among homeless children was explained as a matter which needed the utmost consideration by all health-related stakeholders, including the government. All the participants explained their concerns about the lagging behind of these interventions to children on the street, which had detrimental effects for the community. The participants also revealed their fear of a future outbreak of new HIV infections in the children and other young people due to dwindling interventions which had previously been highly advocated for when HIV/AIDS was a pandemic in Tanzania. In addition, the participants showed concern

about the absence of prevention interventions geared to vulnerable children and, in particular, those who lived on the street. The participants were clear that there was evidence of rape cases and sexual activity among homeless children; therefore, the risk of those infected with HIV/AIDS infecting others was high. Participant 5 explained that:

> *Primary preventive services have been forgotten for homeless children living with HIV/AIDS. Health promoting services should be encouraged to homeless children living with HIV/AIDS. Such as educating them, provide protective gears in an age-appropriate fashion (Participant 5).*

As well, Participant 2 showed concern about the lack of resources for health promotion and prevention services:

> *Due to lack of enough funding from the government, we are unable to reach youth and children's in the streets in our community outreach programs, we expect that children can access to our adult geared prevention strategies and this lead us to miss large number of children as the preventive strategies for adult usually do not interest children's (Participant 2).*

Participant 5 also mentioned the difficulty of integrating community outreach programs for HIV awareness conducted by the hospital for HIV primary prevention for homeless children:

> *It is difficult to go to the street and provide HIV prevention education to homeless children, first is due to their migrant nature, secondly is because the government strategies of prevention has based on PMTCT services and community at large but have not yet reached the vulnerable population such homeless children (Participant 5).*

Participant 3 explained how these children were infected with the HIV/AIDS virus while on the street, particularly given the incidence of rape and sodomy.

> *Most of these children get to our clinic while they are not aware of their HIV status. Considering such cases, we are the ones in position to provide disclosure and we conduct diagnostic measures. For those who had rape incidences due to their lifestyle, we tell them that could also be a fact to their infections. Rape cases occur especially to those children living in the streets without any guidance (Participant 3).*

There was also a fear of proliferation of HIV cases in the future, as mentioned by Participant 7, in relation to her contact with new infections during clinical practice.

> *I think our statistics needs more reflection to rule out decrease of HIV infection or rises. We don't have mass HIV prevention education anymore through varies ways like radios, newspapers, televisions and so forth. This is a problem if people are not educated unfortunately, we healthcare professionals in different health centers have continued to diagnosis new HIV cases every day. Some of these patients are coming with other health complications, when we tempt HIV test is when we know they have HIV infections too (Participant 7).*

The participants' fear of an outbreak of new HIV infections in young people in the future was profound. This was because there were no preventive measures or interventions for HIV/AIDS prevention for street children living with HIV/AIDS. In addition, the creation of awareness through HIV/AIDS interventions, which had previously helped to reduce the infection rate in the country, had been stopped.

4.5 Utilisation of policies and guidelines for the care of homeless children living with HIV/AIDS

The poor utilisation of available policies to protect and enhance care for children living with HIV/AIDS was explained by the HCPs as being hindered by a range of factors, including the lack of availability of practice guidelines which could have helped the

HCPs in the strategic implementation of planned activities according to the policies and, most importantly, a lack of awareness of the available policies to protect children. For example, there was a lack of practice guidelines for the issuing of a HIV diagnosis disclosure, and not knowing how to report when a child was harmed or when their rights had been infringed upon; these issues raised serious concerns for the participants.

Three participants stated that the community at large was not aware of the issues affecting children, such as abuse and neglect, and the available policies that could have been used to support these children when the need arose. They also stated that the country has good policies governing child protection and the utilisation of free services for patients with HIV/AIDS. Nevertheless, it was the lack of awareness of these policies and services, which led to the infringement of homeless children's rights, and their welfare being neglected. They also stated that there was poor utilisation of the existing policies, which were created to protect children from harm. Despite the good policies available in theory, the participants noted that some were not being followed. For example, Participant 3 pointed out the issue of a lack of follow-up of abuse cases:

> *I think we need to create awareness among societies surrounding these children. Some cases show children being raped by adults and no-one has made a serious follow-ups like having to take that children to a health centre to be tested or report the case to the police (Participant 3).*

In addition, Participant 7 discussed the right to access healthcare and the lack of availability of services which were expected to be provided free of charge according to the policy governing the scaling of HIV services for people living with HIV and for children.

> *These children have many challenges; for example, right now, we have difficulties to obtain Antiretroviral (ARVs) drugs into our clinic in general, they are most of the time out of the stock in our hospital pharmacies. When we direct patients to other health centres where they*

can get their monthly drugs, sometimes transport fees are involved to get there. So this means those children living in the streets may not succeed to get their medicine which was supposed to be available for free. Let say a child here at Mt. Meru hospital be told to get his/her ARVs at Usa river, he /she cannot afford to finance. These patients are also prescribed with daily uses of Septrin (cotrimoxazole) anaphylactic for opportunistic infections; before, we used to provide to them free of charge like ARVs. Unfortunately, now they must buy them which add up a burden to a child living with the support of their parents, let alone those, living in the street (Participant 7).

Participants 3, 4 and 7 raised the following questions: What should happen when a child is raped by an older person? What should be done when there is no medication for children which were supposed to be given out for free and are crucial for their well-being? Where are the child protection policies and how can they be utilised in the case of the abandonment of a child and abuse? When and how should abuse cases be reported if they are not widely known about by many community members. Most of these cases of abuse are hidden due to shame and negligence.

Poor utilisation of policies governing the well-being of children was among the recurrent issues mentioned by all the participants. It is a cross-cutting issue which when not well utilised may result in failing to comprehensively care for these children. Children's rights have been denied and this matter has a detrimental effect on the growth of their physical and psychosocial well-being.

4.6 Conclusion

This chapter has presented the findings of the qualitative descriptive study with the aim of exploring how healthcare professionals meet the needs of homeless children living with HIV/AIDS.

The themes and subthemes emerged from the thematic analysis of the data is a result of participants transcript thorough analysis and coding of significant spoken information from their experiences and phrases from the seven participants.

Participants describe their experiences and challenges they face in order to provide care for homeless children living with HIV/AIDS. In describing the lived experience of homeless children, participants explained that these children are homeless due to variety of reasons including family conflict, unwanted pregnancy, poverty, and the impact of HIV illness. In relation to services offered at CTC center participants explained that HCPs are facing challenges in the CTCs in relation to tracking and managing these children due to a lack of skilled staff, poor infrastructure, and poor policy and practice guidelines. This has led the HCPs to fear the possibility of future outbreaks of HIV infections, due to the discontinuation of advocacy and HIV/AIDS preventive measures, which had previously been managed through health promotion and awareness campaigns. The HCPs showed that community mobilisation and networking through the use of community health workers has enhanced their care and their networks for managing children with HIV/AIDS at the community level. Nevertheless, the life of the children on the street remains in crisis, which leads to abuse and premature death on the street.

CHAPTER FIVE: DISCUSSION

5.0 Introduction

Discovering how Health Care Professionals (HCP) manages homeless children living with HIV/AIDS is an integral part of this study. This discussion chapter is based on the five themes that were developed from the research findings, which reflect the meanings and perceptions of the participating HCPs. The themes from chapter four will be discussed in relation to how they might translate into knowledge linked to the current evidence.

5.1 The lived experience of homeless children living with HIV/AIDS

In Tanzania, it is estimated that new HIV infections from mother to child have decreased from 65,000 in 2010 to 14, 000 in 2015 for children aged from 0-14 years (TACAIDS 2015). Several factors have contributed to this achievement including the scaling-up of ART services such as early HIV diagnosis and initiation of HIV treatments, and public preventive awareness measures in the community. Despite this success, however, the disease poses a cross-cutting challenge in the healthcare system and in other socio-economic sectors (UNICEF 2016). This includes an increased mortality rate for the reproductive age population, a diminished labour force, increased poverty, and a growing number of orphans and vulnerable children. It was estimated that by 2013, there were 1.3 million orphans as a result of the death of their parents due to HIV/AIDS (UNAIDS 2015; Fauk 2016). As a rapidly growing city, Arusha faces the challenge of increased numbers of orphans and vulnerable children, the responsibility for which remains in the hands of the government, like-minded stakeholders, and development institutions for proper planning and advocacy. This is because the municipal council is part of the rapidly-growing urban plan which has not yet accommodated the proper foundations of city development, such as proper water and sanitation facilities, good housing, and more employment opportunities, thus creating structural disparities in the

cultural and socio-economic sectors, as well as producing health risks (Dani & De Haan 2008). Therefore, the additional problem of orphans and vulnerable children poses greater risks and adversities for children (Patel & Burke 2009).

Urbanisation has attracted more internal immigrants from the rural areas and other cities, as well as neighbouring countries, which has enhanced opportunities in the growing tourism and commerce industries, and in gemstone mining (World Bank 2009). The high levels of migration have increased the population of Arusha from 1,288,088 in 2002 to 1,694,310 in 2012 (National Census 2012). It has been estimated that 50% of this population are children (UNAIDS 2016). The urbanisation policy has enabled the centralisation of national development activities to local government authorities. Despite the benefits of urbanisation, such as increased population in relation to a growing labour force and market outcomes, resettlement also has its negative side. The major repercussions of urbanisation in Arusha include premature economic growth, which is a burden to the local peasants and many community members who are under-employed. In addition, it is believed that over-population in the Arusha region has contributed to the increased proliferation of HIV infections due to increased sexual activity and promiscuity among community members (UNICEF 2015). The consequences of HIV/AIDS include vulnerable children who are affected by HIV/AIDS and growing homelessness. The theme of the lived experience of homeless children with HIV/AIDS has focused on establishing why children end up living on the street. The second focus is on the effects of child abuse and neglect, and the final sub-theme looks at the death and dying experiences of homeless children living with HIV/AIDS.

According to the HCPs, the main reasons for children living on the street were poverty, abuse and neglect, unwanted pregnancies, and the stigma and discrimination associated with the HIV/AIDS illness.

The co-existence of poverty and HIV illness among children and their families has been reported to increase their vulnerability (Whetten et al. 2011). Children living with HIV/AIDS are at risk of impoverishment after being subjected to abandonment and

neglect, and choosing to live on the street after escaping from their extended families. The HCPs explained that the lived experiences of these children are one of great difficulty.

During the millennium development era, the issue of vulnerable children in Tanzania was put forward as being in a devastating state. Moreover, the Sustainable Development Goals (SDGs) report of 2017 indicated an alarming number of childhood deaths due to the lag in national interventions to eradicate childhood death and other vulnerabilities (Holden, Linnerud & Banister 2017).

The SDGs reflect an accurate picture which is consistent with the participants' perceptions of the lived experiences of homeless children on the street being in a susceptible state. The HCPs expressed their concerns that living on the street makes them susceptible to harm and communicable health conditions, while also infringing their access to the readily available social networks and healthcare systems, which contributes to their poor growth and development. As their health is immunologically compromised as a result of HIV/AIDS infection, facing these situations while living on the street may lead to premature death due to the progression of the HIV/AIDS illness.

For example, in a qualitative study conducted in Northern Tanzania, the respondents, who were children, explained that they were motivated to escape to the street due to abuse and neglect by their extended families (Deb 2016). This was similar to the perceptions of the HCPs that on the street and at the community level in general, children are abused and neglected. The difference between the two studies is that the latter extends the abuse of children to the street in addition to abuse at the family level. The research suggests that among the coping mechanisms for families living with orphans, was to withdraw them from school so that these families could reduce their economic burden by engaging them in the household and in socio-economic activities such as farming and the selling of the families' crop produce (Fauk et al. 2017). Some of these farming activities were characterised as abuse by the children themselves. This reflects the reality of what is happening in these families, as the children themselves

were interviewed and expressed their concern that it was abuse and neglect which forced them onto the street (Delle Fave, Massimini & Bassi 2011). However, this differs from the perceptions of the HCPs which showed that not only in the families, but also on the street, children experienced abuse such as rape and their basic needs were neglected.

Children on the street have been characterised as being resilient and as using various measures to cope with street life (Theron & Malindi 2010). A study conducted in South Africa in a similar context, looked at children on the street using drugs such as marijuana, engaging in sexual intercourse with other children and older people, and using glue and other harmful measures as ways of coping with the daily stress of living on the street. Conversely, the same coping methods could put children who are HIV-positive into life-threatening situations (Theron & Malindi 2010). Their lowered immune system requires a safe environment and a healthy lifestyle to improve their life in order to live longer (Kellehear 2012; Zhao et al. 2014).

Unwanted pregnancy was explained as a major reason for children living on the street. Globally, 80 million unwanted pregnancies are expected to occur each year (Calvert et al. 2013). The research suggests that the most common reasons for the occurrence of unwanted pregnancies in Tanzania are the lack of education on where to access preventative measures for pregnancy, multiple sexual partners, and younger people engaging in sex. Abortion in Tanzania is illegal; therefore, most of these babies will be born with parents who are not ready and lack the capacity to care for their new-born babies (Calvert et al. 2013). The participants identified that there were cases of children being born who were not wanted from the beginning of the pregnancy; therefore, they were abandoned after delivery. Unwanted pregnancies pose an economic and health risk for both the mother and the child, such as contracting HIV illness and death (Plummer et al. 2008).

The environment of the street is not conducive for a sick child. There is evidence of harmful coping skills, lack of basic needs, opportunistic infections, and lack of social

acceptance due to the stigma associated with HIV/AIDS (Kellehear 2007, 2012). Poor access of homeless children living with HIV/AIDS to the healthcare system is detrimental to their well-being. Following all the adversities facing a sick child in the street, death in the street for homeless children with HIV/AIDS is inevitable. The most important question is, how do children die on the street? Is the street a conducive place for dying? Have these children considered this divisive situation of ending their life on the street?

The place of death and advance care planning has been discussed as the most imperative areas for consideration at the end of life. Usually, people choose to die in a hospital or at home with their loved ones (Himelstein et al. 2004). However, the knowledge that children are dying on the street suggests that further comprehensive holistic interventions are needed to transform the lives of homeless children (Padgett, Henwood & Tsemberis 2016).

The government, local authorities, and healthcare professionals are stakeholders in the health and well-being of children with HIV/AIDS. There is a fundamental reason to promote and address the requirements of vulnerable children and to build sustainable compassionate communities (Kellehear 2012). Health settings such as CTC centres are an integral part of the healthcare system, which are needed to fulfil this mission.

5.2 HIV/AIDS treatment, care and support services offered in the CTCs

The global UNAIDS strategy of 90-90-90 by the year 2020 was implemented to ensure that 90% of children living with HIV/AIDS are able to be identified, the second 90 signified the aim of targeting 90% of the identified children to begin medication, and the final part of the strategy was to ensure that 90% of patients adhere to the treatment for their entire lives (Levi et al. 2016). The implementation of this strategy was assisted by strengthening the Care and Treatment Centres along with adopting one of the key strategies of the national Tanzanian Multi-Sectoral Framework III in order to reach the goals of the global HIV/AIDS strategy of (UNAIDS) 2011-2015, which aimed at a "three

zero strategy". This strategy aimed for zero new HIV infections, zero HIV/AIDS-related deaths, and zero stigma and discrimination.

In Tanzania, these strategies have been carried out through collaboration with the government via the Ministry of Health and Social Welfare together with donor funding organisations such as the US President's Emergency Plan For AIDS Relief (PEPFAR), the Global Fund For Tuberculosis and Malaria, and the Elizabeth Glaser Paediatrics Aids Fund (EGPAF) (TACAIDS 2015). The services offered in the CTCs are clinical and psychosocial services for people living with HIV/AIDS. Patients are required to attend on a monthly basis to get their health checked and to take their monthly medication and prophylaxis to combat the proliferation of the HIV/AIDS virus.

Attaining the 90-90-90 goals depends on the achievements of the interventions conducted in the CTCs. Consequently, it was important to look at how HCPs are: i) Monitoring and tracking homeless children living with HIV/AIDS to ensure ART drug adherence; ii) Disclosing HIV/AIDS diagnoses to homeless children living with HIV/AIDS; and iii) Managing homeless children living with HIV/AIDS and the challenges facing the CTCs.

The tracking and follow-up of patients attending the CTC centres is essential in the scaling-up of ART services and enhancing patients' lives. The continuance of ART treatment has been recommended as a way to ensure that patients are increasing their CD4 count level in order to live longer and healthier. However, lost o cases have been reported to be increasingly in the CTC centres (Ostermann et al. 2014). When a patient does not attend a follow-up, it means that they are not adhering with their treatment and that this is compromising their health. Engaging homeless children in lifelong adherence to HIV treatment was considered difficult due to their lifestyle. Homeless children moved from one location to another either to hide their illegal acts or to earn a living to satisfy their basic needs on the street. This situation is difficult for community workers to intervene in. Good Samaritans were expected to bring in children for care once they were found on the street in a sick condition. Other challenges which hindered

the optimal use of ART services, and in bringing homeless children to treatment, were their lack of awareness of their HIV/AIDS diagnosis.

The lack of HIV diagnosis disclosure to children was categorised as a problem for two main reasons. The first was the psychosocial issues related to parents, families, and the community at large, while the second was the challenges facing the CTC centres in general. The psychosocial issues were associated with the stigma of the illness and the guilty conscience of the parents and caregivers. The parents felt guilty about infecting their children and chose to protect them by hiding their illness from them. On the other hand, the CTCs faced challenges which influenced the care they provided. This included a lack of skilled staff and a lack of practice guidelines to support the established activities.

The management of children was to be guided through a foundation of trust and effective communication. The home-based care volunteers played a key role at the community level by ensuring that the link between the healthcare setting and the community level remained active in order to reach the UNAIDS and government targets.

5.3 Community mobilisation and networking

The Ministry of Health and Social Welfare's 2015-2030 strategic plan for the health sector has placed emphasis on public-private partnerships and the importance of networking and community engagement.

The principles of community mobilisation have emerged out of the values of equality, empowerment, social justice, and the inclusion of all community members concerned with decision-making (Ziff et al. 2006). This is usually attained through collaboration and networking of various stakeholders and like-minded partners working together to support ideas or interventions. In recent years, networking has gained popularity as the most common method of distributing resources equally and fairly within society

(Kazungu & Cheyo 2014; Veinot 2009). The use of readily available resources in the community is crucial for the sustainability and growth of that particular community (Mercer & Green 2013). The core stakeholders in Tanzania for the care of children living with HIV/AIDS are the government, non-government organisations (NGOs), faith-based organisations (FBOs), schools, churches, councils, local government leaders, influential people, community-based organisations, healthcare organisations, orphanages, traditional healers, and all community members and grassroots organisations. Engaging communities is the key to alleviating the issues that affect the community at large. The major issues emphasised in the theme of community mobilisation and networking were the role of community home-based care in home-based care programs, and the orphanages.

5.3.1 The role of community home-based care volunteers in home-based care programs

From their inception in 1996, home-based care activities for patients with HIV/AIDS were created to reduce the burden of the hospitals due to a 50% increase in the number of hospitalised patients due to the HIV/AIDS pandemic (Cruz, Maria Leticia Santos et al. 2015; Kacholi 2012). The home-based care program was intended to enhance quality of life and to reduce the costs of care for people living with HIV/AIDS by transferring their care from the hospital to the community, and thus, into the patients' homes. The government, through the Ministry of Health and the Tanzanian Commission for AIDS (TACAIDS) trained cadres to work as volunteers at the community level, known as community health workers (CHWs). Their main role was to provide basic nursing care and initiate referrals for people living with HIV/AIDS to hospital when needed. They were also expected to advocate for the eradication of stigma and the enhancement of drug adherence, and to provide support in mobilising resources and psychosocial support for people living with HIV/AIDS.

The HCPs explained that working with home-based care volunteers had enhanced the effectiveness of the care and improved the link between the hospitals and the community setting. They also approved of the support that the CHWs provided for the retention of patients in treatment; however, this cadre is a forgotten group. Despite their work being recognised by patients living with HIV/AIDS, families, and the HCPs in healthcare settings, their work is very difficult in the framework of volunteerism. For example, CHWs are expected to travel long distances to oversee their patients, as well as being expected to work as volunteers; for most of them, it has become a regular job. A systematic review looking at the effectiveness of CHWs revealed that they were considered to be the 'other hand' of the HCPs (Mwai et al. 2013). This review suggested that payment and recognition for CHWs should be considered (Mwai et al. 2013). However, there should also be more interventions and benefits that can be invested in CHWs, including regular training and feedback on evidence-based knowledge, and psychosocial support for burn-out and grieving, as CHWs face the loss of patients they care about, some of whom become friends due to the trust they create during care.

The involvement of CHWs in the mapping of the resources available at the community level and the referral of patients to access them is crucial. Their role in rehabilitation and prevention of this debilitating illness could be improved and enhanced through ongoing training to improve their skills and understanding of the ongoing strategies.

5.4 Health promotion and primary prevention health services for HIV/AIDS among homeless children living with HIV/AIDS

The World Health Organisation places emphasis on health promotion as a set of activities designed to empower individuals who are at risk due to their lifestyle and behaviours. HIV/AIDS and sexual health have been highlighted as being among the high-risk conditions(*Myanmar Department of Health: Myanmar National Strategic Plan on HIV and AIDS: 2006-2010. Yangon*). Homeless children are vulnerable and their illness can put other children and the community at large at risk of contracting HIV infections,

as it is believed that homeless children engage in sexual activity (Gilks et al. 2006). Despite the fact that HIV/AIDS prevalence in Tanzania decreased from 7% in 2004 to 5.3% in 2012, it has been estimated by UNAIDS that in 2014, 1.5 million people in the country were living with HIV/AIDS. The problem is that the programs that had previously helped to decrease the HIV epidemic in the country have been stopped. This has a potentially negative effect on the possibility of reaching zero HIV infections, as per the UNAIDS policy. This is because there are both daily reported and unreported newly-diagnosed HIV infections in the country. Interventions along the lines of the ABC prevention approach, which aims for Abstinence, Behaviour change through reducing the number of partners, and Condom use, should be advocated among the community along with the up-scaling of ART services (Wilson 2004). The use of policies informed by evidence-based practice should be widely used to attain the zero strategy policy targets (Deeks, Lewin & Havlir 2013).

5.5 Utilisation of policies and guidelines in the care of homeless children living with HIV/AIDS

The global agenda of 'health for all' as part of the Sustainable Development Goals (2030) agenda number 3, intends to leave no-one behind in their health by ensuring equal opportunity for all (Tangcharoensathien, Mills & Palu 2015). However, healthcare professionals have identified several challenges which could hinder implementation. This included a lack of practice guidelines to address the available national and international policies on the particular matter. Secondly, there is a lack of skilled labour to implement the plans and policies, and a lack of awareness of the available policies which support the community among the key stakeholders and the community at large.

Knowledge translation and the proper use of policy in HIV/AIDS interventions have been widely advocate(WHO 2004). However, the implementation of these policies has not been successful due to a lack of practice guidelines to enable these theories to be put into practice. For example, in the current study, the participants discussed the lack of

practice guidelines, particularly for HIV/AIDS diagnosis disclosure to children, and guidelines on how to intervene when a child's rights have been infringed, such as when a child has been raped, or has failed to access healthcare which is offered free of charge (Mulinge 2002; UNICEF. 2009). This was equally true in a study conducted in Tanzania which found that there were insufficient HIV practice guidelines that translated the United Nation's policy goals and how they could fit into local and national practice (Mwangome et al. 2017). It is vitally important to have local tools, as there are major differences in culture and resources in different socio-economic contexts, which affects how a country will reach the international goals and how they should be implemented and reflected at the national level.

5.6 Conclusion

In this chapter, the discussion has focused on the major themes and the associated sub-themes that emerged from the study findings, thus meeting the study objectives. The findings indicated that the lived experience of homeless children living with HIV/AIDS is very precarious and these children are therefore prone to premature death. The CTCs have the potential to enhance the lives of these children; however, a number of barriers, such as the lack of skilled labour and of practice guidelines, hinders effective implementation. The question remaining is how to address the issue of policy utilisation in order to reach the global goals in relation to improvements in health for all. There is also the issue of restoring HIV preventative activities at the community level, particularly for homeless children, so as to reduce the fear that HCPs have in relation to the possible outbreak of HIV infections in the future due to reductions in HIV prevention campaigns at both the local community and national levels.

CHAPTER SIX: CONCLUSION AND RECOMMENDATION

6.0 Introduction

This study has explored healthcare perspectives on the management of homeless children living with HIV/AIDS in Arusha, Tanzania. This chapter will present an overview of how this study will contribute to clinical improvements and the community at large, with several recommendations being made for the care of abandoned children living with HIV/AIDS, and suggestions for future research to be undertaken.

6.1 Background and Summary of the key findings

The aim of this study has been to explore healthcare professionals' perspectives on how they manage homeless children living with HIV/AIDS in Arusha, Tanzania. Homeless children living with HIV/AIDS have been forgotten in the National Costed Plan of Action (NCPA) for the care of most vulnerable children (a donor-funded project in collaboration with Global Funding for HIV/AIDS, Tuberculosis, and Malaria, and the Ministry of Health and Social Welfare in Tanzania); therefore, they tend to be 'invisible'. This study has found that the abandonment of HIV positive children is due to a range of socio-economic factors such as family conflict and breakdown, poverty, unwanted pregnancy, and the HIV illness which leads to the death of their parents. Life on the street is very difficult for a child living with a life-threatening illness such as HIV/AIDS. Homeless children were reported to be facing the following challenges: firstly, they were lacking in their basic needs, such as food and shelter; as a result, their CD4 count decreased and they suffered from opportunistic infections which were not treated, as they could not access healthcare services which then often led to premature death. Dying on the street was seen as unacceptable, as children died in loneliness without the presence of loved ones. Secondly, they engaged in unprotected sexual activity with other homeless children which was detrimental to their health, but also, many were raped by older adults. This situation was considered to contribute to the spread of

HIV/AIDS infection among children on the street and in the community at large. Finally, children on the street received various forms of maltreatment such as abuse and neglect.

The continuum of care offered at the Care and Treatment Centre (CTC) was considered to have enhanced the lives of these children; however, the CTC was faced with a range of challenges, including the following: Firstly, the tracking of homeless children in order to access care was seen as a very difficult process due to the nature of their lifestyle in moving from one place to another to cater for their material needs. As well, these children tended to hide themselves from the public due to their illegal conduct. This led many HCPs to rely on good Samaritans for referrals, and community health workers (CHWs) who usually work as volunteers; therefore, the sustainability of the interventions was not as effective as it could have been. A lack of specialised staff also hindered improvements to care in the CTC centre; for example, a psychologist could have supported the counseling of children with special needs; however, the CTC lacked this skilled specialty. There was also a need for continuous training to provide the HCPs with the necessary skills for such work as the breaking of bad news and difficult conversations with children around disclosing of a HIV diagnosis. Secondly, the CTC was confronted with a lack of resources for improving their interventions; for example, there was a lack of practice guidelines in relation to HIV disclosure for children, a lack of infrastructure to enable HCPs to create HIV prevention awareness at the community level, and poor facilities for psychosocial support interventions for children.

Community engagement through the use of community health workers in home-based care outreach services was identified by the HCPs as effective in areas such as referrals of children to the CTC and drug adherence (Anti-Retroviral Treatment or ART). However, there were challenges in networking with other organisations such as Non-Government Organisations (NGOs), community-based organisations, and faith-based organisations which could have helped in mobilising and sharing of readily available resources. In addition, community awareness about the presence of homeless children

living with HIV/AIDS was regarded as very low. As a result, the community was not aware of the available policies which aimed to support and protect children, and how best to use or apply them. As well, orphanages were encouraged to be used as drop-in centres for rehabilitation.

Finally, despite the suggestion in the literature of the numbers of HIV infections dropping, the HCPs reported having seen increasing numbers of newly diagnosed HIV cases in the Care and Treatment Centres (CTCs).

6.2 Contribution of the study

The integrated literature review, which was presented in chapter, two established a gap in the literature in relation to why HIV positive children are abandoned. There is also no existing literature, which has explored healthcare perspectives on how HCPs manage homeless children living with HIV/AIDS in Arusha, Tanzania. Therefore, this study has contributed to the literature and answered the question of why children living with HIV/AIDS are abandoned, by exploring and understanding the experiences and perspectives of HCPs in relation to how they manage homeless children living with HIV/AIDS.

6.3 Implications of the study

The findings of this study have potential clinical practice implications for the Tanzanian mainland. The study has also provided a number of recommendations at the government level and for the clinical setting in order to improve care for homeless children, including suggestions for further research.

6.3.1 Implications for practice

The findings of this study create an awareness of the presence of homeless children living with HIV/AIDS and their experiences of living on the street. The findings indicate a need for policy-makers to take deliberate action at the government level,

healthcare professionals to do so at the clinical level, and for the community at large to also take action, in order to enhance the lives of children.

The study also makes transparent the socioeconomic challenges facing children living with HIV/AIDS after the death of their parents, which has detrimental effects on their health, may affect their growth, and in particular, has a major effect on having to live while taking lifelong treatment for HIV/AIDS. Therefore, it is crucially important that HCPs are aware of other factors which may result in failure to adhere to HIV treatment and to future follow-up checks in the clinics for some of these children. This could help in observing the patients through a more holistic approach whenever they attend a consultation. A lack of strategies to prevent HIV proliferation among children living on the street could lead to a failure to achieve the national and international Sustainable Development Goals (SDGs) through which HIV/AIDS has been planned to be eradicated.

6.4 Recommendations for practice

The Tanzanian government through the Ministry of Health and Social Welfare to enhance care for homeless children can use the findings from this study. Several potential recommendations, which have been outlined below, have been identified in the area of practice and further research.

6.4.1 Government level

- Community public healthcare interventions such as HIV/AIDS awareness, and home-based care for patients with life-threatening illnesses, including palliative care programs, should be integrated into government primary healthcare programs. This will enhance the sustainability of the programs as they are primarily practiced by private and non-government organisations that rely on donor funding which historically tends to wax and wane according to donor interests and priorities.

- The need to identify potential interventions to enhance links and networking between healthcare settings and other like-minded stakeholders such as local grassroots organisations, faith-based organisations, local authorities, and other influential people, is crucial for resource mobilisation and will minimise the duplication of efforts among local service providers.

- Community Health Workers (CHWs) should be considered for the development of capacity building and training in order to enhance their skills in caring for patients in home-based care programs. This is particularly crucial given that there are inadequate numbers of skilled staff and resources for health interventions at the community level.

- Public preventative HIV/AIDS awareness needs to continue despite the fact that the statistics are showing a decrease in HIV illness. The integration of preventative awareness strategies should be a continuous cross-cutting issue across the entire country until HIV/AIDS reaches zero new cases.

- Institutionalised care in orphanages and other rehabilitation centres should be linked, and should work in collaboration with Primary Health Care (PHC) interventions to enhance the physical and psychological care of vulnerable children.

- Donor funding should aim to prioritise interventions which are sustainable and developmental in nature to alleviate issues affecting children in a culturally appropriate manner.

- Policies and guidelines established to support and protect children should be displayed in the public realm and advertised in national languages to politicians, policy-makers, and the community at large.

6.4.2 Clinical settings

- Clinical tools to enhance tracking mechanisms should be evaluated to integrate the social and economic status of the recipients of care in order to assist HCPs, and particularly clinicians, to offer holistic treatment.

- Practice guideline tools to assist HCPs to implement clinical strategies to align with World Health Organisation directives should be developed in line with the cultural and socioeconomic backgrounds of the local people.

- Continuous improvement training in clinical settings should aim to identify gaps in the skills of HCPs and to provide support when and where necessary.

6.4.3 Recommendations for future research

- Health promotion palliative care interventions aiming to enhance end-of-life care for vulnerable children in low resource settings should be explored to enhance compassion within the community. This approach should include an exploration of place of death and death experiences for homeless and vulnerable children to identify holistic interventions which will support children's preferences and needs when dying on the street.

- Interventions to reduce child abuse and neglect should be evaluated in order to enhance future strategies.

- Advocacy-based interventions in collaboration with government, politicians, and policy-makers should be explored in order to strengthen palliative care strategies for vulnerable children through the development of local and national policies and a budget for palliative and end-of-life care programs for vulnerable children living with life-threatening illnesses.

- Research on the role of community health workers (CHWs) and how they can be better utilised and motivated to enhance the effectiveness of community health interventions in limited resource settings is needed.

6.5 Limitations of the study

This study has been designed to explore the perspectives and experiences of HCPs in the management of homeless children living with HIV/AIDS in Arusha. This qualitative study provides rich, in-depth, and subjective information as a result of interviews conducted with HCPs working at the CTC centre for patients living with HIV/AIDS. Therefore, HCPs who participated in this study reached saturation and was sufficient for this research; however, the findings might not be able to be generalised into other settings. Nevertheless, they might be able to be adapted to other contexts with similar socio-economic backgrounds because this study adhered to a rigorous standardised process and guided interview questions.

Several research limitations were encountered in the process of conducting this study. Firstly, there was a delay in recruiting the participants due to the Care and Treatment Centres for HIV/AIDS being among the busiest clinics in the hospital, which gave health care professionals (HCPs) little time and opportunity to engage in the study. Therefore, because the HCPs were purposefully selected to fulfill the aims and objectives of the study, the researcher had to wait for times at the respondents' convenience. There were also technical issues in conducting the Skype face to face interviews; therefore, the researcher conducted telephone Skype interviews instead. Skype, face to face interviews could have enriched the study by observing the participants' physical expression along with their subjective information in order to generate meaning and knowledge of the phenomena under investigation

In addition, this study could have benefited if an observational approach had been used to explore the culture of healthcare professionals in Tanzania who work with children living with HIV/AIDS. However, due to the limited time of the researcher, interviews

were used which nevertheless provided sufficient verbal data to answer the research questions and to fulfill the study objectives.

6.6 Conclusion

This study has explored how healthcare professionals manage homeless children living with HIV/AIDS in Arusha, Tanzania using a descriptive qualitative approach to ascertain the experiences, knowledge, and understandings of HCPs of the phenomena of research interest. The impact of HIV/AIDS has resulted in many orphans living with HIV/AIDS, and therefore, it is crucially important to find strategies to support these children who end up living on the street despite their health being compromised and weak due to HIV infection.

The study has presented a number of implications for clinical practice, government, and further research. The implementation of these recommendations will contribute to the enhancement of care for homeless children living with life-threatening illnesses, including HIV/AIDS.

Appendix 1: List of search Term

Data base SCOPUS

	Keyword With search Formula	Total number Of Articles Retrieved
1	Child*	2,746,393
2	Adolescen*	2,036,077
3	Infant*	1,240,102
4	Baby*	95,166
5	Babies*	95,186
6	Teen*	41,864
7	Child* or adolescen*or infant* or baby* or babies* or teen	4,264,130
8	Abandon*	68,234
9	Neglect*	180,244
10	Stigma*	50,732
11	Desertion*	1,256
12	Reject*	289,984
13	Child*or adolescen*or infant*or baby*or babies* or teen*or abandon* or neglect* or stigma* or desertion* or reject*	66,199
14	Hiv*	348,809
15	Aids	258,622
16	Acquired human immunodeficiency syndrome	121,374
17	Child*or adolescen*or infant*or baby*or babies* or teen* or abandon* or neglect* or stigma* or desertion* or reject* or hiv or aids or acquired human immunodeficiency syndrome	336
18	Child*or adolescen*or infant*or baby*or babies*or,teen*orabandon* or neglect* or,stigma* or desertion* or reject*	11,332
19	Child*or adolescen*or infant*or baby*or babies* or teen* or abandon* or neglect* or stigma* or desertion* or reject* or hiv or aids or acquired human immunodeficiency syndrome	214

Data base MEDLINE, Psych Inf

	Key Word With Formula	Ovid Medline	Psych inf
1	Child*.tw	1164417	614,802
2	Adolescen*.tw	216563	214918
3	Infant*.tw	347799	73242
4	Baby*.tw	33958	11058
5	Babies*.tw	31786	5479
6	Teen*.tw	25474	19450
7	1 or 2 or 3 or 4 or 5 or 6	1572809	781749
8	Abandon*.tw	16605	10,163
9	Neglect*.tw	46489	36359
10	Reject*.tw	96766	33235
11	Stigma	24920	22196
12	Desertion	198	386
13	8 or 9 or 10 or 11 or 12	183039	99339
14	Hiv*.tw	269736	44371
15	Aids*.tw	134467	34475
16	Acquired human immunodeficiency syndrome*.tw	14	O
17	14 or 15 or 16	338326	59781
18	Child* or adolescen* OR infant* or baby*or babies* or teen*or abandon* or neglect* or reject* or stigma* or desertion*	5040	8207
19	17 and 18	175	145

Data base CINAHL

	Keyword With search Formula	Total Number Of Articles Retrieved
	S3 AND S4 Search modes - Boolean/Phrase	69
S4	S1 N3 S2	1,527
S3	TI (hiv or aids or acquired human immunodeficiency syndrome or human immunodeficiency virus) OR AB (hiv or aids or acquired human immunodeficiency syndrome or human immunodeficiency virus)	60,135
S2	TI (child* or adolescen* or infant* or baby* or babies or teen*) OR AB (child* or adolescen* or infant* or baby* or babies or teen*)	284,557
S1	TI (Abandon* or neglect* or stigma* or desertion* or reject*) OR AB (Abandon* or neglect* or stigma* or desertion* or reject*	22, 832

Appendix 2: Summary of reviewed articles

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
1	Demmer, Craig **AIDS** Care (**AIDS** CARE), Jul2011; 23(7): 873-879. (7p)2011	Exploring perspectives and experience of caregivers of children with HIV/AIDS	13 Women caring for HIV/AIDS children in Kwazulu Natal	Qualitative study using In depth Interviews	-Stigma and poverty was contributing to deteriorating health of children -Care givers failure of hiv disclosure to their children reduce drug adherence	Thematic data analysis was highly followed and matched the methodology chosen.	-This paper draw attention that there is stigma which provides consequence into care of HIV child. -Government does not provide grants for social needs
2	Campbell et al 2012	Explore the difference between experience of poverty stigma and HIV to the children living with HIV/AIDS	Snow ball and convenience sampling recruited 12 children from rural Zimbwabwe	Qualitative study through Use of writing and drawing in data collection and use Quantitative approach by use of Chi square to interpreted themes developed.	Aids affected children suffer multiple stigma of HIV illness and poverty stigma. These two are similar.	Methodological approach during data collection and reporting of findings was complicated due to their expression that one of their limitations was small sample. It is established that quantitative method use big sample. However the study holds water in the subject mater	Poverty can lead to children abandonment. When these children are ill, it worsens the situation. Lack of responsibilities of families and caregivers.
3	Clemo L **AIDS** Education & Prevention (**AIDS** EDUC PREV), Winter1992; 4(4): 308-318. (11p)	Exploring the **stigmatization** of **AIDS** in **infants** and **children**.	31 Lobbyist of HIV issues in USA.	Quantitative method through Survey	At policy level there is no strong legislation to support children with HIV ISSUES. -Data suggest stigma in health care settings and in school children are not accepted	Data was interpreted in Descriptive method compared to quantitative approach expected based on the method of collecting data.	Law reinforcement is crucial in eradicating stigma and neglect of sick children.

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
4	Zabina et al 2004	Why there is Abandonment of infants by HIV-positive women in Russia and what are prevention measures	Purposefully sampling to 13 HIV positive Women in Russia	Qualitative study through semi structured interview	Family was not supportive in care when these women were ill.	-The question design brought in bias for respondent to reply as they had to protect themselves to not look bad as to why they abandoned their children -The authors also proclaimed that among their limit was participant were selected randomly, this does not bring any meaning if the sample their participants purposefully as they said in the method	This study produce the same view of socioeconomic boundaries which lead to abandonment of children
5	Dube et al 2003	Exploring on child abuse, neglect and home dysfunction	8963 adult who attend California primary health care clinic filled in the survey	Quantitative study through Survey	Parents drug use and family misunderstanding Domestic violence Can lead to abuse and abandonment of children	The methodology use and data interpretation was worthwhile trusting.	Other associated factor of abandonment in different settings
6	Ferris et al 2007	Assess the effects of institutionalization care on death and cd4 decline on children with hiv ROMANIA	Cohort of 325 HIV infected children in Romania American children center	Quantitative study through three year following up of children using Kaplan data base analysis	Abandoned children with HIV/AIDS have higher survival rate compared to those cared by extended families	The main domains of observation which was decline of HIV CD4 COUNT, occurrence of death was not reliable as they were not properly documented which made it hard to make comparison	Abandoned children can be well care in institutionalized care and enhance their lives.

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
7	Okagbue-Reaves J Journal of Family Social Work (J FAM SOC WORK), 2005; 9(2): 47-66. (20p)	Exploring the role of kinship in the care of abandoned children living with HIV/AIDS	Grandparents caring for children living with HIV/AIDS in united states	Qualitative data collection through questionnaires and use of Lambda instead of Chi –square as their study population was low and they used nominal's from variables	Grandparents are hesitating to decide to accept children living with hiv /aids as it overwhelm their old compromised health state, and it is economically unbearable.	No limitation of the study noted It is among few studies which explained about being accepted for ethical approval	This study emphasis that older grandparents fail to care for these children living with HIV/AIDS.
8	Coombes R, 2000	From the cradle to the Grave	Children with HIV in United kingdom	Qualitative study using Case Study	Children with HIV are now living longer , there is fear of organ failure, stigma as they grow up and has to face the reality of diagnosis	None explained	Drug resistant due to prolonged use of drugs, and stigma is a problem as children grows older.
9	Bailey et al 2010	Factors associated with abandonment of children with HIV in Ukraine	Cohort of women in prevention of mother to child transmission in Ukraine	Quantitative study use of Baseline survey	Injecting drug users, those parents who were co habituating and lack of family support was an influence of abandonment also those delivered through caesarian section did not abandon their babies	Data were generalized because only 30% of total population were reached	This study emphasis the use of PMTCT services in order to decrease abandonment of children. Suggest follow up care from PMTCT
10	**Bateman c 2010**	A case of Neglect child	Children living with HIV/AIDS South Africa	Case study	Child neglect is growing problem.		Profound evidence that children with HIV/AIDS are neglected

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
11		Caregivers and parents perspective on disclosure of hiv diagnosis to children		Qualitative study using focus group discussion	In resource limited settings disclosure of hiv/aids to children is still under debate and this hinder drug adherence		Caregivers fear on disclosure can harm psychological state of children
12	Machine et al 2016	Failure to engage children in the care in the first three month of diagnosis	313 children living with HIV In Botswana	Qualitative Case control study	Factors for lost follow up relates to those happen during abandonment such as stigma, lack of income for transport , hunger	Due to small data size they decide to use mixed method to triangulate data from different sources	Child rebellion, and not knowing their hiv disease. WHO guideline on starting ART at lower CD4 is contributing factor when children felt being passed the guideline
13	Sanjeeva et al	Exploration on parental concern of HIV/AIDS disclosure children perspective	HIV positive children Age 10-18 in India	Qualitative study through the use of questionnaire	HIV diagnosis disclosure will minimize satigma	Children as the main respondent had bias in talking about sexual issues as they are taboo in India. The paper is worth for review however they did not explain about ethical matters	Parental concern are not matching children view on disclosing their status
14	Jemmot et al 2013	Exploring care giver intention in disclosing HIV status to their children	Adults providing care to HIV positive children in South Africa	Quantitative study through Survey	There is reduced risk of transmission of HIV to other children if children will know about their HIV status early	Study sample was low to establish correlation between variables	The study suggest that children should be introduced about their illness to enhance long life
15	Sherr et al 2016	The effects of caregiver and household HIV on child development: a community-based .	Children and adult South Africa and Malawi	Mixed method	Children with ill care giver had growth problems	Despite the limitation that the caregiver might be bias on their response, researcher reassured them on	Justification of growth problem for children with poor care from ill caregivers Promote community

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
						anonymity which is credibility of the study	Interventions in empowering children
16	Luggala & Mbwambo 2002	Assessing Street Children and Street Life in Urban Tanzania: The Culture of Surviving and its Implications for Children's Health	Children from the street in Dar-esalaam , Tanzania	Unstructured interviews in 10 focus group	Children goes to the street because of poverty at family level and other Issues pertaining family disintegration.	No limitation was explained, however they did not explain about ethical approval for involving children in the study.	Recommendation for Further studies are needed to strategize policy formulation and interventions
17	Bart Rwezaura 2000	The value of a child, marginal law in Tanzania	Children in Tanzania	Qualitative study using Semi-structured Interview	Children are marginalized and not given a priority in meeting their unmet needs.	The rigor as worthwhile to be used for review.	There is a need of reinforcing law in the care of neglected children in Tanzania
18	**Godfrey kacholi 2012**	Assessing the capacity of committees developed to care for most vulnerable children in Tanzania	Most vulnerable children committees Tanzania	Qualitative study Semi structured interview	Lack of enough training to capacitate community empowerment on the care of the vulnerable children	No limitation was explained buy the author however the methodology used and sample size was appropriate	Gaps of established structure which oversee most vulnerable children in Tanzania
19	Campbell et al 2013	I have an evil child in my house Zimbabwe	Care givers caring for children with HIV.	Qualitative study. Case study	Children living with HIV are stigmatized in school, community and in health care settings.	None was observed the study is worthwhile used for review	Stigma is influencing the children to denie their health status and this has impact in their health
20	Cruz et al 2015	The "moral career" of perinatally **HIV**-infected **children**: revisiting Goffman's concept.	Infected children with HIV/AIDS South Africa	Qualitative study Ethnography	Health care workers and stakeholders should be committed to ensuring education and guaranteeing the legal rights of this specific population,	None was observed, the study scored high for CASP assesment	HIV disclosure is among the way of preventing abandonment.

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
					including the continuous provision of quality health care, full access to school and support to full disclosure of HIV diagnosis		
21	Emmet et al 2011	**Predicting virology failure among HIV-1-infected children receiving antiretroviral therapy in**	Cohort of infected children aged 1-16 years on ART ≥6 months receiving care in Tanzania	Quantitative across-sectional study	It is crucial to use national sheet of documentation to enhance follow up, -Encourage disclosure to children and caregivers	One type of sample which was crucial to be involved in order to give meaning in the findings was not used.	Children abandoned are dropping out from care and treatment
22	Azzopardi et al 2014	Aim at assessing medical non adherence in pediatric HIV: Psychosocial risks and intersection with the child protection system for medical neglect	Cohort of 374 children with HIV Canada	Quantitative study	Findings extend the fact that there is prediction of virology failure due to non-adherence	The rigor was rated high based on CASP checklist questions	This study suggest importance of early disclosure to prevent abandonment and medical neglect
23	Abadia Barrero and Castro 2006	Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil	Life trajectory of HIV positive children In Brazil	Qualitative study Ethnography	Stigma reduction can focus on eradicating poverty and inequality	The rigor was rated high based on CASP checklist questions	Stigma is fueling abandonment of children living with HIV.
24	Adeniyi et al 2015	Assessing HIV disclosure to infected children	Maternal mothers infected with HIV/AIDS Oliver Tambo, South Africa	Qualitative study	Community lack knowledge of early infant diagnosis	No study limitation found	Early infant diagnosis and follow up of care will enhance the lives of children with HIV and eradicate stigma

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
25	Rydstrom et al 2015	The study aim to assist legal guardians understand the stigma and quality of life for children with HIV/AIDS	Cross sectional study between legal guardians and children in Sweden	Quantitative	There was a need to educate legal guardian and children about HIV disclosure		HIV disclosure is repeatedly to be key in care for HIV Children's
26	Pegguril et al 2013	Assessing children and their attendance to HIV medication	Cohort of children living with HIV/AIDS in Ethiopia	Data analysis using (EPP) estimation and projection tool.	Majority of children living with HIV/AIDS in Ethiopia are not accessing their treatment	The rigor was rated high based on CASP checklist questions	Other factors such as social, mental, and psychosocial support should be considered in enhancing access to HIV medication.
27	O"donel et al 2013	Assessing why Low rate of HIV testing is occurring in high prevalence area	Children testing for HIV In Tanzania	Quantitative study	Early child hood testing is not common which threaten the health of HIV infected children	This study had limitations, including data based on the report of caregivers. It is possible that the reporting caregiver did not know that the child had been tested,	Early childhood testing is a challenge in poor resource settings
28	Myer et al 2006	Healthcare providers' perspectives on discussing HIV status with infected children	Health care providers in South Africa	Qualitative study Semi structured Interview	There is complexities in HIV disclosure between care givers and health care professionals	The rigor was rated high based on CASP checklist questions	Health providers suggest that disclosure should start at age of 6 years
29	Akani &Erhabor 2006	Exploring Epidemiology of abandoned children with their HIV status	140 children Consecutively recruited with mean age of 11.5+24.1 Port Harcourt Nigeria	Quantitative studies using Chi square analysis	HIV is the cause of abandonment for most children	No limitation was explained, however the paper met high score in CASP checklist	There is high prevalence of HIV children who are mostly abandoned

No	AUTHOR AND DATE	AIMS AND OBJECTIVES	SAMPLE AND SETTING	METHOD AND METHODOLOGY	MAJOR FINDINGS	LIMITATIONS, RIGOR AND VALIDITY	SIGNIFICANCE TO THE ISSUE
30	Cynthia Fair & Brittany Brackett 2015	**"I Don't Want to Sit by You": A Preliminary Study of Experiences and Consequences of Stigma and Discrimination from HIV-positive Mothers and Their Children**	Ten children with HIV positive and their mothers were interviewed In America	Mixed method Of exploration was used	Children chose to hide their mothers sero status to avoid neglecting and stigma from peer.	This study poses significant limitation however its findings are worthy to be included in the study review. They had few participant and secondly their sample selection did not explain about ethical approval since they used children in interview	Children had fear of stigma which might face them in academic environment after disclosure of their status
31	Fournier, B. Bridge, A. Pritchard Kennedy, A. Alibhai, A. Konde-Lule, J. 2014	Hear our voices: A Photovoice project with children who are orphaned and living with HIV in a Ugandan group home UGANDA	Story telling from 13 children living with HIV/AIDS	Qualitative Study	Children suffered high stigma of being orphaned, poor, HIV positive	Photovoice is expensive method Timeline for project start was limited	Policy is only explaining about family is the best option of care for orphan children and institution is the last resort, however does not provide guidelines of institutionalized care, and has little explanation around stigma and neglect facing children during their stay with extended family.

Appendix 3: Evaluation of qualitative research studies included in review

Author and Date	Q1 - clear research aims	Q2 - Qualitative approach appropriate	Q3 - Research design appropriate	Q4 - Recruitment strategy appropriate	Q5 - Data collection methods appropriate	Q6 - Researcher bias recognised	Q7 - Ethical issues considered	Q9 - Findings clearly stated	Q10 - research is valuable
Demmer,Craig **july 2011**	1	1	1	1	1	1	1	1	10
Campbell et al, 2012	1	1	1	1	0.5	1	1	1	9.5
Zabina et al 2004	1	1	1	1	1	1	1	1	10
OkagbueReaves J (2005)	0.5	1	1	1	1	1	1	1	10
Coombes R, (2000)	1	1	1	1	0.5	1	1	1	9
Bateman c (2010)	1	0.5	1	1	1	1	0.5	1	8.5
Machine et al 2016	1	1	1	1	1	1	1	1	10
Sanjeeva et al 2015	1	1	1	1	1	1	1	1	10
Luggala&Mbwambo 2002	1	1	1	1	1	1	1	1	10
Cruz et al, 2015	1	1	1	1	1	1	1	1	10
Bart Rwezaura (2000)	1	1	1	1	1	1	1	1	10
Campbell et al,2013	1	1	1	1	1	1	1	1	10
Godfrey kacholi, (2012)	1	1	1	1	1	1	1	1	10
Adeniyi et al (2015)	1	1	1	1	1	1	1	1	10
Myer et al (2006)	1	1	1	1	1	1	1	1	10
Fournier, B.et al (2014)	1	1	1	1	1	1	1	1	10

Appendix 4: Evaluation of quantitative research studies included in review

Author and Date	Q1 - clear research aims	Q2 - Qualitative approach appropriate	Q3 - Research design appropriate	Q4 - Recruitment strategy appropriate	Q5 - Data collection methods appropriate	Q6 - Researcher bias recognised	Q7 - Ethical issues considered	Q9 - Findings clearly stated	Q10 - research is valuable
Clemo L,1992	y	y	y	y y	y	y	y	y	y
Dube et al 2003	y	y	y	y	y	y	y	y	y
Ferris et al 2007	y	y	y	y	y	y	y	y	y
Bailey et al 2010	y	y	y	y		y	y	y	y
Jemmot et al2013	y	y	y	y	y	y	y	y	y
Luggala&Mbwambo 2002	y	y	y	y	y	Not listed	y	y	y
Emmet et al 2011	y	y	y	y	y	y	y	y	y
Azzopardi et al 2014	y	y	y	y	y	y	y	y	y
Rydstrom et al 2015	y	y	y	y	y	y	y	y	y
Pegguril et al 2013	y	y	y	y	y	y	y	y	y
O"donel et al 2013	y	y	y	y	y	y	y	y	y
Akani &Erhabor 2006	y	y	y	y	y	y	y	y	y

Appendix 5: Evaluation of mixed method research studies included in review

Author and Date	Q1 - clear research aims	Q2 - Qualitative approach appropriate	Q3 - Research design appropriate	Q4 - Recruitment strategy appropriate	Q5 - Data collection methods appropriate	Q6 - Researcher bias recognised	Q7 - Ethical issues considered	Q9 - Findings clearly stated	Q10 - research is valuable
Cynthia Fair & Brittany Brackett 2015	y	y	y	y	y	y	y	y	y
Sherr et al 2016	y	y	y	y	y	y	y	y	y
Campbell et al 2012	y	y	y	y	y	y	y	y	y
Okagbue-Reaves J 2005	y	y	y	y	y	y	y	y	y

Appendix 6: Themes from literature

THEME	ELEMENT	NUMBER	SOURCES
Factors associated with Abandonment	Stigma associated with HIV illness.	9	**Demmer & Craig 2011, Campbell et al 2012, Zabina et al 2004, Dowshen et al 2011, Coombes R, Bateman c,Campbell et al,Cruz et al, Barrero et al, Cynthia Fair & Brittany Brackett**
	Poverty	4	**Demmer &Craig July 2011, Campbell et al 2012, Helena et al,Godfrey Kacholi**
	Care givers roles	6	Zabina et al 2004, Ferris et al 2007, Okagbue Reeves J, Lugalla& Mbwambo 2002, **Godfrey kacholi**
	Access to health care settings	11	Baiely et al, , Sanjeeva et al, Jemmot et al, Sherr et al , Cruz et eal,Emmet et al, Azzopardi et al ,Adeniyi et al, Pegguril et al, Myer et al
	Gaps in law and Policy	6	, Sherr et al ,Luggala&Mbwambo, cruz et al, Ryddstrom et al, Akani &Erhabor, Bonnie Fournier[a,,], et al,

Appendix 7: Ethics approval from Flinders University

FINAL APPROVAL NOTICE

Project No.:	**7577**
Project Title:	Health professionals meeting the needs of abandoned children living with HIV / AIDS in Tanzania
Principal Researcher:	Ms Winfrida Mwashala
Email:	mwas0002@flinders.edu.au

Approval Date:	4 April 2017	Ethics Approval Expiry Date:	**30 July 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 with the addition of the following comment:

Please note that you are not required to retain copies of the audio recordings once the participant has reviewed the interview transcript.

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 **4 April** (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 **4 April 2018** 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;

Kind regards

Andrea

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au

18 TH February 2017

Appendix 8: Letter of authorization to conduct a study from Arusha regional director

UNITED REPUBLIC OF TANZANIA
PRESIDENT'S OFFICE
REGIONAL ADMINISTRATION AND LOCAL GOVERNMENT

Telegrams: **"REGCOM"**
Telephone:**2545608/2544950/2544802**
Fax No. **2545239/254486**
E-Mail: ras@arusha.go.tz
E-Mail: ras.arusha@tamisemi.go.tz
Website: www.arusha.go.tz
In reply please quote:
Ref. No. FA. 80/251/01/12

REGIONAL COMMSSIONER'S OFFICE,
P.O. Box 3050,
ARUSHA.

17th March, 2017

Regional Medical officer,
Mt. Meru Referral Hospital,
S. L. P. 3092,
ARUSHA.

Ref: **PERMISSION TO CONDUCT A STUDY AT MT. MERU REFERRAL HOSPITAL ABOUT HOME LESS CHILDREN LIVING WITH HIV IN ARUSHA**

Reference is hereby made to the letters dated 16th March, 2017 from Miss Winfrida Mwashala (Tanzanian) registered Nurse studying at Flinders University, sturt Rd, Bedford Park SA 5042, Adelade concerning the above underlined subject.

I'm therefore taking this opportunity to introduce to you Masters in nursing student **Miss. Winfrida Mwashala**. She wants to conduct a study at Mt. Meru Referral Hospital for the purpose of "***Homeless children living with HIV in Arusha".***

Regional Administrative Secretary has granted permission for survey/Data Collection from **March, 2017** to **30th November, 2017.**

Please your cooperation is highly expected.

(A.J. Mushashu)
For: REGIONAL ADMINISTRATIVE SECRETARY
ARUSHA

Copy to:
Winfrida Mwashala,
Student of Flinders University
Sturt Rd, Bedford Park SA 5042, Adelaide.
AJM/SAM

Appendix 9: Letter of introduction

Dr Julian Grant

Associate Professor in Nursing-Child and Family Health

School of Nursing and Midwifery
Flinders University
GPO Box 2100
Adelaide SA 5001
Telephone +61 8 82015340
julian.grant@flinders.edu.au
www.flinders.edu.au/people/julian.grant

18 TH February 2017

LETTER OF INTRODUCTION

Dear Sir/Madam,

This letter is to introduce Winfrida Mwashala who is a student in the School of Nursing and midwifery at Flinders University.

She is undertaking research leading to the production of a thesis or other publications on the subject of 'Health professionals meeting the needs of abandoned children living with HIV/AIDS in Tanzania'.She would like to invite you to assist with this project by agreeing to be involved in an interview which covers certain aspects of this topic. No more than 45-60 minutes would be required.
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. You 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 tape 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 name or identity is not revealed, and to make the recording available to other researchers on the same conditions (or that the recording will not be made available to any other person). It may be necessary to make the recording available to secretarial assistants (or a transcription service) for transcription, in which case you may be assured that such persons will be asked to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above.
Thank you for your attention and assistance.

Yours sincerely

Julian Grant (Principle Supervisor)

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number XXX). 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 10: Information sheet

INFORMATION SHEET

(Interviews)

Title: Health professionals meeting the health needs of abandoned children living with HIV/AIDS in Tanzania.

RESEARCHER:	SUPERVISOR 1:	SUPERVISOR 2:
Winfrida Mwashala Flinders University, School of Nursing and Midwifery Bed Ford Park, GPO BOX 2700, Adelaide 5001	Associate Professor Julian Grant Flinders University, School of Nursing and Midwifery Bed Ford Park, GPO BOX 2700, Adelaide 5001 Telephone: +61 8201 2126	Dr Mayumi Kako Flinders University, School of Nursing and Midwifery Bed Ford Park, GPO BOX 2700, Adelaide 5001 Telephone: +61 8201 3387

DESCRIPTION OF THE STUDY

This study will investigate how health care professionals manage the health care needs of abandoned children living with HIV/AIDS in Tanzania.

PURPOSE OF THE STUDY

To improve the health and wellbeing of abandoned children living with HIV/AIDS in Arusha,Tanzania.

WHAT WILL I BE ASKED TO DO?

You are asked to participate in a telephone interview. The researcher, **Winfrida Mwashala** will ask you some questions about your views in general on the issues concerning health needs of abandoned children living with HIV/AIDS in Arusha, Tanzania. Participation is voluntary. The interview will take about 45-60 minutes and will be audio-recorded and typed up. The reason for recording is to help during analysis of information you have provided. You will be offered a copy of the transcript to read and amend prior to analysis.

WHAT BENEFIT WILL I BE GAIN FROM BEING IN THIS STUDY?

There is no direct benefit; however you will contribute to the enhancement of health care needs of abandoned children living with HIV/AIDS in your local area. The findings will increase awareness of the needs and support in future planning's of the project involving abandoned children living with HIV/AIDS.

WILL I BE IDENTIFIABLE BY BEING IN THIS STUDY?

You will not be identified by your name and you will be anonymous. There will be no identified information relating to you as individual. The transcribed file will be stored where only Winfrida Mwashala and her supervisors will be able to access it.

ARE THERE ANY RISKS OR DISCOMFORTS BY BEING INVOLVED IN THIS STUDY?

The researchers foresee minimal emotional distress due to the nature of the study. However, if you do feel distressed after the interview please , contact the Arusha Lutheran Medical Centre counselling services by calling 0736- 502-376. You are advised that if any information regarding illegal activities or conducts is disclosed during the interviews, the principal researcher has a mandate to report this to appropriate government legal services on the matter.

HOW DO I AGREE TO PARTICIPATE?

Participation is voluntary. You can also withdrawal at any time during the study without any negative impact to your work. If you agree to participate please contact the researcher, **Winfrida Mwashala by sending her email to (mwas0002@flinders.edu.au**) and she will get back to you to set up the interview date and time.

HOW WILL I RECEIVE FEEDBACK?

You will be offered a copy of the transcript to read and amend prior to analysis.

The findings of the research interviews will also be published. When this happens all participants will be notified through their email address.

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 7577). 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 11: Consent form

Appendix 11: Consent form

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(By interview)

Project title: Health professionals meeting the needs of abandoned children living with HIV/AIDS in Tanzania.

I ….....

Being over the age of 18 years hereby consent to participate as requested in the …… for the research project on …….

1. I have read the information provided.
2. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:

    - I may not directly benefit from taking part in this research.
    - 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.
    - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

6. I agree/do not agree to the tape 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.

Participant's signature……Date……..

I **Winifrida Mwashala** 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 signature…… ……..Date……

8. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature……Date……..

Appendix 12: Interview guide

Project title: Health worker professionals meeting the needs of abandoned children living with HIV/AIDS in Arusha, Tanzania

1-Can you please tell me how you locate and identify children who have been abandoned from their families who have HIV/AIDS?

Probe -If you manage to locate them how do you track them?

-Is there anything else you would like to share with me about t

2-Can you please tell me if children attending in your clinic aware of their HIV diagnosis?

Probe If they are told of their status can you please tell me who does this and how?

-Is there anything you would like to share with me about this?

3- Can you please tell me how you and your facility provide care to abandoned children living with HIV?

Probe -Is there anything you would like to share with me about this issue?

4-Can you please tell me if there any preventive HIV interventions targeting homeless children?

Probe -If so, can you please tell me about them?

-Is there anything you would like to share with me about this issue?

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