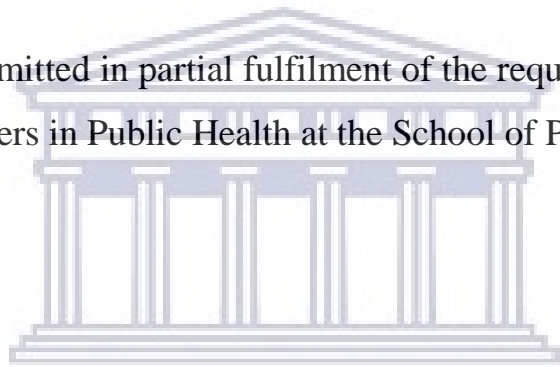


**HIV positive street children's access to treatment for HIV/AIDS in
the District of Katuba, in the south-west of the city of Lubumbashi,
Democratic Republic of Congo (DRC)**

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A mini-thesis submitted in partial fulfilment of the requirements for the
degree of Masters in Public Health at the School of Public Health,



UNIVERSITY *of the*
WESTERN CAPE
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DECLARATION

I declare that *Understanding the patterns of HIV positive street children's access to treatment for HIV/AIDS in the District of Katuba, in the south-west of the city of Lubumbashi, Democratic Republic of Congo (DRC)* is my own work. It has not been submitted for any degree or examination in any university. All the sources that I have used or quoted have been indicated and acknowledged by complete references.

Jean-Jacques Kalonji Somwe

November 2019

Signed:

J. Somwe



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KEY WORDS

- Street children
- HIV/AIDS
- Access to treatment
- Barriers to healthcare
- Child Rights
- Katuba
- Republic of Congo
- Qualitative Study



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ABSTRACT

The number of street children, in the Democratic Republic of Congo (DRC), is estimated at 70,000 and it increases each year. The President's Emergency Plan for AIDS Relief reported a 75.1% of street boys and 81.1% of street girls report multiple sex partners in DRC, thereby increasing their risk for transmission. Access to HIV treatment remains one of the challenges for the street children with HIV/AIDS. A study conducted in Lubumbashi and Kipushi in the Province of Haut Katanga, found that 78.2% of street children have no access to health care. The District of Katuba as in other local districts in the province, has seen a growing number of street children in recent years. This research aims to investigate factors that prevent street children living with HIV from accessing HIV/AIDS treatment in Katuba. This qualitative research was conducted using in-depth interviews, with a purposive sample of ten street children. Two key informant interviews were also conducted, one with the programme manager from the organisation Zone de Santé Bukama that works with street children and the other a medical doctor from Katuba general hospital both of which provide services to street children living with HIV. Thematic analysis was used to identify recurring themes for data interpretation. **Results:** In general, the street children living with HIV in this study experienced numerous challenges in accessing HIV treatment. The social environment (the streets) in which the children live seemed to play a significant role in their attitude toward HIV/AIDS treatment. Some of the reasons why these children found it challenging to seek HIV/AIDS treatment include the lack of access to transportation, lack of food to take with medicines, negative attitude of health care workers, shortage of HIV drugs, misconception surrounding HIV drugs, prostitution as a barrier and HIV related stigma and discrimination. **Conclusion and recommendations:** It is clear that challenges occurred at the individual, socio-economic, community and health system levels. Therefore, interventions are needed at all these levels in an integrated manner. For instance, at individual level, engaging with the street children living with HIV directly when designing intervention programmes; using peer-led programmes to equip them with skills to develop their self-efficacy in making informed choices regarding the treatment of HIV/AIDS; social-economic barriers can be reduced by adopting a feeding scheme that act as incentives for participants to seek and adhere to HIV/AIDS treatment; at community level, stigma and discrimination of these children should be addressed through education; at the health system level, the negative attitude of health personnel and drug shortage should be addressed.

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CHAPTER ONE: INTRODUCTION

1.1. Background

Street children are boys or girls aged under 18 who have left their home environment due to problems and end up on the street (including unoccupied dwellings and wasteland) which has become a new home and a source of livelihood (UNICEF, 2001). Often these children live in the street without any adult supervision, and they are inadequately protected (Black, 1993; Mella, 2013). The exact number of street children is still a subject of discussion among scholars as some state that it is impossible to come up with an exact number of street children. Some researchers believe that the number of street children could be estimated into tens of millions across the world (de Benítez, 2011; Reale, 2008). However, UNICEF (2012) estimates that up to 120 million children worldwide live on the streets of around the world with a precarious standard of living.

The Democratic Republic of Congo (DRC) has seen an increase of children living on streets. A study conducted in the DRC estimated around 70,000 street children live on streets across the country and 20,000 for Kinshasa (capital city) alone, with the number increasing each year (Boniface et al., 2017). The abuse and abandonment of children accused of sorcery and it being responsible for the various economic and social problems that affect families; and the impact of HIV/AIDS on families and children affected by or infected with the virus are two major contributing factors resulting in increasing numbers of street children in the DRC (Tate & Stauss, 2006).

A study conducted in the DRC has shown a prevalence rate of 75.1% of street boys, and 81.1% of street girls reporting multiple sex partners, thereby increasing their risk for HIV transmission (PEPFAR, 2012). According to Tate and Stauss (2006: 57), one of the non-governmental organisations (NGOs) (Youth Movement for Excellence) in the DRC, which cares for street children and widows, reported that ‘nearly half of the children they care for are affected by HIV/AIDS’. The HIV/AIDS awareness and prevention campaigns with street children stressing ABC (Abstinence, Be faithful, and use Condoms) have to date failed; this could be due to the nature of street life not allowing viable interventions to be implemented (Tate & Stauss, 2006).

The public and private health services in general and in particular HIV/AIDS treatment are very difficult for street children to access due to the absence of financial means to pay for the services and also to psychological barriers related to the negative attitude of health workers towards the street children (Elliott, 2013). Any HIV-positive street child needs a great deal of medical, emotional, and practical support from a parent or caregiver, but many of them do not get it. As stated earlier, these children live on the street without any adult supervision, and they are inadequately protected hence, the responsibility falls on the society at large and in particular on the state, to care for these children (Boniface et al., 2017).

A study conducted in Lubumbashi and Kipushi in Haut Katanga Province, DRC, has found that 78.2% of street children have no access to health care (Boniface et al., 2017). Under the Convention on the Rights of a Child (CRC), which the DRC was a signatory to, the DRC government has an obligation to progressively realize children's right to health which includes protecting children from all forms of violence, injury or abuse, neglect or negligent treatment (United Nation, 1990). While the DRC government has gone a long way toward realizing the right to health of all the children, it has failed to prioritize the problem of HIV/AIDS among the most at risk/vulnerable group (street children), nor has it succeeded in protecting these children against abuse (Tate & Stauss, 2006; Boniface et al., 2017). This violates its obligations under the Declaration of the Rights of the child (the basis for the CRC) which in Principle 6 states that: 'Society and the public authorities shall have the duty to extend particular care to children without a family and to those without adequate means of support' (United Nations, 1959:164).

1.2. Study setting

Despite having an abundance of natural resources as well as the diversity of its botanical resources, the DRC has been ranked as the most impoverished country in the world with a GDP per capita of US 25 cents (Ulloa, Katz & Kekeh, 2009). Access to health services remains one of the most significant challenges facing Congolese people since gaining independence in 1960. Health facilities coverage in DRC is estimated at 37 % of the population, or approximately 18.5 million people, have no access to any health care (Ulloa, Katz & Kekeh, 2009). Lubumbashi is the second-largest city in the DRC and regional capital of Haut Katanga province. It is also named the mining capital of the DRC, acting as a hub for many of the country's biggest mining companies (Ulloa, Katz & Kekeh, 2009). Katuba is one of districts of the city of Lubumbashi.

The population of Lubumbashi city is estimated around 1.5 million (World Population Review, 2018).

A study conducted in Lubumbashi and Kipushi found that 72.3% of street children have no access to education despite the assertion of the right to education of children recognized in articles 28 and 29 of the CRC as well as Articles 43 and 44 of the Constitution of the Third Republic in the Democratic Republic of Congo (DRC, 2006). The under-five mortality rate is estimated at 205 deaths per 1000 and infant deaths are estimated at 129 deaths per 1000 live birth (UNICEF, 2008).

Other predicaments facing children in the DRC including Lubumbashi is the phenomenon of a child soldier and child labour. Children are frequently snatched from their families by rebel groups to become soldiers (UNICEF, 2008). It has been estimated that one in ten child soldiers - 30,000 children - are found in the DRC (UNICEF, 2008). Amnesty International (2016) estimates that 40,000 young boys and girls work in cobalt mines in the Katanga province, Lubumbashi (Amnesty International, 2016). This is given the fact that more than half the world's cobalt comes from the DRC, that one-fifth of it is extracted by artisanal (or informal) miners. These children work for a shift of up to 24 hours underground; most earn less than \$2 (1.80 euro) a day - and may only receive half of that (Amnesty International, 2016). Several years of war have created a humanitarian crisis in the DRC in general and Haut Katanga province in particular with extensive disruption of civil society, the economy, and provision of essential services with devastating impacts on the social determinants of children's health. The DRC national government and Katanga / Lubumbashi local government have failed to provide a sound public health and human rights policy and leadership to address the social determinants of children's health (Boniface et al. 2017).

With regard to HIV/AIDS treatment, the DRC has a range of stakeholders implementing HIV/AIDS treatment such as the Ministry of Health through general hospitals and local clinics and the National AIDS Commission, United Nations agencies, the Global Fund to Fight AIDS, Tuberculosis and Malaria and the United States President's Emergency Plan for AIDS Relief. These institutions worked with local community health centres spread across the country to assist with funding, capacity building in delivery of HIV/AIDS treatment. For instance, community-based antiretroviral medicine distribution points and community-based early warning systems

such as of the organisation de Zone de Santé Bukama, are designed to help in reducing drug stock-outs and improve the quality of HIV services, especially to reach out to the most vulnerable population such as street children living with HIV. In Katuba there are two places that street children are able to access HIV/AIDS treatment namely the Katuba General Hospital and Zone de Santé Bukama. The researcher, who is DRC national, is working at the Centre for Justice and Crime Prevention (CJCP), a non-profit organization that specializes in early violence prevention research and interventions in South Africa schools. The researcher's interest in the topic arises from projects that he conducted with children and youth in South Africa schools and communities on the fight against xenophobia.

1.3. Problem Statement

Currently, there are thousands of children living on the streets of Lubumbashi city in DRC who suffer from extreme poverty. The District of Katuba, in the south-west of the city of Lubumbashi, created in 1950 to respond to the growing urbanisation of the city of Lubumbashi does not escape the global phenomenon of street children. Like other local districts, Katuba has seen a growing number of street children in recent years (Boniface et al., 2017). Street children are victims of sexual, physical, emotional abuse, disease and accidents. They are exploited by adults who use them for illegal activities such as stealing and looting in exchange for a small sum of money to the detriment of their health and their well-being and in violation of basic human rights (Tate & Stauss, 2006). Street environments place children at risk for HIV infection and other sexually transmitted infections (STIs). Rape, anal sex, unprotected sex with the opposite sex and survival sex are among the factors which increase street children's vulnerability (Mandalazi, Banda & Umar, 2013). These children lack access to health, food, housing and other basic needs (Boniface et al., 2017). The lack of access to health services including the treatment for HIV/AIDS constitutes a paramount violation of human rights (Tate & Stauss, 2006). There is therefore a tremendous need for coordination and accessibility to health care services for street children in the district of Katuba, Lubumbashi. This study therefore aimed to explore the factors that influenced street children with HIV/AIDS accessing HIV/AIDS treatment in Katuba, Lubumbashi, DRC.

1.4. Rationale

In order to address the problem of street children with HIV/AIDS, this research aimed to understand some of the factors that inhibit street children's access to the treatment for HIV/AIDS in Katuba district. A coherent understanding of what hinders the access to treatment of street children infected by HIV/AIDS, can inform a set of recommendations for street children's future health service accessibility. It is hoped that this research study, although conducted in one district, will have relevance for the rest of the city of Lubumbashi and Province of Haut Katanga, DRC.

1.5. Study aim and objectives

This study aimed to explore HIV positive street children's access to HIV/AIDS treatment in the district of Katuba, Lubumbashi, DRC.

The objectives were as follows:

- To explore with street children living with HIV, the factors that inhibit them from accessing treatment for HIV/AIDS in the district of Katuba, Lubumbashi.
- To explore with key informants the factors they believe prevent street children with HIV/AIDS from accessing HIV/AIDS treatment in the district of Katuba, Lubumbashi.
- To explore the participants' recommendations that can be used as a foundation for development of guidelines to improve access to HIV/AIDS treatment for the street children with HIV/AIDS in the district of Katuba, Lubumbashi.

Chapter 1 presented the background to this study. Chapter 2 provides a literature review which presents a discussion of previous studies on the topic. This is followed by the study methodology in chapter 3 which describes the sample, the research methods, the process of the collection of data and analysis, rigour ensured in the study and the ethical considerations. Chapter 4 presents the key findings from the study which is followed by the discussions of the key findings and the limitations of the study in chapter 5. Lastly, chapter 6 draws conclusions from the main findings and makes recommendations for a way forward.

CHAPTER TWO: LITERATURE REVIEW

This chapter reviews literature related to HIV positive street children's access to treatment for HIV/AIDS to place this research topic in the broader context. However, although internationally there is a wide range of literature on children in general, there seems to be a paucity of literature on street children and more specifically those living with HIV/AIDS. It is therefore anticipated that this research will make a significant contribution in filling this gap.

The chapter begins by defining street children, followed by a discussion about the reasons they become street children. This is followed by an overview of the general health status of street children. Street children's vulnerability to HIV/AIDS is discussed next. A discussion of the international and national policies for the protection of street children, a description of the DRC health care system and street children challenges to access to healthcare globally and in the DRC follows. The chapter ends with a description of some best practices for HIV positive street children's care.

2.1. Defining street children

Street children are boys or girls aged under eighteen who have left their home environment due to problems and end up in the street (including unoccupied dwellings and wasteland) which has become a new home and a source of livelihood (UNICEF, 2001).

There is a distinction between "children who live and sleep on the streets" and "children on the street" who earn their living or beg for money on the street and return home at night (UNICEF, 2019). The difference is that in the former version, the children have made the street their permanent home, whereas the latter version, they maintain contact with their respective families. Street children in the DRC fall under the definition of children who live and sleep on the street because most of them do not maintain contact with their family and lack the parental, emotional and psychological support that is generally found in parenting situations (UNICEF, 2019). Often, the term street children are used interchangeably to mean both concepts. However, this study uses the definition of children living on the street as street children.

2.2. Why they become street children

The phenomenon of street children is multifaceted. The combination of familial, economic, social and political factors plays a vital role in the decision to leave home and embrace the street as their home. It is therefore difficult to single out one or more causes. However, studies conducted among street children have shown that family, poverty, abuse and war are the main reasons why they left home for the streets. For example, a study conducted in Australia among 302 homeless young people (12–20 years old), found that family conflict or family breakdown was evident in all of the participants' reasons for leaving home (Mallett, Rosenthal & Keys, 2005). Even though young people who experience abuse during childhood may leave home to go and live on the street to avoid it, this may just shift the types of abuse that they might encounter (Coates & McKenzie-Mohr, 2010).

In the DRC, the two successive civil wars, one that began in 1996 and the other in 1998 contributed enormously to an increase in street children (Tate & Stauss, 2006). The two wars left more than 3.5 million Congolese civilians dead and devastated the country. Some children living on the streets lost parents in the war either directly during the conflict or due to hunger or disease (Tate & Stauss, 2006). Violence in the home has been identified as another significant factor for children running away from home. Stepmothers or stepfathers are often considered as the perpetrators of the abuse, giving differing treatment (including harsh punishment) to children from former marriages as compared to their biological children (Tate & Stauss, 2006). Other common phenomena are children accused of sorcery –. It is estimated that as many as 70% of street children had been accused of sorcery in their homes before coming to live on the streets (Tate & Stauss, 2006).

The HIV/AIDS pandemic remains a significant factor which pushes the children onto the street. The national HIV/AIDS prevalence rate is 4.2 % in the DRC, and it is estimated that one million Congolese children have been orphaned by this epidemic (Tate & Stauss, 2006). These children are less likely to go to school and, more likely to be working on the streets to support their families. They face other considerable disadvantages in comparison with other children (Tate & Stauss, 2006). Lack of education amongst the street children in the DRC was identified as one of the reasons that they began spending time on the street (Tate & Stauss, 2006). More than 4.4

million children in DRC, (nearly half the school-age population) are not in school (UNICEF, 2008).

2.3. General health status of street children

Living in an environment generally regarded as dangerous, street children incur considerable risks which can have an impact on their health status. As a consequence of living on the street, many of their rights are often compromised, such as the right to food, healthcare and education. Street children often do not have the means to access a healthy and sufficient diet. They do not have money to buy food, thereby running the risk of malnutrition (Berezima, 2003). Street children are often subject to abuse, neglect, exploitation, or in extreme cases, murder by clean-up squads hired by businessmen, criminal gangs and very often, the police because the street children are deemed to discourage customers from supporting these businesses (Berezima, 2003).

A study conducted by Gebers (1990) found that street children who are admitted to hospitals, are mostly treated for wounds – 34% of street children had suffered head injuries of which 52% was as a result of assault and 48% as a result of accidents (Gebers, 1990). Prostitution and sexual abuse are also serious health risks for street children (Jeal & Salisbury, 2004).

Street children often do not have access to sanitary facilities and therefore lack adequate hygiene and are exposed to different kind of diseases as a result. Often they also use alcohol, drugs and inhale natural gas, which are used to help them to forget about their current living conditions (Berezima, 2003). Unfortunately, these practices have a negative impact not only on their physical and psychosocial development but also on their social and economic development (Berezima, 2003).

2.4. Street children's vulnerability to HIV/AIDS

As discussed earlier, street children are a vulnerable group of population in our society. They face multiple challenges due to the nature of their lifestyle and environment in which they are living and exposing them to different kind of diseases, including that of HIV/AIDS. Street children are known to engage in sexual activity with peers and adults from within and outside their social circles (Anarfi, 1997). Sex is often unprotected, and consequently, street children are at increased risk of contracting STI's, including HIV (Anarfi, 1997). A study conducted among street youth in Canada found that unprotected sex, intravenous drug use, prostitution and

incarceration were linked to street youth HIV infections (DeMatteo et al., 1999). HIV seroprevalence rates for street youth are 10–25 times higher than other groups of adolescents (Tadele, 2000). This could be because street children are usually unsupervised and as a result, they have the opportunity to engage in sexual activity with multiple partners (Owoaje & Uchendu, 2009). Richter and Swart-Kruger (1995), argue that the poor conditions that street children live under, combined with the harsh circumstances of street life, soon contribute to the child's lowered immunity, morbidity, ill-health and eventually, the child's heightened susceptibility to HIV/AIDS in particular (Richter & Swart-Kruger, 1995).

A study conducted in Kenya by Kaime-Atterhög et al. (2007) amongst street children has found that street children are at high risk of contracting HIV/AIDS due to the following reasons: (1) living on the streets with freedom and independence without adult care (2) street children have multiple or diverse sexual partners, including peers on the streets, as well as adults from outside their social circles (3) street children live outside of the mainstream society and they are often illiterate. As a result they do not have full access to information and preventive services that other children in their age group would receive from home, school, sport centres, the radio or through printed matter (4) the delay in seeking medical attention until their condition becomes severe has a massive impact on the development and complications of HIV/AIDS. For instance, some opportunistic diseases could be treated or prevented if diagnosed in time (Kaime-Atterhög et al., 2007).

A study conducted in the DRC has found that the lack of knowledge or misconceptions about HIV transmission were common among the street children in Kinshasa. Thirty eight percent of street children interviewed reported that HIV could be transmitted through a mosquito bite or witchcraft (Kayembe et al., 2008). Most of the street children interviewed were already sexually experienced and have had multiple sexual partners while not using condoms consistently; this may explain the high rate of symptoms suggestive of STI observed in this group (Kayembe et al., 2008). The authors concluded that since STIs are known to increase the risk of HIV, this is an indication that the prevalence of HIV might be high in this group (Kayembe et al., 2008).

2.5. International and national policies related to the rights of children

The United Nations (1959) adopted the Declaration on the Rights of the Child for the protection of the child as the child's '... physical and mental immaturity needs special safeguards and care, including appropriate legal protection, before as well as after birth' (United Nations, 1959:164). For instance, Principle 4 states: 'the child shall have the right to adequate nutrition, housing, recreation and medical services' (United Nations, 1959:164). The Declaration formed the basis for the United Nations' Convention on the Right of the Child which came into play in 1990.

This was closely followed by the adoption of the Organisation of African Unity's Charter on the Rights and Welfare of the Child by the Assembly of Heads of State and Government held in Addis Ababa in 1990. The Charter defined a child as being a human being below the age of 18 years and states in its article 14: 'Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health. This includes the provision of nutritious food and safe drinking water, as well as adequate health care' (United Nations, 1990: 2). Furthermore, the Charter advocates for no separation of children from their parents; every effort must be directed to have children live with their parents. In the eventuality of the separation of children with their parents, the Charter calls for special protection, i.e. providing the children with alternative family care and 'States to take all possible steps to trace and reunite children with parents' (United Nations, 1990: 2).

The DRC has ratified both the United Nations Convention on the Rights of the Child and the Organisation of African Unity's Charter on the Rights and Welfare of the Child. The country ratified other international treaties that protect the basic human rights of children such as the U.N. Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment (Convention against Torture), and the U.N. Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), which has particular relevance for the rights of girls in the DRC (Tate & Stauss, 2006). Article 53 of the Constitution of the DRC states that 'everyone has the right to a healthy environment' (DRC, 2011: 22) and the Family Code (Article 239) of the DRC provides for the supervision of the State as a support mechanism for minors whose parents are unknown; abandoned children; children without family (DRC, 1987).

Despite the existence of these international and national policies, the rights and welfare of children especially those who live in difficult circumstances, such as street children, are not being observed or implemented (Boniface et al., 2017). Rahmat (2015:309) states that ‘... policy is only as good as its implementation’. Unfortunately, in developing countries, most of the policies are not implemented fully because of lack of trained staff and financial resources (Rahmat, 2015).

2.6. DRC healthcare system challenges

The national and district health system of DRC are casualties of a long series of conflicts and wars which have destroyed clinic and hospital infrastructures; resulted in the flight of health professionals and the interruption of drugs and other medical supplies (Wembonyama, Mpaka & Tshilolo, 2007). Hence, children who have HIV/AIDS and other related diseases find it difficult to access medical assistance. The few and isolated health centres across the country are poorly equipped, and there is a lack of manpower and medical equipment (Wembonyama, Mpaka & Tshilolo, 2007). These health centres depend heavily on foreign donors and missionaries who do not always provide adequate funding to support comprehensive primary health care programmes (Wembonyama, Mpaka & Tshilolo, 2007). For instance, in 2003, the national government only spent 0.7 % of its total expenditure of GDP on health (Equinet, 2007). The United Nations Commission on Social Development recommends at least 5% of a country GDP should be spent on health (Equinet, 2007).

2.7. Street children’s challenges to access health care

Street children face incredible challenges in maintaining their health and well-being. They are the ‘most marginalised, neglected part of society with very negligible access to health care’ (Eshita, 2018: 9). The social determinants of health is a confirmation that economic and social conditions shape the health of individuals and communities (Wilkinson & Marmot, 2003). Unfortunately, these children live in extreme poverty and they lack healthcare support, which negatively impacts on their health (DeMatteo et al., 1999).

Street children in general, and in particular those infected by HIV/AIDS find it difficult to access public and private health services due to lack of money. As a result, many of them do not complete their treatment (Eshita, 2018). Another reason for not accessing or completing treatment are the psychological barriers related to the negative attitude of health workers, in

general, and in particular nurses, towards these children (Elliott, 2013). For instance, a study conducted in Dhaka city found that 'doctors refuse to treat or operate needy street children because of their unclean appearance' (Eshita, 2018:2).

The high level of mobility of street children makes it difficult for governments, communities, and public health officials to develop appropriate prevention strategies and to carefully monitor the spread of HIV infection in this vulnerable population (DeMatteo et al., 1999). Other potential barriers are attributed to street children's lack of knowledge on how to access appropriate health care, not trusting adults or authority and concerns about confidentiality, which is compounded by fear of being reported to authorities (Elliott, 2013). Often public hospitals expect street children to pay user fees and purchase medicines from private medical shops. As a result, many of them do not complete their treatment (Society for Nutrition, Education and Health Action, 2008). Other barriers to health care include the need to present a health card or supply a permanent address; the perceived need for an adult's consent or involvement; and services that are poorly coordinated or difficult to access (Farrow et al., 1992). Kelly and Caputo (2007) argue that to remove systemic barriers to health care, it is crucial to not only improve the health care of street children, but it is also of paramount importance to understand the concepts that hold and influence street children's desire, willingness or ability to access health care service.

2.8. Best practices for street children accessing healthcare services

One of the challenges encountered in reviewing best practices is that little information exists in terms of systematic analyses of street children interventions; this is primarily due to the transient nature of the population and the difficulty in developing precision-based outcome measures (Robertson & Toro, 1999). From existing sources, it is apparent that some organisations, communities and individuals have managed to develop strategies to help HIV/AIDS-affected street children. For instance, the Baaba project in Uganda, a peer-led HIV prevention programme with street children has been deemed to be a successful intervention in addressing the challenges facing HIV positive street children in Uganda. The project revolved around a group of 170 trained peer educators, or Baabas who planned and implemented HIV/AIDS prevention activities (Mitchell, Nyakake & Oling, 2007). One of the characteristics of this project is that it adopts a life skills approach which tackles not only HIV/AIDS prevention but also issues that are central to street life, such as drug abuse and rape.

There is strong evidence that street children and youth can make highly effective peer educators (Mitchell, Nyakake & Oling, 2007) as they can assist their peers on other social issues which are beyond HIV prevention, such as general hygiene. Peer educators tend to prefer talking to peers who are similar to themselves (Mitchell et al., 2007). The study found that matching peers based on 'street life' experience alone was not enough; Baabas worked better with peers of the same sex and similar age. Also, there was strong evidence of Baabas acting as role models, not only in relation to preventive behaviour but also as young people attempting to rehabilitate and take on responsibility (Mitchell, Nyakake & Oling, 2007). Ultimately, the best practices should be based on the rights of the child as stipulated in the United Nations Convention on the Rights of the Child.

The international day for street children which is commemorated on April 12 of each year with different themes is a good way to address street children's plight at international level through advocacy, lobbying and activism. This is important because governments alone cannot possibly solve this global crisis. Therefore, civil society organisations (e.g. faith-based organisation and non-governmental organisation) have to emerge as prominent stakeholders in addressing the needs of the increasing numbers of street children (Ferguson et al., 2008).

Another example is the work of the Brazilian Center for the Defense of the Rights of Children and Adolescents (SOS Crianca) which ensures that young people have access to the health care they needed. This was done through the development of new legislation by lobbying politicians and policymakers based on the International Declaration of Children's Rights (Filgueiras, 1992). This legislation facilitated much-improved health care services for HIV positive street children. For instance, a doctor would make appointment times more flexible for HIV positive street children, or a nurse would come to assist with counselling sessions; all of these flexibilities on the part of health personnel were to accommodate the needs of street children to better access health care (Filgueiras, 1992). This support has helped to change the attitude of other health professionals towards street children. HIV positive street children are now able to go to public health facilities and be treated well (Filgueiras, 1992). Another strategy consisted of having street educators to reach out to street children and to educate them on their right to use public health care facilities. The educators worked nightly on the streets, giving advice and counselling and assessing the children's health problems. In the mornings and afternoons, the educators went

with them to the clinics or follow up with other types of referrals (Filgueiras, 1992). These cases illustrate the various ways that interventions have been implemented to address street children's health care needs.

Although there is a dearth of literature on the topic, it can be concluded from the literature reviewed that street children generally and in particular HIV positive street children, are ill-prepared to face the future; they are required to care for themselves in an environment of discrimination that denies them the protection of their basic human rights such as access to healthcare. Hence, being street children means 'growing up without companionship, love and protection, having no access to education or medical services, losing all dignity and becoming an adult before even having been a child' (Mandalazi, Banda & Umar, 2013:1). However, some practices have been implemented which shows promise for street children to be able to access healthcare including HIV treatment freely and without fear of discrimination or rebuttal.



CHAPTER THREE: METHODOLOGY

3.1. Introduction

This chapter presents the methodology used to conduct the study. It sets out the aim and objectives of the study, the study design, the study setting and population. It then describes the sample size and sampling approach for the study population. Methods used to collect and analyse data, study rigour, and ethical considerations are also presented in this chapter.

3.2. Study aim and objectives

This study aimed to explore HIV positive street children's access to HIV/AIDS treatment in the district of Katuba, Lubumbashi, DRC.

The objectives were as follows:

1. To explore with street children with HIV/AIDS, the factors that inhibit them from accessing treatment for HIV/AIDS in the district of Katuba, Lubumbashi.
2. To explore with key informants the factors they believe prevent street children with HIV/AIDS from accessing HIV/AIDS treatment in the district of Katuba, Lubumbashi.
3. To explore the participants' recommendations that can be used as a foundation for development of guidelines to improve access to HIV/AIDS treatment for the street children with HIV/AIDS in the district of Katuba, Lubumbashi.

3.3. Study design

This was a descriptive qualitative study given that it sought to explore the perceptions, opinions and experiences of participants about the access to HIV/AIDS treatment for street children infected by HIV/AIDS. Blaxter Hughes & Tight (1996:61) stated that qualitative research focused "on exploring, in as much detail as possible, smaller numbers of instances or examples which are seen as being interesting or illuminating and aims to achieve 'depth' rather than 'breadth'. By utilising a qualitative approach, the researcher was able to develop an in-depth understanding of the access to HIV/AIDS treatment for street children.

3.4. Study population and sampling

The study population for the study was the street children of Katuba with HIV/AIDS below the age of 18; this age group is consistent with the definition of a child (Kaime, 2009). It was

anticipated that the selected street children with HIV/AIDS, given their experience with living on the street, would be a rich source of information and provide valuable insight on access to the treatment for HIV/AIDS. Key informants who provided services to HIV positive street children of Katuba were also recruited. The sample for the key informants was drawn from two institutions. The first was Zone de Santé Bukama, a local health centre financed by an International Non-Profit Organisation (NPO), which worked with street children infected with HIV/AIDS. The Zone de Santé Bukama offered other services including the provision of food and clothing for the street children living with HIV/AIDS. The organisation also facilitated the street children's reunification with their biological family. It further provides social, emotional and spiritual support to street children with HIV/AIDS. The second institution was Katuba general hospital in the city of Lubumbashi. Purposive sampling was used for this study.

According to Rice and Ezzy (1999) sampling strategies in qualitative research were designed to produce information-rich cases that would yield in-depth understanding of all aspects of the phenomenon under investigation. The Zone de Santé Bukama linked the researcher to the street children with HIV/AIDS whom they attended to, for the interviews. The inclusion criteria for the street children included: they had to be HIV/AIDS; aged below 18 years old of either gender; those who assented and whom the Zone de Santé Bukama gave consent to participate. The exclusion criteria were street children with HIV/AIDS above 18 years, those below 18 years who did not assent and those whom the Zone de Santé Bukama did not give consent to participate. A sample of ten street children with HIV/AIDS who participated in activities at Zone de Santé Bukama was purposively selected with the help of the programme manager at the local NPO. Six boys and four girls infected with HIV/AIDS were selected to start with and if saturation had not been reached then more would have been recruited. However, this was not necessary as data saturation had been reached as no new knowledge was emerging by the tenth participant.

Two key informants were identified based on their experience and position in their institutions local general hospital and Zone de Santé Bukama. The key informants included:

- A Programme Manager of street children outreach programme of Zone de Santé Bukama, who oversees the implementation of the programme. This key informant provided a professional and expert perspective on issues faced by street children with HIV/AIDS.

- A medical officer from the Katuba general hospital, who had the responsibility of facilitating the street children's health care in the city of Lubumbashi. This key informant provided information of how street children accessed health care, including the treatment of HIV/AIDS.

The inclusion criterion was that the key informants had worked for at least 2 years in their field serving street children.

3.5. Data collection

Individual in-depth interviews were conducted with the sample of street children with HIV/AIDS between January and March 2019. The researcher contacted the authority at the Zone de Santé Bukama, informed them about the study, provided them with necessary details about the study purpose and process and requested their permission to conduct the study.

The researcher and programme manager from Zone de Santé Bukama provided potential participants (HIV positive street children) with the necessary information about the study (Appendices: 1, 2, 3, 4 & 5) a week before the data collection started. The programme manager asked street children who came to the centre whether they would voluntarily agree to participate in the study. All HIV positive street children approached agreed to participate in the study. An appointment was made with the first ten who assented to meet with the researcher. Information about the study was provided in written and verbal format in participants' local language, namely Swahili.

Each interview lasted between 30–45 minutes. Interviews were conducted in participants' preferred language (Swahili or French). The interviews took place in one of the meeting rooms at Zone de Santé Bukama for the participants, which provided a safe and private space for the interviews. Most of the participants were outspoken, energetic and engaging. They were comfortable with the seating arrangement and pre-interview informal exchange. However, two participants (a girl and boy) were suspicious of the researcher and his assistant of being secret government agents wanting to extract information from them and have them arrested. They were convinced that their answers provided could be used as a case for conviction. To clarify the misunderstandings, the researcher went through the information sheet for the second time to address their concerns. After clarifying this to each of the two participants separately, they were happy and eager to participate in the interviews.

In addition to collecting socio-demographic information (age, previous place of residence and education level), the semi-structured interview guide (Appendices: 13, 14 & 15,) for the HIV positive street children included questions related to the participant's experience living on the street, HIV/AIDS testing and treatment experience, and questions on experience of accessing HIV treatment. The interview guide was piloted with two HIV positive street children; these street children were not part of the sample. The pilot assisted in modifying the interview guide - for instance a question on experience of HIV/AIDS diagnosis for the first time was changed to "what was the participants' experiences when blood was taken (using a small needle) to test for HIV/AIDS by a doctor for the first time". This question was then used because most of participants associated the HIV/AIDS testing to a needle being use on them to take blood.

In relation to the key informant interviews, the researcher contacted the two key informants personally at their work places, informed them about the study and provided them with necessary details and asked if they were willing to participate in the research process. The interviews with the key informants were held at their respective places of work, using a semi-structured interview guide (Appendices: 16 & 17). All interviews were audio recorded with permission and transcribed verbatim at the end of the day's data collection process by a researcher assistant, experienced in qualitative research and transcribing. The research assistant accompanied the researcher in the field for the interviews and his main role was that of transcribing all the audio-recorded interviews. The researcher conducted all the interviews himself. There was no need for an interpreter or translator as the researcher himself was fluent in both Swahili and French.

3.6. Data analysis

Data analysis is a valuable tool in qualitative research methods to elicit meaning from the transcribed text. The thematic method of data analysis as described by Braun & Clarke (2006) was used in this study. The data analysis process began alongside data collection and this was particularly helpful as it helped the researcher to refine the prompt notes within the interview guides. Vast amounts of data were obtained from the in-depth individual interview transcripts and field notes and as such a systematic approach was imperative (Pope, Zieland & May, 2000). The first step taken was data familiarisation, which was followed by a process of coding and categorizing the content into themes then finally integration and interpretation. These steps are described below.

3.6.1 Familiarisation

This phase involved the researcher immersing himself in the data by reading and re-reading of transcribed data and field notes and listening to the recordings over and over. It is important for the researcher to gain an overview of the data before delving into the intricacies of analysis. During the familiarisation stage the researcher took note of the important words and phrases related to the study topic. Where the data was not clear, the researcher proceeded to read the transcripts again and also listen to the audio-recording again and check with the participants involved. Familiarisation was important in starting the process of searching for meanings from the data and to make a summary of key impressions. Following familiarisation, the next step was to identify and note patterns from the transcripts through coding.

3.6.2 Coding

Robson (2011) recommends that meanings should be coded as they are described by the participants to ensure that the data were a true reflection of the meanings which the participants meant for them. The researcher examined the data in order to identify codes that described the contents of a line or even a paragraph. The researcher coded the chunks of data by using highlighters and inserting comments in the text to identify sections of the data. The researcher continued coding all the transcripts matching data extracts that demonstrated a particular code or added new codes where necessary. The codes were first hand-recorded in the margins of the printed transcripts, and then entered the electronic version of the same transcripts as additional comments by the researcher.

3.6.3 Identifying themes

Next, the transcripts of the interviews of participants and key informants were read and re-read to identify reoccurring themes. This involved organising several different codes around a common theme – using a cut and paste method to move the data into different documents organised around themes, to ensure that the themes identified are within the context of the study objectives. The researcher then reviewed the tentative themes. The researcher reviewed the themes by examining the themes in relation to the data and considered whether they appeared in a consistent pattern. In the process some themes were abandoned and some modified.

3.6.4 Integrating the themes

This final step of data analysis assisted the researcher to integrate the highlighted common themes and the shared experiences of the participants to address the aim and objectives of this study to assist with final interpretation. This was done by describing the experiences of the street children in relation to their access to HIV treatment, as well as the views of the key informants. Finally, connections were made between repeated codes and themes.

3.7. Rigour

Rigour in qualitative research is defined as the trustworthiness of the research (Holloway & Wheeler, 1996). The researcher used triangulation, verification and reflexivity as a means to ensure rigour. Triangulation of sources utilises different data collection sources to increase rigour (Mays & Pope, 1995). The researcher used different sources of information, i.e. street children and key informants from Zone de Santé Bukama and Katuba general hospital to ensure rigour through triangulation. This illuminated the same issues from a different perspective. The researcher summarised key points at the end of each interview to verify with each participant that his understanding and interpretation of their experiences, opinions and perceptions was accurate. The researcher used a personal journal of thoughts and feelings for reflexivity purpose which he maintained throughout the research process for personal monitoring as a form of rigour (Malterud, 2001). For transferability, the researcher has provided detailed descriptions of the setting and, participants, to give the context of study. In-depth methodological description has also been given to allow the integrity of research results to be scrutinised so that it can be replicated in similar contexts.

3.8. Ethical considerations

Ethics approval was obtained from the University of the Western Cape Bio-Medical Research Ethics Committee to conduct the study (Appendix 18). Permission was also obtained from the Provincial Ministry of Health of Haut Katanga Province to have access to the local hospital and from the Zone de Santé Bukama which worked with street children infected by HIV/AIDS (Appendix 19).

The purpose and objectives of the study were explained to the street children before information was collected from them. The researcher explained to them why and how they were selected. The participants were informed that participation in the study was voluntary. Only willing

participants who understood and agreed to participate in the study were recruited as study participants. Assurance was given of anonymity and confidentiality of their participation and personal information in a form of a letter as well as verbally explaining the research study and requesting their informed assent and consent (Appendices 1, 2, 3, 4, 5, 8, 9 & 10).

Permission from all participants was also obtained to audio-record the interviews. Since the street children with HIV/AIDS fall in the category of minors (WHO, 2003), consent was obtained from the Zone de Santé Bukama program manager who worked with and mentored the street children with HIV/AIDS, in lieu of parental consent. Assent forms were then presented to street children with HIV/AIDS, to obtain their permission to participate in the study. The participants were informed that they were free to withdraw from the study at any time without any negative consequences to themselves or services that they were receiving.

The real names of participants were excluded from the transcripts and pseudonyms were used instead. Privacy of the in-depth interviews was ensured by having the interviews in a private room. The study documents were all securely locked in the researcher's office with no access to anyone else and a code-controlled computer was used to store the data. Given the sensitive nature of the research, participants were informed that follow-up counselling and psycho-social support were available if any of the participants felt that this was necessary. However, these services were not utilised as all participants were comfortable with the questions asked throughout the entire process and none of them requested any of these services.

CHAPTER FOUR: RESULTS

4.1. Introduction

This chapter presents the major research findings of this study. Firstly, a biographical profile of the research participants is given and secondly a presentation of the themes - street children's experience of living in the street, current procedures for the treatment of HIV positive street children, barriers to access HIV treatment, factors facilitating access to HIV/AIDS treatment and participants recommendations - and sub-themes that emerged from the process of data analysis followed by recommendations identified by the participants as a way of alleviating the challenges.

4.2. Profile of the research participants

A total of twelve participants were interviewed in this study; ten of whom were HIV positive street children and two key informants namely the coordinator of Zone de Santé Bukama who worked with HIV positive street children and a medical doctor who worked at Katuba general hospital. Of the ten HIV positive children, six were males and four females. The HIV positive street children interviewed were between the age of 12 and 17 years old and were all living on the streets of Katuba District. The two key informants have more than five years' experience each in their respective related fields of work. All names used here are pseudonyms to protect the identity of the participants.

4.2.1. Description of HIV positive street children

The description of the participants includes their pseudonym; age; sex; and place where they came from originally.

4.2.1.1. Participant 1

[Name: Kibambe; Age: 16 years; Sex: male; came from: Mbujimayi]

Kibambe was interviewed at Katuba Zone de Santé Bukama; he was physically weak. He was born in Mbujimayi - province's capital of Kasai, central. He lost both parents when he was nine years old, and a few years later, he lost the only sibling (brother) he had under circumstances that he could not remember clearly. The loss of his brother had a tremendous emotional impact on the interviewee; he was tense and emotional charged when remembering the passing of his brother.

After the death of his brother, the participant decided to move to Lubumbashi. When he arrived there, he joined other homeless children to live on the streets of Katuba. He was tested and told that he was HIV positive along with his friends shortly after he started living on the street.

'I took a train, and brought me here, in Lubumbashi. I did not have a place to stay then I joined a group of other friends, and we decided to live here in Katuba, in the streets' [Kibambe].

4.2.1.2. Participant 2

[Name: Dorcas; Age: 17 years; Sex: female; came from: District of Kamalondo]

She has been living on the street for the past three years. She described herself as a sex worker, a job she was forced to do in order to survive the street hardship. Dorcas dropped out of school when she was in grade six, primary school. She attempted to join the women's professional training centre which trains women on how to cook or decorate the house - this training does not require any formal qualification or school certification. Unfortunately, she could not start the training because of financial reasons due to the level of poverty that her family was faced with:

'My father wasn't working. My Dad and Mum are around. They are suffering a lot; they will go and beg money and food in town. I was always left with my little siblings at home. We remained behind with nothing, no foods. If they find some money, they will buy maize flour and vegetables; sometimes there was nothing to put in the vegetable (cooking oil) [Dorcas].

The participant left home because of poverty and misery that her family was subjected to:

'The suffering was too much...it was too much; then I decided that I have to go and look for better life because, myself, I don't want to suffer that way [Dorcas].

The participant discovered her HIV status shortly after the delivering of her first child. The baby did not survive.

4.2.1.3. Participant 3

[Name: Mamy; Age: 12 years; Sex: female; came from: Likasi]

Mamy was the youngest participant interviewed. She has been living on the street for the past two years and she knew about her HIV status a year ago. Both her parents died when she was six-years old. Subsequently, she stayed with her aunt for four years until she was accused of

being a witch and she was chased from the home. She could not find any other place to stay and therefore landed on the street.

'I was chased by my aunty – my father's sister. She said I witched her - the reason why she can't conceive. She was so upset with me, throwing all my belongings out of the house and asked me to go and never come back. I had no place to go and I decided to live on the street [Mamy].

4.2.1.4. Participant 4

[Name: Edo; Age: 14 years; Sex: male; came from: Kenya district]

Edo left his parents' house when he was eleven years old and since then he has been living on the street of Katuba. He attributed his stepmother's attitude towards him being the main reason that he ran away from home and now living on the street. He was diagnosed HIV positive at the age of 12.

'My step-mother beat me every day, one day she hit me with a broom to my head and I collapsed. I was almost dead- it was bad and I was hospitalized for long time. When come back home from hospital she continued beating me; one day I packed my clothes in a plastic bag and ran away from home for good and live on the street' [Edo].

4.2.1.5. Participant 5

[Name: Bex; Age: 15 years; Sex: male; came from: Quartier Bel' Air, Lubumbashi]

Bex's parents died from HIV/AIDS when he was ten years old. He then moved to stay with his uncle for four years. He described his stay at his uncle's home as bad experiences of abuse. He was always beaten up by his uncle's wife. When his uncle died, he decided to leave home and go live on the street. He was made aware of his HIV status at the age of 10.

'I was the only one who cleaned the house, fetched water. Everybody was sitting doing nothing. Whenever I told my uncle's wife that I was tired, she beat me up and deprived me to wear my clothes for days. I remained with one shorts and t-shirt for days. One day she burnt my clothes because I told her that I was tired and I had no strength to fetch water. My uncle never said anything to stop the abuses because he was always sick. When he died, I decided to run away from home and live on the street' [Bex].

4.2.1.6. Participant 6

[Name: Kenda; Age: 15 years; Sex: female; came from: Quartier Bel' Air, Lubumbashi]

The participant has been living in the street for the past three years. She ran away from an abusive aunt to live on the street. She knew of her HIV status two years ago.

'I was beaten every day by my aunt for no reason. I hate her and I couldn't stay in her home. I met a friend of mine who was living on the street and told me I was welcome to join them. Since then I have been living in the street'[Kenda].

4.2.1.7. Participant 7

[Name: Olivier; Age: 16 year; Sex: male; came from: Katuba, Lubumbashi]

The participant was orphaned at the age of five; both his parents having died from HIV/AIDS. He stayed at an orphanage until he turned 13 and then decided to join his friends (street children) to live on the street because he did not like the strict conditions imposed at the orphanage. He knew about his HIV/AIDS status when he was staying at the orphanage- they use to take them to the hospital for the treatment.

'The orphanage was not my place; people there are stringent; I was made to go to bed very early and have to wake up early. It was very boring place to stay, and I decided to join my friend on the street to make money'[Olivier].

4.2.1.8. Participant 8

[Name: Kabibi; Age: 16 years; Sex: female; came from: Mbujimayi]

Kabibi left Mbujimayi for Lubumbashi to look for her brother. However, when she got there, she was told that her brother had left the city a few years ago. She has been living on the street for the past two and a half years. She was diagnosed with HIV/AIDS 3 years ago.

'I did not have any other place to go and do not have any relative other than my brother here in Lubumbashi. I would love to go back home but did not have money, so I started spending my time on the streets'[Kabibi].

4.2.1.9. Participant 9

[Name: Ilunga; Age: 14 years; Sex: male; came from: Katuba Kananga]

Ilunga lost both his parents to HIV/AIDS at the age of nine. He stayed briefly in an orphanage and joined his friends to live on the street of Katuba because he could not bear the conditions at the orphanage. The participant has been staying on the street for more than three years. He discovered his HIV status while staying at the orphanage five years ago.

'At the orphanage, I only eat beans every day; life was not exciting for me there that's why I decided to run away and join my friends in Katuba's street. I can now make my own money and buy nice foods'[Ilunga].

4.2.1.10. Participant 10

[Name: Juma; Age: 13 years; Sex: male; came from: Katuba Salongo]

Juma's story was similar to that of Ilunga. He lost both his parent to HIV/AIDS at the age of five. He stayed at an orphanage until he turned ten years old and he joined his friends to live in the street of Katuba after that. He also discovered his HIV status while staying at the orphanage. Juma has been living on the street for three years,

'I did not like the place; I always do the same thing when my friends who left asked me to join me; I did not hesitate. I run away from the orphanage to join my friends on the street of Katuba' [Juma].

4.2.2. Description of key informants

4.2.2.1. Informant 1

[Name: Rose; Sex: female; – Title: Project coordinator at Zone de Santé Bukama. Area: Katuba]

Rose has been working at the centre for street children in Katuba for the past six years. She holds a diploma in nursing studies from the University of Lubumbashi. She is a single mother and has a passion for helping homeless children, especially the orphans as result of the death of both her parents to HIV/AIDS. The centre has an orphanage that accommodates children as young as two years old. At the time of the interview, the centre accommodated forty children, male and female aged below ten. When children turn ten, they are transferred to shelters or adopted. However, there were instances where children as old as 15 were still staying at the orphanage. Although the centre only offers accommodation to orphans aged below ten, homeless children above ten years old have access to other services provided there such as counselling, social support activities (distribution of clothes, foods and preservatives) and the provision of Antiretroviral Treatment (ART).

4.2.2.2. Informant 2

[Name: Dr Eduard; Sex: Male; Title: Medical Doctor at Katuba General Hospital; Area: Katuba]

Dr Eduard has been working at Katuba general hospital for the past seven years as a general medical practitioner and coordinator of a HIV/AIDS project which oversees the treatment of HIV positive street children and orphans. Katuba general hospital is a public institution sponsored by the central government of the DRC. Like other public health institutions, Katuba general hospital faces multiple challenges, from lack of funds to not having enough health professionals to attend to the needs of HIV positive people in general, and in particular that of HIV positive street children. One of the serious challenges is that of drugs supply, where the hospital runs out of drugs at times, especially the antiretroviral drugs.

The themes and sub-themes that emerged from the findings are discussed next.

4.3. Street children's experience of living on the street

4.3.1 Safety and security

Safety is the condition of being protected from danger or risk, while security is freedom from danger or fear (Young, 2003). All ten HIV positive street children had experienced safety and security issues at some point while living on the street. They faced all kinds of abuse from adults, law enforcers or police and the community in general. The participants felt that their entire lives were at the mercy of other people. One participant related a story of his friend who was kidnapped from the street by an older man who then raped him:

'A friend of mine was taken by a man in the car and he went with him for a while and brought him back with money. He was raped by that man who then gave him some money. We are looking for that old man, and we will arrest him. Since then my friend has been meeting with that guy to make more money, but he doesn't tell us the truth of the kind of business he is doing to have all that money'[Kibambe].

Some of the HIV positive street children live in abandoned houses, with no roof, no water or electricity compromising their safety.

After my test (HIV/AIDS), I continue living on the streets. I was raped two times; there are a lot of problems in the streets. We were sometimes staying in unfinished housing construction [Dorcas].

Street children are first in line to face the community's fury whenever there is a robbery just because they were living on the street. The community suspected them of being responsible for

break-ins or thefts in the community. One participant shared his experience of abuse from a community member:

'Somebody stole money from a taxi driver, now people are saying it must be us. Every time if something goes wrong or missing in this community, people blames us ...they wanted us to be arrested. They blame my friend that he stole the money of the taxi driver – money that he works for the entire night and have it stolen...it's painful, but it's not us. We are being blamed that we are thieves, but we are not' [Kibambe].

4.3.2. Prostitution

Prostitution seemed to be more common amongst the female participants than their counterpart male participants, although it does also happen amongst the males as demonstrated earlier. A sixteen years old female participant narrated how she started prostitution:

'I left the street and I went to stay with two old prostitute women, I was like their housekeeper, they do not own the house. It is the place where you found me; there are small rental rooms. They were taking money from potential clients on my behalf without my knowledge¹. One day I said: " No, I can't work anymore". They told me that if I don't want to work as housekeeper, then I have to join them to do prostitution, then I said ok I will do it. At beginning it was tough, I was scared since I lost the baby, but what was I going to eat or how was I going to live? That's why I decided to become a sex worker' [Dorcas].

4.3.3. Child labour

All street children interviewed were aged below eighteen years old, yet they started working when they were ten or nine years old. The kind of jobs the participants were forced to do varied from carrying out heavy containers of water from one place to another, to cleaning houses and domestic work. A fourteen-year-old male participant says:

'I try to get small job here and there, for instance, carrying heavy luggage of people in the markets or fetching water in the buckets for the restaurants to wash dishes in return I get something to eat' [Edo].

¹ The two old prostitute women were requesting money from male clients and promised them that they would have sex with Dorcas. This was done without Dorcas' consent or knowledge.

4.4. HIV screening process for street children

Although most of participants were aware of their HIV status, most of them had limited understanding prior and after the HIV diagnosis. Health Workers (responsible for the screening of the street children), would walk into street children spaces and conduct the screening for HIV. Prior to the screening, the participants were not told directly what was being done and why. The way the whole screening process took place did not give them an understanding of the condition they suffered from. As one participant stated:

'I saw two men come toward me and my friends (we were many) and they asked us to follow them to an open field in the neighborhood, not far from where I sleep. They said to us that they were going to help us - they will give us work and will send us to school. That very day, we were given cool drinks and bread. They had small needles and injected and take blood from our fingers, all of us. After sometime, they divided us in two groups and then they told the other group of my friends to go and they will call them later. Myself and other two friends, were told to remain in that open field with them. They told us that if we cooperate, they will help us. I did not know the kind of help they were saying. Few days later one of my two friends died' – [Kibambe].

Health workers used symbols or analogies to convey the message to the participant in the hope of getting their cooperation to be tested. Once found positive, as in the case of Kibambe, they would be convinced to take up treatment in exchange for a parcel of food or clothes. Participants were told that if they did not take the medication they would die, which scared them into taking the ARVs. However, few participants were fully aware of their condition. This was the case for one participant who learnt about her status only after the delivery her baby at the hospital:

'Doctors told me that they didn't know if it was AIDS for sure, they had to do more exams to determine if it was AIDS. I said, my God, let it not be AIDS. After 6 months I went for the exams, I was told that it was a fact that I had HIV/AIDS. I was very sad, and I was stressing; the doctors called me and told me that the disease I have is like a malaria if you don't take the drug, I will die. That is the way I knew that I have HIV/AIDS and I am following what I was told to do' [Dorca].

Although Dorcas was the same age as some of the other street children (with limited understanding of HIV/AIDS), she was knowledgeable about her condition, and from the interview, she appeared to be an intelligent and confident young woman. One of the key

informants, Dr Eduard stated that : ‘HIV status should only be revealed to mature children who will be able to handle the news’.

4.5. Current procedures for the treatment of HIV positive street children

Katuba general hospital offers health care including HIV/AIDS treatment. It is located in the outskirts of the district of Katuba; most of the patients have to walk long distances or take a bus to reach the hospital. The hospital has a special unit that treats HIV positive orphans and street children, which is free of charge for them. The treatment process starts with a diagnosis often conducted by a trained health service provider at the hospital. Once the HIV status is established, the child’s name is added to the hospital registry. HIV positive street children are reminded to come back to hospital after a month to collect their medicine, usually three days before the drugs are finished. This strategy was put in place by the hospital authority to avoid any interruption of the treatment. Upon arrival at the hospital, a new test for CD4 is conducted on HIV positive street children to determine the severity of infection and to assist the service provider to decide on a correct dosage for the next month. The one-month follow is very important for monitoring purpose i.e. to see how the children are coping given the fact that most of them do not have permanent addresses as they are living on the streets. However, the current process has its limitations and challenges that are discussed below.

4.6. Barriers to access HIV treatment

The interviews conducted with HIV positive street children and key informants revealed that the current system of accessing to treatment of HIV/AIDS by HIV positive street children remains a challenge.

4.6.1. Lack of access to transportation

All street children interviewed concurred that the distance between the place they live and the hospital (approximately 10 km), was a barrier. Rough terrain and lack of road infrastructure can be a challenge in itself in some areas, especially during the rainy season. Participants explained how difficult it was to find money for a bus ticket to transport them to the hospital every month which often prevented them from attending the hospital:

‘Other day I walked a long distance to the hospital to collect my medicine. I was very tired. The hospital is very far. I only go to the hospital if I have a bus ticket, I cannot walk again’ [Mamy].

Most of the HIV positive street children were not working and had no financial support from either the Government or local organizations. To raise funds, they had to beg on the street, and yet most of time, the money raised was not enough to purchase a bus ticket. Participants admitted that sometimes they made enough money from street begging activities, but still they had to choose between buying food and paying for a bus ticket. Hence, lack money to pay for transportation impedes the HIV positive street children from going for regular screening and collection of their repeat medication from the hospital.

4.6.2. Lack of food to take with medicines

All the street children interviewed stated that it was very difficult for them to take antiretroviral medication on an empty stomach. They described their experience of taking medicine without food as painful:

'The drugs are so strong when you take them without food; you get headache and dizziness; you become very weak. I don't take the medicine unless I have foods' [Bex].

HIV positive street children do not always have access to enough food for an active, healthy life because they lack money or other resources. Most of them will rather skip taking the medicine on an empty stomach for fear of the side effects of the drugs if they do so.

4.6.3. Attitude of health care workers

Each participant had his/her own experience in encountering service providers. There were those nurses who were described as not kind, but on the other hand those who were caring. For instance, one participant states that:

'When I arrive at the centre there are two ladies [nurses], I don't know them, but they are very kind to me, they take me as their child, they put a cartoon video for me to watch while waiting to take my medication. But if they are not there, other staff only tell us to wait outside, not talk to us kindly like the other two ladies [Kibambe].

While health workers' positive attitude encouraged HIV positive children to seek and adhere to treatment, their negative attitude had the opposite effect. Participants were offended by the negative attitude of health care workers which discouraged them from seeking treatment. As one participant stated:

'They look at us as animals and they don't want to be near us for fear of getting dirt. I personally, do not want to go back there to face that humiliation again' [Kenda].

4.6.4. Shortage of HIV drugs

From the conversation with one of the key informants, the main challenge remains the shortage of drugs that the hospital experiences from time to time. This situation has contributed negatively to treatment and adherence among HIV positive street children. They claim that the hospital sometimes ran out of medicine for days. All patients, including HIV positive street children, are then told to leave and return after a few days, or sometimes a week.

'The appointment cannot be respected because the stocks are not always enough for all the HIV positive patients. We give to each patient a quantity of medicines to last for a month, having reached thirty days, ideally we should have new stock ready. Unfortunately, it isn't always the case – we do run out of medicines sometimes. In the case we do not have medicines, we tell the HIV positive street children to go home and come after three to five days. Usually after five days children should have the products [Dr Eduard].

This unfortunate situation has a serious effect on HIV positive street children who struggle to get to the hospital in the first place, as one participant shared:

'Once I felt headache and seeing some pimples on my body, then I do go to hospital, I walk. Last time I went there, I was told to wait for a long time and told later that there were no medicines. I had to go back empty-handed, I am tired of going there' [Kimbabe].

Dr Eduard stated that there was a point where the hospital introduced a tracking system, i.e. contacting the patient in advance and let them know whether to come or not to fetch the drugs. This system could not work for HIV positive street children as most of them did not carry a mobile phone nor had a fix address. The information therefore was only delivered to them when presenting physically at the hospital.

4.6.5. Misconception surrounding HIV drugs

It is obvious that there were misconceptions around the side effects produced by the HIV drugs. One participant said:

'I am afraid of these drugs, my friend died shortly after taking these drugs, and all my friends keep remind me of that incident whenever I am about to take the medicine. It is very hard for me to continue to take these drugs when I know very well it killed my friend' [Kimbabe].

When he was asked if he truly believed that these medicines are causing him harm instead of curing his sickness, he participant responded:

'Big man, these medicines are killing us. One of my friends runs away; I remain alone. I wanted as well to run, but they kept me here, and I was told that they are going to help me' [Kimbabe].

All participants referred to the level of physical discomfort they felt after taking the antiretroviral treatment. For most of the HIV positive street children, the perception was that there was conspiracy to have them killed when asking them to take the medication. Negative perceptions about the medication made these street children not follow through with the treatment.

4.6.6. Prostitution as a barrier

A female participant shared her personal experience as a sex worker. She narrated how difficult it was to adhere to the treatment while on business because of lack of access.

'As sex worker, I have to be seen healthy, carrying medicine during my work when I am accompanied by clients will raise suspicious of my health status. Nobody likes to have sex with a sick HIV/AIDS woman ...I don't want to lose money' [Dorcás].

Sometimes the participant would stay at a client's place for days without taking any drugs for fear of being chased or beaten up by her male client once he discovers that she is HIV positive. At one time, the same participant had to travel to Kolwezi - a city situated in the South-East of Lubumbashi, which has attracted a number of sex workers because of the mining boom and the increasing number of "creuseurs"². Most of these young men are single and once paid, they indulged themselves in promiscuity. The participant stayed in Kolwezi for weeks on end, and as a result she ran out of treatment (ARVs). There was nowhere else she could access the ARVs, so she stayed for weeks without taking any medications. She described the experience as very painful because, during that period, she developed a rash on her body which she thought could have been as a result of not taking the medication.

² Name given to young people who extracted minerals illegally in private mining concessions - an area allocated by government or other body for the extraction of minerals.

4.6.7. HIV related stigma and discrimination

The street children raised concern about the location of the centre (a building at hospital designated for the treatment of HIV/AIDS), which is separate from the main hospital buildings. They claimed that this arrangement enforces stigma:

'You see for me to go and get the drug at the hospital is not easy, it is not only me who goes there, all people with the disease like mine go there. So, people, who have headache or other diseases they go there too. I meet there a lot of people³. So, I do feel a little bit of shy. Other people just want to know if you have HIV/AIDS and start making mockery of you' [Dorcas].

The female participants including the sex workers were worried about being seen by their clients or community members when going for their HIV treatment.

'Everybody knows that if somebody goes to that side of building, he/she is HIV positive' [Edo].

Another female participant when asked why she does not want to go to the hospital for her medicine, she said:

'This disease is a sickness of disgrace and humiliation. I don't want to be seen by other people getting in that building' [Dorcas].

There was not much of a relationship between the community members and the street children as noted earlier. This is why the HIV positive street children avoided by all means to be seen at the centre by community's members for fear of further rejection as they are already discriminated against for being street children.

Despite the above challenges in accessing HIV treatment, the HIV positive street children highlighted some facilitators that encouraged them to access treatment.

³ Other people (not HIV patients) go to a different building at the hospital, opposite to the centre for HIV/AIDS that is attached to the hospital. From there, they are able to see who goes to the centre for the HIV/AIDS. HIV positive street children therefore feel shy to be seen by those people.

4.7. Factors facilitating access to HIV/AIDS treatment

4.7.1. Encouragement from and positive attitude of service providers

Participants also highlighted some factors that made them continue accessing their medicine. One of those factors was the message of encouragement and persuasion from service providers.

'I was told by my doctor that HIV/AIDS is like any other disease, I will live longer if I take the medicine regularly otherwise' [Mamy].

This message has resonated well with most of the participants. Kind words, words of encouragement and good advice from caregivers and medical personnel had a positive impact on HIV positive street children to continue accessing their treatment.

For some participants, like the sex worker, the nurses' attitude constituted a motivating factor for not missing her hospital appointment.

'Whenever I arrive at the hospital to take my medicine, the nurses make sure that they pack for me free condoms because they know the kind of work I am doing, they are very kind' [Dorcas].

4.7.2. Material incentives

Another motivation factor was the distribution of clothes and food as an incentive for HIV positive street children. The coordinator of Zone de Santé Bukama acknowledged that without the food programme and distribution of clothes, no street children would have come to the centre for counselling and collection of their medication.

It is not easy to recruit the street children, especially those infected by the HIV/AIDS. I approached them with something in the hand to give, like food, clothes, etc. once they receive the handout they become more cooperative and engaging. [Rose]

The participants made some recommendations on how to improve access to health care for HIV positive street children.

4.8. Participants' recommendations

4.8.1. Accessible transportation to health facility

The access to transport to a healthcare facility was found to be one of the barriers. Both availability and affordability of transport were issues raised by all HIV positive street children in delaying access to health care. The participants made it clear that the antiretroviral treatment was vital in their life and a hope to live longer; hence, not able to access them was inhumane.

'I was told that if I do not take the medicine my life will be shorten yet no one seems to care to give us money for a bus ticket to collect the medication ... this is inhumane' [Edo].

They suggest that the health facilities should make transport arrangement for them or provide them with bus fare to be able to go to the hospital to collect the medicines.

4.8.2 Provision of food

Participants suggested that the hospital have a feeding scheme where HIV positive children could obtain the medication and food parcels too, which would see them through until the next appointment. The doctor also suggested that a feeding scheme for HIV positive street children could be sponsored by either the national or provincial government and be placed under the supervision or coordination of the hospital; in this way the feeding program would be sustainable and effective.

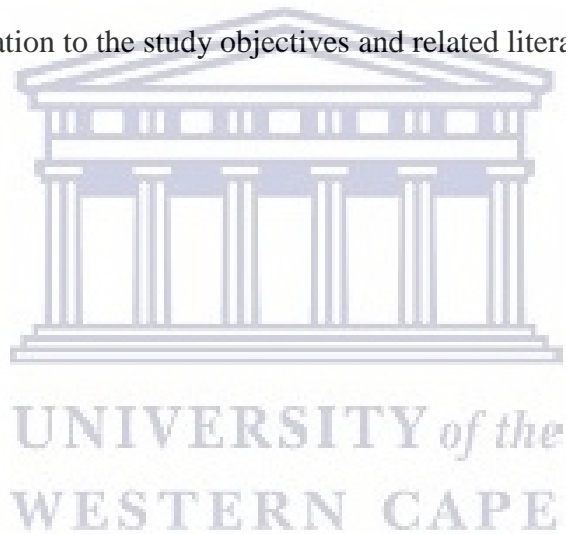
4.8.3. Financial support for non-profit organizations

There was a suggestion made by the coordinator of Zone de Santé Bukama about how to improve the service at the centre to be able to provide appropriate services to all HIV positive street children. She said that since the government does not have any programmes in Katuba that address HIV positive street children's predicament, the government should support local organizations in terms of funding so that they are able to improve services at the local level.

4.8.4 Addressing stigma

The participants suggested that the hospital has to rethink the process of dispensing antiretroviral medication because the current arrangement is not working for them. They would like the medication to be brought to their respective areas where they are living to avoid stigma. This means that their privacy will be secured and no one will know that they are sick. At the same time, the problem of transportation will be solved.

This chapter presented the main findings of the study. In general, HIV positive street children have experienced difficulties in accessing treatment of HIV/AIDS in the District of Katuba. Some of the reasons why they were faced with those challenges include lack of access to transportation due to absence of financial support. Lack of food to take with medicines was perceived by the participant as a major barrier to accessing the treatment. The perceptions of some participants on the negative attitude of health care workers made them reluctant to access the treatment. Shortage of HIV drugs and misconception surrounding HIV drugs were also factors which contribute to non-adherence to the treatment. Prostitution was perceived by mostly female participants as a negative factor as they ran out of medication at times and did not have timely access to further medication. Also, HIV related stigma was identified as another factor which discourages participants to seek the HIV treatment. The following chapter discusses and analyses these results in relation to the study objectives and related literature.



CHAPTER FIVE: DISCUSSION

5.1. Introduction

The purpose of this chapter is to discuss the key themes emerging from this study – individual level barriers, socio-economic barriers, community level barriers and health system barriers – in relation to the literature.

5.2 Individual level barriers

Individual level factors played a key role in whether participants sought HIV/AIDS treatment or not and was also a determining factor in treatment adherence. The study identified misconceptions about ART, lack of understanding of HIV/AIDS status, side effects of ART as key factors which served as challenges for the participants not accessing the treatment.

5.2.1. Misconceptions about antiretroviral therapy

Misconceptions about ART have been found to be common among HIV positive people (Davis et al., 2018). In the current study, the participants perceived ART to be the cause of death of their friends who were on ART. This finding is supported by a study conducted in three African countries (Kenya, South Africa and Tanzania) on the prevalence of HIV/AIDS myths and misconceptions which revealed that myths and misconceptions are at odds with how much participants know about HIV/AIDS (Mwamwenda, 2015). Better knowledge of the disease would have increased the participants chances to make an informed decision on the type of treatment they would like to have and commit seriously to adhering to the treatment by accessing their treatment regularly. A guide on top 10 HIV treatment myths and misconceptions recommends that: ‘It is very important that people living with HIV make decisions about their health based on sound knowledge and ability to dismiss myths and misconceptions about the HIV treatments’ (Living Positive Victoria, undated). With an increase in the use of ART in low-resource settings, children, like the participants, with HIV/AIDS tend to live longer (WHO, 2019) and hence the need to increase their knowledge on HIV treatment to dispel misconceptions and have a good understanding the importance of accessing their medication regularly.

5.2.2. Lack of understanding and knowledge of HIV/AIDS

Most of participants did not have a clear understanding of HIV/AIDS as a disease. A study conducted in Kinshasa, DRC (2008) found that thirty eight percent of street children interviewed

reported that HIV could be transmitted through a mosquito bite or witchcraft (Kayembe et al. 2008). This lacking of knowledge and understanding can be attributed to the current protocol observed by health personnel, in the DRC, of not disclosing HIV status to a child who is identified as immature, i.e. not able to cope with the emotional effect from HIV/AIDS status disclosure. There has been a debate around the disclosure of HIV positive status to the infected child. The specific age to which an HIV infected child can be disclosed to, was said to be between ages 4 and 6 years, and it was emphasized that health care providers should consider children's cognitive-developmental ability before any disclosure (Sariah et al., 2016). However, the lack of understanding of the disease seemed to create a lack of urgency among the participants to take the treatment seriously.

5.2.3. Side effects of ART

Another factor that emerged clearly from the findings was that participants were not motivated to seek the HIV treatment because of ART side effects. Studies have shown that sometimes, side effects that may not seem serious such as rash, nausea, or fatigue, can be a sign of a life-threatening condition (WHO, 2019). However, this can be managed if a proper channel of communication is maintained with a health care provider about any side effects that a person might have. A health care provider can determine the cause of the side effect and able to recommend ways to treat or manage the side effect (WHO, 2019). Being underprivileged and marginalized, participants did not seem keen to engage people in general, for fear of rejection. Therefore it could have been challenging for the participants to engage with health care providers on drug side effect experienced and, as a result, participants rather opted not to access the treatment further.

5.3. Socio-economic barriers

It is clear from the findings of the study that the barriers to accessing the HIV/AIDS treatment as perceived by the participants is determined by the factors that emanate mainly from socio-economic factors. Factors such as money to buy food and prostitution as a consequence of poor socio-economic status, prevent street children with HIV/AIDS from accessing treatment.

5.3.1. Lack of money for food

It was the perception of the HIV positive street children that lack of food contributed enormously to not adhere to the treatment of HIV/AIDS. There is strong evidence that street children do not

have money to buy food, thereby running the risk of malnutrition (Berezina, 2003). The participants made it clear that they could not take medicine if they had not eaten. Hence, adherence to the treatment was difficult because the participants experienced challenges in feeding themselves. The implication of this is that it could lead to drug resistance. The social context of poverty (one of major characteristics of street children) often changes the priorities of impoverished persons, frequently relegating important issues such as adherence to medication as less concerning than meeting basic subsistence needs (Riley et al., 2007). A study conducted in California among homeless and unstably housed women on basic subsistence needs and overall health has found that the factor with the strongest effect on overall mental health was unmet subsistence needs (i.e., food, hygiene, and shelter needs), followed by poor adherence to antiretroviral therapy (Riley et al., 2011). Most of the participants could not anticipate the danger of drug resistance because of their conviction i.e. if they do not have food, then they will not take medication. This finding suggests that the HIV positive street children will not fully adhere to their treatment until their subsistence needs are met. Failure to adhere to a treatment can have a harmful effect for the patients, which in turn leads to greater cost of care. However, the provision of incentives such as food, clothes and transport fare can have a positive impact on increasing access to treatment and thereby facilitating adherence among the HIV positive street children. In their systematic review of peer-reviewed empirical evaluations of incentives for medication adherence incentives DeFulio and Silverman (2012) found that incentives show substantial promise for antiretroviral adherence, but they question the sustainability of such incentives.

5.3.2. Negative effect of prostitution

Female participants perceived prostitution as a factor which stopped them from taking and accessing ART. Prostitution was used as a means of survival from poverty and as such participants stopped taking and accessing medication in order to appear healthy to their clients. Taking the medication would have raised suspicion of their HIV/AIDS status, resulting in lost opportunity to earn an income. Prostitution as a means of survival amongst street children in Katuba is confirmed by the Fondation Scelles findings which stated that 'prostitution is always a present option for street children to make money to provide for their own basic needs; hence, the bodies of street children become nothing more than a means of survival' (Fondation Scelles, 2016:03).

Another study conducted in the USA among street children has found that prostitution of children is closely tied to life on the streets. Street children may become involved in prostitution through loneliness and emotional vulnerability as well as homelessness and the need to survive (Gaetz et al., 2013). So, prostitution remained for most of the street children a means of survival through the exchange of sex for food, money, shelter, drugs, or protection, which puts them at risk of exposure to HIV (Gaetz et al., 2013).

5.4. Community level barriers

Double stigma of being a street child and HIV positive, which can be as a result of myths and lack of knowledge, was seen as a strong community level barrier to accessing HIV/AIDS treatment. The study revealed that participants perceived HIV/AIDS treatment in the public institutions, where they were seen by the public, contributed to stigma as HIV/AIDS was considered a disease of disgrace and humiliation. A study conducted by Campbell et al. (2005) supports the findings which showed that stigmatization serves as a strong deterrent to young people seeking HIV/AIDS treatment in general. HIV/AIDS is still regarded as taboo in the DRC and HIV-related stigma still a major concern and remains a synonym for death in the DRC (Khonde, 2006). There is limited knowledge among the people that someone with HIV can live a normal and healthy life (Khonde, 2006). Unlike South Africa, where HIV activists have had a strong voice for many years (Mbali, 2005), people in the DRC are not exposed to this kind of information, and even if they are, it is on a much smaller scale. HIV therefore remains shrouded in mystery and fear. This constitutes one of the major obstacles for the participants to be motivated to seek HIV/AIDS treatment.

The popular view amongst Congolese people is that people suffering or dying from HIV/AIDS are suspected to either having had contact with foreigners or have been living abroad. Research conducted in the region found that HIV/AIDS infection was lower in the DRC compared to its neighbouring countries such as Uganda, and Zambia. As a result, those who became infected with HIV were rejected and excluded as social outcasts. These perceptions seem to have permeated views about who is to blame for the misfortune of HIV infection thereby creating a culture of blame of others being responsible for their misfortune adding to the stigma (Khonde, 2006).

5.5. Health system barriers and facilitators

Health system factors included the disruptions in the HIV drugs supply and attitude of staff.

5.5. 1. Stock-out of HIV drugs

The stock-out of HIV drugs was perceived as a factor that contributed to discouragement of HIV positive children accessing HIV/AIDS treatment. Drugs shortages were reported as common, which had a negative impact on the health of HIV positive street children. In some instances, participants waited for weeks to acquire antiretroviral drugs. The study found that there was reluctance among the participants when told to return to the hospital to collect the drugs because of factors such as lack of transportation, food and stigma. It is therefore clear from the findings that even though the street children made an effort to access the treatment, the stock-out of HIV drugs created a barrier to them actually receiving the treatment, thereby threatening adherence too. If treatment is not adhered to as prescribed, it may result in further complication such as drug resistance which is on the rise and established as one of the greatest threats to global health and if it is not urgently addressed, it may result in death, an increase in new and hard-to-treat infections and increased health-care costs (WHO, 2019). Therefore, to attain high-quality ART service delivery, WHO (2019) recommends a routinely monitoring quality-of-care indicators associated with and predictive of the emergence of drug-resistant HIV; identifying gaps in service delivery and, if found to be present, swift implementation of specific and evidence-informed actions to improve clinic and programme performance (WHO, 2019).

5.5. 2. Health care workers' attitudes

The findings suggest that there were health care workers who showed respect towards the participants, while others did not show any respect or kindness to participants. This then had consequences for whether the street children accessed treatment or not. For instance, health care workers' positive attitude encouraged the participants to continue seeking HIV/AIDS treatment. The positive attitude of service providers can assist the street children in seeking HIV/AIDS treatment without feeling marginalised and therefore should be encouraged and supported.

However, the negative attitude of health care workers had a devastating negative impact on some of the participants. As a result, they decided not to access the treatment which would most likely be detrimental to their health. Much of the literature suggests that health care workers in Sub-Saharan Africa rarely show positive attitudes towards patients who access HIV counselling,

testing, and treatment services (Dapaah, 2016). Other studies support this finding. For instance, a survey conducted in Dhaka city found that doctors refused to treat street children because they appeared dirty (Eshita, 2018). It is important that the positive attitude of service providers should be encouraged and supported as it can assist the participants in seeking HIV/AIDS treatment without feeling marginalised.

The findings in this study reveal that being a street child predisposes them to challenging factors such as sexual exploitation, poverty, barriers to accessing healthcare and its related consequences, marginalization and stigma. These factors put them at risk for HIV. Accessing ART in turn has further challenges which also then impacts on adherence treatment. This is because the nature of street life probably has not allowed viable interventions to be adequately implemented (Mandalazi, Banda & Umar, 2013). Also, the environment exposure itself (street) may impact the HIV/AIDS prevention strategy, treatment and adherence (Marshall et al., 2009). These findings are supported by several studies, which established that a long duration of homelessness is a predictor of behavioral outcomes associated with poor sexual health (Ennett et al., 1999). Article 25 1 (United Nations, 1948: 4) states that all children, whether born in or out of wedlock, shall enjoy the same social protection. This is including the right to access all medical services, sanitation, adequate food, decent housing, healthy working conditions, and a clean environment. It is clear based on this Article that the fundamental human rights of these HIV positive children have been violated. It is now upon the society at large and public authority to remedy the inequalities so that HIV positive street children are able to enjoy all the fundamental rights such as right to adequate food, shelter, HIV/AIDS treatment and education.

5.6 Study limitations

All twelve participants for this study were drawn only from those attending the Zone de Santé Bukama in Katuba 1. The District of Katuba is one of the largest districts in Lubumbashi which comprises of a few zones (Katuba 1, 2, 3; Kananga, Salongo, Foyer and Kisanga). However, given the widespread prevalence of street children in Lubumbashi and Haut Katanga province in general, the researcher thought it was most convenient for purposes of this study and ease of access, to recruit participants from different zones in Katuba district only. The researcher did not attempt to recruit HIV positive street children from other zones for various reasons such as inexistence of centres or health clinics which meant it would have been difficult to access HIV

positive street children. It must be acknowledged that the findings of this study are drawn from a small, purposeful sample and it might be limited in their applicability. As such it cannot be assumed that they represent the range of experiences and opinions of all HIV positive street children living in the Katuba District and for that matter, HIV positive street children in other settings. There is always a risk of participants not divulging true information and experiences for fear of negative repercussions especially in their unique circumstances, as was evident in some cases in this study. However, this challenge was overcome once they were convinced of the importance and purpose of the study.



CHAPTER SIX: CONCLUSION

This chapter presents a conclusion of the study and some recommendations on improving the access to HIV/AIDS treatment by HIV positive street children in Katuba District, Lubumbashi.

6.1. Conclusion

This study aimed to explore HIV positive street children's access to HIV/AIDS treatment in the district of Katuba, Lubumbashi, DRC to better understand the challenges faced by the participants in accessing HIV treatment. The information obtained from this study will hopefully contribute to improve understanding of the HIV positive street children in relation to access to the HIV/AIDS treatment. This additional knowledge can provide a basis for the development of interventions that will be acceptable to this marginalised population in a bid to improve their accessibility to HIV/AIDS treatment and achieve their basic human rights.

Currently, there are thousands of children living on the streets of Lubumbashi who suffer from extreme poverty. They do not have access to adequate health, to food, housing and other basic needs. Street children are vulnerable and as a result they experience victimisation, abuse, discrimination and harassment. The street environment offers no protection against such vulnerability. Participants discussed in this study experience the disadvantages of socioeconomic deprivation and face additional barriers to health care services because of their social marginalisation.

The findings of this study indicate that there are multiple challenges faced by HIV positive street children in accessing health care services, including the HIV/AIDS treatment. These challenges include extremely poor socio-economic conditions, lack of transportation to access health services and lack of money for food to take with their medication, negative attitude of health care workers, shortage of HIV drugs, misconception surrounding HIV drugs, prostitution and HIV related stigma and discrimination. These obstacles are coupled with a lack of clear understanding of HIV/AIDS as disease. These findings corroborate with results from other studies and literature. Given what we know from this study about the challenges for HIV positive street children in accessing the health care services and the implications this has for the community and society at large, strategies to address the needs of HIV positive street children must be a priority for local and central government and those charged with providing health care. Responding to

the plight of these children requires not just implementation of health and social services but above all a legislative change, which reflects the needs and rights of the marginalised status of these children. It is clear from the findings of this study, that HIV positive street children have different needs, from those not HIV positive, since they are subject to different constraints and conditions. Interventions designed for HIV positive street children require more specific and localised attention based on their circumstances. The following recommendations are therefore proposed.

6.2. Recommendations

6.2.1. Individual level barriers

The misconceptions about HIV/AIDS and lack of understanding of it at participant / individual level had a negative impact on access to HIV/AIDS. This challenge can be addressed by adopting a proactive approach such as the use of peer educators to improve the street children's understanding. There is strong evidence that street children can make highly effective peer educators (Mitchell, Nyakake & Oling, 2007). Peer educators reinforce their own learning by instructing others and learners feel more comfortable and open when interacting with a peer. This study therefore recommends that local organisations consider working with HIV positive children through a peer outreach programme by using children who were on the streets previously, which can be more attractive to the street children thereby reducing their ignorance about HIV/AIDS.

6.2.2. Socio-economic barriers

This study has revealed how social-economic context within which the HIV positive street children live contributed negatively to accessing treatment for HIV/AIDS. The lack of money for food can be addressed by having feeding programmes at both the hospital and Zone de Santé Bokama. If these programmes are successfully implemented they can assist in addressing the challenges related to lack of food. Also, the feeding scheme can act as incentives for participants to seek and adhere to HIV/AIDS treatment. The feeding programmes can reduce the need for prostitution amongst the participants as most of them were doing it for the purpose of having money to buy food.

Most participants raise the issue of transportation to a healthcare facility being a barrier to seek the treatment. This can be resolved through two strategies: (1) hospital and health centres to

supply participants' with transport fare as which will attract can street children to actively attend to medical appointments. This will mean that the hospital (HIV department) and Zone de Santé Bokama need to have a budget set aside for this specifically. (2) To have a well thought through outreach program with well trained and dedicated community health carers who will be willing to travel to hand over antiretroviral drugs to street children; to help them to understand the risk involve if not taking and adhering to treatment; carrying out screening; and making referrals to health and social services when needed.

6.2.3. Community level barriers

Street children who are HIV/AIDS, face stigma at two levels, firstly as street children, secondly as an individual living with HIV/AIDS. Usually stigma occurs because people lack proper information. The community in general should be educated on the issue of street children and HIV/AIDS. As the street children phenomenon arising, community members are forced to share the space with street children hence, awareness campaigns to educate the community members on the social and medical challenges of these children will be beneficial in the short term for the local community and society at large

For the long-term strategy, the main causes (poverty, abuse and lack of parenthood) that forced participants onto the streets must be addressed through preventive initiatives – by reducing the numbers of families living in poverty and supporting families so they can raise their children safely. Therefore, local and central government should come up with programmes such as poverty reduction intervention strategies to target the most impoverished families and communities. Training such as parenting skills to equip beneficiaries with knowledge and skills where parenting is concerned should also be provided to improve parent/caregiver-child relationships.

6.2.4. Health system barriers and facilitators

In order to alleviate negative opinions that some of health staff might have, the hospital management, especially for the department dealing with HIV positive street children should include training and awareness of their staff making them aware of street children's needs, fears and specific challenges they face because of their circumstances.

The shortage of HIV drugs occurred quite often. This can be addressed by identifying the underlying causes of drug shortages and addressing these. Proactive measures can be taken by

using the available resources to help with a plan to manage the shortage of medicine. For instance, to develop a plan for managing drug shortages should include: assessment, preparation and contingency. Also, the hospital should outline responsibilities, communications and decision making during each phase and have a key person who takes the lead in implementation, coordination and monitoring to ensure that stock outs can be avoided as far as possible.

Further areas of development of successful health services for HIV positive street children would mean frequent medical attention; follow up by qualified medical personnel. This can only be achieved through a strong coalition of local organisations through lobbying and advocacy in realisation of the human right of these children by holding the government accountable for the equitable access of HIV positive children to HIV treatment. Two key documents that can be consulted are: 1) Global standards for quality health care services for adolescents: https://www.who.int/maternal_child_adolescent/documents/global-standards-adolescent-care/en/ 2) Guidelines on Best Practices for Adolescent- and Youth Friendly HIV Services: <https://bettercarenetwork.org/sites/default/files/sr-16-134-en.pdf>



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7. REFERENCES

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APPENDIX 1: PARTICIPANT INFORMATION SHEET (Street children / English)



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INFORMATION SHEET

Project Title: *HIV positive street children's access to treatment for HIV/AIDS in the District of Katuba, in the south-west of the city of Lubumbashi, Democratic Republic of Congo.*

What is this study about?

This is a research project being conducted by **Jean-Jacques Somwe** at the University of the Western Cape. We are inviting you to take part in this research project because you are HIV positive and living on the street in Katuba district now. The purpose of this research project is to know what your experiences as a street child with HIV/AIDS is of getting treatment for HIV/AIDS in the district of Katuba. It is hoped that with what you have to say, we can better understand what affects getting to treatment for HIV/AIDS which can help improve such services in Katuba district.

What will I be asked to do if I agree to participate?

The researcher will ask you to participate in an interview, and during the meeting, the researcher will ask you about your experience as HIV positive street child's access to treatment for HIV/AIDS in the District of Katuba and about suggestions on how to improve these services. We will be taking notes of our discussions during the interview with you. With your permission, we will make use of an audio tape recorder to get more information which is needed for this

research. The discussions will take approximately 45 minutes, and the interviews will take place where you feel most comfortable to talk.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, we will not put your name on the transcription, but instead, we will use a pseudonym. This pseudonym will be used by the researcher to link the transcript to your identity, and no one other than the researcher will have access to this information. The transcripts will be kept in a lockable filing cabinet, and we will use password-protected computer files. The research will also involve audio-taping. The audio-tapes will solely be used during transcribing and the data analysis process. The audio-tapes will be kept under lock and key no one other than the researcher and the transcriber will have access to them. If we write a report or article about this research project, your identity will be protected.

By legal requirements and professional standards, we will disclose to the appropriate individuals and authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

You may encounter some risks from participating in this research study. Talking to people about yourself or other have some risks. We will ensure such risks are minimized, but if happened we are going to take appropriate action such as to make an appropriate referral to a suitable professional for further assistance or intervention.

What are the benefits of this research?

You may not get any direct benefit from this study. However, the information we will gain from you may help in improving HIV positive street children's access to treatment for HIV/AIDS in the District of Katuba and other Districts in the city of Lubumbashi.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you

decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by **Jean-Jacques Somwe** at the University of the Western Cape. If you have any questions about the research study itself, please contact Florent Mpia at +243-997-803-988. Florent Mpia is a Medical Doctor who works at Mwangaza local NPO in Lubumbashi, Haut Katanga Province, DRC. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee

BIOMEDICAL RESEARCH ETHICS COMMITTEE

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APPENDIX 2: PARTICIPANT INFORMATION SHEET (Street children / French)



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FEUILLE D'INFORMATION

Titre du projet : *Accès des enfants séropositifs des rues au traitement anti-VIH / sida dans le district de Katuba, au sud-ouest de la ville de Lubumbashi, en République démocratique du Congo.*

De quoi parle cette étude ?

Il s'agit d'un projet de recherche mené par Jean-Jacques Somwe à l'Université de Western Cape. Nous vous invitons à participer à ce projet de recherche parce que vous êtes séropositif et que vous vivez dans la rue dans le district de Katuba. Le but de ce projet de recherche est de connaître votre expérience en tant qu'enfant des rues vivant avec le VIH / SIDA dans le cadre d'un traitement contre le VIH / SIDA dans le district de Katuba. Nous espérons que ce que vous avez à dire nous permettra de mieux comprendre ce qui affecte l'accès au traitement du VIH / SIDA, ce qui peut aider à améliorer ces services dans le district de Katuba.

Que devrais-je faire si j'accepte de participer ?

Le chercheur vous demandera de participer à une interview et au cours de la réunion, il vous posera des questions sur votre expérience en tant qu'enfant séropositif vivant dans la rue et bénéficiant d'un traitement contre le VIH / SIDA dans le district de Katuba et sur des suggestions

pour améliorer ces services. Nous prendrons des notes sur nos discussions lors de l'entretien avec vous. Avec votre permission, nous utiliserons un magnétophone pour obtenir plus d'informations nécessaires à cette recherche. Les discussions dureront environ 45 minutes et les entrevues auront lieu dans les endroits où vous vous sentez le plus à l'aise.

Ma participation à cette étude sera-t-elle confidentielle ?

Nous ferons de notre mieux pour que vos informations personnelles restent confidentielles. Pour protéger votre confidentialité, nous ne mettrons pas votre nom sur la transcription, mais nous utiliserons plutôt un pseudonyme. Le pseudonyme sera utilisé par le chercheur pour relier la transcription à votre identité, et nul autre que le chercheur n'aura accès à cette information. Les transcriptions seront conservées dans un classeur verrouillable et nous utiliserons des fichiers informatiques protégés par mot de passe. La recherche impliquera également l'enregistrement audio. Les bandes audios ne seront utilisées que pendant la transcription et le processus d'analyse des données. Les cassettes audios seront conservées sous clé, sauf le chercheur et le transcripteur y aura accès. Si nous écrivons un rapport ou un article sur ce projet de recherche, votre identité sera protégée.

Selon les exigences légales et les normes professionnelles, nous divulguerons aux personnes et autorités concernées les informations qui nous parviennent à notre attention concernant les cas de maltraitance ou de négligence à l'égard des enfants, ou de préjudice potentiel pour vous ou pour autrui. Dans ce cas, nous vous informerons que nous devons rompre la confidentialité pour nous acquitter de notre responsabilité légale de faire rapport aux autorités désignées.

Quels sont les risques de cette recherche ?

La participation à cette étude de recherche peut présenter certains risques. Parler aux gens de vous-même ou d'autres comporte certains risques. Nous veillerons à ce que ces risques soient minimisés, mais si cela se produit, nous allons prendre les mesures appropriées, telles que le renvoi approprié à un professionnel approprié, pour une assistance ou une intervention ultérieure.

Quels sont les avantages de cette recherche ?

Cette étude ne vous apportera peut-être aucun avantage direct. Cependant, les informations que nous obtiendrons de votre part pourraient contribuer à améliorer l'accès des enfants des rues séropositifs au traitement du VIH / sida dans le district de Katuba et d'autres districts de la ville de Lubumbashi.

Dois-je participer à cette recherche et puis-je arrêter de participer à tout moment ?

Votre participation à cette recherche est totalement volontaire. Vous pouvez choisir de ne pas participer du tout. Si vous décidez de participer à cette recherche, vous pouvez cesser de participer à tout moment. Si vous décidez de ne pas participer à cette étude ou si vous cessez de participer à n'importe quel moment, vous ne serez pas pénalisé ni ne perdrez les avantages auxquels vous avez autrement droit.

Et si j'ai des questions ?

Cette recherche est menée par Jean-Jacques Somwe à l'Université de Western Cape. Si vous avez des questions concernant l'étude de recherche proprement dite, veuillez contacter Florent Mpia au + 243-997-803-988. Florent Mpia est un médecin qui travaille à une ONG de Mwangaza, à Lubumbashi, dans la province du Haut Katanga, en RDC. Si vous avez des questions concernant cette étude et vos droits en tant que participant à la recherche, ou si vous souhaitez signaler tout problème que vous avez rencontré concernant l'étude, veuillez contacter :

Prof Uta Lehmann

Directeur: École de santé Publique

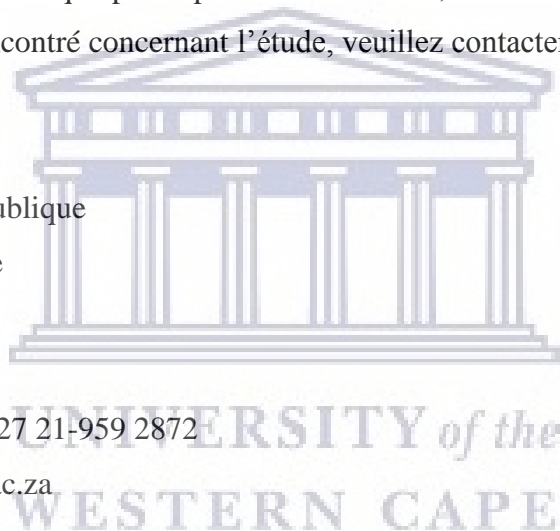
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Prof Anthea Rhoda

Doyen de la Faculté des sciences communautaires et de la santé

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Cette recherche a été approuvée par le comité d'éthique de la recherche biomédicale de l'Université de Western Cape.

RECHERCHE BIOMÉDICALE Committee ÉTHIQUE

Bureau de recherche

Nouveau bâtiment des arts,

Bloc C, dernier étage, salle 28

Université du Western Cape

Boite Privé X17

Bellville 7535



UNIVERSITY *of the*
WESTERN CAPE

APPENDIX 3: PARTICIPANT INFORMATION SHEET (Street children / Swahili)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

INFORMATION SHEET

Kichwa cha Mradi: *Utoaji wa VVU wa watoto wa mitaani wa VVU / UKIMWI katika Wilaya ya Katuba, kusini-magharibi mwa mji wa Lubumbashi, Jamhuri ya Kidemokrasia ya Kongo.*

Utafiti huu ni nini?

Huu ni mradi wa utafiti unaofanywa na **Jean-Jacques Somwe** katika Chuo Kikuu cha Western Cape. Tunakualika kushiriki katika mradi huu wa utafiti kwa sababu sasa unaishi mitaani kwa wilaya ya Katuba. Madhumuni ya mradi huu wa utafiti ni kupata ufahamu juu ya uzoefu wa upatikanaji wa watoto wa mitaani mitaani kwa VVU / UKIMWI katika wilaya ya Katuba. Inatarajia kuwa kwa ushirikishwaji wako, ufahamu wa nini kinachoathiri upatikanaji wa tiba ya VVU / UKIMWI utafanywa ambayo inaweza kusaidia kuboresha huduma hizo katika wilaya ya Katuba.

Je, nitaulizwa kufanya nini ikiwa nikubali kushiriki?

Mtafiti atakuomba uweze kushiriki katika mahojiano, na wakati wa mkutano huo, mtafiti atawauliza kuhusu uzoefu wako kama upatikanaji wa mtoto wa mitaani wa VVU kwa matibabu ya VVU / UKIMWI katika Wilaya ya Katuba na kuhusu maoni juu ya jinsi ya kuboresha huduma hizi . Tutachukua maelezo ya majadiliano yetu wakati wa mahojiano na wewe. Kwa

ruhosa yako, tutatumia rekodi ya tepi ya sauti ili kupata maelezo zaidi ambayo yanahitajika kwa utafiti huu. Majadiliano yatachukua muda wa dakika 45, na mahojiano utafanyika ambapo unasikia vizuri kuzungumza.

Je! Ushiriki wangu katika utafiti huu utahifadhiwa siri?

Tutajitahidi kuweka maelezo yako ya kibinafsi kwa siri. Ili kusaidia kulinda siri yako, hatutaweka jina lako kwenye usajili, lakini badala yake tutatumia pseudonym. Pseudonym hii itatumiwa na mtafiti kuunganisha nakala kwa utambulisho wako, na hakuna mwingine isipokuwa mtafiti atakayepata maelezo haya. Hati hizi zitahifadhiwa katika baraza la mawaziri la kufungua, na tutatumia faili za kompyuta zilizohifadhiwa na nenosiri. Utafiti huo pia utahusisha kuandika sauti. Tapeti za sauti zitatumika tu wakati wa kuandika na mchakato wa uchambuzi wa data. Kanda za redio zitawekwa chini ya kufungwa na ufunguo hakuna mtu mwingine isipokuwa mtafiti na mtunzi atawafikia. Ikiwa tunaandika ripoti au makala kuhusu mradi huu wa utafiti, utambulisho wako utahifadhiwa.

Kwa mahitaji ya kisheria na viwango vya kitaaluma, tutawafunua watu na mamlaka zinazofaa habari ambazo huja kwa tahadhari yetu kuhusu unyanyasaji wa watoto au kutokujali au kuwa na madhara kwa wewe au kwa wengine. Katika tukio hili, tutawajulisha kuwa tunapaswa kuvunja usiri ili kutimiza wajibu wetu wa kisheria kutoa taarifa kwa mamlaka zilizochaguliwa.

Je, ni hatari gani za utafiti huu?

Unaweza kukutana na baadhi ya hatari kutokana na kushiriki katika utafiti huu wa utafiti. Kuzungumza na watu kuhusu wewe mwenyewe au nyingine kuna hatari. Tutahakikisha kuwa hatari hizo zinapunguzwa, lakini ikiwa tumefanya tutafanya hatua zinazofaa kama vile kutoa rufaa sahihi kwa mtaalamu mzuri kwa msaada zaidi au kuingilia kati.

Je, ni faida gani za utafiti huu?

Huwezi kupata faida yoyote ya moja kwa moja kutoka kwa utafiti huu. Hata hivyo, taarifa tutakayopata kutoka kwako inaweza kusaidia kuboresha upatikanaji wa tiba ya watoto wa mitaani wa VVU / UKIMWI katika Wilaya ya Katuba na Wilaya nyingine katika mji wa Lubumbashi.

Je, ni lazima niwe katika utafiti huu na nipate kuacha kushiriki wakati wowote?

Ushiriki wako katika utafiti huu ni kwa hiari kabisa. Unaweza kuchagua kutoshiriki. Ikiwa unaamua kushiriki katika utafiti huu, unaweza kuacha kushiriki wakati wowote. Ikiwa unachagua kushiriki katika utafiti huu au ukiacha kuhusika wakati wowote, hutaadhibiwa au kupoteza faida yoyote ambayo unastahiki.

Nini kama nina maswali?

Utafiti huu unafanywa na Jean-Jacques Somwe katika Chuo Kikuu cha Western Cape. Ikiwa una maswali yoyote kuhusu utafiti wa utafiti yenyewe, tafadhali wasiliana na Florent Mpia saa + 243-997-803-988. Florent Mpia ni Daktari wa Madaktari ambaye anafanya kazi katika NPO ya eneo la Mwangaza huko Lubumbashi, Mkoa wa Haut Katanga, DRC. Je! Unapaswa kuwa na maswali yoyote kuhusu utafiti huu na haki zako kama mshiriki wa utafiti au unataka kutoa ripoti yoyote ya matatizo uliyoyaona kuhusiana na utafiti, tafadhali wasiliana na:

Prof Uta Lehmann

Mkurugenzi: Shule ya Afya ya Umma

Chuo Kikuu cha Rasi ya Magharibi

Kibinafsi Private X17

Bellville 7535

Tel: +27 21-959 2809 Faksi: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

Prof Anthea Rhoda

Mshauri wa Kitivo cha Sayansi za Jamii na Afya

Chuo Kikuu cha Rasi ya Magharibi

Kibinafsi Private X17

Bellville 7535

chs-deansoffice@uwc.ac.za

Utafiti huu umeidhinishwa na Kamati ya Maadili ya Mafunzo ya Biomedical ya Chuo Kikuu cha Western Cape

UFUNZO WA UFUNZO WA UCHIMUJI WA UFUNZO

Ofisi ya Utafiti

Jengo la Sanaa,

C-Block, sakafu ya juu, chumba 28

Chuo Kikuu cha Rasi ya Magharibi

Kibinafsi Private X17

Bellville 7535



APPENDIX 4: PARTICIPANT INFORMATION SHEET (Key Informant / English)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

INFORMATION SHEET

Project Title: *HIV positive street children's access to treatment for HIV/AIDS in the District of Katuba, in the south-west of the city of Lubumbashi, Democratic Republic of Congo.*

What is this study about?

This is a research project being conducted by **Jean-Jacques Somwe** at the University of the Western Cape. We are inviting you to participate in this research project because you are providing service to street children. The purpose of this research project is to gain insight into the experiences of street children with HIV/AIDS's access to treatment for HIV/AIDS in the district of Katuba. It is hoped that with your participation, an understanding of what affects the access to treatment for HIV/AIDS will be elicited which can help improve such services in Katuba district.

What will I be asked to do if I agree to participate?

You will be asked to participate in an interview conducted by the researcher. During the interview you will be asked about your experience and opinion on the issue of street children with HIV/AIDS's access to treatment for HIV/AIDS in Katuba district and about suggestions on how to improve these services. During the interview we will be taking notes of our discussion and with your permission will also use an audio tape recorder in order to adequately collect all

the information that is needed for the study. The interviews will last approximately 45 minutes and the interviews will take place at your office.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity we will do our best to keep your personal information confidential. To help protect your confidentiality, we will not put your name on the transcription but instead we will use a pseudonym. This pseudonym will be used by the researcher to link the transcript to your identity and no one other than the researcher will have access to this information. The transcripts will be kept in a lockable filing cabinet and we will use password protected computer files. The research will also involve audio-taping. The audio-tapes will solely be used during transcribing and the data analysis process. The audio-tapes will be kept under lock and key no one other than the researcher and the transcriber will have access to them. If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

There may be some risks from participating in this research study. All human interaction and talking about self or other carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the street children with HIV/AIDS's access to treatment for HIV/AIDS in

Katuba district. We hope that, in the future, other people might benefit from this study through improved understanding of street children with HIV/AIDS predicament where the treatment for HIV/AIDS it concerns.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by **Jean-Jacques Somwe** at the University of the Western Cape. If you have any questions about the research study itself, please contact Florent Mpia at +243-997-803-988. Florent Mpia is a Medical Doctor who works at Mwangaza local NPO in Lubumbashi, Haut Katanga Province, DRC. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann

Director: School of Public Health

University of the Western Cape

Private Bag X17

Bellville 7535

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Research Office

New Arts Building,

C-Block, Top Floor, Room 28

University of the Western Cape

Private Bag X17

Bellville 7535



APPENDIX 5: PARTICIPANT INFORMATION SHEET (Key Informant / French)



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Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

FEUILLE D'INFORMATION

Titre du projet : *Accès des enfants séropositifs des rues au traitement anti-VIH / sida dans le district de Katuba, au sud-ouest de la ville de Lubumbashi, en République démocratique du Congo.*

De quoi parle cette étude ?

Ceci est un projet de recherche mené par Jean-Jacques Somwe à l'Université du Western Cape. Nous vous invitons à participer à ce projet de recherche car vous êtes un prestataire de services pour enfants des rues. L'objectif de ce projet de recherche est de mieux comprendre les expériences des enfants des rues en matière de traitement du VIH / SIDA dans le district de Katuba. On espère qu'avec votre participation, une compréhension de ce qui affecte l'accès au traitement du VIH / SIDA sera obtenue, ce qui peut aider à améliorer ces services dans le district de Katuba.

Que me demanderai-je de faire si j'accepte de participer ?

Vous serez invité à participer à une entrevue menée par un chercheur. Au cours de l'entretien, vous serez interrogé sur votre expérience et votre opinion sur la question de l'accès des enfants des rues au traitement du VIH / SIDA dans cette communauté (district de Katuba) et sur les suggestions pour améliorer ces services. Au cours de l'entretien, nous prendrons note de notre

discussion et utiliserons également un magnétophone afin de collecter adéquatement toutes les informations nécessaires à l'étude. Les entretiens dureront environ 45 minutes et les entretiens auront lieu dans votre bureau.

Est-ce que ma participation à cette étude resterait confidentielle ?

Les chercheurs s'engagent à protéger votre identité et la nature de votre contribution. Pour garantir votre anonymat, nous ferons de notre mieux pour garder vos informations personnelles confidentielles. Pour aider à protéger votre confidentialité, nous ne mettrons pas votre nom sur la transcription mais nous utiliserons un pseudonyme. Le chercheur utilisera ce pseudonyme pour associer la transcription à votre identité et personne d'autre que le chercheur n'aura accès à cette information. Les transcriptions seront conservées dans un classeur verrouillable et nous utiliserons des fichiers informatiques protégés par mot de passe. La recherche impliquera également l'enregistrement audio. Les bandes audio seront uniquement utilisées lors de la transcription et du processus d'analyse des données. Les bandes audio seront gardées sous clé et personne d'autre que le chercheur et le transcripteur n'y auront accès. Si nous rédigeons un rapport ou un article sur ce projet de recherche, votre identité sera protégée.

Conformément aux exigences légales et / ou aux normes professionnelles, nous divulguerons aux personnes et / ou aux autorités compétentes les informations qui nous parviennent concernant la maltraitance, la négligence ou un préjudice potentiel pour vous ou d'autres personnes. Dans ce cas, nous vous informerons que nous devons briser la confidentialité pour remplir notre responsabilité légale de signaler aux autorités désignées.

Quels sont les risques de cette recherche ?

La participation à cette étude de recherche peut avoir certains risques. Une interaction humaine et parler de soi ou de l'autre comportent certains risques. Nous minimiserons néanmoins ces risques et agirons rapidement pour vous aider si vous ressentez un inconfort, psychologique ou autre pendant le processus de votre participation à cette étude. Si nécessaire, une référence appropriée sera faite à un professionnel approprié pour une assistance ou une intervention ultérieure.

Quels sont les avantages de cette recherche ?

Cette recherche n'a pas pour but de vous aider personnellement, mais les résultats pourraient aider le chercheur à mieux connaître l'accès des enfants des rues au traitement du VIH / SIDA dans le district de Katuba. Nous espérons qu'à l'avenir, d'autres personnes pourraient bénéficier de cette étude grâce à une meilleure compréhension de la situation des enfants des rues et sur l'affaire de traitement du VIH / SIDA.

Dois-je participer à cette recherche et puis-je cesser de participer à tout moment ?

Votre participation à cette recherche est entièrement volontaire. Vous pouvez choisir de ne pas participer du tout. Si vous décidez de participer à cette recherche, vous pouvez cesser de participer à tout moment. Si vous décidez de ne pas participer à cette étude ou si vous arrêtez de participer à tout moment, vous ne serez pas pénalisé ou ne perdrez aucun des avantages auxquels vous êtes par ailleurs admissible.

Et si j'ai des questions ?

Cette recherche est menée par Jean-Jacques Somwe à l'Université de Western Cape. Si vous avez des questions concernant l'étude de recherche proprement dite, veuillez contacter Florent Mpia au + 243-997-803-988. Florent Mpia est un médecin qui travaille à une ONG de Mwangaza, à Lubumbashi, dans la province du Haut Katanga, en RDC. Si vous avez des questions concernant cette étude et vos droits en tant que participant à la recherche, ou si vous souhaitez signaler tout problème que vous avez rencontré concernant l'étude, veuillez contacter :

Prof Uta Lehmann

Directeur: École de santé Publique

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E-mail: soph-comm@uwc.ac.za

Prof Anthea Rhoda

Doyen de la Faculté des sciences communautaires et de la santé

Université du Western Cape
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Cette recherche a été approuvée par le comité d'éthique de la recherche biomédicale de l'Université de Western Cape.

RECHERCHE BIOMÉDICALE ADMINISTRATION ÉTHIQUE

Bureau de recherche
Nouveau bâtiment des arts,
Bloc C, dernier étage, salle 28
Université du Western Cape
Boite Privé X17
Bellville 7535



UNIVERSITY *of the*
WESTERN CAPE

APPENDIX 6: CONSENT FORM (Key Informant / English)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 **Fax:** 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

CONSENT FORM

Title of Research Project: *HIV positive street children's access to treatment for HIV/AIDS in the District of Katuba, in the south-west of the city of Lubumbashi, Democratic Republic of Congo.*

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that the audio recording will be used during the study. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name:

Participant's signature:

Date:

APPENDIX 7: CONSENT FORM (Key Informant / French)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 **Fax:** 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

FORMULAIRE DE CONSENTEMENT

Titre du projet de recherche: *Accès des enfants séropositifs des rues au traitement anti-VIH / sida dans le district de Katuba, au sud-ouest de la ville de Lubumbashi, en République démocratique du Congo.*

L'étude m'a été décrite dans un langage que je comprends. Mes questions sur l'étude ont été répondues. Je comprends ce que ma participation impliquera et j'accepte de participer de mon propre choix et de ma propre volonté. Je comprends que mon identité ne sera divulguée à personne. Je comprends que l'enregistrement audio sera utilisé pendant l'étude. Je comprends que je peux me retirer de l'étude à tout moment sans donner de raison et sans crainte de conséquences négatives ou de perte d'avantages.

Nom du participant:

Signature du participant:

Date:

APPENDIX 8: ASSENT FORM (Street children/ English)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

ASSENT FORM

Title of Research Project: HIV positive street children's access to treatment for HIV/AIDS in the District of Katuba, in the south-west of the city of Lubumbashi, Democratic Republic of Congo.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that the audio recording will be used during the study. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name:

Participant's signature:

Date:

APPENDIX 9: ASSENT FORM (Street child / French)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

FORMULAIRE DE CONSENTEMENT

Titre du projet de recherche: *Accès des enfants séropositifs des rues au traitement anti-VIH / sida dans le district de Katuba, au sud-ouest de la ville de Lubumbashi, en République démocratique du Congo.*

L'étude m'a été décrite dans un langage que je comprends. Mes questions sur l'étude ont été répondues. Je comprends ce que ma participation impliquera et j'accepte de participer de mon propre choix et de ma propre volonté. Je comprends que mon identité ne sera divulguée à personne. Je comprends que l'enregistrement audio sera utilisé pendant l'étude. Je comprends que je peux me retirer de l'étude à tout moment sans donner de raison et sans crainte de conséquences négatives ou de perte d'avantages.

Nom du participant:

Signature du participant:

Date:

APPENDIX 10: ASSENT FORM (Street children/ Swahili)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 **Fax:** 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

FUNA FUNA

Kichwa cha Mradi wa Utafiti: *Utoaji wa VVU wa watoto wa mitaani wa VVU / UKIMWI katika Wilaya ya Katuba, kusini-magharibi mwa mji wa Lubumbashi, Jamhuri ya Kidemokrasia ya Kongo.*

Utafiti umeelezwa kwangu katika lugha ambayo ninayielewa. Maswali yangu kuhusu utafiti yamejibiwa. Ninaelewa nini ushiriki wangu utahusisha na nikubali kushiriki katika uchaguzi wangu mwenyewe na mapenzi ya bure. Ninaelewa kuwa utambulisho wangu hautafunuliwa kwa mtu yeyote. Ninaelewa kuwa rekodi ya redio itatumika wakati wa utafiti. Ninaelewa kwamba nipate kujiondoa kwenye utafiti wakati wowote bila kutoa sababu na bila hofu ya matokeo mabaya au kupoteza faida.

Jina la mshiriki:

Sahihi ya mshiriki:

Tarehe:

APPENDIX 11: CONSENT FORM (NPO Person / English on behalf of street children)



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E-mail: soph-comm@uwc.ac.za

CONSENT FORM

Title of Research Project: *HIV positive street children's access to treatment for HIV/AIDS in the District of Katuba, in the south-west of the city of Lubumbashi, Democratic Republic of Congo.*

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what the children will involve and I therefore give permission for children to participate of their own choice and free will. They understand that their identity will not be disclosed to anyone. They understand that the audio recording will be used during the study. They understand that they may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name:

Participant's signature:

Date:

APPENDIX 12: CONSENT FORM (NPO person / French on behalf of street children)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

FORMULAIRE DE CONSENTEMENT

Titre du projet de recherche: *Accès des enfants séropositifs des rues au traitement anti-VIH / sida dans le district de Katuba, au sud-ouest de la ville de Lubumbashi, en République démocratique du Congo.*

L'étude m'a été décrite dans un langage que je comprends. Mes questions sur l'étude ont été répondues. Je comprends ce que les enfants vont impliquer et je donne donc la permission aux enfants de participer de leur propre choix et de leur libre arbitre. Ils comprennent que leur identité ne sera divulguée à personne. Ils comprennent que l'enregistrement audio sera utilisé pendant l'étude. Ils comprennent qu'ils peuvent se retirer de l'étude à tout moment sans donner de raison et sans crainte de conséquences négatives ou de perte d'avantages.

Nom du participant:

Signature du participant:

Date:

APPENDIX 13: IN-DEPTH INTERVIEW GUIDE FOR STREET CHILDREN (English)

1. Tell me about your experience living on the street

Probe: for sleeping arrangements; access to and quality of food; safety issues

2. Tell me about any medical treatment you've received.

3. Tell me about your HIV treatment

Probe: their experience of being tested for HIV; what the motivation was for being tested

4. Tell me what happened after testing

Probe: whether they start treatment after being diagnosed, If yes, was treatment ever interrupted? If not, why was treatment interrupted?

5. Are you currently receiving any HIV-related treatment?

If yes, what type of treatment? If not, why are you not currently on treatment?

6. Do you ever go for periods of time without treatment or miss doses?

Probe: for why doses were missed or treatment discontinued e.g. distance to health facility, attitude of staff etc.

7. Is there anything that you think will make access to HIV treatment better for street children?

8. What else would you like to share with me about the street children (like yourself) access to treatment for HIV/AIDS in Katuba?

APPENDIX 14: IN-DEPTH INTERVIEW GUIDE FOR STREET CHILDREN (French)

1. Parlez-moi de votre expérience dans la rue.

Sonde: pour les arrangements de sommeil; accès et qualité des aliments; des problèmes de sécurité

2. Parlez-moi de tout traitement médical que vous avez reçu.

3. Parlez-moi de votre traitement du VIH.

Sonde: leur expérience du test du VIH; quelle était la motivation pour être testé

4. Parlez-moi ce qui s'est passé après les tests.

Sonde: s'ils commencent un traitement après avoir été diagnostiqués, si oui, le traitement at-il été interrompu? Si non, pourquoi le traitement a-t-il été interrompu?

5. Recevez-vous actuellement un traitement lié au VIH?

Sonde: Si oui, quel type de traitement? Sinon, pourquoi n'êtes-vous pas actuellement en traitement?

6. Avez-vous déjà passé des périodes sans traitement ou des doses manquantes?

Sonde: pourquoi les doses ont-elles été manquées ou le traitement interrompu, par exemple, distance d'y arriver au centre de santé, attitude du personnel, etc.

7. Selon vous, y aura-t-il quelque chose qui améliorera l'accès au traitement du VIH pour les enfants des rues?

8. Que souhaiteriez-vous partager avec moi sur l'accès des enfants des rues (comme vous) au traitement du VIH / SIDA à Katuba?

APPENDIX 15: IN-DEPTH INTERVIEW GUIDE FOR STREET CHILDREN (Swahili)

1. *Niambie juu ya uzoefu wako ulioishi mitaani*

Probe: kwa mipango ya kulala; upatikanaji na ubora wa chakula; masuala ya usalama

2. **Niambie kuhusu matibabu yoyote uliyopata.**

3. *Niambie kuhusu matibabu yako ya VVU*

Probe: uzoefu wao wa kupima VVU; nini motisha ilikuwa ya kupimwa

4. *Niambie kilichotokea baada ya kupima*

Probe: kama wanaanza matibabu baada ya kugunduliwa, Ikiwa ndio, matibabu ilikuwa milele kuingiliwa? Ikiwa sio, kwa nini tiba iliingiliwa?

5. *Je! Sasa unapokea matibabu yoyote yanayohusiana na VVU?*

Probe: Ikiwa ndio, ni aina gani ya matibabu? Ikiwa sio, kwa nini hupatiki sasa?

6. *Je! Umewahi kwenda kwa kipindi cha muda bila matibabu au kukosa dozi?*

Probe: kwa nini dozi zimekosa au tiba imekoma k.m. umbali wa kituo cha afya, mtazamo wa wafanyakazi nk.

7. *Je, kuna kitu ambacho unafikiri kitasaidia kupata matibabu ya VVU bora kwa watoto wa mitaani?*

8. *Nini kingine ungependa kushirikiana nami kuhusu watoto wa mitaani (kama wewe mwenyewe) upatikanaji wa matibabu ya VVU / UKIMWI Katuba?*

APPENDIX 16: IN-DEPTH INTERVIEW GUIDE FOR KEY INFORMANT (English)

1. What is your opinion regarding the Street children with HIV/AIDS's access to treatment for HIV/AIDS in the District of Katuba?
2. In your opinion, what are major challenges for the street children with HIV/AIDS to access HIV/AIDS treatment in Katuba?
3. How do you think the services can be improved if you think it needs to be improved?

APPENDIX 17: IN-DEPTH INTERVIEW GUIDE FOR KEY INFORMANT(French)

1. Quelle est votre opinion sur l'accès des enfants de la rue vivant avec le VIH / SIDA à un traitement anti-VIH / SIDA dans le district de Katuba?
2. A votre avis, quels sont les principaux défis pour les enfants des rues vivant avec le VIH / SIDA à accéder au traitement du VIH / SIDA à Katuba?
3. Comment pensez-vous que les services peuvent être améliorés?

APPENDIX 18: PERMISSION LETTER FROM UWC



OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION

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12 December 2018

Mr J-J K Somwe
School of Public Health
Faculty of Community and Health Science

Ethics Reference Number: BM18/9/16

Project Title: Street children's access to treatment for HIV/AIDS in the district of Katuba, in the south-west of the city of Lubumbashi, Democratic, Democratic Republic of Congo (DRC).

Approval Period: 12 December 2018 – 12 December 2019

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

A handwritten signature in black ink that reads 'Josias'.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*


BMREC REGISTRATION NUMBER -130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE

APPENDIX 19: PERMISSION LETTER FROM MINISTRY OF HEALTH, DRC

République Démocratique du Congo
Province du Haut - Katanga

Lubumbashi, le 25 JAN 2019



DIVISION PROVINCIALE DE LA SANTE
Bureau du Chef de Division

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N° DPS/H KAT/900/CD/PX/ /JMK/ 2019

Copie pour information à:

- Madame la Responsable du Comité d'éthique de la Recherche
Université de Western Cape
Afrique du Sud

Objet : Avis favorable



A Monsieur Jean Jacques KALONJI SOMWE
Ecole de Santé Publique/Faculté des Sciences
De Santé et de la Communication
Université de WESTERN CAPE
Afrique du Sud

Monsieur,

J'accuse bonne réception de la lettre du Comité d'éthique de la Recherche de l'Université de Western Cape relative à l'approbation de votre projet "Accès des enfants des rues au traitement du VIH/SIDA dans le District de Katuba" et vous remercie pour le choix porté sur cette Zone de Santé.

Y faisant suite, je tiens à vous assurer que notre d'accord est donné pour vos recherches, néanmoins il serait souhaitable que le protocole nous soit également partagé pour une meilleure imprégnation du projet.

Agréer, Monsieur, l'expression de mes sentiments patriotiques.



**UNIVERSITY of the
WESTERN CAPE**

LE CHEF DE DIVISION PROVINCIALE
DE LA SANTE/HAUT KATANGA

Dr Jean Marie KAPWEMBE KISASEMBE