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AN INVESTIGATION INTO THE CHALLENGES FACED BY THOSE INFECTED WITH HIV AT BIRTH, THE SUPPORT SYSTEMS AVAILABLE TO THEM AND THEIR EFFECTIVENESS: CASE STUDY MASHONALAND WEST PROVINCE.

BY

MAZHAMBE JANE

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GWERU ZIMBABWE

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DEDICATION

I dedicate this document to my late husband Talent Mazhambe and our beautiful children Danielle M, Donnell and Daisy Mazhambe. You are my life guys, I love you.

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I owe it to my supervisor Dr P Bhebhe, to acknowledge his work and dedication, he read every word of this research and was very patient to correct and advise even at the worst of times.

To my fellow comrades of Adult Education; Kungeni Phillip, Sanangura Suggest, Mpofu Emile and Nyakonda Harmony I say '*together we succeeded in pulling this heavy wagon let's not tire but continue the good work.'*

I would like to thank my mother Elizabeth Mutyiri and my young brother Emmanuel Mutyiri for encouraging me and nurturing my potential. I wouldn't have done it without your support guys, I love you.

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Well, all is not because I am special or clever, but because of Jehovah's endless grace.

ABSTRACT

Children born with HIV survive with the pain and fears that come with it. They face many challenges some of which may even be life threatening. This therefore, requires them to have a clear understanding of their status and an effective and reliable support system so that they can effectively deal with these challenges. Mashonaland West Province is one of the Provinces with the highest HIV prevalence, prostitution, early marriages and pregnancies, hence this research intends to better help the community and the nation as a whole, better deal with this predicament. An inquiry was made on the HIV perinatals understanding of their status and the ART regimen, the challenges they face, the support systems available to them and their efficiency. Questionnaires, interviews and observations were used to collect data from nurses, HIV infected perinatals and guardians. Results showed that the challenges they are facing include stigma, disclosure, poverty, sex and reproductive issues, feelings of resentment, lack inefficient support system and access to ARVs. Identified support systems were local support groups, information walls, ART regimen, hospital counselling services, churches and the family institution. All these support systems were not given a total thumps up by the very people they are mostly designed for. Therefore, among other recommendations, the government and NGO's should erect a suitable and reliable support system and also expand services of Africaid Zvandiri Adolescent Support Group across the nation. Lastly, the media and publishing companies should create a platform for the HIV perinatals to share, learn, have fun and address their concerns.

ACRONYMS/ ABBREVIATIONS

AIDS	:	Acquired Immune Deficiency Syndrome
HIV	:	Human Immuno-deficiency Virus
ART	:	Antiretrival Therapy
NGO	:	Non –governmental Organisations
UN	:	United Nations
UNAIDS	:	United Nations Programme on HIV/AIDS
WHO	:	World Health Organisation
MTCT	:	Mother –to Child Transmission

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CHAPTER ONE

THE RESEARCH PROBLEM

1.0 INTRODUCTION

"No child should be born with HIV; no child should be an orphan because of HIV; no child should die due to lack of access to treatment," urged Ebube Sylvia Taylor, an eleven year old born free of HIV, to world leaders gathered in New York to share progress made towards achieving the Millennium Development Goals by 2015. Brave as this plea may seem, I feel, many like Ebube, seem to be forgetting that there actually is a considerable population that was born with HIV, survived with it and are still surviving with it. Innocent as these children are, they face tremendous challenges that cannot be possibly matched to any other. Yes the pain, the distress, the confusion, yes the feeling of an uncertain and a seemingly hazy future, yes the fears of stigmatization, yes the fears of being abandoned by family and friends, yes the constant fear for one's health and ultimately one's life ……..yes, many fears and many feelings. These innocent, brave and troubled souls clearly require a strongly efficient support system. The question and thus problem, is that of the existence of such support systems and their impact. This chapter focused on the background to the study, statement of the problem, research questions, significance of the study, delimitations, limitations and a summary.

1.1 BACKGROUND TO THE STUDY

HIV/AIDS was in 2006 the leading cause of death worldwide for people aged 15-49 years. The same year (2006), it was estimated that 2.3 million children under the age of 15 years were living with the virus mainly as a result of mother to child transmission (MTCT) 90% of these children

were living in sub Saharan Africa (Gliemann et al 2008). Chevo and Bhatasa (2011) say, an estimated 3.4 million children under the age of 15 years are living with HIV globally..

In addition, UNAIDS estimates that, about 14 million women of childbearing age currently live with HIV/AIDS in the world, giving birth to children with an elevated risk of HIV infection and death before the age of 5 years.

Wattana Janjaroen and Suwanee Khamman (2002) quote official sources as saying that in Thailand, over 4,000 children are newly infected by HIV each year, and they estimate that 63,000 children were infected with HIV by the end of 2000. They note that the number of new infections through mother-to-child transmission in Thailand increased from 0% in 1987 to 14% in 2000 (MOPH, 2001).

Avert (2011) reveal that, the HIV and AIDS epidemic is believed to have originated on the African continent, and this is where the disease is currently causing the most problems. In particular, Sub-Saharan Africa is experiencing disease prevalence rates unlike anywhere else in the world (Avert, 2011). UNAIDS estimates that 24.5 million of the 34.3 million global infections are in Sub- Saharan Africa. An estimated 8.57% of adults (defined as those aged 15–49 years) are infected in the region. Every year, over half a million newborns are infected with HIV in sub-Saharan Africa through mother-to-child transmission (MTCT).

On a positive note, of all health crises in the African region, HIV/AIDS has attracted the most political support and resources (Avert 2011). Programmes for the prevention of mother-to-child transmission (PMTCT) of HIV include antenatal HIV testing and counselling, avoiding unintended pregnancy, provision of appropriate antiretroviral (ARV) regimen for mothers and newborns, and support for safer infant feeding options and practices.

Despite efforts to scale up, less than ten percent of pregnant women in Africa infected with HIV receive interventions to reduce MTCT. Even in settings where effective prophylaxis is available to prevent transmission during pregnancy and childbirth, there is often a major gap in service provision in the postnatal period. Few PMTCT programmes successfully reach mothers and newborns after discharge to provide support for the infant feeding choices or to provide ongoing care and treatment (Rashida Ferrand et al 2009).

About 1,3 million Zimbabweans estimated to be living with HIV and AIDS 618,980 adults (78%) and 46,319 (41%) children were receiving Anti-Retroviral Treatment (ART) by December 2014.

About 60% of all ART patients are females (The Herald 18/08/15). 6,6 percent of new HIV cases were from mother-to-child transmission (UNAIDS 2012).

Even though Zimbabwe archieved a 65% reduction in new HIV infections among children between 2009 and 2015, there were 4 900 infections in 2015 (UNAIDS 2016). Before 2010 a Zimbabwean baby born to a mother living with HIV had one in four chances of being infected. In 2015 the odds had fallen to one in fifteen (UNAIDS 2015).

Given the above statistics and efforts, HIV infection spread rapidly between 1991 and 1996 - but the country was able to function for several few years before HIV-related preventions, awareness and medications were effectively introduced. During this period the family institution was more than active and children continued to be born, some HIV infected and some not. Beyond infancy, there were long-term survivors who remained and remain, unidentified as HIV-infected throughout childhood and into adolescence.

Even with a generally well informed nation today perinatal cases (HIV infections at birth) flourish. Even though some infants died due to infections, some young people live with perinatally acquired HIV, which they contracted from their mothers in the womb, at the point of delivery or shortly after birth and/or while being breastfed. They are a hidden group, fiercely protected by a medical profession that never expected them to grow from babies into children, much less teenagers, they seek to exist under society's radar, to avoid being branded by the stigma that it attaches to HIV.

In one comprehensive survey done by UNICEF (2013), a third of children with perinatally acquired HIV, admitted to having considered killing themselves. There are also direct challenges besides stigmatization like a child's lifelong adherence to medication, many infections and occasional illnesses, fears for the future, death and uncertainties. Despite the government's initiatives in the past decade to reduce mother-to-child transmission in Zimbabwe, I feel the nation is ignoring this population that critically needs attention. The continuing fears and ignorance about teenagers with perinatally acquired HIV in society, however, continues to make it necessary for these young people to lead double lives, despite the damage that living double lives can it do to them and the general population. Statistics show that young people with chronic conditions are more likely to report more than four simultaneous risky behaviours than healthy teenagers, including unprotected sex. To avoid or rather reduce the impact of this ticking time bomb, are there any support systems put in place for individuals with perinatally acquired HIV? If so how effective are they? To date there has been extensive research on HIV for the general population and the support systems available to them and not at all particular to HIV perinatals. The researcher therefore intended to study and fill the gap in question.

1.2 Statement of the problem

Our nation can safely yell, 'progress', or 'achievements' when all societies accept and stop stigmatizing all young people and teenagers with perinatal acquired HIV and after the infected group receive help to accept in their minds, their behaviour and their emotions, that they have HIV and HIV doesn't have them. The Zimbabwean government has made various valuable strides towards the reduction of mother-to-child transmissions (MTCT) but these efforts are not 100% effective entailing that thousands of children are still falling prey to perinatal acquisition of HIV. Plus or minus 4 900 babies are still infected at birth (Rashida et al 2013)

Mashonaland West being the area under study, is a province comprising of small towns and people live in standard village settings where almost everyone is linked or knows the other and HIV education awareness is valued by a few. This entails that stigmatization fuels for those living with HIV as everyone or someone would know of their status and hence discriminate against them. To date the province is one of the highest in HIV prevalence rates and more so among women (UNICEF 2014). This is so because it is characterized by little to no industries, high rates of girl child school dropouts and prostitution. Since the beginning of the HIV era in 1981 to around 2005 when the strict implementation of the prevention of mother-to-child transmission (PMTCT) process for all pregnant women began, MTCT (mother to child transmission) was high and infant mortalities were also high.

Survivors of HIV perinatal infections have been a hidden group. Others are familiar with their HIV status others are not. The existence of this population demands that it be attended to, as some of them due to lack of advice and support systems commit suicide, refuse to take their medication, fall into depression, influence their peers to live recklessly and engage in reckless sexual behaviours spreading infections to the general public.

These acts of confusion and despair do not only affect the individuals in question but their effects spill into the country's economic, cultural, social and environmental development. This research sought to discover the existence of support systems put in place for this group and their impact or effectiveness and bring in new knowledge to better implement existing programmes and find new suggestions to curb the problem

1.3 Research Questions

- Who are the perinatally infected?
- Are there any support systems put in place for the perinatally HIV infected in Mashonaland West?
- What is the impact of these support systems?
- How does the lack of effectiveness of support systems affect the lives of those with perinatal acquired HIV?
- How can the problems be resolved?

1.4 Significance of the Study

This study was important not only to the researcher but also to those infected with HIV/AIDS, government, Midlands State University, community, companies and the economy. The significance of the study was explained in the sub-headings below.

1.4.1 The researcher

To the researcher, the study enhanced her ability to deal with HIV related issues that affect teenagers as she mentored teenagers voluntarily at a local High school in Karoi. The research improved the researcher's analytical skills in assessing the effectiveness of programmes aimed at improving the wellbeing of teenagers born with HIV. In addition this study was an impartial

fulfillment for the completion of my Bachelor of Adult Education Degree at Midlands State University

1.4.2 The HIV Perinatally Infected

Persuading adolescents to take their treatment seriously isn't easy. Just like any other teenager, their health is neither their first priority nor organisation their strongest suit. This study therefore, sought to ensure that the infected shared their problems and had the courage to demand and utilize support systems put in place in prioritizing their health. Understanding that a problem shared is a problem solved, would continue to help them accept that, they have HIV but HIV doesn't have them, that is, it doesn't define who they are.

1.4.3 The Community

The study was also important to the community as it provided a platform for them to better understand their role in the lives of infected and affected by HIV. The stigma that society places on HIV had another, even nastier knock-on effect: it meant that children could not be told of their diagnosis until they were judged to be able to keep it confidential. The consequence of this was that unlike other childhood diseases, children born with HIV often learn of their diagnosis after they had already absorbed the fear and believed the lies about the disease that swirl around society. The trauma could be deep and long-lasting.

1.4.4 Midlands State University

On the 20th of May 2016 The Chronicles reported that 47% of the University of Zimbabwe (UZ) students tested positive to the HIV virus. Taking into consideration that, almost half of UZ students tested positive there is need to sit in on the matter, especially when the HIV testing at UZ is said to have been influenced by the reckless sexual behaviours of Midlands State

University (MSU) students, as said by Mambewu, the Provincial Coordinator for National AIDS Council Midlands. Therefore this study enabled MSU chancellors to device an in house inquiry of available support systems for those infected, their efficiency and ways to reduce the spread of HIV amongst students.

1.4.5 The Government.

An AIDS-free generation can only be achieved through strong leadership from Governments, with partners aligning their support to common objectives. This study sought the wholehearted participation of civil society and affected communities, not only as implementing partners but also in planning, decision-making, awareness-raising, advocacy and accountability. Reduced numbers of HIV/AIDS cases meant reduced medical costs for the government and a healthy nation's workforce and thus high gross returns.

1.5 Delimitations

Though HIV/AIDS acquired perinatally and the support system required to contain it is a national issue, this study was geographically confined to Mashonaland West Province in Zimbabwe. The perinatally infected participants were drawn from Karoi Distict Hospital and Chinhoyi Provincial Hospital. The study was undertaken from the beginning of September 2016 to the end of March 2017. The focus of the research was to assess the availability and effectiveness of the support systems put in place for the teenagers born with HIV. The impact of these support systems have long term and short term effects on those infected and the general population. Therefore the research sought to ascertain the support systems and their effects and ways in which they could be used to assist the perinatally infected teenagers today and in the future.

1.6 Limitations

1.6.1 Time

Due to time and financial constraints this study was limited only to Mashonaland West. As an adult I am a mother, a breadwinner, a student, a daughter and so on, therefore juggling all this for me meant time which turned out to be limited. The same can also be said for the participants of this research who also had competing needs to return to.

1.6.2 Financial Constraints

All participants came from different parts of the province thus the issue of transport and costs was a limitation, considering that I was sponsoring myself even though I am unemployed I however, made appointments with the major hospitals in an effort to question and address the participants when they gather as a group to receive medication. I printed questionnaires, made observations and conducted interviews at the gathering.

1.6.3 Pollarised Society

There is always suspicion among human kind. Due to fear of stigmatization and labelling, the participants were not so willing to divulge their accurate life experiences to a stranger since they were at an age and status where privacy is key.

1.6.4 Informed Consent

Last but not least was the limitation of informed consent. The bulk of the participants were minors ranging from infancy to the age of 21 years. The participants consent therefore was sought from their guardians and considering the sensitivity of the matter, this was a stumbling block.

DEFINITIONS

HIV/ AIDS

HIV stands for human immunodeficiency virus, which is the virus that causes HIV infection. AIDS stands for acquired immunodeficiency syndrome. AIDS is the most advanced stage of HIV infection. HIV attacks and destroys the infection-fighting CD4 cells of the immune system. Loss of CD4 cells makes it difficult for the body to fight infections and certain cancers. Without treatment, HIV can gradually destroy the immune system and advance to AIDS (Lamptey et al 1993).

Perinatal HIV Infections

Infected pregnant women can pass HIV to the fetus during pregnancy or delivery, as well as through breast-feeding. Those that were infected with HIV at birth have what is called Perinatal HIV infection. Some of these people will develop AIDS as a result of their HIV infection (Shaeffer 1994).

Transmission

The spread of HIV from person to person is called HIV transmission.

Mother-to-child transmission (MTCT)

The spread of HIV from an HIV-infected woman to her child during pregnancy, childbirth, or breastfeeding is called mother-to-child transmission of HIV (UNAIDS 2014).

ART and ARV

The use of HIV medicines to treat HIV infection is called antiretroviral therapy (ART). ART involves taking a combination of HIV medicines (called an HIV regimen) every day. HIV medicines are called anti-retrovirals or ARVs (UNAIDS 2014)

Opportunistic Infections

Opportunistic infections are infections and infection-related diseases that occur more frequently or are more severe in people with weakened immune systems than in people with healthy immune systems.

1.7 Summary

Chapter one has introduced the topic of research by discussing the background toy the study, statement of the problem, research questions, significance of the study, delimitations and limitations of the research. The next chapter's focus was on reviewing related literature in relation to the research questions.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

2.0 INTRODUCTION

Children infected by HIV/AIDS at birth carry a burden so heavy, that sometimes it claims their lives due to several illnesses or leads them to kill themselves. Efforts have been made in various parts of the world to try and address the imminent challenges that people living with HIV face. However little to no mechanisms had been made specifically for individuals living with perinatal HIV in Mashonaland West Province. In this chapter, I presented research findings and case studies from all over the world related to this study, on the understanding of perinatal HIV infection, its challenges, availability and effectiveness of mechanisms put in place for those born and living with HIV. To conclude this chapter, a summary was drawn at the end of it.

2.1 Understanding Perinatal HIV Infections

HIV is spread through contact with certain body fluids from a person infected with HIV. These body fluids include: blood, semen, pre-seminal fluid, vaginal fluids, rectal fluids and breast milk. Mother-to-child transmissions (MTCT) occur during labour, delivery and breastfeeding and it is the most common way that children become infected with HIV.

MTCT is the most significant source (90%) of HIV infections in children below 15 years of age (D'Cruz 2004). However, HIV medicines, given to HIV-infected women during pregnancy and childbirth and to their babies after birth, reduce the risk of mother-to-child transmissions of HIV.

Between 1980 and 2005 among the 10 million children born in Zimbabwe a cumulative 504 000 were vertically infected with HIV. By 1997, it was estimated that 29.4 million adults and 1.1 million children were infected with HIV worldwide (UNAIDS, 1998). As of 2010 it is estimated

that about 170 000 children between 0-14 years of age are living with HIV/AIDS of which 3.4% of children are long term survivors following MTCT.

The first HIV case reported in Zimbabwe, was in 1985 in Northern District of Hurungwe (Patel et al 2012) In this District AIDS cases increased exponentially from 19 in 1986 to 290 in 1987 and 433 in 1988. As early as 1987 the prevalence had shot up to 3.2% and interestingly all infections were found in the 17-30 years age group where conception is at its highest (Loodts and Van de Perre 1989).

However, taking into consideration such factors as under diagnosis, denial, delays in reporting, high sexual activities and conception, based on the infected age group, HIV continued to spread with little to no containment. During this period and thereafter children were and are still being born infected by the virus (WHO Report 2012)

Sadly there was so much denial even in the government until 1990. Routine antenatal care clinics commenced at a snail's pace in 1990 and prevalence exceeded 10% (UNAIDS 2014) To date, Mother to child Transmission (MTCT) of HIV is a huge problem in Zimbabwe which has become the major cause of infant and child mortality (UNAIDS 2014).

Situational Analysis of HIV and AIDS In Zimbabwe As of December 2014:

- Estimated number of people living with HIV – 1,390,211
- Prevalence of HIV – 15%
- Estimated HIV incidence in 15 – 49 years – 0.98
- Estimated number of new infections – 69,105
- Estimated annual HIV deaths – 63,853
- Number of people in need of ART – 905,368

- Adults on ART: 618, 980 (76.9%)
- Children on ART: 46,319 (40.5%)
- Estimated AIDS Orphans - 889,339 (ZNH/AE Report 2013, ZDHS Report 2010/2011 and MOHCW ART programme data)

Now that we know the numbers let us look at case studies from United Kingdom (UK), Australia, Haiti, Ghana, Rwanda, Zambia and Zimbabwe to understand the challenges faced by HIV/AIDS perinatals and the support systems developed for them by their governments.

2.1.1 CASE STUDY OF UK

Clive was nine years old when he discovered he was HIV positive. The devastating news that his mother, doctors and support workers had spent years preparing to break to him in the gentlest manner possible, was divulged inconsiderately by a careless receptionist at his local hospital.

"My mum had brought me to see the doctor in London December 2011, because I had earache, and this woman just read it out loud from my notes as she was typing my details into the computer," says Clive. "I remember standing there, with my mother's hand around mine, as these feelings of complete confusion and fear washed over me"

Clive credits the medication given to his mother during her pregnancy for protecting him then from her HIV infection. But, he says, something went catastrophically wrong at the point of delivery, and the infection was passed into his own bloodstream.

After that day at the hospital, however, Clive refused to take medication. "I suddenly realised that the pills my mum had been giving me every day – that I had thought were sweets, were medicine," he says. "After that day at the hospital, I would lock myself in the bathroom when my mum took them out of the cupboard. Or I'd pretend to swallow them, then throw them away"

Clive's resistance to taking medication became more deep-rooted as he grew up. "The medication makes me feel sick – I was sick every time I took it from 10 to 13 years old. Other times, I just don't want to remember that side of me. I want to be normal.” Clive takes his pills sometimes, he says, but then stops for months at a time. "I know I'm killing myself," he says (Tookey 2012).

But a decade of sporadic adherence to his drug regime had stunted the teenager's growth. It had left him close to death three times, and caused him to develop resistance to a number of the drugs that could have almost guaranteed him a long and healthy life.

There are hundreds of thousand children like Clive in the world, young people living with perinatally acquired HIV, contracted from their mother in the womb, at the point of delivery or shortly after birth, while being breastfed.

But there was a time lag before science reduced the likelihood of transmission between mother and baby so dramatically, and when infected babies were still being born in their numbers. The seismic shift that happened in these few years was that these HIV-positive babies were, for the first time ever, being born into a world where they were able not just to survive, but to thrive.

"In earlier days, most babies with HIV had a short life and our task was to make the quality of that life reasonable," said Diane Melvin, a consultant clinical psychologist at St Mary's hospital in London. "We never expected these babies to live. They were certainly not expected to survive adolescence." (Tookey 2012)

But that is exactly what they are now doing. Of the 1,200 children born with HIV and living in the UK and Ireland today, just 60 are under four years old. Around 400, in contrast, are aged between ten and fourteen years, and another 300 are between 15 and 19. In the UK in 2014, the adult rate of HIV prevalence was 0,19 percent (AVERT) compared to 16,7 percent in Zimbabwe

(UNAIDS). Furthermore, in the UK 91 percent of HIV positive adults were on treatment compared to 63,4 percent in Zimbabwe (UNAIDS).

In the UK in 2014, only 29 children were newly diagnosed with HIV and only three children were known to have acquired HIV from their mothers (AVERT). For comparison, the current adult prevalence rate in the United States is 0.5% with roughly 1.5 million children and adults living with the disease (AVERT). In all of Sub-Saharan Africa however, there are now roughly 22.5 million adults and children living with the disease (AVERT) living our continent flashing danger.

Despite medical caution, however, the first cohort of teenagers born with HIV shows every sign of rude health. In what must be the most under-celebrated triumphs of modern medicine, in the last two years, the oldest survivors of childhood HIV have grown into young adults even though the above remarks reveal that they are still treated as experiments.

It is a group that came in all shapes and sizes: some had problems, some were doing well, some were even starting on their own families. What they all shared, however, was the desire to live as normal lives, thus the critical need for efficient support systems.

"Society forced me to live two lives, one of which I had to be honest about my status and one in which I had to keep it completely secret," says Clive. "It angers me that HIV is considered such a dirty thing by so many people. Why are people more sympathetic to those with cancer than those with HIV? It is partly because I had to live this life of shame and secrecy that I found it so hard to take my meds."

Clive’s case study was similar to so many, as it enveloped the challenges of being born with HIV. Based on the above information, the doctors never expected these children to survive let

alone pass the adolescence stage to young adulthood, therefore they are still considered as experiments and this chapter shall even show that not many funds are open for this group as they are considered a closed market. However their existence demands attention and this related literature was reviewed with regard to the challenges they face and the support systems in existence in other countries and in Zimbabwe. The Chapter will thus review cases of other countries and how they have dealt with their challenges.

2.2 CHALLENGES FACED BY PERINATALS

«. . . the AIDS pandemic confronts us with a full range of development issues . . .issues of poverty, entitlements and access to food, medical care and income, the relationships between men and women, the relative abilities of states to provide security and services for their people, the relations between the rich and the poor within society and between rich and poor societies, the viability of different forms of rural production, the survival strategies of different types of household and community, all impinge upon a consideration of the ways in which an epidemic such as this affects societies and economies» (Barnett and Blaikie 1992.5).

2.2.1 HIV diagnostics and medicines for children

A study by Arndt and Lewis (2014) on paediatrics and HIV/AIDS enlighten that, MTCT of HIV accounts of the 2.3 million children under the age of 15 years living with HIV almost 90% of them, are in sub-Saharan Africa. It is estimated that, of these children, 780 000 need antiretroviral therapy (ART). Despite a 40% increase in the number of children receiving ART in 2010, children comprise only 6% of the people on treatment globally whereas 14% of the people in need of treatment are children (Arndt and Lewis, 2014). The Zimbabwe Network of People Living with HIV (ZNNP+) says that only 40% of children infected in Zimbabwe are receiving ARV's.

In the United States there has been administering of ARV drugs to HIV-infected mothers and their infants, elective caesarean section for HIV-infected women who reach term without achieving plasma HIV virologic suppression, and providing replacement feeding instead of breast milk to infants of HIV-infected mothers WHO (2013). Altogether, these mechanisms eliminate MTCT in the longrun.

In the United States and Europe, however, all HIV-infected women are still advised against breastfeeding, regardless of ARV use and maternal plasma HIV suppression, because neither maternal nor infant ARV prophylaxis completely eliminates breast milk HIV transmission (residual transmission can be as high as 5%) and safe and affordable replacement feeding is available (Rwebembera 2013)

However, outside the United States infant replacement feeding confers an unacceptably high risk of HIV-unrelated morbidity and mortality (including in many sub-Saharan African countries). The additional strategy of administering ARV drugs to mothers or infants during breastfeeding has become an effective means to allow breastfeeding while reducing the risk of HIV transmission. To reduce transmission during breastfeeding postnatal preventions called peri-partum ARVs are administered to the infected mother and their infant (Gliemann et al 2014). This option only reduces but does not eliminate MTCT.

In Zimbabwe therefore, because of the state of the country's economy, replacement feeding is unaffordable to many, therefore, HIV infected mothers are encouraged to breast feed exclusively for six months. Breast feeding is the most adequate infant feeding practice that also provides protection against diarrhoea and acute respiratory infections especially in early life.

A study in the USA by Newell et al in (2013) points out that, the options for children lag behind significantly. This is so because, in high-income countries the market for HIV medicines for children has almost disappeared as new HIV infections among children have been virtually eliminated. As a result, the incentive for companies to develop formulations for children has reduced as the numbers of children living with HIV are high in low- and middle-income countries. These economically developing countries represent a less viable commercial market since the countries are poor and can't afford them. Having established that there is now life with the available medications, how can perinatals conquer the challenges they face and ho have others done it?

Cheerfully tucking into cheesecake while describing her plans for the future, Martha an Australian citizen makes a claim that is barely believable. "If I could live my life again and not be positive, I wouldn't want to," the 20-year-old announces. "It sounds weird, I understand that," she acknowledges. "But I've achieved more things by being positive than I would have if I had been born negative. It's made me a much more educated person and put some amazing experiences in my path. I have spoken at three international AIDS conferences, presented at three Children's HIV Association (CHiVA) conferences, met MPs, been a mentor to other young people born with HIV, and have written magazine articles for Positively UK [a peer-led support group for HIV-positive people across the UK]." She pauses for breath. "If someone offered me a cure, I might take it," she concedes. "But not definitely. HIV is a really small part of my life. I have HIV; HIV doesn't have me. We're alive: we were not supposed to be." (UNAIDS, 2006:14 Report on the Global AIDS Epidemic).

Children and families infected by HIV like Martha should not be afraid to openly access HIV testing and treatment services for fear of negative reprisals. Through being open about HIV,

having accurate information about the virus and sharing experiences, the fear around the disease can be dispelled, making people less afraid to seek and access essential HIV services. Group counselling and the empowerment of parents to discuss their status and situation with their children should has helped other teenagers with perinatally acquired HIV, to refuse to let the disease define them. They take their meds and forge ahead, living confident and strong lives.

2.2.2 Disclosure of HIV Infection Status

Late diagnosis and disclosure among children infected with HIV is also of great concern. Guardians are usually reluctant to take their children for Voluntary Counselling and Testing (VCT) and even when they do, disclosing to their children may be delayed. Most perinatally infected children learn of their HIV diagnosis by name between ages of 8 and 10 years (Berry and Lennon 1998).

When they get to know it still makes it no better. The consequence of this is that unlike other childhood diseases, children born with HIV often learn of their diagnosis after they have already absorbed the fear and believed the lies about the infection that swirl around society. Children continue to feel isolated and unable to talk about their problems outside the home because of the shame associated with being infected with HIV and AIDS. The trauma can be deep and long-lasting, leading to severe depression and suicide cases. HIV infection remains a stigmatizing diagnosis (Asenso-Okyere et al, 1993).

Many parents do not take their children for reviews after testing for HIV due to fear of disclosure, denial of status, insufficient knowledge about HIV, accusations about who is the actual “giver or source of the HIV infection” and incongruent health education on HIV and

AIDS and the management thereof in the case of babies with HIV, with specific reference to incorrect and/or insufficient information. (Abrams, 2009).

2.3 CASE HAITI

In Haiti, Chi et al (2013) conducted a study on counselling and support on HIV infected children. Young girls and boys aged 13−19 who are infected with HIV or at high risk of becoming infected receive quality specialized care, prevention and treatment in a youth-friendly clinic. In the clinic's first year, these adolescents' adherence to treatment increased from 12 per cent to 70 per cent. Learning of a new diagnosis of HIV infection for oneself or one's child is emotionally devastating for most people. While providing a listening ear and emotional support, clinicians also can offer hope and reassurance about the availability of effective treatment that can result in improved quality of life and survival for people living with HIV infection in the United States (Modiselle 2014).

ART prevents HIV from multiplying and reduces the level of HIV in the body. Having less HIV in the body protects the immune system and prevents HIV infection from advancing to AIDS. ART can't cure HIV, but it can help people infected with HIV live longer, healthier lives. Haiti clearly dealt with HIV issues by increasing access to ART and youth friendly clinics

However, accessibility to ART is also limited due to constrained human and financial resources. The health system continues to suffer brain drain of qualified professionals. For a country like Zimbabwe currently characterized by poor economic performance, a low level of donor funding and limited access to international borrowing the extent of the problem is worse.

2.4 GHANA

The West African country of Ghana serves as another example of how to effectively combat HIV/AIDS. Through the use of strong governmental commitment to fight the disease, Ghana currently experiences stable HIV/AIDS prevalence rates of 1.5 and 2.3% among men and women respectively (PRB, Ghana, 2010). Since the first reported case of HIV in the country in 1986, the disease has remained stable throughout all areas of the Ghanaian population (USAID, Ghana, 2010). One of the major reasons Ghana has been so successful in stabilizing the disease is the Governments dedication to providing affordable and easily accessible antiretroviral therapy for people living with HIV/AIDS (USAID, Ghana, 2010). Along with providing therapy, high rates of male circumcision throughout the whole country have also helped contribute to the success of programs for prevention and treatment of HIV As part of the nation's attempts to raise funds for the control and management of HIV/AIDS Concerning treatment of children born with HIV the infected receive anti-retroviral drugs and these also serve as a support system. For the adults ARV's are now given for free and without a long list of requirements except a positive HIV test. (USAID, Ghana, 2010).

The Zimbabwean government has done its fair share in providing free and easy access of ARVs, therapy and high rates of male circumcision across the country stabilized the increase of HIV in Ghana. Institutions like ZICHre and PSI Zimbabwe are providing free male circumcision to reduce HIV transmission.

2.4.1 Access and Adherence to care and treatment

In 2015, an estimated 1.8 million children under the age of 15 years were living with HIV, but just 49% had access to the life-saving medicines. While this was an improvement compared to 21% in 2010, it means that half the children in need of treatment did not have access to medical

treatment. Zimbabwe is among the 20 countries identified by WHO as having the highest unmet needs for ART (Safman 2004).

Infants and young children depend on their adult caretakers for adherence. The Antiretroviral programme, is a programme to which they must adhere with relentless precision. "For treatment to be effective, one needs 97% adherence of taking the pill at the same time every day," says Nimisha Tanna, from Body and Soul, a pioneering charity dedicated to transforming the lives of children, teenagers and families living with, or affected by HIV. "It is very important," she adds. "Otherwise the virus wakes up, mutates and can become permanently resistent to the treatment you're taking." (Woodman 1996:97)

Developmentally normal behaviors and stages for toddlers and adolescents can make adherence to medications especially difficult. Persuading adolescents to take their treatment seriously, isn't easy. Just like any other teenager, their health is not their first priority nor organisation their strongest suit. Poor adherence leads to poor health outcomes in many cases and are even fatal in some. Therefore, HIV treatment demands very high levels of adherence to drug regimens to avoid the development of viral resistance and the loss of future efficacy of anti-HIV drugs. The need for intensive education and support for children and adolescents living with HIV infection cannot be overstated (SAfAIDS, 2009).

2.4.2 Growth, body composition and survival

Plan International (2006) says gastrointestinal infections, a common cause of childhood malnutrition and growth retardation, also contribute significantly to poor growth in HIV-infected children. Children infected with HIV appear to be especially vulnerable to diarrhoeal diseases. In

a longitudinal study of HIV infected children in Kinshasha, Republic of Congo, it was found that HIV-infected children had increased rates of acute and chronic diarrhoea: 90% of infected children had one or more episodes of acute diarrhoea and chronic diarrhoea was 6 times as likely to develop in HIV-infected children as in uninfected children (McGarry 2009).

Additional episodes result in further deteriorations in growth, thus in many regions of Saharan Africa, diarrhoeal diseases represent an important and potentially modifiable factor with regard to growth disturbances in HIV-infected children. This has led to the establishment of nutritional gardens in Zimbabwe as a working support system for the infected (Sauvageot et al 2010).

2.4.3 Stigma

The stigma that society places on HIV has another, even nastier knock-on effect: it means that children cannot be told of their diagnosis until they are judged to be able to keep it confidential, hence becoming a major obstacle in accessing prevention and care. HIV/AIDS stigma has been an impediment to the uptake of voluntary counselling and testing of HIV.

In Zimbabwe discrimination of HIV positive people is prohibited under National HIV/AIDS Policy of 2000 and the Statutory Instrument (SI 202) of 1998 which also prohibits HIV screening for purposes of employment. Ignorance, misinformation, and fear in families and communities cause people living with HIV infection to keep their status a secret. However, this practice has negative consequences, such as isolating the HIV-positive individuals from social support and risking additional spread of HIV to sexual partners. In addition this consequently violates Criminal Law (Codification and Reform) Act 23 of 2004 which makes it a crime for a person who knows that he or she has HIV/AIDS to infect another, even between husband and wife.

In a study conducted by D'Cruz (2010) Pauline was infected with HIV at birth and is now a 24 year old mentor for the perinatally infected. Asked about the problems faced by children growing with HIV today, she angrily says that, "From what the young people tell me, the situation around HIV in schools and society in general hasn't improved at all.

"It doesn't occur to people that you can be born with HIV and live a normal life," she adds. Children and adolescents who have HIV infection can participate fully in the educational and extracurricular activities in school. There is no obligation to notify school personnel of a student's HIV infection status. Planned disclosure to family members and friends can increase practical and emotional support for the HIV-positive person. Sexual partners can make informed decisions about how to protect themselves from exposure to HIV.

2.5 RWANDA

In Rwanda, 1,458 women attending antenatal and pediatric clinics at the Centre Hospitalier de Kigali received pre-and post-test counseling, were shown an educational video, and were given free condoms. One year later, HIV seroconversion rates had decreased significantly (from 4.1 to 1.8 per 100 person-years among women whose partners were tested and counseled) (World Health Organization, 1992). Several institution-based programs in Africa have demonstrated changes in risk behaviour (Wynendaele et al., 1995). Innovative approaches to disclosure and psychosocial support are being scaled up; young people accompanied by parents and guardians are informed of their status in groups and are encouraged to participate in follow-up support sessions (Lamptey, Johnson, and Khan 2012)

Results of an HIV counseling and testing program demonstrated an increase in condom use. The initiation of an education, STD treatment, and condom distribution program for all professionals

led to a reduction in the incidence of urethritis (Loodts and Van de Perre, 1989; World Health Organization, 1992)

2.5.1Psychological Support

Like Rwanda, Zimbabwe institution-based intervention programmes target academic institutions, different company employees and their families (Williams and Ray, 1993). These programmes provided STD treatment, behavior-change intervention, circumcision and condoms. The interventions employed a combination of drama, printed materials, group talks, and interpersonal counseling by peer educators.

In a survey by Cohen and Lungu (2010), successful interventions being undertaken by organizations in Zimbabwe and the United Republic of Tanzania, extended essential psychosocial support to children who are infected by HIV/AIDS, in order to stimulate new awareness of needs and to open new doors for action. It focuses on what can be done for the child of an infected parent before and after the parent dies, to enable the child to cope better with the situation. It advocates for parents living with HIV/AIDS to discuss their status and situation with their children and to live positively and stay healthy in order to postpone orphan hood. In contrast to adults, disclosure of HIV status to children and adolescence should be undertaken over time, providing sequential pieces of practical health information that match the developmental capacity of the child. This process builds a strong foundation for children to participate meaningfully in their HIV care.

2.6 CASE STUDY ZAMBIA

In Zambia routinely testing all children and adolescents attending clinics where HIV is likely to be an underlying cause of illness is a highly effective strategy to identify HIV-exposed and HIV-

infected children who were either missed during the early postnatal period, or who acquired HIV later in infancy via breastfeeding. This includes testing children attending tuberculosis (TB) clinics, malnutrition clinics, or admitted to inpatient pediatric wards. For example, 29% of children admitted to an inpatient pediatric ward tested HIV-positive. Similarly, in Uganda, 31% of children admitted to the nutrition ward were found to be HIV-infected. In Malawi, routine HTC offered by lay counselors to children in the pediatric inpatient ward found an 8.5% prevalence rate, double the national 4.8% prevalence rate for children of the same age.

2.7 ZIMBABWE

Zimbabwe has embraced the UNAIDS 90-90-90 approach to ending the HIV pandemic in 2020. In accordance to World Health Organisation (WHO) 2015 guidelines it is a 'Treat All' approach where every HIV positive individual is eligible for ART. Initiating testing and treatment for all people diagnosed with HIV regardless of symptoms or clinical stage. In Zimbabwe, a patient is now encouraged to take an HIV test before receiving medical attention at any given hospital. This bold recommendation means that all individuals diagnosed with HIV should be offered treatment (PEPFAR CDC 2016).

In addition, Africaid has been running Zvandiri House Training and Support Centre in Avondale Harare since 2005. This is a drop in centre where HIV positive children adolescents, young adults and their care givers come for information, counselling, clinical assessments and reproductive health services. Life skills training programmes are run here for children, adolescents and young people from across and young people come to use the liabrary and Information Technology lab where they are trained in IT skills. It is a very busy place with each room being filled with young people running their own training workshops, counselling sessions, IT trainings, creative arts programmes, team meetings and interactive programmes. After

receiving funding in 2012 from Child Protection Fund in Zimbabwe as well as Maruva Tust Zvandiri has scaled up to clinics across Harare. These centres are established at Newlands Clinic, Rutsanana Clinic, Wilkins Hospital and Mabvuku Polyclinic. Wilkins is already assistingadolescents and young people on a daily basis who are attending OI clinics. Below are some remarks from Zvandiri Adolescent Support group:

Tanaka 9 years old, "I was born with HI, I want to change the way the world thinks about children like me, so I am training doctors, nurses and communities how to care for children with HIV. I will make a difference."

"Most people say when times are hard, wait for the storm to pass Well Zvandiri has taught me to dance to the storm" Alice aged 17 (Africaid Zvandiri 2017)

2.7.1 Being Perinatal Adolescents

Children born with HIV infection in the world during the 1980s are now young adults. They continue to be the pioneers who challenge the global assumptions and identify unmet needs for care and support services (Hatloy et al 1998).

There is a pressing need to develop and implement programs to transition youth successfully to adult HIV health care clinicians. Practical concerns and psychological concerns, such as the issues of long-term supportive relationships, sex, protective measures, issues of reinfection and new infections, issues to do with the future, having children and families, how to embrace HIV and live a happy and content life and how to relate to the society and its stigmatization. For instance in every school, every drama, every social discipline reference and every story amoung peers the end result or punishment or consequence of promiscuity is the dreaded HIV. Now how

would it feel to know that you were born with the very virus that everybody conceives to be a curse and for you it was not your choice or your fault? Painful and depressing for me at least

Dr Caroline Foster, a consultant in adolescent HIV at Imperial. "Adolescent survivors of HIV are a new and challenging population," says Dr Steven Welch, a consultant paediatrician at Birmingham Heartlands hospital. "The challenge is that, having got to the stage when we can enable young people to survive with HIV, we can't also give them the quality of life to go with it. But this is entirely new territory for us all, pediatric HIV consultants have never had to deal with adolescents, or their parents. And how do we help a young person, for example, who is about to have their first sexual experience but already has a sexually transmitted disease?" (UNAIDS 2011)

UNAIDS estimates suggest that over half of new HIV infections are occurring among young people (13-24 year olds) – or over 7,000 new infections a day worldwide (UNAIDS 2004) The USAID/UNAIDS/UNICEF report, *Children on the Brink 2004*, envelopes that these highly sexually active individuals engage in reckless sexual behaviours risking the spread of the HIV pandemic.

A research conducted at a number of HIV care and support centres in Uganda revealed that only about one tenth of 15−19 year olds in the sample of the study had never talked to their parents or guardians about their sexual and reproductive health needs. Therefore there is need to the design of specific interventions for parents raising adolescents who were infected with HIV perinatally, and to a renewed focus on these young people's prevention needs (Abrams, 2009).

2.7.2 CASE STUDY KARIBA MASHONALAND WEST

Following the diagnosis of the first case of HIV-infection in the Northern district of Hurungwe, (Mashonaland West) in 1986, cases have increased exponentially from 19 in 1986 to 290 in 1987, 433 in 1988, and 545 during the first quarter of 1989. As early as 1987 the prevalence had shot up to 3.2% and interestingly all infections were found in the 17-30 years old group. Mashonaland WEST province still has the highest number of perinatal HIV infections.

COBASYS Kariba Report (2012) indicated that Kariba urban has a number of economic activities and groups that could be tapped into to facilitate an efficient HIV/AIDS treatment and support system at primary care level. Economic activities included fish farming, tourism industry and vending. It also has social groups that are potential channels for enabling an interlinked system delivering on HIV/AIDS activities including Home Based Care, Support groups, primary care volunteers and PLWHA income generating projects.

All the Kariba Health facilities provide Voluntary Counselling and Testing (VCT) services; Prevention of Mother to Child Transmission (PMTCT) services, Provider Initiated Testing and Counselling (PITC) services. However, the district relied on the Chinhoyi provincial hospital for the CD4 counting machine more than 150km away from Kariba. Even so, the services for CD4 counting were often unreliable due to power cuts, trained human resources amongst other factors. Furthermore, the members of the African apostolic faith church were noted to object health services, this was observed as one of the largest barriers to HIV treatment interventions.

2.7.3 Poverty

Zimbabwe's long running economic crisis has not spared the health sector, and there have been large cuts in public health spending. In 2015, despite a total budget of US$396 million, allocated

for the health and child welfare ministry, experts say domestic funding for HIV/AIDS remained inadequate. The current economic crisis, if prolonged, is likely to worsen such outcomes unless efforts are undertaken to mitigate its impact (Lock 2012).

AIDS places an increased economic burden on households needing to pay for drugs and funerals, putting particular pressure on women and girls caring for AIDS patients. Children may have to drop out of school. They also become susceptible to child abuse and exploitation as they are forced to do anything to earn a living and bring food on the table (UNICEF, 2007).

In Africa over eleven million children have lost at least one parent to the disease, hence the sprouting of such type of households (Church World Services, 2008). A study carried out by UNIAIDS (2013) in Harare, showed that out of the 50 boys and girls born with HIV, 32 of them had lost their parents due to HIV and AIDS related illnesses. They had no option but to drop out of school and start to look after themselves and their younger siblings.

Cornered by poverty and already infected by the one thing that everybody dreads for them to go on and sell their bodies for money and a better life, these adolescents and young adults are living reckless sexual lives. Some even claim to take revenge for being born infected, by spreading HIV as much as they can, partying from one club to the next not considering anything as they consider their fate sealed. They are young, vibrant, beautiful, and look healthy. Thus if one sexual partner doesn't use protection or consider HIV tests before any sexual encounter HIV would spread like wild fire (Gillespie and Kadiyala 2005).

For instance, if one 18 year old perinatal had multiple sexual partners, some married and some single, for money and material things, this young girl and more others would be slowly

destroying the country's economy, health system, family institution, work-force and future generations.

2.8 SUMMARY

This chapter dealt with related literature concerning children born infected with HIV in various aspects and in different places around the world. Highlighted are some ways how children contract HIV before birth, at birth and soon after birth, challenges faced by these children, the impact of some support systems available and their implications to these children. Some case studies on children born infected with HIV in several countries and conclusion and recommendations in the studies have also been reviewed. The following chapter is chapter 3 which deals with methodology.

CHAPTER 3

RESEARCH METHODOLOGY

3.0 INTRODUCTION

The approach and specific techniques implemented in this research were the general contents of this chapter. The research methods used in this study, that is, the steps and procedures that were used to collect, analyse and interpret data were the main discussions of this chapter. This chapter therefore, looked at the research design, population and sample, research instruments, data collection procedures ethical considerations and data analysis plan. A summary of this chapter, was drawn thereafter.

3.1 RESEARCH DESIGN

A research design is the structure of a plan and strategy of investigation conceived in order to obtain answers to the research questions. In other words, it refers to the description of the way of procedure and structure, under which the study is carried out (Coyle & Lyons 2007).

Coolican (2006) aptly characterized research design as a blueprint or overall framework of the study that stipulates what information is to be collected by which procedure and from what source.

A research design therefore is concerned with turning a research question into a project that can be carried out to give a precise, fair and clear picture of what the research is all about.

There are many types of research designs, some of which include exploratory, conclusive and descriptive research designs. For this study I used a descriptive research design.

3.1.1 Descriptive Survey

Cohen (2004) say, a descriptive research design is used to collect information concerning the current status of the situation to describe what exists with respect to conditions in that particular situation.

Shuval et al (1986) adds that, a descriptive survey is concerned with conditions that are held, processes that are going on, effects that are evident and trends that are developing. Descriptive surveys are useful for explanatory studies and thus are well suited for collecting information about specific characteristics in a large population and ongoing as is with the nature of this study.

Descriptive survey research describes data and characteristics about the population or problem being researched. The contextual nature of the data to be investigated in this research is mostly wordy and descriptive. Essentially the quality of the characteristics of the population such as perceptions and attitudes were suitably analyzed more in words than numerical equations.

Using the descriptive research design, I studied the behaviours, attitudes, practices and characteristics of the HIV perinatally infected in a relatively straight forward approach (Merrin and Simpson 1984). Because participants provided insights into their life experiences and behaviours, the descriptive survey allowed me to capture statistical information about events as well as conceptions of how people infected with HIV at birth experience events and their world resulting in the production of this unique project.

3.2 POPULATION AND SAMPLE

3.2.1 Population

A research population is a collection of individuals or objects that become the main focus of a scientific query or investigation (Chimedza, 2003). In support Fobil (2001) points out that a research population is also known as a well-defined collection of individuals or objects known to have homogeneous characteristics.

According to Best and Khan (2003), target population refers to any group of individuals that have one or more characteristics in common that are of interest to the research. In the current study, the population was the 1 355 perinatally infected individuals according to statistics provided by Chinhoyi Provincial Hospital and 6 nurses from Opportunistic Infections (OI) making a total of 1 361. This population covered the age group of 0 to 25 years. It was therefore necessary to include the consent of parents for those children that could not speak for themselves and the parents' full participation for those children under 12 years. The homogeneity of these 1361 participants was that there were all infected with HIV at birth, which was also a characteristic the researcher was interested in, and were all residents of Mashonaland West Province, Zimbabwe

3.2.2 Sample

According to Chimedza (2003) a sample is a representative or a proportion of the population. The concept of sample arose from the inability of the researchers to access all the individuals in a given population due to various reasons which included distance, prohibitive costs and inadequate time and the feasibility of carrying out a study on a large population. In support, Hart (2005) highlights that, sampling is a procedure for the generalisation about a population without

researching every unit in that population. This entailed that sampling helped to derive conclusions that would apply to the entire population or to provide conclusions that could be generalised to the rest of the population.

Mulwa (2006) asserts that the sample size varies according the nature of the study. This qualitative study used a small sample of 136 participants, allowing me to focus on the uniqueness of data not its quantity.

3.2.2.1 Stratified Random Sampling

According to (Thomson 1997) stratified random sampling is a type of random sampling which involves surveying a selected group of subjects from a larger group of people. I chose stratified random sampling as it allowed sampling of each subpopulation from the main population separately. It made sense to partition this study's population into groups based on age and experiences. For instance I randomly sampled ten percent of 0 to 12 years and 13 to 25 years males and females in respect of their strata. This proved to be an easy and effective way to get unbiased results.

3.2.3 Sampling Techniques

Somekh and Lewin (2005) pointed out that there are two types of techniques, that is, probability and non-probability sampling. I mainly used the probability sampling technique where the chance of selection for a respondent was known (Sales and Folkman 2000). The Orangi Pilot Project (1995) describes probability as a chance of any element being included in the sample and is known to be with equal chance like any other element of being selected.

The probability sampling was used on selecting the perinatally infected participants by means of choosing every tenth person in the hospital database. This provided an equal opportunity to all

participants to be chosen into the sample. The researcher then specifically used stratified random sampling in order to group participants into age group of 0 to 12 years 13 to 25 years and (level by level) and nurses. A tenth of the participants (136) including 6 nurses were be sampled. This entailed that purposive sampling (non-probability) was partly used on the choice of nurses in the opportunistic infections (OI) department at Chinhoyi Provincial Hospital and Karoi Hospital because of their experience and knowledge with regard to my research.

3.3 INSTRUMENTATION

Research instruments are used by researchers to capture and/or collect data during a research. For an effective result both quantitative and qualitative approaches were used. Leedy (1997) supports the use of numbers as a way of expressing indescribable data as it would be used to try and help to predict reasonable expectations.

For instance qualitative survey in this study was used to inquire on how those born HIV infected felt, how it affected their lives, how stigma affected them, their true understanding of the pandemic, their understanding on issues to do with sex, protection, child bearing and fears of disclosure. On the other hand, quantitative data was useful in issues of support systems, their existence, efficiency and frequency of HIV perinatals actually using them. In addition also, was the collection of the numbers of children born and living with HIV over the years and the sexual partners they have had, the average numbers of children born with HIV to date, even after the implementation of prevention of mother-to-child transmission (PMTCT), progress and so on.

3.3.1 Questionnaires

Leedy (1997) states that a questionnaire is a common place instrument for observing data beyond the physical reach of the observer. Mellenbergh (2008) suggested that questionnaires are

designed using dichotomous (yes/no) type of answers, multiple choice (select answers) and open ended questions. In this study, the questionnaires had both open ended questions and closed questions in-order to allow respondents using their own wording in explanations. I personally crafted the structure of the questionnaires, using open ended questions to try to probe for more information from the respondents.

HIV/AIDS is a very sensitive matter therefore to ensure the respondents' anonymity and privacy, which encourages honest answers, I used questionnaires. Thirty parents and guardians of participants under 12 years and ninety 13 to 25 year old participants were selected to complete the questionnaires. Questionnaires were chosen for these particular participants as they were the literate of the group and the questionnaires allowed them privacy. Respondents had the opportunity to respond to questions during their own time outside the daily pressure of work and school

Data collected through questionnaires were gathered following a standard uniformed question presentation, without bias, such that tabulating responses was relatively easy. Considering the large number of participants I was dealing with, the use of questionnaires also saved my time, human and financial resources. However, I could not customise the questions to suit different individual participants, hence the need to use interviews.

3.3.2 Interviews

For Tuckman (2002) as cited in Cohen & Manion (2004), an interview provides access to the mind of the interviewee and makes it possible to understand the perceptions, opinions and thoughts of the interviewee.

Brink (1996) also defines an interview as a method of data collection in which an interviewer obtains responses from the subject in a face-to-face encounter in a structured, semi structured or unstructured manner. Structured interviews are formalized in, such a way that all respondents hear the same question in the same order and in the same manner. Unstructured interviews leave the wording and organization of the question and even the topic to the discretion of the interviewer. Semi-structured interviews allow the respondents "a considerable degree of latitude" (Bell 1993:94)

In this study, semi-structured interviews were done on nurses and some of the guardians of the HIV perinatals. I conducted face to face interviews with one participant at a time. The hospital staff were kind enough to give us one of their offices to use for these interviews and that's where they were held. I had constructed guidelines to what questions I needed to ask, but the lrespondents were given freedom to talk about the topic and give their views. I collected more intimate facts and information as I conducted these interviews because there was room to probe and observe non-verbal behaviour, thereby assessing the respondents' motives. The greatest value of these semi-structured interviews, lay in the depth of information and detail that I secured. This encouraged me to develop new ideas, adjust questions and change direction as new insights emerged. Most of my participants were more disposed to express themselves in interviews than they were with filling out a questionnaires. However, some guardians were not willing to participate in these interviews thinking that they would be published and some felt that

privacy was being violated. I in turn ensured them that I would not need their names and those of their dependents and that all of the information we discussed would be kept confidential and only for research purposes.

3.3.2.1 Types of questions

Open- ended/ Divergent Questions

In this research, I employed different types of questions so as to obtain useful information from the participants.

These types of questions were described by Watt et al (1996) as a set of broad questions that require the respondents to exercise their right to present their opinions, views, suggestions or conclusive ideas to a given scenario. I used open questions when I needed explicit divergent and exploration of respondent's mind towards the area of study. Questions such as 'Describe how you feel about being born HIV positive and why?' and 'If you are sexually active, how do you feel about protecting others'?.

The open questions provided the bases for actual conclusive answers to the research**,** they also encouraged open expression of one's mind and reduced the element of bias.

3.3.2.2 Closed/ Convergent questions

Convergent questions, also known as closed questions are those questions with limits placed on the response to be given to them. A convergent question by its nature has a more narrowly defined correct answer, the answer is generally short, requires little reflection and requires that the respondent recall from memory a bit of factual information (Watt et al, 1996).

I used closed questions to allow for quick responses, easy understanding and to limit chances of misunderstanding by the respondent for example ‘Are you sexually active?’

3.4 ETHICAL CONSIDERATIONS

Ethics mean moral principles that control or influence a person’s behaviour a philosophical discipline that is concerned with human conduct and moral decision making. According to Akinade (2005) ethics are normative in nature and focus on principles and standards that govern relationships between individuals, such as researcher and participants. I considered informed consent and participation, anonymity, confidentiality, privacy, protection from harm and honesty as the moral principles that guided my conduct with participants as I carried out this research.

3.4.1 Informed Consent

The ethical consideration of informed consent meant that prospective research participants must be fully informed about the procedures and risks involved in research and must give their consent to participate. In this research, younger participants’ parents were asked for their consent and agreed to have their children participate and even participated for them in cases where participants were below the ages of 10. Informed consent was sought before participation and was sought freely, without undue inducement or pressure. Participants were free to withdraw their consent at any time without any penalty or prejudice. Consent was sought by signing an informed consent form which clearly stated the implications of partaking in the research as well as the potential benefits derived from taking part. Consent was also sought with regard to the nature of the research which required rather personal and private information from the participants.

3.4.1.1 Participation

Participation in this research was voluntary and participants were free to withdraw from the research even when it had started when they didn't feel comfortable. This was explained in the vernacular language to participants while asking for their participation.

3.4.2 Anonymity

Anonymity meant that participants' actual identities were not revealed for their security and protection of their reputation. There were no names on questionnaires, no place names and no personal names in this study. For interviews, I asked whether the participants were comfortable for us to use pseudo names just for their comfort and confidence in anonymity.

3.4.3 Confidentiality /Privacy

The ethical consideration of confidentiality required that I made sure that participants were assured that collected information would not be made available to anyone who was not directly involved in the study. All data collected was treated confidentially and was used solely for the purpose of this research.

3.4.3.1 Privacy

Privacy required that I conduct programmes such as interviews in a secure and private venue where no prying eyes and ears could have access. In this study, the ethical consideration of privacy was adhered to as I requested a room at the hospitals where interviews were held.

3.4.4 Protection from Harm

When conducting research especially with human subjects, researchers must avoid or minimize harms and risks and maximize benefits; respect human dignity, take special precautions with vulnerable populations; and strive to distribute the benefits and burdens of research fairly. The no harm principle was adhered to during the data collection period. Respondents were treated with respect and dignity throughout the study. Anonymity also meant to protect participants from any harm.

3.4.5 Honesty

Honesty in conducting this scientific enquiry entailed that I had to be very honest, especially because I was dealing with human subjects. I honestly reported data, results, methods and procedures, and publication status as it was unethical to not fabricate, falsify, or misrepresent data. One should not deceive colleagues, research sponsors or the public. In this research therefore, participants were not lied to, everything was so transparent for all the participants.

In addition the information used in this study was the researcher's origination, but for all data that was borrowed from the work of other people, the researcher cited the authorities, acknowledged in the reference section.

3.5 DATA COLLECTION PROCEDURES

Leedy (1997) expresses that data are those facts that any particular situation gives information or impression to an observer. He goes on to describe data as merely representative of the truth, and it involves collection of observations related to a given set of variables.

3.5.1 Data Organising

When conducting any study, it is important to organise data. The process of organising data involves scanning, arranging and sifting of data (Coffey, 1996). I arranged the data I collected after selecting what was important and discarding the irrelevant information (sifting).

3.5.2 Procedure

I was given an introductory letter by the Department of Adult Education stating that I was a research student from Midlands State University. I took it to the Mashonaland West Provincial Medical Director of the Ministry of Health and Child Welfare. This letter was accompanied by a hand written letter stating my research topic and requesting permission to carry out the research in their province at selected hospitals.

Interviews and questionnaires were designed and arranged and administered to participants. The researcher arranged for the interviews with the relevant authorities and the interviews were conducted. The respondents were required to fill in the questionnaires on spot as that was the only time they were gathered as a group.

3.6 DATA ANALYSIS PLAN

3.6.1 Data Analysis

A data analysis plan involves searching for meaning through direct interpretation, observations, experiences and reports by participants. Bogdan and Biklen (2003) say data analysis plan is setting out how to work with the data, organising it, breaking it into manageable units and coding it. The aim of data analysis plan is to discover patterns, concepts, themes and meanings. Egger and Carpi (2008) say, that data analysis is sometimes interpreted as manipulation of data to

achieve the desired results. Data analysis involves evaluation and reporting what the data denotes after presenting it through the different forms.

An important aspect of data analysis plan is the search for meaning through direct interpretation of what is observed by the researcher as well as what is experienced and reported by the subjects. Bogdan and Biklen (2003) say data analysis plan is setting out how to work with the data, organising them, breaking them into manageable units, coding them, synthesising them and searching for patterns. The aim of data analysis plan is to discover patterns, concepts, themes and meanings. This made it easy to use relevant data and present it through tables, charts, graphs and even text.

I gathered, organized and presented data and expressed it in percentages highlighting the views of the community. The data were presented in the form of tables and pie charts as a way clearly showing the findings. Narrative descriptions were analysed in relation to given circumstances and relationships. Tables were used because they condensed numerical data and thus making it easier to understand. Graphs were also used because they gave a pictorial appeal which made them easy to understand and compare. Descriptive data collected were linked to statistical data so as to reveal the impact of existing support systems.

3.6.2 Descriptive Data Analysis

Descriptive analysis sought to describe, expound and interpret conditions of the perinatally HIV infected. It was concerned with conditions, trends that were evident, practices, structures, opinions held, ongoing processes, differences or relationships that exist between variables.

In this study, I analysed the relationships that existed between people infected with HIV at birth, the society and support systems enacted to help lessen the effects of this condition.

3.6.3 Causal Comparative Research

There exists variants of descriptive data analysis, but in particular, I made use of the causal comparative analysis. It was a type of descriptive research which described conditions that already existed.

The causal-comparative method commences with an effect and seeks possible causes; hence I utilised this branch of descriptive data analysis paying particular attention to the effects of ineffectiveness of support systems for those HIV infected at birth.

To accomplish this, I analysed the impact of support systems in Mashonaland West, which had shown that they were, to a larger extent, ineffective. This condition obviously had a cause, hence the researcher sought to unearth the possible causes, effects and suggest possible solutions to mitigate the negative impact.

3.7 SUMMARY

The chapter covered the research design that was used in carrying out the research study. The descriptive survey, which allows the use of qualitative and quantitative research techniques, was used because the two research techniques complement each other. The chapter also explained the targeted population; sample used and sample size as well as the sampling procedures. The sampling methods used, were probability and non-probability sampling techniques. Research instruments used are questionnaires, interviews and observations. Advantages of utilising such instruments were highlighted. The data collecting procedures then followed and were expounded.

CHAPTER 4

DATA PRESENTATION, ANALYSIS AND DISCUSSION

4.0 INTRODUCTION

Data collection is a vital process in research and a foundation of every research. When data are accumulated it does not mean anything, unless they are organized, arranged and presented in a manner suitable for assessment, analysis and evaluation (Ayle 1999). This chapter dealt with data presentation, data analysis and a discussion. Data were presented in the form of tables, bar graphs, pie charts, line graphs and narrative text. Thereafter a summary concluded the chapter.

4.1 PRESENTATION AND ANALYSIS OF FINDINGS

Research findings were presented in relation to research questions raised in chapter one and reviewed related literature. Two differently structured questionnaires were used for parents and guardians of participants under 12 years, participants between 13 and 25 years of age. The researcher also conducted interviews with parents of the under 12 perinatals, a few participants of the 13 to 25 age group and nurses. Although questions and tools used in this research were structured differently, the information asked was centered on the challenges faced by HIV perinatals, availability and effectiveness of support systems and what was being currently done and recommendations to address these challenges.

Table 1 Total Distribution of Research Instrument

Respondent	**Questionnaires**	**Returned**	**Interview**	**Observations**	**Total**
Parents of the 0 to 12 years Participants	30	28	8	1	**37**
13 to 25 years Participants	90	82	10	1	**93**
OI Nurses			5	1	**6**
Total	**120**	**110**	**23**	**3**	**136**

The distribution table above shows that 30 questionnaires were distributed to parents and guardians of under 12 participants and 28 were completed and successfully returned. However because the questionnaire was more centered on the infected child, 8 interviews with the parents were set since they were also affected and or infected.

The table also shows that 90 questionnaires were given to the 13 to 25 participants and only 82 were completed and returned. 10 interviews were conducted with some of these participants. In addition the table shows that no questionnaires were given to OI nurses but 5 interviews were held with them. One observation was made on the way these nurses were treating these perinatals and the support systems the hospitals supposedly had.

Therefore, the return rate of questionnaires was 92% and 100% for interviews.

4.1.1 GENDER AND AGES OF HIV PERINATAL PARTICIPANTS

Table 2 Gender and Ages of Participants

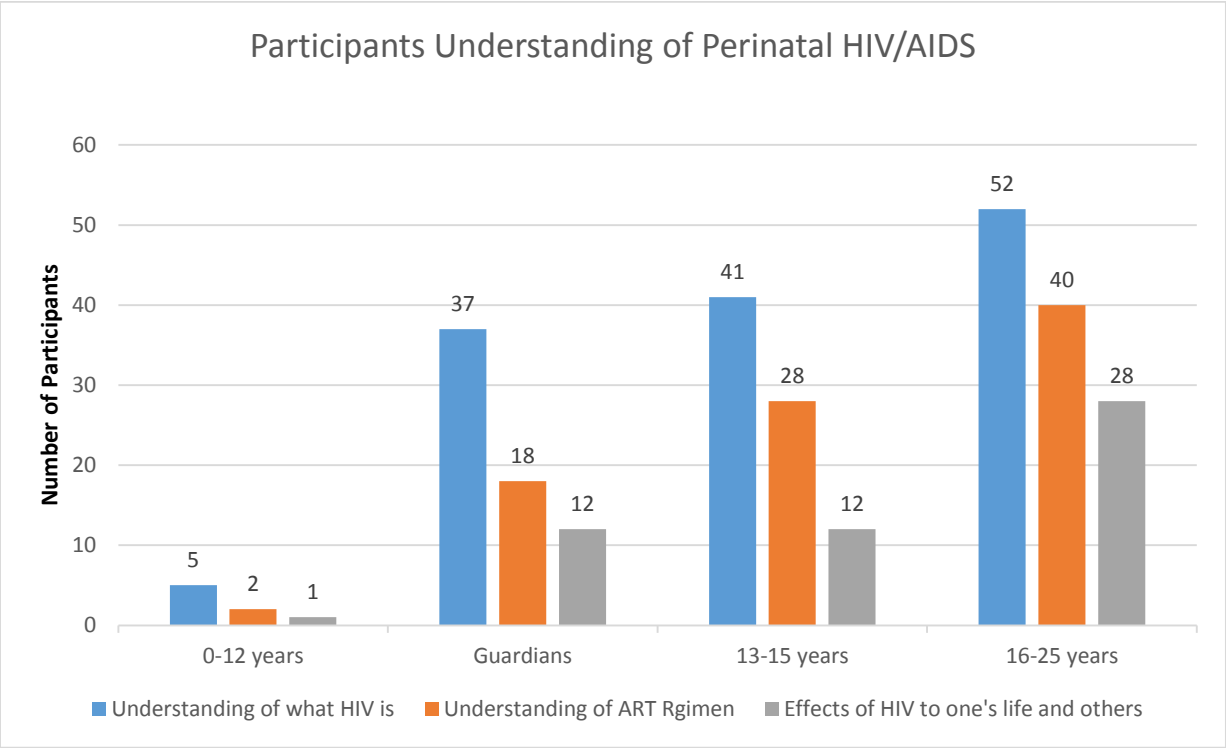
GENDER	0-12 **YEARS**	**13-25 YEARS**	**NURSES**	**TOTAL**
FEMALE	23	62	**4**	**85**
MALE	14	31	**2**	**45**
TOTAL	**37**	**93**	**6**	**136**

The above table shows that they were 23 females and 14 males on the 0-12 age group. On the 13-25 age group there were 62 females and 31 male participants. All participants added up to 85 females and 45 males. This presentation showed that across all ages, there were high rates of HIV/AIDS infections in females than males.

According to Global UNAIDS (2010) slightly more than half of all people living with HIV are women and girls. In sub-Saharan Africa, more women than men are living with HIV, and young women aged 15–24 years are as much as eight times more likely than men to be HIV positive

4.1.2 PARTICIPANTS' UNDERSTANDING OF PERINATAL HIV

Fig (i) Participants Understanding of Perinatal HIV/AIDS



The graph above shows the results that came out after participants were asked several questions in trying to test their understanding of what HIV is, their understanding of the ART regimen and their understanding of the effects of HIV on their lives and others. On the 0-12 years age group 5 participants all above 7 years were able to say what HIV is and how it leads to AIDS. 2 participants knew that one had to take drugs to minimise the HIV virus referring to it as a 'flu' which required one to wear warm clothes and drink hot tea to keep warm. 1 participant said that they knew that they were not supposed to make blood contacts or share toothbrushes with others as this would hurt their friends.

All of the 37 guardians who were interviewed had a general understanding on what HIV was but with regard to the ART regimen, how it works, why they were supposed to maintain the same

timetable when taking drugs and how to minimize side effects only 18 (58%) attempted some questions. 12 participants which was (31%) of the guardians knew a little on the impacts of HIV. The other 69% were either ill-informed or filled with fear over the future lives of their children and some even pointed out that they were just taking care of them waiting for God's time (death).

UNIAIDS (2009) says that the target group for any HIV/AIDS intervention was 13 to 25 years age group because they are the highly sexually active individuals. However, the research showed that there were either not empowered at all or ignorant of what they were being taught. All the 93 of them (100%) could at least explain what HIV was. 73% understood the ART regimen but when asked if they had ever missed following timetables of taking their pills all them said they occasionally fell off track, either at parties or watching TV or forget pills whilst visiting. This information plus other failed questions on how HIV affected self and others led to the 43% that the graph presents.

4.1.3 PARTICIPANTS PERCEPTION ON IDENTIFIED CHALLENGES

Table 3 Yes and No responses by participants of identified challenges

GUARDIANS of the 0-12yrs Participants				**13- 25 YEARS PARTICIPANTS**			
Total- (27 respondents)				**Total- (82 respondents)**			
QUESTION	**YES**		**NO**	**QUESTION**	**YES**		**NO**
Have you explained and or disclosed to the child their status?	6		21	Do you find it hard to disclose your status to friend and family?	74		8
Do you feel your child discriminated because of his/her HIV status?	22		5	Do you think there is still stigma associated with HIV/AIDS?	20		62
Is being born with HIV affecting your child's growth (illnesses)	18		9	Is being born with HIV is affecting your body composition? (illnesses, growth)	42		40
Is it difficult for you to access your ARVs?	21		6	Is it difficult for you to access your ARVs?	6		76
Do you adhere to all requirements when it comes to the child's ARV treatment?	20		7	Do you adhere to all requirements when it comes to your ARV treatment?	62		20
Do you have anyone or anywhere to go, when you are facing HIV related issues?	23		4	Do you have anyone or anywhere to go to, when you are facing HIV related issues?	12		70
Are the child's biological parents still alive? (double tick for both alive, one tick for one)	1 8	2 9	10	Are your biological parents still alive? (double tick for both alive, one tick for one)	1 19	2 8	55
Can you afford all necessities required to boost one's health?	6		21	Can you afford all necessities required to boost one's health?	16		66
Do you let your child play and mix with others?	19		8	Are you sexually active?	63		19
Do you have any fears concerning your child's future?	25		2	Have you had more than 1 sexual partners?	55		27
Is it difficult for you to administer the treatment to the child?	3		24	Have you always practiced safe sex?	37		45
Do you think it is difficult being an HIV perinatal child?	26		1	Do you think it is difficult being an HIV perinatal adolescent?	63		19
Do you believe you know all there is to know for the child to live positively?	10		17	Do you believe you know all there is to know for you to live positively?	23		59
Do you believe they are support systems put in place for your child to feel safe?	8		19	Do you believe that your actions today and those of others can lead to an HIV free nation tomorrow?	37		45

The table above shows the challenges that HIV/AIDS perinatals in Mashonaland West. 22% of the guardians acknowledged explaining and/or disclosing to the child their HIV status whereas

78% said that the idea of telling their children such complicated things terrified them. 90% of the 13-25 years age group said that they found it hard to disclose their status to anyone as they feared stigma. Only 10% indicated disclosure of their status to family and friends.

Most guardians (81%) thought that being born with HIV affected their children's growth in terms of continued illnesses. Only 19% said that HIV did not stagger their children's growth at all. 76% of the adolescents however, felt that they were no different to their HIV negative peers in terms of growth an illnesses.

55 % of both the adolescents and the guardians said there was still stigmatization but 45% said that they did not suffer from any discrimination. 30% of the guardians said they wouldn't let their children play with others for fear of stigmatization. Only 25% of all participants both guardians and adolescents found it difficult to access ARVs because of distance to their 'chosen' places of collection otherwise ARV treatment was accessible to more than 75% of participants. However the administration of the treatment by guardians was said to be easy by 89% of them.

Adherence to all requirements when it came to their ARV treatment was 75% which was a good number though the 25% of non-adherence could still claim lives. In addition the table also shows that 80% of all participants indicated that they couldn't afford other required necessities. Relying on unbalanced foods and poor diets minimize the strength of the ART.

Considering that only 15% of the participants had both biological parents surviving, 25% only had one parent surviving and more than 60% were completely orphaned the participants desperately needed efficient support systems. However, only 20% said they had a person, place or system, which they relied on when facing HIV related issues. 80% of participants without an efficient support system were left with hospital facilities rigged with queues and fatigued nurses for help.

77% of the adolescents and young adults said that they were sexually active, 67% of them with more than one partners and 55% adhering to the safe practice of using condoms during sex. 70% of these individuals said they did not believe they knew the basic necessary information about HIV/AIDS and how they could live positively and happy. 45% of them said that they didn't believe that their actions and those of others could lead to an HIV free generation tomorrow.

4.1.4 INTERVIEW RESPONSES BY 6 NURSES ON SUPPORT SYSTEMS

Fig(ii) Available Hospital Support Systems by Nurses.

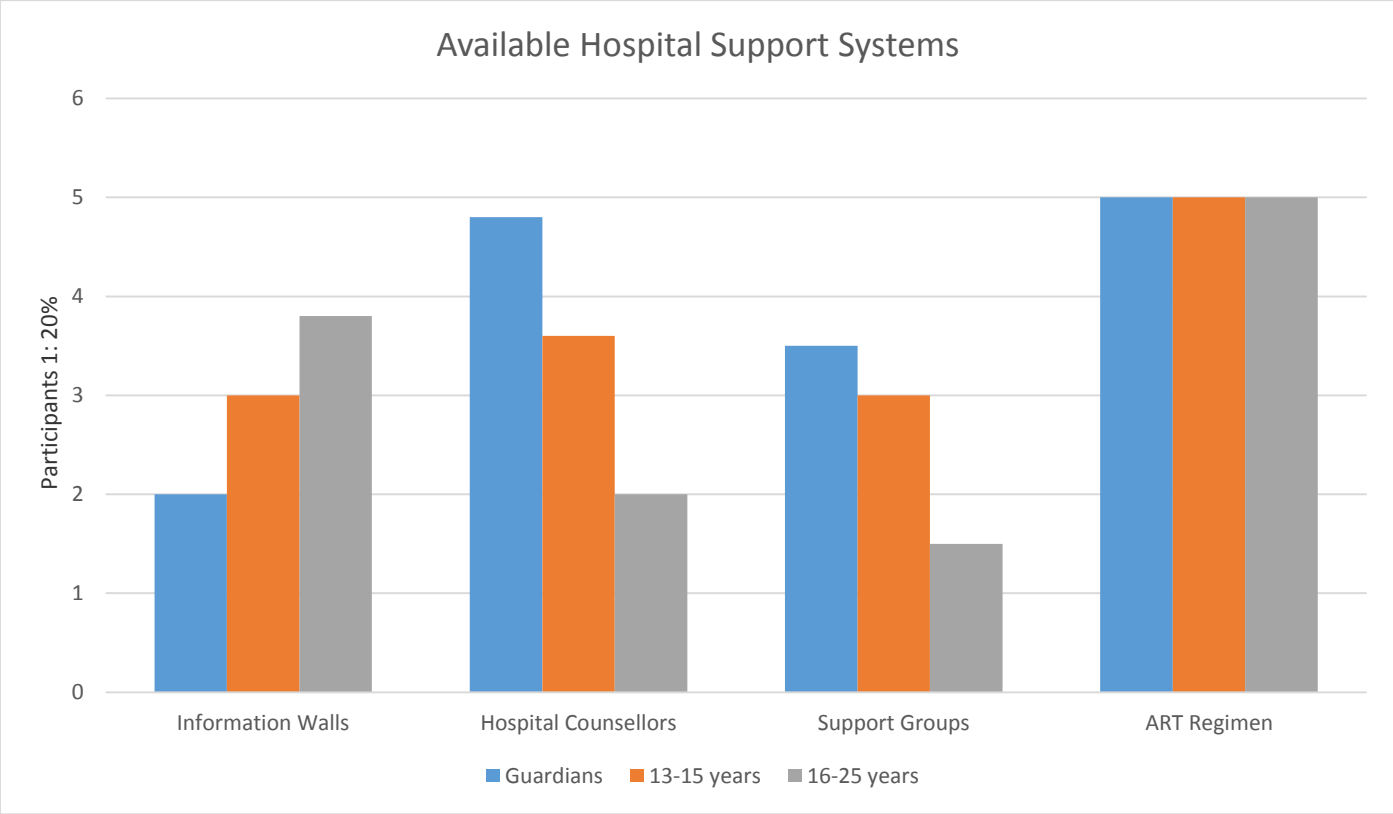


Fig two above presents the support systems working in Mashonaland West hospitals according to the 6 interviewed nurses. Of all the support systems the ART regimen was used by all HIV perinatals. Records also showed that 96% of the guardians, 72% of the 13-15 year olds and 40% of 16-25 year olds, used hospital counselling services. 70% of the guardians, 60% 13-15 year olds and 30% 16- 25 year olds admitted to utilizing the services of local support systems. Finally,

70% of the 16-25 year olds, 60% 13-15 year olds and 40% guardians, recorded frequently using hospital information walls more than any other support systems.

4.1.5 SUPPORT SYSTEMS AVAILABLE IN MASHONALAND WEST

Fig (iii) Participants perception on Effectiveness of Available Support Systems

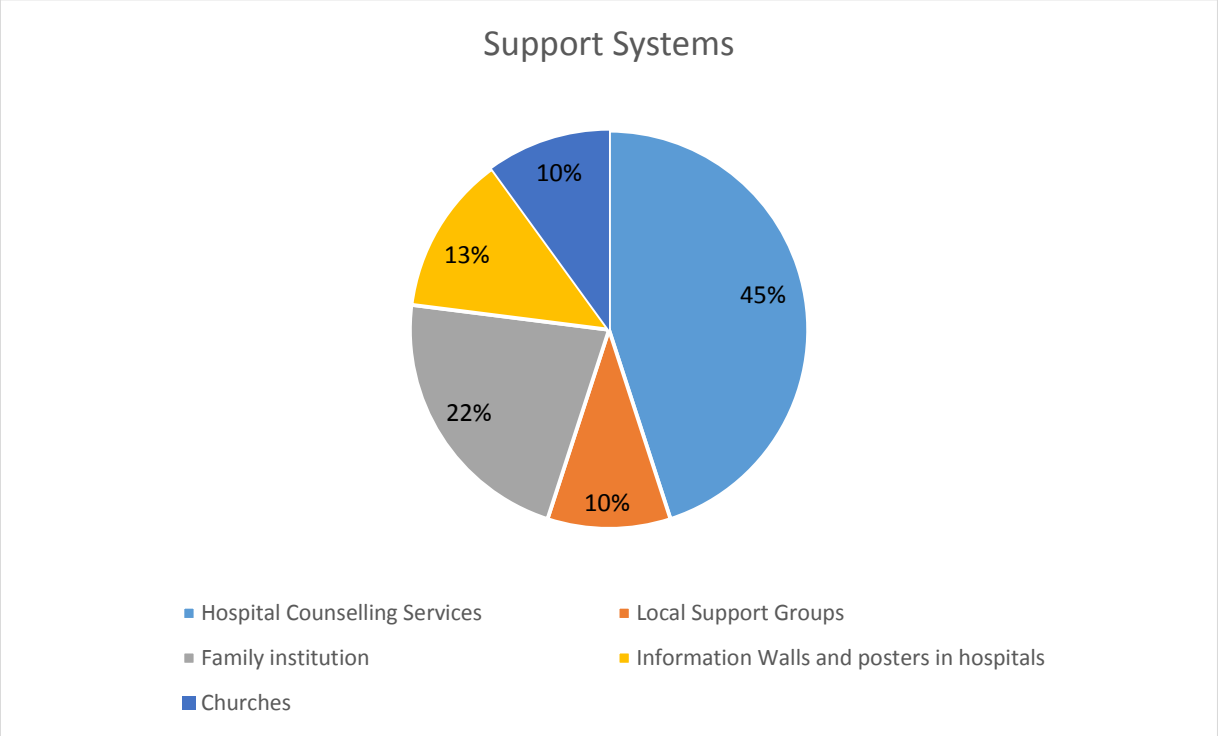
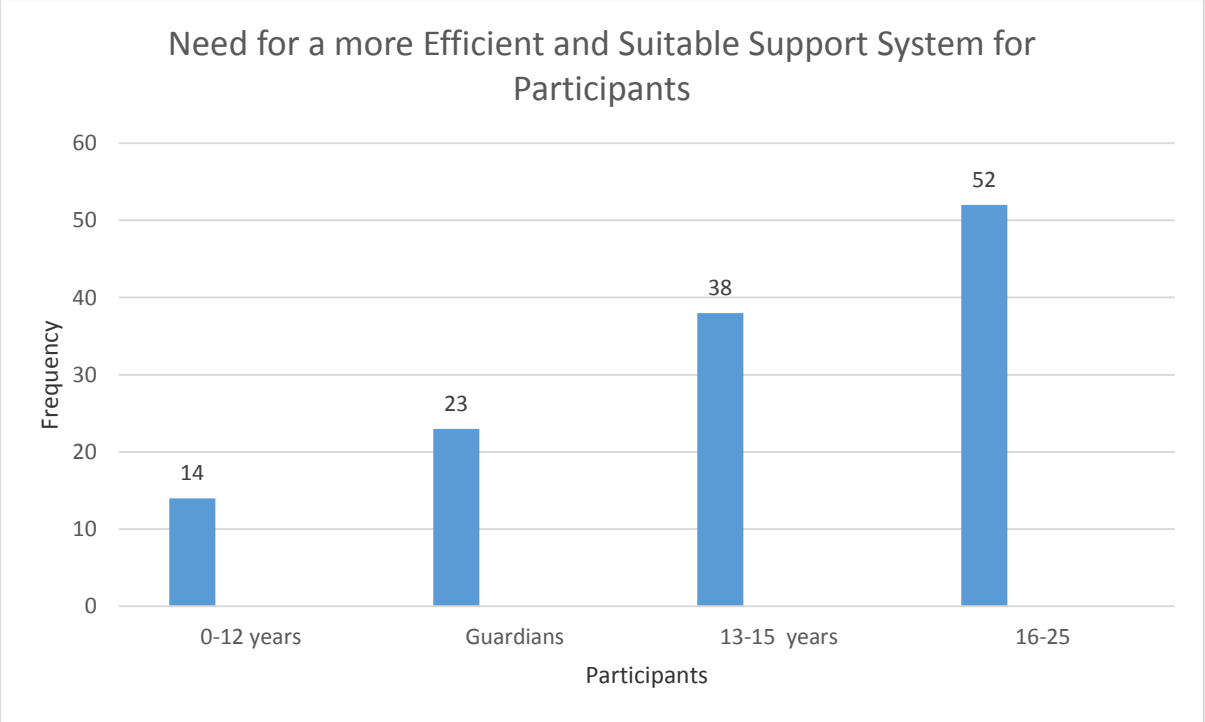


Fig three presented what participants identified as the available support system in Mashonaland West and how frequent they had used them, thus determining the effectiveness of the given systems. 45% of the participants agreed that the hospital counselling services were the only system effective enough to consult. 22% said the family institution as the most effective support one could ask for. 13% also hinted that the information walls, posters and various media services were helpful especially with other private issues like sexually transmitted diseases. 10% of the participants also felt that the church saved their lives by being of emotional and psychological support. Finally 10% of the participants mainly guardians said they used the local support groups that were for all ages.

4.1.6 THE NEED FOR A MORE EFFICIENT AND SUITABLE SUPPORT SYSTEM

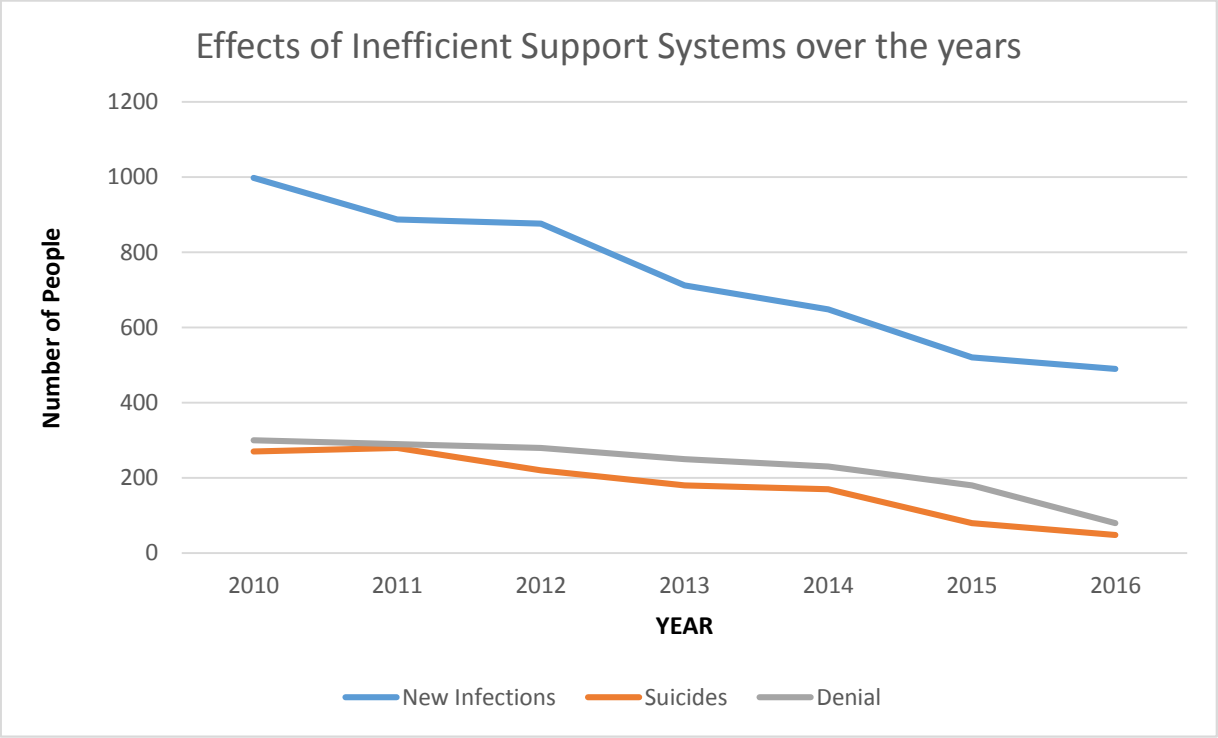
Fig (iv) Need by participants for a more efficient system



Given the support systems that were working then in Mashonaland West fig 6 shows that participants clearly needed a more suitable and a more effective support system. Asked about whether they were content with the support provided to them, all participants said no they needed to feel they belonged to a given group, have fun, share, learn and be amongst their peers. The graph showed that 14 participants of ages 0-12 years, 38 of ages13-15 year olds and 52 of ages 16-25 years and 23 guardians, agreed that they needed more support from their fellow Zimbabweans. This need for a new more fitting support system tallied with the ART regimen with a 100% percentage rate.

4.1.7 EFFECTS OF LACK OF EFFECTIVE SUPPORT SYSTEMS OVER THE PAST 6 YEARS.

Fig (v) Effects of Support Systems Efficiency over the past 6 years



The above figure shows that in Mashonaland West 300 people in 2010 denied that there were HIV positive even after several tests and even refused to get further checked for treatment. However, as the years went by and more awareness was brought to the people and support systems were being utilized by many, the numbers continued to drop at a steady rate to less than 80 recorded in 2015. The same with suicides 280 people were recorded throughout the province to have killed themselves because of their HIV status in 2010. The numbers have since gone down to less than 48 in 2016. New Infections have reduced nearly by half from 998 to 490 in six years.

4.2 DISCUSSION AND ANALYSIS OF FINDINGS

All that was presented in this study was gathered using questionnaires, interviews and observations. The responses of nurses, guardians of the 0-12 participants, the 13-15 year olds and the 16- 25 year olds were captured on their understanding of the perinatal HIV phenomenon, challenges they faced, the availability and effectiveness of support systems and the effect of the support systems over the years. Because of the sensitivity of the study, however, some participants were reluctant to participate in the research and share their true experience at first, thus the 92% questionnaire return rate. Below is the discussion and analysis of the findings in relation to literature reviewed.

4.2.1 UNDERSTANDING PERINATAL HIV INFECTION.

All participants had a general idea of what HIV is and what it entailed. One of the five 12 year olds I interviewed explained HIV as a 'flu like' virus that just slows down how one's body works in terms of 'healing powers' which was quite accurate if I may say.

However, more than a quarter of the participants could not explain how the ART regimen worked. Questions like what happens if you delayed taking your pills for about 15 to 20 minutes from your daily taking routine, were vaguely answered. Responses included 'I don't know, nothing, I get sick…..' leading me to the conclusion that participants had little understanding of perinatal HIV.

The majority of the guardians and participants acknowledged that it was difficult being born with HIV and that they feared for their lives and the lives of their infected children. Asked to elaborate on the fears, participants pointed out they feared early deaths and issues to do with marriage and having children of their own.

4.2.2 CHALLENGES FACED BY HIV PERINATALS

4.2.2.1 Disclosure

All participants said disclosure is the hardest of all the processes related to HIV. Some guardians were still lying to their children coming up with excuses like, 'they are too young to understand.' When asked if they were going to tell the child, some bluntly said no, some said I am waiting for them to write their grade seven exams then I will disclose and some said they were leaving it to fate. As Abrams (2009) said, there is need to the design of specific interventions for parents raising adolescents who were infected with HIV perinatally, and to a renewed focus on these young people's needs and feelings.

4.2.2.2 Stigma

The HIV perinatal participants still feel the wrath of stigma even in the very places they are supposed to feel safe. One guardian said that some nurses address us as 'varwere vemapiritsi' (pill patients). Another 15 year old said 'in class all they say to a child who is naughty is 'uchaita AIDS' (you will contract AIDS), those who dramatise show AIDS is a product of promiscuity, how am I supposed to feel knowing that I did nothing wrong but I have it'. So yes, some parents said they couldn't let their children play with others for fear of discrimination. As said by Asenso-Okyere et al, (1993) children continue to feel isolated and unable to talk about their problems outside the home because of the shame associated with being infected with HIV and AIDS. HIV infection remains a stigmatised diagnosis.

4.2.2.3 Growth and body Composition

Children on ART may have thin legs, a bellied stomach and fat around the cheeks. Such distortion of physical appearance is at times a result of the complicated dynamics of the HIV or

the side effects of anti-retro viral treatment tablets (Van De Walle 2010). Contrary to what Van De Walle said, body composition was not an issue with regard to the parrticipants. Most of them thought they were even more beautiful and more, well-built than those that weren't HIV infected. This may be so because Mashonaland West used to be the bread basket of Zimbabwe and even though the province wasn't producing as much as it used to, its residents were truly far from starving. Only a few guardians referred to the constant recurring of illnesses as a stumbling block for their children's growth.

4.2.2.4 Access to ARV's

All the participants felt ARV's were readily accessible. Over the years, there were conditions before receiving ART now the 90-90-90 policy UNAIDS (2015) recommends the ART treatment to be given to anyone who tests positive instantly. However a few guardians complained that it was difficult and expensive for them and their children to come for collection of pills every month or so, but rather to receive treatment that would last for three to six months.

4.2.2.5 Adherence to drugs

The majority of the participants acknowledged that they had missed their prefect timing for drug intake or forgot to take them at some point. Others even admitted to taking drugs and alcohol with their medication. All this emanated from ignorance, less care of self and little understanding of how the drugs worked. However, Woodman (1996:97) "For treatment to be effective, you need 97% adherence of taking the pill at the same time every day, otherwise the virus wakes up, mutates and can become permanently resistant to the treatment."

4.2.2.6 Orphans and Poverty

The participants said they were orphans and were poor so they could not afford basics, education, balanced diets and good health. A few participants ranging from 0-12 still had both

parents alive and the majority from 13-25 years had either lost one parent or both of them. This meant that standards of caregiving were depreciating by the number of parents lost and even by the health status of those alive leading to more and more poverty just as Klain et al (2004) said, HIV fuels in poverty.

4.2.2.7 Sex

First of all 70% of the participants said they didn't believe that their actions and those of others today, would lead to an HIV free nation tomorrow. Some of them acknowledged using drugs, taking alcohol daily and dating anyone that swinged their way. These feelings had a lot to do with the fact that they had already contracted HIV, so recklessness had virtually no other damaging consequences. Revelations showed that the young adults carried so much resentment and anger that they did not mind spreading the virus.77% of the 13-25 year old participants acknowledged to be sexually active, 55% having safe sex and 45% unsafe sex. 68% said they had had more than 3 sexual partners. Why unsafe sex and why many sexual partners, was mostly related to resentment, anger, money, and/or ignorance, they felt that they didn't have anything else to lose'. However by recklessly spreading the virus they would be violating Criminal Law (Codification and Reform) Act 23 of 2004 which makes it a crime for a person who knows that he or she has HIV/AIDS to infect another, even between husband and wife.

Not known many teens however, is that apart from committing a grievous crime, having unprotected sex exposes them to three things; sexually transmitted infections, HIV re-infections where one receives a different type of virus from another infected person and adding more of these culprits into one's system (importing virus) through exchange of sexual fluids (UNIAIDS 2010).

4.2.2.8 A Comfortable Support System

The majority of participants were asked if they had an HIV related issue where and/or who would they go to and answers were mostly long pauses full of doubts. The uncertainty of who to talk to, go to for advice and/or just vent without feeling judged is the comfortable support system that these youngsters, adolescents and young adults didn't have. We all need someone sometimes.

4.2.3 IMPACT OF NON EFFICIENT SUPPORT SYSTEMS

Long back when HIV was a taboo, it was unheard of to have AIDS discussed in churches, in families and in public. All people knew was HIV was a punishment, a deadly result of prostitution. In one comprehensive survey done by UNICEF (2013), a third of children with perinatally acquired HIV, admitted to having considered killing themselves. Therefore when one was told there were HIV positive there were three choices deny it to self, accept it and be angry and resentful or suicide. All these misguided decisions had presented themselves in many cases over the years, hence the need for efficient support systems that could help one cope with feelings of hopelessness.

UNAIDS estimates suggest that over half of new HIV infections are occurring among young people (13-24 year olds) (UNAIDS 2004). Most of the young adult participants said that sometimes it felt good to just spread the virus to as many people as they could because they also did not deserve to be infected but they did, so it seemed fair to share the feeling. The nurses' interviews indicated that before support systems were set, people faced many challenges that made them deny their status' and refuse to take their medication, leading to early deaths and/or commit suicide. In support Berry and Lanon (2000) agreed that the trauma can be deep and long-

lasting, leading to severe depression and suicide. Over the past six years however, the records showed that denial, new infections and suicides are declining steadily.

4.2.4 AVAILABLE AND EFFECTIVE SUPPORT SYSTEMS

During their interviews nurses identified four support systems, the ART regimen, Hospital counselling services, information walls and local support groups. The most efficiently used of these support systems was the ART regimen which was used by 100% of those infected with HIV. Guardians of the 0-12 and the 13-15 age groups participated in local support groups and hospital counselling services. However, the 16-25 year olds hardly used hospital counselling and support groups but information walls. This was so because adolescents and young adults valued their privacy, they didn't trust easily and they didn't like being mixed with adults. Asked why they didn't like attending support groups with every other infected people one young adult said, "All they talk about is prayer, God and abstinence, how do they expect us to do that. I want to have fun, be young, have sex, children and have my own family one day."

In what the young lady said, there existed a gap in the world of perinatal HIV support systems in Mashonaland West. This was where Africaid Zvandiri Adolescents Support Groups came in, as they provide a forum to share, learn, feel loved, have fun and feel supported. Zvandiri Adolescents Support groups provide a sense of belonging making the words 'a problem shared is a problem solved' meaningful and Mashonaland West perinatal adolescents and young adults crave a similar platform.

In addition to the four support systems identified by nurses participants added two more, the church and the family. One 16 year old said, "My Pastor saved my life. I only found out that I was HIV positive after I tried to donate blood at school, I had no one to ask because both my parents were deceased and l lived with my aunt. I saved $0.10 a day until I had $0.50 and bought

rat poison on my way home. However, I wanted to pray first so I went to church. When I got there the Pastor saw me crying and came to talk to me so I told him everything. He consoled me and read me a verse that generally said that there is nothing that one can face in life that has not been met by others. He assured me that with God's help I would conquer it all. So yes I am conquering HIV with the help of God."

Family was also mentioned by many as a true anchor of support. At 25 years one girl said, "Opening up to my family was the hardest decision I ever made. I had all kinds of thoughts in my head about how they would reject me. I got sick one day and had no choice but to tell them but I did it at hospital in front of a nurse for my protection (laughing) we all went for counselling and now, I have never felt so loved and accepted.

However there were challenges of transport expenses since Mashonaland West is a big province to travel through. I therefore, made appointments with two hospitals to conduct my study with their patients when they came to collect their quartely pills. By doing this I was able to get the attention of many after the nurse in charge of Opportunistic Infections addressed all the patients and asked for their consent on my behalf. I discussed with the participants the ethics around my study and also asked for written consents from all participants below 12 years of age. The adolescents and young adult participants were afraid of being labelled and judged at first, but I assured them that there was no need for personal names and no names for places. However, I had educational fun during this research, I made a few friends amongst my participants and I am glad that I got to share this journey of life with such strong people who had conquered the deadly virus

4.3 Summary

This chapter presented data accumulated by questionnaires, interviews and observations, and discussed them in relation to related literature. Tables, bar graphs, pie chart, line graph and clustered columns were used to present findings. Results indicated that although many HIV perinatals understood what HIV was on the surface, many participants admitted to have a lot of things they don't know concerning the pandemic and how they can live a happy positive life. Challenges faced by perinatals were also discussed as well as the available support systems and their efficiency. Participants however, voiced their need to have a more suitable platform where they can discuss their issues learn and have fun. The results generally tally with existing related literature except for some knowledge gaps the researcher identified. The next chapter looks at the summary of the study, conclusions and recommendations.

CHAPTER FIVE

SUMMARY CONCLUSIONS AND RECOMMENDATIONS

5.0 INTRODUCTION

Finally, it is the summary, conclusions and recommendations of this research. This chapter discusses the whole project by summarising all other Chapters that were the research problem, literature reviewed, research methodology and presentation and analysis of data. Based on the findings in Chapter four I made conclusions and recommendations to the government, NGO's, perinatal HIV infected, those affected by HIV and other researchers.

5.1 SUMMARY

This research investigated the challenges faced by individuals infected by HIV at birth and the availability and effectiveness of support systems for them case study of Mashonaland West. I was prompted to research on this topic because of the experiences of a 15 year old HIV perinatal who only found out her status whilst playing HIV testing pranks with her friends. These findings hit her so hard that even after six months of counselling and treatment she committed suicide. The research was conducted on the background that there were children, adolescents and young adults living with HIV and they were a population that receives limited attention as these ages were the most private and the most protected.

In the beginning children that were infected at birth died of numerous diseases and now that they were surviving the medical world and the society at large were not ready for them and they do not know how to help them. Regardless of all this the HIV perinatals were growing into a world that has many pre-consumptions about HIV and they face many complex challenges that they need efficient support systems. The research questions therefore were, whether there was

understanding of what perinatal HIV was, the challenges the perinatals face, whether there were any support systems available and their effectiveness.

In Chapter two, literature reviewed revealed that HIV is world over and its effects had left many nations on their knees especially in Africa. In an aim to learn what was happening in other countries case studies of the United States of America, China, Australia, Ghana, Uganda, Rwanda, Malawi, South Africa and Zimbabwe were reviewed. These studies made it possible to understand how other countries dealt with the problem and the extent to which their citizens were affected. Some of the conclusions made were that internationally because of their well developed economies a lot of research and medical progress had been made with regard to HIV and that not many cases of perinatal HIV had been recorded and those that had were immediately given attention and kept under control. For example in the USA PMTCT started way before Africa and HIV positive mothers did not breastfeed their children eliminating all chances of MTCT to zero. In Zimbabwe, however, HIV mothers breastfed extensively which only reduced the transmission chances but not eliminate them. In Rwanda like many countries, HIV perinatals were facing challenges of disclosure, stigma, poverty, access to ARV and so on, however, the county had came up with innovative approaches to disclosure and psychosocial support. In Zimbabwe particularly Harare there was an efficient support group set for adolescents by Africaid called Zvandiri and it had helped many perinatals to learn, share, have fun and have a sense of belonging.

In Chapter three, I used the descriptive survey methodology because it enabled me to collect statistical information as well as the various perceptions and experiences of my participants. This research was a case study therefore the descriptive study allowed me to tap into individuals'

personal feelings and experiences and also from written records and observations. My population was 1361 HIV perinatals inclusive of 6 nurses according to information provided by Chinhoyi Provincial Hospital. I used stratified random sampling and purposive sampling technique in order to group my participants with regard to their age and purposively select OI nurses.

Questionnaires, interviews and observations were used as research instruments. I used questionnaires with closed and open questions so I could capture personal accounts and also allow participants to be honest. HIV is such a sensitive issue and using questionnaires that allowed for anonymity allowed the participants pour it all out. Interviews were used on OI nurses and a few willing HIV perinatals so as to allow for probing. For capturing of emotions and reality I had to observe one participant from each group allowing me to get to the bottom of sensititive issues such as sex, stigma by health personnel, family and society.

Chapter 4 presented the research findings. Tables, bar graphs, pie charts, line graphs and clustered columns were used to present findings. From the data presented participants acknowledged that they expected more in terms of the standards of support systems to enable them rise above their predicament. The challenges faced by HIV perinatals are not particular to Mshonaland West Province but some of them differ from what was discussed in related literature.

5.1.1 Summary of Findings

a) Understanding of perinatal HIV and the ART regimen

The general overview presented was that there was clear understanding of what HIV is. However, the ART regimen was only understood by very little hence the majority of the

participants reported to have missed taking occasionally, taking them with drugs and so on. This tendency could be life threatening hence the need for support systems to constantly remind and teach.

b) Challenges faced by HIV perinatals in Mashonaland West

As the case with many case studies reviewed the participants revealed that they faced the challenges of disclosure, stigma, illnesses, fears about the future sex and having their own children and an efficient support system. However, contrary to some challenges reviewed in literature participants said HIV was not affecting their growth composition and that looked even more beautiful and that ARV's were accessible to all though in small amounts at a given time

c) Available and effective Support System

Nurses and participants interviewed revealed that support systems working at the local hospitals, in the society and at home were, churches, family institution the counselling systems, information walls, support groups and the ART regimen. Their records showed that the ART regimen was 100 % effectively utilized by all participants, the counselling system, family, churches and local support groups was only used more by participants below 15 years as well as their guardians. However, the young adults were clearly not comfortable consulting these support systems so they opted for information walls for learning materials, churches and family.

d) Effects of a non-efficient support system

Over the years, denial, high rates of new infections and suicides have been the results of a non-effective support system. The findings however, reflected that perinatals were becoming more

accepting of their predicament with the help of the mentioned support systems and the above effects were dropping in steady numbers.

e) Need for a more effective support system

The majority of the participants who were at a sexual age, critical and suitable for more consulting and who were at an age where their emotions and perception proceeds all, that is, the 13-25 year olds preferred that there be a more suiting, more effective support groups that was more welcoming for their ages, to have fun, learn, and share their various opinions like Zvandiri Adolescents Support Group.

5.2 CONCLUSIONS

- It has been concluded that individuals infected by HIV at birth have many challenges even beyond our expectations and they needed several interventions
- Mashonaland West Province health system and society had a wide gap to feel in-order to make the HIV perinatals not feel stigmatized.
- Based on the data I concluded that the HIV perinatals did not have adequate lifesaving knowledge to accept their predicament
- From the analysis of data collected it has been concluded that the available support systems are not working effectively
- It has been concluded that the most delicate ages of HIV perinatals (13-25 years) are not benefiting from most, if not any of the support system available in Mashonaland West Province.

- It has been concluded that quarterly ARV collection intervals and the hustles that come with collection were the only obstacles in ARV accessibility.
- It has been concluded that an in-effective support system yields dangerous results for the infected and society in general.

5.3 RECOMMENDATIONS

The conclusions made to this study above, entail that as a people we work towards the betterment of this group of people and those affected by their predicament. Listed below are recommendations made to the Minister of Health and Child Care, Dr David Parirenyatwa, the NGOs and the Minister of Media Information and Publicity.

5.3.1 Government (Ministry of Health)

- Dr David Parirenyatwa should make ARV's available at every clinic in-order to bring the medication closer to the people. With this 90-90-90 policy more cases are bound to come up and be in need of ARV's therefore increasing the queues, stress and fatigue involved with ARV collection. For infected HIV perinatals in remote areas the government should deploy a few nursing staff to the people to give them ARV's with the help of village health workers.
- The government should extend training to its health workers and education staff that awakens them to the extent of damage they can cause by using 'phrases', examples, illustrations and/or statements that discriminates or stigmatizes the HIV infected perinatals in their proffessions.

- Yes our government is making progress in eliminating HIV with the 90-90-90 policy and the implementation of PMTCT however, if those that are infected now don't take initiative to stop the spread of HIV then their efforts could be in vain. Therefore, the government should erect everywhere, a strong support system, a place HIV perinatals can call home, that solely deals with the infected in-terms of educating them, having them share their experiences, have fun, do experiments and learn from their mistakes and correct them

5.3.2 NGOs

- Come up with Child-sensitive and AIDS-sensitive social protection programmes
- The Africaid Zvandiri Adolescents Support Group in Harare in particular should expand its platform to help young HIV infected to have a sense of belonging and enjoy the comfort of others who share their predicament as they learn and explore their lives.
- All HIV/AIDS related NGOs should focus on changing the behaviours of our society if we are to eliminate HIV by 2020 as planned. Creating awareness in terms of sex, HIV and acceptance is the only gap that parents of Zimbabwe have left open to the social media to fill. Instead of letting parents live their child's sex education to his or her peers and internet the NGO's should teach parents that its ok to talk about sex and their child's fears and expectations, be a friend and still be their parents.

5.3.3 MEDIA

- The Minister of Media Information and Publicity should have a segment on radio created, airing and addressing the views and fears of these young individuals getting them to open up and feel considered.
- Dramas, textbook, poems, songs and so on are meant to teach young boys and girls not hurt them. Publishers of textbooks and actors should eliminate the stereotype mindset where HIV is a product of promiscuity and the end to one's life and drumrolls the end. Rather publish books that educate and also consider that 1 in every 5 readers is either affected or infected by HIV/AIDS.

QUESTIONNAIRE FOR THE GUARDIANS OF THE 0-12 YEARS

My name is Jane Mazhambe, a student at Midlands State University. I am carrying out a study in Mashonaland West, on the challenges that the individuals infected with HIV at birth face and the availability and effectiveness of support systems available to them. Information that you shall provide will be used strictly for educational purposes and no interference will occur against you or your child's need for privacy.

1. Have you explained or disclosed to the child their status?	yes	no
2. Do you adhere to all requirements when it comes to the child's ARV treatment?	yes	no
3. Do you have a go to person, place or system, when you are facing HIV related issues?	yes	no
4. Can you afford all necessities required to boost one's health?	yes	no
5. Do you let your child play and mix with others?	yes	no
6. Do you have any fears concerning your child's future?	yes	no
7. Is it difficult for you to administer the treatment to the child?	yes	no
8. Do you think it is difficult being an HIV perinatal child?	yes	no
9. Do you believe you know all there is to know for the child to live positively?	yes	no
10. Do you believe they are support systems put in place for your child to feel safe?	yes	no

Comments……

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13-25 YEAR OLDS QUESTIONNAIRE

My name is Jane Mazhambe, a student at Midlands State University. I am carrying out a study in Mashonaland West, on the challenges that the individuals infected with HIV at birth face and the availability and effectiveness of support systems available to them. Information that you shall provide will be used strictly for educational purposes and no interference will occur against you or your need for privacy.

1. Do you find it hard to disclose your status to friends and family?	Yes	No
2. Do you think there is still stigma associated with HIV/AIDS?	Yes	No
3. Do you think being born with HIV is affecting your body composition? (illnesses, growth)	Yes	No
4. Is it difficult for you to access your ARVs?	Yes	No
5. Do you adhere to all requirements when it comes to your ARV treatment?	Yes	No
6. Do you have anyone and/or anywhere to go when you are facing HIV related issues?	Yes	No
7. Can you afford all necessities required to boost one's health? 8. Are you sexually active?	Yes	No
9. Have you had more than 3 sexual partners?	Yes	No
10. Have you always practiced safe sex?	Yes	No
11. Do you think it is difficult being an HIV perinatal adolescent?	Yes	No
12. Do you believe you know all there is to know for to live positively?	Yes	No
13. Do you believe that your actions today and those of others can lead to an HIV free nation tomorrow?	Yes	No

a) What is your understanding of HIV and the ART regimen?.....

b) Describe how you feel about being born with HIV and why?.....

.....

c) Who or where do you go to when you are stressed and why?.....

.....

d) If you are sexually active how do you feel about protecting yourself and others during sex?.....

.....

e) Describe the type of support system you would feel comfortable to utilize?.....

.....

f) Are there any things you do because you are HIV positive that you wouldn't do if you weren't?.....

.....

g) Do u ever take drugs or alcohol with any of your ARV's?…….....

h) Can you say you are responsible for your actions sexually? Why?

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NURSES INTERVIEW GUIDE

1. How difficult is the process of disclosing one's HIV status especially if it's a child, a teenager or young adult?
2. Over the past six years how would people react to this disclosure?
3. What challenges are these young perinatals facing in your opinion?
4. What health cases are they bringing to the hospital?
5. What support systems are present at this hospital?
6. How efficient are they?
7. Over the past six years what changes do your records show in-terms of new infections?
8. What initiatives are being implemented to eliminate HIV/AIDS?
9. How are people receiving the 90-90-90 policy?
10. Do you have counselling sessions regularly with HIV perinatals?

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