

To investigate the extent to which under-five HIV positive children access Antiretroviral Therapy (ART) – A case of Siavonga District of Southern Province of Zambia

by

Lontia Chinkubala

Assignment presented in fulfilment of the requirements for the degree of Master of Philosophy (HIV/AIDS Management) in the Faculty of Economic and Management Science at Stellenbosch



University

Supervisor: Dr. Greg Munro

March 2015

Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

March 2015

Abstract

The impact of HIV/AIDS has affected all categories of people in society, including children under the age of five. This segment of the population depends entirely on adults and older children in order for them to survive. This research endeavoured to investigate the extent to which under-five HIV positive children access ART in Siavonga District in the Southern Province of Zambia. The necessity of such information for all cannot be over-emphasised as this category of the population under study is among the most neglected when it comes to issues of HIV/AIDS. Under-five HIV positive children need special attention in order for them to enjoy their right to survival and development.

In terms of methodology, the research took an interpretive approach as it employed the qualitative methodology in its endeavours, in order to get an in-depth understanding of people's views on the topic under research. Different interview schedules were used to collect data from community members, Community Health Workers (CHW), Home-based Care Providers (HBCP), staff of the Ministry of Health and District AIDS Task Force (DATF).

The findings of this research addressed all the objectives but one. This research revealed that almost all the community members in Siavonga District had general knowledge about HIV/AIDS and the need for under-five HIV positive children accessing antiretroviral therapy. However, their attitudes and practices varied when it came to the application of this knowledge.

According to respondents, the major challenges that under-five HIV positive children were facing when it came to accessing ART were as follows: food insecurity, followed by access to health facilities and social matters. Others included stigma and discrimination, long distances to health facilities, inadequate disposable income at household level and negative attitudes by some people who think that it is a waste of time and resources to give too much attention, including ART to under-five HIV positive children whom according to them will die soon. However, the majority of respondents indicated that there was need to accept these children like any other as

they too had the right to live; hence, they needed care and support which included facilitating their access to ART.

This research was an eye opener to all duty bearers to recognize and acknowledge the importance of under-five HIV positive children's access to ART. This will contribute towards enhancing the will to step up efforts for this intervention. From the findings, it is evident that there is need for income generating activities to provide disposable income to people of Siavonga District so that they give appropriate support, particularly to children who are infected or affected by HIV/AIDS. Furthermore, more resources are required from NGOs, government and other stakeholders to enhance not only sensitization on the importance of the target population's access to ART, but also provision of these ART services. All relevant stakeholders should heed the call to aggregate information for under-five HIV positive children in question so as to specially target interventions accordingly.

Opsomming

Die impak van MIV/Vigs raak alle kategoriee van mense in die samelewing, insluitende kinders jonger as vyf jaar oud. Die segment van die bevolking is heeltemal afhanklik van volwassenes en ouer kinders om te oorleef. Hierdie navorsing poog om die omvang van kinders jonger as vyf, wie MIV positief is, se toegang tot antiretrovirale terapie (ART) in die Siavonga Distrik van die suidelike provinsie van Zambia te ondersoek. Die noodsaaklikheid van sodanige inligting vir alle sektore in die samelewing kan nie oorbeklemtoon word nie, aangesien hierdie kategorie van die bevolking een van die mees verwaarloosde is wanneer dit kom by MIV/Vigs verwante kwessies. Kinders jonger as vyf wie MIV positief is, moet spesiale aandag ontvang sodat hulle reg op oorlewing en ontwikkeling kan geskied.

In terme van die metodologie het die navorsing 'n beskrywende benadering gevolg om die kwalitatiewe metode in sy poging, ten einde 'n in-diepte begrip van mense se standpunte oor die onderwerp onder navorsing te kry. Verskillende onderhoude is gebruik om data in te samel van gemeenskapslede, gesondheidswerkers in die gemeenskap, tuisversorgers, personeel van die Ministerie van Gesondheid en Distriks vigs-taakspan.

Die bevindinge van hierdie navorsing het al die doelwitte, behalwe een, aangespreek. Die navorsing het getoon dat byna al die gemeenskapslede in Siavonga Distrik algemene kennis het oor MIV/Vigs en die behoefte van kinders jonger as vyf se toegang tot ART. Hul houdings en praktyke verskil egter in die toepassing van hierdie kennis.

Volgens die respondente is die grootste uitdagings wat kinders jonger as vyf ondervind wanneer dit kom by toegang tot ART is voedselonsekerheid, gevolg deur toegang tot gesondheidsfasiliteite en sosiale aangeleenthede. Ander sluit in stigma, diskriminasie, lang afstande na gesondheidsfasiliteite, onvoldoende besteebare inkomste op huishoudelike vlak en negatiewe houdings van sommige mense wat dink dat dit 'n vermorsing van tyd en hulpbronne is om aan kinders jonger as vyf te spandeer, aangesien, die kinders in elk geval (volgens hulle) binnekort sal sterf.

Die meerderheid van die respondente het aangedui dat dit nodig is om hierdie kinders soos enige ander kind te aanvaar en dat hulle ook die reg het om te leef: daarom dat hulle sorg en ondersteuning benodig, wat die fasilitering van hul toegang tot ART insluit.

Hierdie navorsing het weer die klem geplaas op die belangrikheid van kinders jonger as vyf se toegang tot ART. Dit is duidelik dat daar 'n behoefte is aan inkomste-genererende aktiwiteite en om besteebare inkomste aan die mense van Siavonga Distrik te voorsien, sodat hulle toepaslike ondersteuning kan bied, veral aan kinders wat deur MIV/Vigs geraak word. Verder is meer hulpbronne nodig van nie-regeringsorganisasies, die regering en ander belanghebbendes, nie net om die belangrikheid van die teikenbevolking se toegang tot ART nie, maar ook vir voorsiening van hierdie ATR dienste.

Acknowledgements

My sincere gratitude go to all those who have rendered assistance to me in one way or the other throughout my research period. These include the following:

My children namely Mariah Celeste Newa, Nkosha Athanasius Newa, Chikatizhyo Newa, for being there for me in all my efforts and to whom I dedicate this thesis; Save the Children Norway for sponsoring me to do this course; Professor Jan Du Toit and his team for introducing this wonderful and life-saving programme; my Study Leader, Dr. Greg Munro for coming in handy with his guidance just when I was about to lose hope!; Dr. Evan Malambo Mbozi for the consultations; Lecturers Francis Sichimba, Given Hapunda and Haatembo Mooya from the University of Zambia who enhanced my knowledge and skills in research; Mr. Henry Longwani Chaile for the encouragement, support and consultations; Mrs. Chrisencia S. Sampa and Mrs. Bertha Kabengele Mbozi for holding me so as not to fall when I tumbled due to once social stress including work load; Mwaka Chilinya and Godfrey Kalaluka from DATF, who not only helped to mobilize the respondents/participants but also went round with me to assist in case of need for translation; Dr. Mwaba, Mrs. Mukate and the entire Siavonga District Health Management Team for the information provided; other friends and colleagues, too numerous to mention, for the encouragement as well as material and moral support. My special thanks go to all those who volunteered to participate in this research either as respondents or informants.

Table of Contents

Declaration.....	1
Abstract.....	2
Opsoming.....	4
Acknowledgements.....	6
Table of Contents.....	7
Acronyms.....	9
Chapter 1: Introduction.....	11
1.1 Background.....	11
1.2 Statement of the problem.....	14
1.3 Significance of the research study	15
1.4 Aim and objectives of the research.....	15
1.5 Justification of the research study.....	16
Chapter 2: Review of related literature	17
2.1. Prevention.....	17
2.2. Information and awareness.....	18
2.3. Impact on children.....	18
2.4. ART services.....	19
2.5. Availability.....	20
2.6. Affordability.....	20
2.7. Suitability.....	21
2.8. Influence.....	21
2.9. General practices.....	22
2.10. Policies, guidelines and strategies.....	24
Chapter 3: Research methodology.....	26
3.1. Research design.....	26
3.2. Data collection.....	27
3.3. Sampling.....	27
3.4. Data analysis.....	28

3.5. Informed consent.....	29
3.6. Ethical consideration.....	29
Chapter 4: Results.....	30
4.1. Number of under-five HIV positive children.....	30
4.2. Care-givers' levels of awareness, attitude and practice.....	32
4.3. Antiretroviral Therapy available in Siavonga District.....	41
4.4. Accessibility and affordability of services.....	44
4.5. Limitations of the study.....	51
Chapter 5: Recommendations and conclusion.....	52
5.1. Recommendations.....	52
5.2 Conclusion.....	53
References.....	54
Addendum A:	59
Addendum B:	60
Addendum C:	61
Addendum D:	65
Addendum E:	66

Acronyms

AIDS – Acquired Immune Deficiency Syndrome

ANC – Antenatal Clinic

ART – Antiretroviral Therapy

ARV – Antiretroviral (drug for treatment of HIV/AIDS)

ACRWC – African Charter on the Rights and Welfare of the Child

CHAZ – Churches Health Association of Zambia

CHW – Community Health Workers

COH – Corridors of Hope

CT – Counselling and Testing

VCT – Voluntary Counselling and Testing

DATF – District AIDS Task Force

DHS – District Health Statistics

DHO – District Health Office

HBCP – Home Based Care Providers

HIV – Human Immunodeficiency Virus

IEC – Information Education and Communication

MDG – Millennium Development Goals

MESVTEE – Ministry of Education, Science, Vocational Training and Early Education

MOH – Ministry of Health

MTCT – Mother-to-Child Transmission

NAC – National AIDS Council

NASF – National AIDS Strategic Framework

NHSP – National Health Strategic Plan

PEP – Post-Exposure Prophylaxis

PMTC – Prevention of Mother-to-Child Transmission of HIV

PLWHA – People Living With HIV/AIDS

SCI – Save the Children International

SCN-Z – Save the Children Norway in Zambia

SFH – Society for Family Health

SNDP – Sixth National Development Plan

SPSS – Software Package for Social Sciences

STI – Sexually Transmitted Infections

TBA – Traditional Birth Attendants

UNAIDS – Joint United Nations Program on HIV/AIDS

UNCRC – United Nations Convention on the Rights of the Child

UNDP – United Nations Development Program

UNGASS – United Nations General Assembly Special Session

WVI – World Vision International

ZARAN – Zambia Association for Research on AIDS Network

ZCC – Zambia Council of Churches

Chapter1: Introduction

1.1. Background

Zambia has since independence in 1964 enjoyed peace and a stable political and economic base. In this regard, she has been qualified by the World Bank as a middle income country. In spite of this promising situation, Zambia has not been spared by the impact of the global challenges such as economic crisis of 2009/2010, which resulted in increased interrelated causes of poverty that has adverse effects on children; limitations within legal reforms and processes; inconsistent and low levels of implementation of government legislation and policies; contradictions within the dual legal system (statutory and customary); adult assumptions, attitudes and behaviour towards children; masculinity and gender stereotypes; the low status of women and children, culture of silence on sensitive issues such as sexuality and HIV/AIDS, and the lack of priority given to children's rights, what with the non-domestication of women and child related conventions.

This country is currently ranked 141 on the Human Development Index (UNDP, 2014). In terms of child mortality, Zambia records approximately 1%, with some 85,000 deaths in under-fives reported annually. These deaths emanate mostly from the four infectious diseases, which also have a close relationship with paediatric HIV/AIDS – pneumonia, diarrhoea, malaria, measles, and new-born complications - with malnutrition underlying a majority of child deaths (Save the Children, 2011). All these put together deny children an opportunity to fully enjoy their welfare and protection from the impact of epidemics and pandemics, including HIV/AIDS.

In Zambia the first AIDS case was reported in 1984. In spite of National AIDS Surveillance Committee (NASC) and National AIDS Prevention and Control Program (NAPCP) having been established to handle HIV and AIDS issues, discussing this deadly pandemic was taboo. Not until 1987 when first Zambian President Kenneth Kaunda disclosed that his son had died of the pandemic did many politicians and general public begin to openly talk about it. To date no known cure has been confirmed even though treatment of opportunistic infections is possible (<http://www.avert.org/hiv-aids-zambia.htm#sthash.ip7aelCe.dpuf>).

A landlocked country situated in the Southern part of Sub-Sahara Africa, Zambia shares boundaries with eight countries. These are Angola, Malawi, Tanzania, Mozambique, Democratic Republic of Congo, Namibia, Botswana and Zimbabwe. It has a population of 13,460,305, of which 51% are children (DS Lands, 2014). The country is divided into ten provinces which are further divided into 103 gazetted districts (GRZ, 2014, unpublished).

According to Alta van Dyk (2005), “AIDS is an abbreviation for Acquired Immune Deficiency Syndrome. We say that this disease is *acquired* because it is not a disease that is inherited. It is caused by a virus (the human immunodeficiency virus - HIV) that enters the body from outside.” In order for this research to make more sense to the readers, it is imperative to understand the meaning of certain terminologies used herein. The following are some of the selected terminologies: *Immunity* is the body’s natural ability to defend itself against infection and disease; a *deficiency* is a short coming – the weakening of the immune system so that it can no longer defend itself against passing infections; a *syndrome* is a medical term for a collection of specific signs and symptoms that occur together and that are characteristic of a particular condition (Dyk, 2005).

There are two commonly known types of HIV namely HIV 1 and HIV 2. HIV 1 is the most common type that is found in almost all the parts of the world and is the one that contributes to pediatric infection of the pandemic. HIV 2 is only found in West Africa, Mozambique and Angola. HIV 1 is further subcategorized in Africa as A,B,C,D,E, where A and D are the ones mostly found in East and Central, C in Southern, and A recombinants in the West (Tindyebwa, Kayita, Musoke, Eley, Nduati, Coovadia, Bobart, Mbori-Ngacha and Kieffer, 2005).

The global picture regarding the HIV/AIDS pandemic continues to be gloomy in spite of many efforts by different actors to reverse the situation in terms of infection rates. A report on MDGs reveals that there are more than 300,000,000 children living with HIV and AIDS. On the other hand the world has recorded a 20 percent decline in new infections. Reasons include more people accessing anti-retroviral therapy as well as behavioral change and communication, among others. However, there is still need for a lot of resources for more interventions (UNDP, 2014, *MDG*).

This is a research study, for which the aim was “To find out to what extent under-five HIV positive children access ART in Siavonga District”.

Siavonga district is located about 219 km from Lusaka the capital city of Zambia. The district has a total population of about 18,638 people (DS Lands, 2014). It is one of the four districts that form the Gwembe valley, a stretch which borders with neighbouring Zimbabwe. Others are Gwembe, Siavonga and Chirundu (new and just separated from Siavonga).

Like other districts in Zambia, Siavonga has continued to suffer the consequences of the HIV/AIDS pandemic. Due to its location as a border town, it is not only congested, but also provides fertile ground for different economic and social activities. This district is also a breeding ground for many illicit activities such as unprotected and illegal sex, thereby leading to increased rates of sexually transmitted infections.

HIV/AIDS cuts across all age groups including the under-five children. In spite of the existence of ART services, the research found out that there is a small number of under five HIV positive children accessing these services due to different factors, among them, Stigma, discrimination and self stigmatization. Related to this is another strand to the argument, that many children do not fully enjoy their rights as outlined in the United Nations Convention on the Rights of the Child (UNCRC) and the African Charter on the Rights and Welfare of the Child (ACRWC). Another factor is inadequate health personnel trained in paediatric HIV/AIDS, focusing on children under the age of five. To crown it all, the policies and guidelines on children have very little to say about this segment of the population in as far as the pandemic is concerned.

Children that are infected with HIV present with different symptoms among them weight loss, slow development in terms of growth, prolonged fever, oral thrush (candidiasis), chronic diarrhea, tuberculosis, recurrent bacterial infections, pneumonia, anemia, swelling of lymph nodes, herpes infections skin infections and allergies (Evian, 2000, 2003 as cited by Alta, 2005, p. 46).

In terms of viral load, adults differ from children in that when infected with HIV it takes longer to develop into AIDS for the former than the latter. When mother-to-child transmission of HIV occurs, be it through breastfeeding or at birth, rapid *progressors* develop symptoms within 6 to 12 months and usually a child dies within two years of their life; while slow *progressors* slowly begin to develop symptoms after one year. With good ART the latter category can thrive up to teenage years (Tindyebwa *et al*, 2005).

Dyk (2005) outlines the goals of antiretroviral therapy as follows: *Virological goal*, which aims to reduce the viral load as much as possible; *Immunological goal*, helps to restore and/or preserve the immunological function; *Therapeutic goal* for improving the quality of life; *Epidemiological goal* helps to reduce the disease burden and death especially at family and community level.

Given all the above information, the question is: ‘To what extent do under-five HIV positive children access ART?’

1.2. Statement of the problem

The devastating impact of HIV/AIDS has continued to haunt all aspects of children’s lives in Siavonga District, where this research was conducted. Out of the eleven districts in the Southern Province of Zambia, Siavonga is one of the areas hardest hit by HIV/AIDS, with a prevalence rate of 6.5% (DHS-Siavonga, 2011). It has two border posts namely Kariba and Chirundu where different drivers of HIV/AIDS occur, which may contribute to the high HIV prevalence rate. At the time that this research was conducted, the district had a total of 47 trained health workers operating in 16 health facilities including two hospitals. Only six out of all the trained health workers had had training in paediatric HIV/AIDS. Out of the six ART centres in the district, only one was being manned by someone trained in paediatric HIV/AIDS. To support these trained medical personnel, there were 48 Community Health Workers (CHWs) and Home Based Care Providers (HBCP) as well as 22 Traditional Birth Attendants (TBA). However, not all of these were active due to lack of incentives as all these are volunteers (*ibid*).

Like many rural districts, information pertaining to paediatric HIV prevalence in Siavonga district is limited despite that this category of key population is the most at higher risk of contracting the pandemic. (UNAIDS report on the Global AIDS epidemic, 2013). The above scenario prompted the researcher to select Siavonga as a study area.

1.3. Significance of the research study

During this research it was found out that there is little information about under-five HIV positive children and their access to ART. Therefore, the results of this study will enhance the data bank on this topic particularly for children under the age of five. The results of this study will further assist in advocacy work for such children as they have special needs that require special attention. In addition, this information will be used to attract potential donors/funding agencies and thereby contribute to evidence-based programming. It will also add value to the work of future researchers, policy and decision makers as well as enhance recognition as well as open more avenues for possible interventions for under-five HIV positive children.

1.4. Aim and objectives of the research

1.4.1. Aim

To assess the extent to which under-five HIV positive children access antiretroviral therapy (ART) in Siavonga district, in order to advocate the scaling up of appropriate interventions for this category of the population.

1.4.2. Objectives

1. To investigate the number of under-five HIV positive children in Siavonga district who do not access ART, as compared to those that are eligible out of the total population of the target group.
2. To find out the factors hindering under-five HIV positive children from accessing ART in Siavonga district, but also to understand the corresponding implication of lack of access.
3. To assess care givers' (parents' or guardians') and medical practitioners' knowledge about, as well as attitudes and practice towards under-five HIV positive children accessing ART.
4. To identify the ART services available in the district.
5. To find out how suitable, accessible, affordable and readily available these ART services are to

under-five HIV positive children.

1.5. Justification of the research study

Children are the ‘window of hope’ for any country. There is a saying in one of the Zambian local languages (Chibemba) which states that, “*Imiti ikula e mpanga*”. The literal translation of this is that today’s tree nursery will be tomorrow’s forest. This means that unless children are well nurtured and protected, the nation will be deprived of a healthy and productive populace. The result of such a situation is that there will be low gross national product (GDP) and this will lead to underdevelopment of the country.

Most of the information available on paediatric HIV/AIDS generalises for infected children within the 0 to 15 age category. This study endeavoured to focus specifically on children below the age of five because they are in the most crucial development period of life. These children are entirely dependent on their parents or guardians for their survival. Many a time, debates on children’s wellbeing often involve representatives from giant institutions and in the process the ‘voice’ of the parents and communities go unheard. This, coupled with the culture of silence as well as inadequate information about the subject matter increases the challenges faced by under-five children infected by HIV (Save the Children Norway, 2012).

Chapter 2: Review of related literature

Introduction

This Literature review focuses on the following major themes: Prevention, ART services, general practices and national policies and strategies.

2.1. Prevention

In Zambia messages about prevention of HIV transmission began almost immediately the pandemic was discovered. This is observed by an American journalist (among others) who is quoted as saying, "Zambia is waging one of the world's most aggressive educational campaigns against AIDS, surpassing anything being done in the United States". The sensitization campaign was done through media which included distribution of pamphlets and posters showing how dangerous HIV and AIDS were and prevention messages such as: "Sex thrills, but AIDS kills". Depending on their evolving capacities, children have not been excluded from these campaigns, but have been taught at least the biological facts in school (AVERT, 2012) found at <http://www.avert.org/hiv-aids-zambia.htm#sthash.ip7aelCe.dpuf> and re-accessed on 16/12/2014 at 19:10 hours).

However, in spite of the above, the challenge is that many people in Siavonga district have a behavioural and attitude problem that make them and their children more susceptible to HIV/AIDS. The most common ways in which children get infected with HIV are through: mother-to-child transmission (MTCT) either during delivery or through breastfeeding; tattooing which is done mostly by using unsterilized razor blades or pricked by other sharp instruments which could be contaminated with blood infected with HIV; and if subjected to transfusion using HIV infected blood. Some children have become infected through sexual abuse by HIV positive adults who believe that having sexual intercourse with a virgin child can cure or cleanse them, among other reasons. In most cases, it is difficult to know when a child under the age of five is sexually abused, especially when there are no visible serious injuries, as they do not usually speak out. One example is a case of three children who were reported in the Post as being sexually abused by their grandfather each time they visited him. After being examined at the

hospital, one of them was found with an infection. Two of these children were below six years old while the youngest was in baby class at a nursery school. The same Newspaper talks about a grade seven pupil who defiled a grade one pupil (Post Newspaper of Friday November 9, 2012, p. 6). The HIV/AIDS pandemic has been perpetrated mostly by duty bearers such as parents, guardians and neighbors, who are supposed to protect these children.

2.2. Information and awareness

Despite efforts by many stakeholders in sensitizing communities on the dangers of HIV/AIDS, there are still many misconceptions about this pandemic. This leads to resistance to change in behavioral patterns (Avert at <http://www.avert.org/hiv-aids-zambia.htm#sthash.ip7aelCe.dpuf>). There is still a general resistance by many especially men to practice safer sex by using condoms. This increases the chances of women being infected with HIV, who in turn transmits it to their babies (MCTC). Some IEC materials that have been distributed to the general public even in simplified and local language versions have not been adhered to. Efforts by the Ministry of Health to enable all the women who go to health centers for anti natal and post natal care receive information about this deadly pandemic, are bearing fruit at a snail's pace. The inclusion into the curriculum by Ministry of Education, Science, Vocational Training and Early Education (MESVTEE) of an addendum on information about HIV/AIDS is but slowly sinking as adherence is still a concern (MESVTEE, 2012).

Illiteracy levels are quite high among women, who are the majority among the care givers in Siavonga district. The question is, how many have access to information and make use of it to protect themselves, their partners and their children from HIV/AIDS or adhere to the requirements of ART? After being equipped with information, does this help to avoid stigma and discrimination?

2.3. Impact on children

In 2002 the National HIV/AIDS/STD/TB Council (NAC) was enacted to coordinate a multi-sector response to HIV and AIDS and guide the implementation of the National HIV and AIDS Strategic Framework. Due to its magnitude and devastating impact, HIV/AIDS was declared by

late President Levy P. Mwanawasa (SC), a national emergency that could culminate into a disaster if not properly attended to. In view of this, the President also promised the provision of antiretroviral drugs within that year to 10,000 deserving persons; and, another 100,000 by end of 2005. This indicated change of attitude and political will, which Lewis, who was U.N. Special Envoy on HIV/AIDS to Africa (2005) states as, ‘an entirely new level of determination’ to confront the epidemic (*Times of Zambia Newspaper*). However, the question still stands – to what extent do under-five HIV positive children access ART?

2.4. ART services

Support to PMTC has been going on since 1999. However, this has faced a number of challenges such as women shunning the health centres and preferring to deliver at home, just in case they are HIV positive. <http://www.avert.org/hiv-aids-zambia.htm#sthash.ip7aelCe.dpuf>.

Stringer, et al (2008) also echoes this statement as he points out that, “Despite the availability of proven interventions for the PMTCT and substantial donor investments for implementing them in developing countries, pediatric AIDS remains a largely uncontrolled epidemic.

Tindyebwa et al, (2005) mention two types of services available for HIV-infected children namely HIV disease staging and ARV therapy. *“Disease staging, with or without laboratory support, follows HIV diagnosis. Staging HIV disease provides a guide to the prognosis and interventions needed at the different stages... ARV therapy demands to counsel for and provide ARV drugs. Give children ART according to international or national guidelines, which take into account that not all HIV-infected children are eligible for ART... In the absence of laboratory confirmation of HIV, provide ARV drugs for HIV-exposed younger infants (less than 18 months, with a positive anti-body test) only if there is evidence of immunodeficiency (CD4% < 20% or WHO pediatric stage 3 or 4)... In all cases where younger infants (< 18 months are started on ARV drugs in the absence of a virologic test, you must perform an antibody test at 18 months to determine whether to continue with ARV drugs.”* (p. 65)

A research by ZARAN, indicates that, “In Zambia, children are being treated with nevirapine (NVP), zidovudine (ZDV/AZT), and lamivudine (3TC) syrups or suspensions as well as with the fixed combination of combivir (AZT + 3TC) and triomune (3TC, d4T and NVP). There is no single recommended ARV regime for children. This is attributed to the fact that the type of treatment prescribed for children depends on a number of factors including age, weight and nutrition status of the child, and the availability and form of medication (i.e. syrup or tablet). On the other hand, it doubts the availability of child-friendly PEP.

This situation poses a challenge in that these tablets are not only unpalatable to children, but also there is likelihood to under or over dose the child.

2.5. Availability

Overall, ART services are supposed to be provided in Zambia free of charge and are supposed to be distributed to ART centers countrywide. Practically, this is not the case, especially for Siavonga district which has only six ART centers. According to NAC Coordinator (2006, unpublished), out of about 62000 HIV positive people who were accessing ART, only 2900 were children (5%). This figure does not give a breakdown of how many of these children were under the age of five. This just confirms that there is no particular attention paid to HIV positive children under this age category. Although the Zambian government through NAC provides guidelines on ART in general, there is no particular information on administration to children under the age of five (MoH, 2011).

2.6. Affordability

One challenge for many under-five HIV positive children accessing ART lies in the fact that the majority of the population in Siavonga District live far away from health centers. The issue of either transport costs or difficult terrain, coupled with uncertainty on safety and security render it difficult for children under the age of five to access the services as they rely on the mercy of those who keep them to take them to ART centers. Some of the parents and guardians of under-five HIV positive children would rather send ‘unsuspecting’ younger children to take their siblings to health centers because they (adults) do not want to be seen to be associated with children who are HIV positive.

A number of infected children have already lost one or both parents to HIV/AIDS or other causes. Therefore, they are being looked after by either their ageing grandparents or siblings who are equally young. Both these categories of care givers can hardly manage to walk long distances to ART centers.

Children who are on ART need a lot nutritious food or balanced diet as the ARV that they take stimulate their appetite and make them crave nice food, most of which is expensive. High poverty levels among most rural dwellers make it difficult for them to afford these foodstuffs. What could be worse is when resources are depleted due to other demands such as schools fees, medical bills, clothes, food for other members of the family, to mention but a few.

2.7. Suitability

In Siavonga like many other parts of Zambia, there are no separate ART centers that are meant specifically for children. Hence, under-five HIV positive children and their care givers are left to wait in long queues hungry and tired, before they are attended to. Due to these socio-economic constraints they prefer cheaper ways such as home medication or going to traditional healers (*Ing'ganga*).

Although there is ARV in syrup form, most children in Siavonga and other hard to reach parts of the country are treated using tablets because the syrup is not readily available due to erratic supplies. This is associated to poor cold chain management from the central board of health, which is the major source of these medicines. Some ART centers have no proper storage facilities (Siavonga DHMT, Unpublished).

2.8. Influence

Religious beliefs and practices also contribute to the refusal by affiliates to use safer methods like condoms. An article from a research done by Agha, Hutchinson & Kusanthan (2006), indicates that “Inhibitive cultural beliefs and practices, coupled with high illiteracy levels play a major role in preventing under-five HIV positive children from accessing ART. When a baby or infant is ailing, many families resort to treating such a child at home using traditional medicines,

which include not only roots and herbs but also tattooing. The concoctions that are administered at home usually do not have specific dosages. These increase the risk of children being stressed, traumatized or dehydrated. Tattooing could lead to excessive loss of blood as well exposure to contamination that could lead to further infections.

2.9. General practices

According to a research by ZARAN (2006), “Zambia’s apparent neglect of HIV infected children is not unique; in the global fight against HIV/AIDS, HIV infected children worldwide have received relatively little attention compared to other infected and affected groups. This is especially true concerning access to treatment. This neglect for HIV infected children is a result of several factors such as: few HIV positive children in developed countries which are the originators of funding; logistical issues concerning the treatment of children; a lack of government policies on Paediatric HIV treatment; a lack of public awareness and discourse regarding children’s rights and HIV treatment access; and stigma and discrimination against HIV positive children.” (ZARAN, 2006. p. 6)

Stigma and discrimination has also seen some family members on one hand refusing to eat from the same plate as those that are infected, thereby making the latter feel isolated; but on the other hand they scramble for the little quality food that is supposed to be reserved for HIV infected children who need it the most.

Although there has been a slight improvement in sexual behavioral practices, condom use is still low among Zambians. This is due to a number of factors including the following: Mythically, it is believed that condoms cause infertility; demand to use condoms by either partner is seen as a sign of not trusting the other; sex is not enjoyed to the maximum (*why use a raincoat when taking a shower?*); it is a power issue for most men who, by refusing to use condoms, exhibit that they are in control; increased poverty levels have also contributed to women and girls engaging in illicit sex as a source of livelihood, as they charge more money they do sexual intercourse directly without protective measures; non availability of this commodity in most communities (Bond & Dover, 1997).

Although many Zambians have adequate knowledge about STIs and HIV/AIDS, the majority still engage in extramarital unprotected sex. Most of the perpetrators are men who have disposable income that they can distribute to poverty stricken vulnerable women. This is evidenced by a reasonably increased number of children who are born out of wedlock. The prevalence rate of HIV infection among adults is 16%, most of whom have acquired the pandemic through heterosexual practices (Kimuna et al, 2005). Under-five HIV positive children are vulnerable to opportunistic infections such as pneumonia, diarrhea, malaria, measles and other complications. Due to poverty, ignorance and negligence, these children are exposed to the above-mentioned vices as most families in Siavonga district cannot afford warm clothing and blankets, good hygiene practices and nutritious food. Most of them are subsistence farmers, petty traders or casual workers who do not accumulate enough disposable income for their households.

PMTCT is one of the ways in which HIV infection can be reduced among under-five children. Although there have been efforts by government and its cooperating partners to promote this service, adherence has been a challenge. To illustrate this, is a research carried out in Lusaka by Stringer, *et al* (2008), using an anonymous cord blood surveillance for HIV antibodies and detectable nevirapine (NVP) drug levels. *“This study, which recreated the PMTCT cascade for 10 194 women delivering over a period of three months across all of Lusaka’s 10 public-sector facilities, demonstrated three critical areas of program effectiveness that are not measured by most process indicator - derived PMTCT cascades: (1) women refusing testing were more likely to be HIV-infected than those accepting testing, (2) laboratory result errors and seroconversions caused a proportion of women (6%) who should have received prophylaxis not to receive it, and (3) one-third of women who were given a NVP tablet for self-administration at labor onset did not actually swallow the pill. This surveillance study demonstrated that despite a seemingly robust PMTCT program in Lusaka, only a minority of HIV-infected women and HIV-exposed infants (30%) were receiving even minimum prophylaxis and that field effectiveness was likely much lower than estimated from standard process indicators”* (p. 2).

2.10. Policies, guidelines and strategies

The United Nations have less than one year more to meet the targets that they declared that they would reach in terms of addressing the deadly HIV and AIDS pandemic. Yet a lot still needs to be done. A report by UNAIDS illustrates this - (http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf re-accessed on 16th/12/2014 at 19:55).

In order to stay in tune with global trends in addressing the deadly HIV/AIDS pandemic, Zambia has joined the rest of the world to adhere to policies and procedures that guide these efforts. However, government escapes the responsibility to be held fully accountable to implementing them in that it has put a condition that implementation can be done only when resources are available (find reference). In addition, none of these documents clearly focuses on under-five HIV positive children.

These policies, guidelines and strategies include the following: MDG number six – “Combat HIV/AIDS, malaria and other diseases”, the Paris Declaration, UNGASS Declaration, Universal Access, Abuja Declaration, African Union Maseru/Maputo Declaration, and SADC Protocols. At country level different frameworks have been developed. These include the National HIV and AIDS/STI/TB Act (2002), National Decentralisation Policy (2002) National HIV and AIDS/STI/TB Policy (2005), National HIV and AIDS Strategic Framework (2006-2010), Fifth National Development Plan (2006-2010), Population Policy (2007), Reproductive Health Policy (2008), and the Zambia Decent Work Country Programme (ZDWCP) 2007-2011 (Zambia UNGASS Report, 2010).

The SNDP outlines measures that government will take to address issues of maternal and child health, which include the fight against HIV and AIDS. These include finalization of the National Health Policy of 1992; develop a comprehensive national Health Act; speed up the National Decentralisation Policy; National Health Strategic Plan 2011 to 2015, among others. This is in an effort to bring health services as closer to people’s homes as possible (SNDP 2011 – 2015, pg 85).

Zambia has joined the rest of the world in signing and ratifying relevant regional and global conventions that relate to the plight of children. The challenge is that most of these instruments are not domesticated so as to hold policy makers and implementers accountable should they fail to adhere to them.

One such convention is the United Nations Convention on the Rights of the Child (UNCRC), which outlines four principles upon which the rights of the child can be promoted or upheld. These are the *Best Interest of the Child*, *Survival and Development*, *Non Discrimination* and the *right of the Child to be heard (Participation)*. These are briefly explained below:

“Article 24 (Health and health services): Children have the right to good quality health care – the best health care possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy. Rich countries should help poorer countries achieve this.

Article 25 (Review of treatment in care): Children who are looked after by their local authorities, rather than their parents, have the right to have these living arrangements looked at regularly to see if they are the most appropriate. Their care and treatment should always be based on “the best interests of the child”. (See Guiding Principles, Article 3)

Article 26 (Social security): Children – either through their guardians or directly – have the right to help from the government if they are poor or in need.

Article 27 (Adequate standard of living): Children have the right to a standard of living that is good enough to meet their physical and mental needs. Governments should help families and guardians who cannot afford to provide this, particularly with regard to food, clothing and housing.” (UNCRC, 1989)

Chapter 3: Research methodology

Introduction

This chapter outlines how the research was designed. It explains how respondents were sampled, how data was collected and analysed as well as the tool used.

3.1 Research design

This research utilised predominantly a qualitative approach. However, some quantitative data in terms of statistics and tables were also gathered. The emphasis on qualitative data collection was to get respondents' in-depth ideas and feelings about paediatric HIV /AIDS from their own lived experiences and perspectives (Huberman & Miles, 2002).

Data collection took place at various points; either at the health office, ART center or the respondent's home in the community using a participatory approach. It also gave an opportunity to these participants, especially women who are mostly affected by the culture of silence, a chance to express themselves on this matter that affected them. In addition, qualitative data made it easier to follow cause and effect, since one could track people through their lives or ask them to tell their lived experiences with under-five HIV positive children (Gilbert, 2012). Both secondary and primary data was collected. Primary data collection was through focus group discussions using interview schedules that were developed for this purpose. The researcher took cognizance the fact that the level of understanding of the different research participants was different based on their educational levels. Hence, to ensure that language was not a barrier administering of the data collection tool varied accordingly, with translators from DATF used where necessary. Secondary data were collected even though there was not much about under-five HIV-positive children. Some quantitative data were also collected from document review such as records from the targeted ART centres, District Health Office and other information data bases.

3.2. Data collection

Interview schedules were used to collect data. They were designed in such a way that one catered for community members i.e. Parents, Guardians, care takers; while the other one for Community Health Workers, Home-based Care Providers, staff of the Ministry of Health and District AIDS Task Force (DATF). Pre-testing of research tools was done to ensure that the instruments used were responsive to the research topic, hence brought out the required information from participants.

3.3. Sampling

One of the non-probability sampling procedures namely purposive sampling was employed as the main technique in this research. The reason was that the researcher selected specific respondents that were deemed relevant for this particular research from the categories of the main duty bearers. All these respondents were in one way or the other involved in HIV and AIDS related work, either as workers at health centres, co-ordinator or committees members of DATF, or volunteer community members (CHW, TBA or HBCP). In terms of sampling, there were two categories of respondents, namely health workers and community members. However, the characteristics of each member in each category also differed. Such differentiation might have affected the way the respondents answered the questions. In order to uphold the principle of confidentiality, no real names of respondents are used.

In the first category there were five participants who were actually employed either at a clinic or hospital, among them were two medical doctors. There were two participants who were home-based care providers and one member in the role of co-ordinating the HIV and AIDS activities. This brought to eight the total number of respondents in this category. All the respondents in this category were asked to answer the same questions. The assumption was that since in spite of them coming from the health/HIV and AIDS sector their characteristics were different; hence, the research was likely to yield different responses.

There were seven community members who were asked to answer the same questions, though each one was different from the other. These were parents, guardians and care takers. It was

likely that their responses to the questions might have been influenced by the specific characteristic that each member had.

3.4. Data analysis

All relevant data were captured from the respondents through field notes. Qualitative data were analysed by way of generating themes, categorising, analysis of the text, and case study. The initial coding and categorization of the themes as well as all the works were done by the researcher. Data were analysed manually and no software was used for this purpose.

During this research, the research built rapport with the respondents; this gave them confidence and trust to reveal data about the topic of research. By choosing this method, the researcher's aspirations to understand the extent to which under-five HIV positive children access ART in Siavonga district, were fulfilled.

Analysis of qualitative data involved theming and sub-theming, categorizing, coding, data display, as well as conclusion drawing. The Interpretive Process was used. As stated by Huberman and Miles (2002), *“by deconstructing, capturing, bracketing, constructing, and contextualizing the phenomenon under investigation, the researcher brings it into sharper focus. The researcher's goal in undertaking these interpretive activities, as indicated earlier, is to create a body of materials that will furnish the foundations for interpretation and understanding. Interpretation clarifies the meaning of an experience. Interpretation lays groundwork for understanding, which is the process of interpreting, knowing, and comprehending the meaning of an experience. Understanding, through the location of meaning in the experiences of interacting individuals, is the goal of interpretive interactionism (p. 360).*

The use of grounded theory featured in this research. In grounded theory, the process of data collection ran alongside that of analysis and became gradually more focused as the project progressed (Gilbert, 2012:85). As this was predominantly qualitative, it followed the inductive model (Creswell, 1994).

3.5. Informed consent

Prior to conducting interviews, each of the respondents were given a consent form to sign. This stipulated what the research was all about and why it was important for participants to be part of this study. Participants were also assured of the observance of the principle of confidentiality by the researcher. To ensure that they understood what they were getting into, the researcher read through and explained the contents of the form. In case of any uncertainties, contact details of the researcher were included in the form.

3.6. Ethical consideration

Throughout the research period, the researcher complied with research ethical principles. Participants to this study were briefed prior to conducting the research so as for them to understand what was involved in this research and why it was important for them to participate. Through the efforts by DATF and the MOH to mobilise participants, the researcher directly contacted the participants and discussed the benefit of this research. They (participants) understood that they were free not to respond to questions that they felt uncomfortable about. Those who were able to read were given time to read and re-read all the research related documents and were given the freedom to ask questions if they did not understand any question or suggest changes as necessary, without distorting the meaning. This helped them to make an informed decision on whether to go ahead and participate or not. Those that agreed to be part of this study were assured of confidentiality of the data that they would give out and anonymity of their identity. Since participation in this research was voluntary participants were informed that they were free to discontinue if they felt so without the fear of being victimised.

In order to proceed with this study, written permission was obtained from the following authorities: Ministry of Health in Zambia, represented by the then Acting District Medical Officer for Siavonga District Health Management Board; National AIDS Council represented by the District AIDS Coordinating Advisor; Ethical Committee for University of Stellenbosch; as well as the participants themselves who signed the informed consent forms prior to the interviews.

Chapter 4: Results

Introduction

The findings of this research are presented based on the objectives set, upon which themes and sub-themes have been generated. These themes and sub-themes have helped to categorise responses. In order to understand the influence each respondent had over the discussions and how they interpreted the questions, it is important to understand these categories as outlined under Design and Methodology.

4.1. Number of under-five HIV positive children who do not access ART

Quantitative data from Siavonga District Health Management Team

Item	Description	Quantity
1	Public and Private health facilities providing ART	6
2	Health facilities that provide ART services with no ARV stock outs of >2 weeks in the last 12 months	3
3	Persons with advanced HIV infection receiving ART (not disaggregated according to age)	Male: 1744 Female: 2730
4	Community adherence supporters/Home based care providers trained to provide ART services	123
5	Service providers trained to provide ART services	33
6	Service providers trained in the diagnosis and treatment of STIs according to national guidelines	Male: 8 Female: 9
7	Service providers trained in standards for infection prevention and health center waste storage and disposal	37

8	HIV +ve pregnant women receiving a complete course of ARV prophylaxis to reduce the risk of MTCT	23
9	HIV exposed infants seen in the first two months of life for check up	197
10	Infants tested for HIV and received test results	94
11	HIV positive infants	26
12	HIV exposed infants receiving co-trimoxazole prophylaxis	337

During this research efforts to obtain data that was segregated according to age were not fruitful. The information that was available generalised children between 0 to 15; and, also separating these from adults. On the number of under-five HIV positive children accessing ART, only one respondent mentioned the number (approximately 30) that accessed one kind of ART or the other, be it ARV or just care and psycho-social support. This data was not disaggregated. The rest of the respondents had no specific data. At one ART centre, only ten under-five HIV positive children out of the 84 community members who were on ART were confirmed to be among this number. Others were just categorised as children in the age group between 0 to 15 years old.

All the respondents said they did not know the actual number of under-five children who were infected by HIV in their catchment areas. Those who came close to mentioning the numbers admitted that they were only speculating. Even some of the medical personnel were frank enough to admit that they had not bothered to segregate data for this category of children. Mr. 'R' fell short of the answer when he said that in his catchment area there were *about* 100 people who were living with HIV/ AIDS. He said out of this number, about 30 were children, but he didn't know how many were under the age of five.

4.2. Care givers' levels of awareness, attitude and practice towards under-five HIV positive children's Access to ART

4.2.1. Awareness about HIV and AIDS

From the responses, the research showed that almost all participants knew a lot about HIV and AIDS, how it is acquired, transmitted and its effects on the human body. Whereas health personnel knew a lot more about technical aspects of the pandemic, community members' knowledge was based more on their experience and basic training that they underwent such as in psycho-social counselling or as home-based care providers.

Some of this knowledge that this research brought out included the following that: HIV is a virus that causes AIDS. It comes as a result of lowered immune system of human beings. It attacks the immune system and causes deficiency in immunity. Eventually this leads to damaging the immune system. AIDS is not a single disease but a syndrome.

HIV causes AIDS and the victim develops opportunistic diseases such as diarrhoea; these opportunistic diseases can be treated by accessing antiretroviral, but not for the virus itself; the pandemic is transmitted through exposure to contaminated blood from sexual intercourse, sharp objects and blood transfusion; AIDS is acquired and not a single disease.

They also knew that this pandemic can be prevented by avoiding direct exposure to contaminated blood, but also abstaining from unprotected sexual intercourse and being faithful to one faithful partner. The correct usage of condoms was also cited as one preventive measure. However, both community members and medical personnel indicated that there was resistance when it came to usage of condoms by many regardless of their educational background. This was probably due to the myths surrounding it such as: condoms caused impotence; use of the same could indicate lack of trust and inadequate love for each other, to name but a few examples.

The participants also talked about how they gained the knowledge on HIV. The medical personnel said that they had been working in the health sector particularly on HIV/AIDS issues

for a long time and so they have vast experience in the health sector and a lot of information on HIV/AIDS. They came to know a lot about the pandemic over the years. (But the question still stands: what was done for children under the age of five who were infected with HIV?)

On the other hand the other category of respondents said that they came to know about HIV/AIDS because they had been trained either in Psycho-social counselling or as home-based care providers. One gave an elaboration that some thought that it was because of what their parents did, e.g. adultery, that is why they were punished by ancestors. Some of the questions that helped to further probe participants' knowledge about HIV/AIDS are illustrated below.

What is Antiretroviral Therapy (ART)

Variously the respondents gave the following answers: ARVs were for boosting the immune system of people who suffer from HIV/AIDS; reduction of HIV related illnesses or death; prolong and improve the quality of their life; ARVs was medicine; helped to improve the health of those who had the disease so that they could live longer. The respondents could not talk about the other types of therapy other than general medication and medicine given to those who suffer from HIV/AIDS and other types of care like food, hygiene and love.

Opinion about under-five HIV positive children accessing ART

To a larger extent, responses were that these children must also be taken to the hospital to receive medicine and it is the duty of those who looked after them to ensure that the children took their medicine at the right time. They said those children needed it and must be taken to the health facility to be attended to. Only one respondent was doubtful of whether it was necessary to that these children needed to access ART in order to prolong their life.

The researcher's reflection is that there was really no detailed discussion with the respondents on this question; as a result their inner feelings on this topic did not really come out in the open. However, it was Mama 'L' who held practical knowledge on HIV/AIDS since she is living with HIV herself and belonged to a support group of HIV infected people living positively.

The case study below represents some recorded sentiments:

Case study 2

Mama 'L' (37 years) of Siavonga District is married to her late sister's widower. She inherited the marriage due to pressure from the relatives that she had to take care of the children that her late sister left orphaned after her demise following a long illness. She became the second wife as her husband who was already in a polygamous marriage. She is also HIV positive. She now takes care of two HIV positive children, one of them is under the age of five, the target group for this research.

Mama 'L' said that she knew about HIV and AIDS because apart from her being HIV positive, and that she had been living with this problem since 2009, her husband and two of her step children were also HIV positive. She explained that she married her husband in 2008 after his wife died and left young children. According to the Tonga tradition, she was obliged, even though she did not like it, to inherit her late sister's husband so as to take care of the half-orphaned children. She did not know that her sister died of AIDS. "I put myself into problems by accepting to marry my then brother-in-law", she lamented and shed tears. "This child (carried on her back) has been in and out of hospital since he was born. They told us that he was HIV positive last year (2011). Right now I am from the hospital to get more medicine for him. He is on ARVs", Mama 'L' said (she broke down).

Causes of HIV and AIDS

The major cause of HIV/AIDS that all the respondents gave is having sexual intercourse with an infected person. Other causes included anything else that had infected blood, instruments which were contaminated with blood if that blood contained HIV, e.g. razor blades during making tattoos, same injection at the hospital, mother-to-child transmission during child birth, breastfeeding and exposure to infected blood e.g. through transfusion. However, only five of them mentioned how care takers could protect themselves from HIV infection by not exposing

themselves when for instance cleaning open wounds and cuts of those ailing. Others said that doing so would show their loved ones that they did not care much.

Modes of transmission

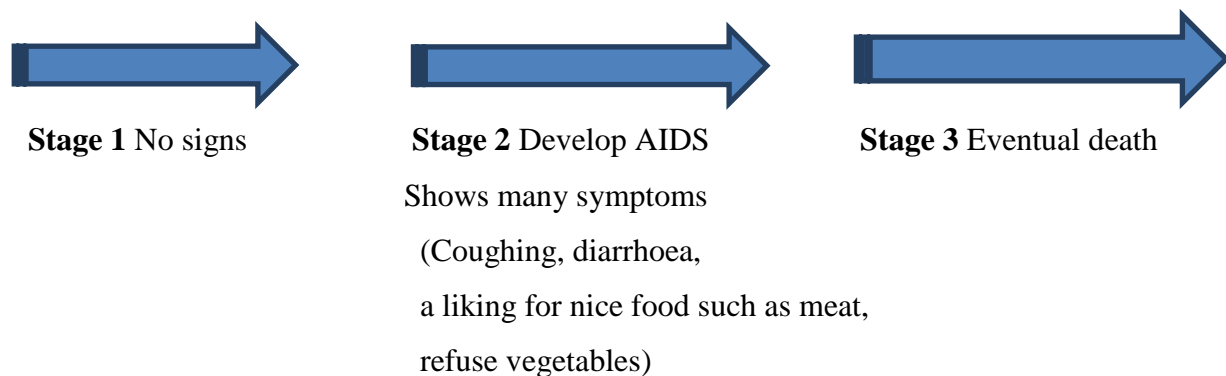
The respondents did not answer this question. They referred the researcher to the answers they had given in question 2.

This raised a query for the researcher on whether the question was not constructed properly or respondents just did not understand the difference between 2 and 3 of the questionnaire. One respondent said, “As above”, and he laughed.

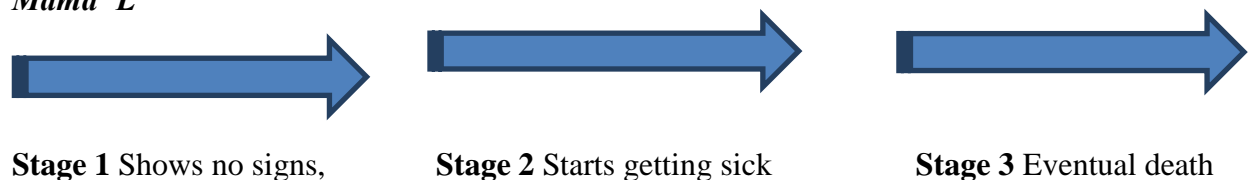
Stages of the HIV and AIDS Pandemic

The five community members had their own interpretation of the stages of the disease as is presented below. However, all of them got the stages right and differed only in detail. Ms. ‘M’ had more details at stage 2. For her this is not a lived experience. She got knowledge through training sessions. On the other hand Mama ‘L’ had more details on stage 1. She was able to explain at that stage because she was in it as an HIV/AIDS positive person. Mr. ‘E’ did not have enough details. Like Ms ‘M’ his knowledge of HIV/AIDS was from the training that he received.

Ms ‘M’

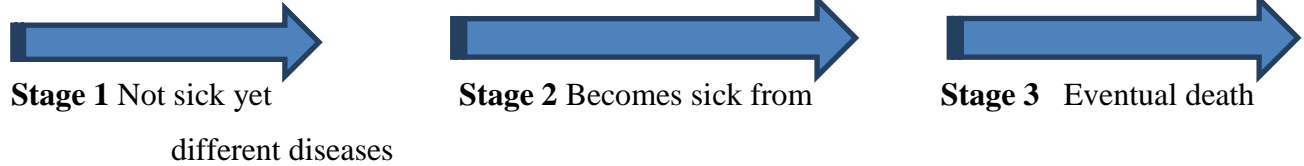


Mama ‘L’



denial, just all right, active
and ‘can marry another woman’

Mr. ‘E’



Treatment

The researcher gathered information that ARV tablets for adults and seprine tablets were used to treat people who were HIV positive. It was further mentioned that Oral ARV and seprine syrup for children were also used.

Mama ‘L’ used her practical example by saying that she had just come from the hospital to get medicine for her baby still on her back. “There was medicine at the hospital,” she said without going into detail about the names of medicines she got for her baby. She also said that those who were ‘courageous’ (indicating fear of being diagnosed positive) enough could go and be tested and if found positive they could be advised to start taking medicine. Mr. ‘E’ just said, “ARVs” without any elaboration.

Care

On how people, especially under-five children who were HIV positive were cared for, respondents gave various answers including the following: it was by going to hospital to seek medical attention: some trained people went to the homes of those who had AIDS to encourage them to take their medicine and eat a good diet (no elaboration was made on what was meant by ‘good’ diet). Probably the researcher did not probe enough.

On the other hand the researcher learnt that care was given to children as an obligation by the family. One respondent pointed out the significance of this care by saying, “These children love me more than the other wife of their father’s because her, she does not take care of them”, she

said. However, she did not say what the nature of that care was. She just spoke about care in general terms.

On the other hand, one of the respondents did not answer the specific question about how to care for children under the age of five. He only gave a general answer about people living with HIV/AIDS and even then he mentioned one solution only, namely the provision of food.

Prevention

The modes of prevention that were mentioned during this research are as follows: avoiding unprotected sex (some added ... “with an infected person”), but if they cannot they must use a condom. On this, one respondent was quick to point out that this was difficult in marriage as husbands refused to use them giving the reason that only prostitutes could demand the use of condoms. Another measure of prevention mentioned was avoiding being pricked by sharp instruments that were contaminated with infected blood. One responded said that as home based care providers (HBCP), they were urged by staff at the hospital to advise parents and guardians to be careful when handling children who were HIV positive. She gave an example that when cleaning them, if they had a sore or wound, they could possibly infect others.

Abstinence, being faithful to one faithful sexual partner and avoiding infected blood transfusion were also some preventative measures that almost all respondents cited. Three respondents (community members) did not seem to have ideas about other means of prevention. The researcher did not believe that they did not have the answers because in questions 1 and 2 they came up with some lists of prevention. It could have been that they did not understand the question or that the researcher did not probe enough.

Where people seek medical attention

In answer to this question the respondents said they sought medical attention mostly from their local health centres. However, some preferred to go to other health centres including private clinics that were far away for fear of being stigmatised. Others that were superstitious consulted witchdoctors as they believed the source of this pandemic to be witchcraft, bad omen or having

slept with a widow or widower who had not been cleansed. Hence, they sought traditional medicine.

Knowledge of under-five child that is HIV positive/Relationship to respondent

One respondent answered ‘no’ to this question. However, she said that there were other children in her village who look like they had AIDS but they were not taken to the clinic to be tested and get medicine.

Support given to under-five HIV positive children

On the support given to under-five HIV positive children who needed or were on ART, the responses were as follows:

1. People who did door to door visitation to monitor adherence. This was so because sometimes the diet for these children was poor because some parents did not know how to take care of their children or families; but for others they did not just have enough money to buy good food.
2. People needed more information
3. Cleaning the children
4. Giving them food and medication as per advice from the health/ART centre
5. They had to show love. This respondent recommended that NGOs should train more community members who are responsible and can explain in a friendly manner to their fellow members
 - Helped the parents of these children by encouraging them to go to the hospital to get medication for their children
 - Parents or guardians adhere to prescribed dosage for children
 - More volunteers to help with outreach programs

4.2.2. Attitude towards HIV/AIDS positive people

The emphasis of the research was not just people in general but those with HIV/AIDS and especially the under-five children. The continuum of participants’ attitudes differed from an attitude of personal concern to the attitude of a worker who stands aloof. This depended on the type of jobs they were doing and the circumstances they were in. The following information

came out: Some respondents, including one nursing sister, said that over the years of their interventions on HIV and AIDS, they had developed a positive attitude towards orphans and vulnerable children including those with HIV/AIDS. Upon analysing the data closely, it became clear that this positive attitude was not so much a concern for these children but because it was their duty as medical personnel and care givers to show a positive attitude towards every patient.

Furthermore on the sub-theme of attitude, all participants responded that they viewed people as human beings regardless of their status. Two of the respondents who brought out this point emphasised the human right to live, this was an indication that they had certain attachments to the children. One female participant said she did this because she was both a mother and professional who believed in helping children. Another one (male) said, “I have a positive attitude towards people who are HIV positive because my father and brother died of AIDS and my sister is on ART because she is HIV positive but living positively”. He argued that it was not the children’s fault that they were infected with HIV; hence, the need to assist them.

The sub-theme on acceptance and non-discrimination brought out issues related to the ones on attitude outlined above. One respondent who disclosed that he was HIV positive said that he knew that it was important for others to accept PLWHA, just as his wife had accepted and continued to love him as a human being. He also revealed that his attitude towards under-five HIV positive children was that he did not look down on them because it was not their fault that they were infected. Therefore, he saw no reason to discriminate against them. He emphasised (showing emotions) that, “They are victims of circumstances. They did not choose to be born from parents who were HIV positive.”

It was clear from his own explanation that his positive status had something to do with the way he looked at other people in a similar situation.

‘Part of one’s target group’ is another sub-theme that was identified during this research. As far as participants were concerned, they had the responsibility to embrace children and others with HIV/AIDS because they all formed part of their target group be it formally or informally. One

participant said that he sympathized with them as long as these people were there but only to advance his work. In all the discussions he did not cite a situation that affected him personally or his family. Others acknowledged the importance of under-five HIV positive children as being an important constituency of their responsibility.

In an effort to uphold the principle of Inclusiveness, under-five HIV positive children were accepted as participants' family members even though some were being segregated. The research found out that discussing HIV/AIDS helped families not to discriminate against anyone who was HIV positive, regardless of their age, status in society or even nationality. According to the information gathered from some of the respondents, family members and the community at large especially pregnant women were encouraged to go for VCT so that they could know their status; and, if detected early, HIV/AIDS could be treated although it could not be cured. But the scenario was that others did not heed this advice.

Something that came out from one respondent was that it was clear in her case that her attitude was influenced by what was happening in the family. She had five of her family members whom she suspected that they were counselled and tested positive to HIV. She added that all children not only under-five children must be taken to the hospital whenever they were given an appointment and parents or those who keep them must make sure that they take the medicines that they are given. However, she regretted that many people did not follow the advice especially for children who could not be forced since they did not know about HIV/AIDS.

One nurse in her practical way in answer to the question said, "You can see that I am taking care of this child, (pointing at the baby said to be HIV positive); so I see them just like any other children. If I don't take care of them where can they go? I have already accepted their father and they are also my children since they were born by my sister. So I have to bear the consequences. I just pray that I don't fall ill quickly, otherwise we shall all suffer as there will be no one to take care of all of us." This was a typical example of acceptance.

4.3. Antiretroviral Therapy (ART) available in Siavonga District

4.3.1. Availability

According to the findings of this research, services in terms of general therapy such as guidance, counselling, testing and others, were readily available. However, antiretroviral (medicine) were sometimes in short supply especially syrup for under-fives. In some cases, tablets had to be administered as an alternative.

All the respondents stated that Siavonga district had a variety of ART for children, but that not all deserving children accessed these due to various reasons. A number of institutions had put in place different interventions ranging from information on prevention including prevention of mother-to-child transmission of HIV and AIDS, care and treatment, psycho-social support as well as strengthening capacity of service providers, whether medical personnel, community based organisations and faith-based organisations. Specifically, respondents cited the following: health education on the importance of hygiene; provision of food supplements such as small but nutritious fish (kapenta), beans, mealie meal, cooking oil, groundnuts and milk to HIV positive people including demonstrations on how to prepare balanced meals. Once in a while eggs and goat meat or pork were provided. At some centres HBCP also helped with the feeding programme i.e. to teach people how to prepare local food for themselves and children so that they could take medicines because these medicines made them feel very hungry.

Other information gathered on services included encouraging parents and guardians to belong to support groups not only for income generating activities but also to encourage one another on how to cope with the pandemic (catharsis); moral and spiritual support was also given by way of prayers for and with family members. Respondents also said that activists on HIV and AIDS encouraged everyone to go for counselling and testing so as to know their status and possibly protect their loved ones from getting infected. The research also found out that community members were sensitised on the importance of sharing information among friends and family members including youths and children; discouraging mothers, especially those that are HIV positive, from doing heavy work; routine check-ups e.g. checking both child's mouth and mother's breasts for possible sores which may facilitate the transmission of HIV and people

should behave if they had open sores or wounds; mothers are advised to breastfeed exclusively for at least six months; encouraging delivery at health centres; offering peer education even to other patients with different ailments; In all these, behavioural change was emphasised.

To further illustrate the responses for this topic, the researcher used the case study below. It should be noted that the responses from the participants were almost identical and even listing would have been limited. The case study captures most of the antiretroviral therapy services mentioned by respondents.

Case study 1

Mrs 'X' doubles as a Nurse and a Psycho-Social Counsellor. She worked for one of the ART centres, which is about seven kilometres from the main road that goes to Siavonga District Hospital. The researcher and her interpreter visited the centre around 09:00 hours. Upon arrival at the centre the first impression of Mrs. 'X' was that she was a very active person. She was found holding a meeting with headmen for the ART catchment area. The researcher found out that the purpose of this meeting was to discuss the role of the Community Health Workers and TBAs (Traditional Health Attendants).

On a personal level, Mrs 'X' called herself a mother and a professional. At 54 years old, she had vast experience in the health sector and now was about to retire. Over the years of her career she had been working on issues related to HIV/AIDS and its life cycle. This included how the pandemic could be prevented from and mode of transmission of the infection, its progression into AIDS, care and treatment, mitigation and psycho-social support and the ultimate devastating impact.

On the question about the kind of antiretroviral therapy services Mrs. 'X's answer was that the under-five HIV positive children were able to be tested, after their parents/guardians had been counselled, although sometimes random tests were done without their consent. ARV in syrup form was available for infants and babies. Like adults, children who developed multiple complications related to HIV/AIDS were put on Highly Active

Antiretroviral Therapy (HAART). However, she cited the problem of the supply not being consistent, probably due to the fact that the centre was very far from the district office in Siavonga. She went on to say that the supply at the district hospital was also erratic in that management there relied on the service of one company namely Medical Stores, which worked with the Central Board of Health to supply these drugs. “But at times the district uses part of the grant, which is also not regular, to purchase critical or urgent drugs if need be. However, those who wish can get ARVs from Churches Health Association of Zambia”, she said.

Services available for HIV positive persons including Under-five HIV Positive Children

For the services available for HIV positive members of the community, especially under-five HIV positive children, the respondents gave a number of these as listed below:

1. Got tested and re-tested for CD4 count after 6 months
2. Tested for their weight
3. Teaching about HIV and AIDS
4. Supplementary feeding to very needy or malnourished children. She went on to give examples (given the food pack, HEPS (High Energy Protein Supplement), cooking oil, salt and sugar to help them when they were taking medicine. Shaking her head she said, “Huh! They are difficult when it comes to feeding, especially this young one!” pointing at the baby on her back, she sighed.
5. VCT screening
6. Treatment and male circumcision.

These activities were done every time these children were taken for review. If they were found wanting, the children were put on treatment.

The Pratt Pouch Project

In addition to the above information, the researcher found out about the existence of the Pratt Pouch project, which was being piloted in Siavonga district by the Ministry of Health in partnership with Duke University’s Pratt School of Engineering. Under this project, an ARV

called nevirapine was being administered to new born within 6 to 12 hours to curb mother-to-child transmission of HIV. Additionally, each HIV positive mother is given seven pouches of nevirapine to give to their babies within six days. The seventh pouch is a spare one in case of loss or damage. To effectively administer the Pratt Pouch, pharmacists and nurses in Siavonga were being trained on skills to fill and seal the pouches as well as educate clients on the use of the product. To elaborate, demonstrations were being held. In addition, traditional birth attendants and community health workers were also being trained on how to assist women who deliver at home on the correct way to use the pouch (http://www.intrahealth.org/blog/zambia-could-be-first-country-distribute-pratt-pouch-nationally#.VNv73_39mYM).

4.4. Accessibility and affordability of services

4.4.1. Accessibility to antiretroviral therapy

Some respondents stated that services to the health centres were accessible while others said these were not. The latter stated factors such as long distances coupled with bad terrain, for some community members to reach the centres. This posed a threat in terms of security and safety. On the other hand, some people managed because they had no other way out as they were in dire need of ART.

4.4.2. Affordability

All the respondents said that antiretroviral therapy was free. Only those who preferred to go to private health facilities got these services at a fee.

How institutions address HIV/AIDS related stigma and discrimination

On addressing stigma and discrimination the respondents said that it is mostly through sensitization of all community members to accept the reality and offer the necessary care and support to the families affected by the pandemic.

In partnership with other stakeholders the Ministry of Health had put in place a multi-sector approach to combat HIV and AIDS by providing knowledge on prevention including of mother-to-child transmission, materials and equipment for testing, counselling services, treatment and

psycho-social support. The institution had trained and continued to train CHWs and TBAs on skills that incorporate HIV/AIDS. Counselling and guidance as well as related services were free for all community members including under-five HIV positive children. One of the respondents was quoted as saying, “Through talking openly to community members about HIV and AIDS, some of them respond very well but others, hm! They do not want to talk about it.” (Puts up a face as if disgusted).

Who else can assist these children and in what ways?

On this question, respondents cited the church (Faith-Based Organisations), families/community members, the medical personnel, organizations such as Save the Children, CHAZ (Churches Health Association of Zambia) and all those concerned about the issue. Ways in which these stakeholders could offer support in whatever ways that were in line with their mandates and jurisdictions.

An appeal was made to the researcher to advocate (‘raise their voices in unison’, as one of them said...) to appeal for more assistance to the children of Siavonga and their families. She went on to say, “Everyone can assist these children - starting with the family as the primary care giver, the government, different NGOs and FBOs. The type of assistance includes money, clothes, shelter, food and anything that could be of use by the children and their families.”

Another respondent cited Mtendere Hospital as being instrumental in reaching out to children in communities. He further explained that these organizations could assist with clean water, beddings, education, and shelter for some who stayed in poor houses. More trained HBCP were required and emphasis was placed on those who were willing to help without demanding payment (voluntarism).

How many more of these children can access ART?

This research found out that was need for both health staff and other community members trained to help sensitize the community members. Three respondents said that this could be achieved through what was called ‘Reflect’ Group Circles, Stepping Stones, Group discussions

and one-on-one discussions. It was further explained that these groups encouraged people to go for VCT and also they helped those who were found with HIV to go to the nearest health centre that could refer them to hospital if they were very sick.

The respondents did not really address the issue of how many *more* children can access ART. The researcher wondered whether the question was clear enough or not.

Family members who have been counselled or tested for HIV

One respondent said that did not know anyone in her family who had been counselled and tested for HIV. The researcher noted a contradiction here. In the introduction when she was asked why she had gone to the clinic, she said that she had taken her grandchild who was HIV positive for under-five clinic. She might have forgotten what she had said in the introduction.

One respondent did not give any answer to this question. The researcher noticed a pattern in this group. As the interviews progressed the respondents started giving shorter and shorter answers. This was surprising because they were not interviewed together. In any case they came from different health centres and were not interviewed on the same day. It could be that they were tired or maybe the questions were too many for them.

Stigma and discrimination

On what the respondents thought about the stigma and discrimination attached to under-five HIV positive children and what families and the communities do about it, Ms 'M' said some children that suffer from HIV/AIDS are being stigmatized by their family members. She said that families and communities must accept these children and show love and care because they are the ones who know the difficulties that they are facing. She said they could do a lot and she gave an example of herself and how she took care of her children. She did not elaborate how she takes care of her children.

According to one respondent, stigma was bad. “It can kill, just like witchcraft,” he said. He went on to say that families can stop this by talking to one another so as to understand HIV/AIDS and know how to manage their lives.

4.4.3. Challenges

The respondents said that under-five HIV positive children faced a number of challenges. Some of these challenges were community-based, i.e. happening at home where the people who took patients to the hospitals or clinics lived. Other challenges had to do with the inadequacy of the health centres to provide services. The coding below summaries the challenges mentioned above

Code	Category	Frequency	%
Food	food insecurity at household level non-utilisation of the locally-available foodstuffs malnourished children inadequate food food difficult to find in the community poor rains that made people not to cultivate enough	6	18.2
Social matters	wives usually hiding their status from their husbands fear of stigma and victimization men shifting attention to other women or divorcing denial parents feel shy to go with their children to the HIV/AIDS section for fear of being labelled positive	5	15.2

(see table below).

Access to health facilities	delays in seeking medical attention community reluctant to take their children to the clinic access to health facilities no energy to go the clinic due to illness most parents or guardians shun taking children who are sickly to the hospital.	5	15.2
Care and support	inadequate care and support inadequate trained health personnel insufficient funding young children cannot say when they are sick	4	12.1
Adherence	adherence for some of those who are on ART was difficult over adherence on the part of children parents not helping children to take medicines at the required time parents not following the prescribed dosage for children.	3	9.1
Poverty	high poverty levels community members dependent on piece work or petty trading Parents are poor and cannot give these children the food	3	9.1
Ignorance	ignorance as illiteracy levels were very high most mothers or care takers were not educated	3	9.1
Stingy men	stingy men men reluctant to spend resources on under-five HIV positive children	2	6

Distance	long distance to health centres	2	6
	Total:	33	100

As can be seen above the biggest challenge affecting matters of HIV/AIDS among the studied population is food insecurity at 18.2% followed by social matters (15.2%) and access to health centres also at 15.1%. Another important issue is inadequate care and support at 12.1%. It also shows that there were more issues that are of concern than the minor issues. These include adherence to prescribed regulations from the health centres (9.1%), high poverty levels (9.1%) and ignorance (9.1%).

4.4.4. Interventions

The researcher was informed that most of these interventions were done through community outreach according to zones in the catchment areas; reaching community members through headmen/women and the chiefs, but mostly in the health centres especially during anti-natal and under-five clinics.

The other information gathered during this research was that some institutions trained community home-based care providers (HBCPs), traditional birth attendants (TBA) and community health workers (CHW) who usually went round to help others follow instructions on ART. They encouraged expectant women to deliver at health centres as opposed to doing it at home. In circumstances that one delivered at home, TBAs and CHWs should assist them to get to the nearest health centre within the shortest possible time. This was to facilitate medical check-up and if found positive children would be given post-exposure prophylaxis (PEP) within 72 hours of delivery. In addition, health centres provided treatment for those that were found wanting including the constituency for this research, under-five HIV positive children.

It was evident from this research that some respondents did not know about any interventions apart from being sensitised on the deadly pandemic. Others were talking about interventions on a high level like construction of mothers' shelters or PMTCT (Prevention of Mother to Child Transmission) centres, which were supported by some organisations with the participation of

community members. Whereas these are helpful, it is the activities (interventions) that were carried out there that are more important.

Another finding was that the respondents talked about interventions in general. There was little mentioned of interventions that directly benefited under-five children. They took it for granted that once the parents or community members were assisted then benefits would spill over to children, when in actual sense this was not always the case.

Any other comments

Respondents emphasised the need to share the results of this research widely so that more people can know the needs of children with HIV and AIDS, for them to inject more resources to assist them.

One respondent said that he was appreciative of the fact that he was chosen from all the HBCPs to be among the interviewees for this research and contribute to speaking out on behalf of these ‘voiceless’ children. He wished the researcher good luck and success in this research. Another one said that he was happy that someone had gone to talk about under-five children who were HIV positive. He added that many people including himself just generalized without disaggregating data so as to treat the age category in question with care and caution as they were delicate. “This research is very good!” he said.

Almost all respondents echoed the need for parents to enable under-five HIV positive children not only access ART, but also keep them on treatment consistently until such a time when a child would grow up and understand the disease and would be able to take drugs without supervision. One of them said that this battle was for everyone, starting from individuals, family, community and indeed the whole nation.

It was acknowledged by all respondents that HIV/AIDS is a serious issue that affects everyone in her community. It needed total attention so that those who were in need could be helped. The main problem was on parents who, when given an appointment to take their children to the clinic

they did not do that. Instead they just decided to do other things than to save the life of their children. “This mainly happens to those parents whose status is HIV positive and they are still in denial. They do not accept their status; as a result it is even hard for them to let their children be on treatment. They don’t take it as a serious issue”, Ms. ‘M’ said.

Mr. ‘E’ said he wished that more people could access ART as all services were free. He said that people must feel free to go to health centres for assistance.

4.5. Limitations of the study

The major limitation of this research was the non-availability of disaggregated data specifically for children under the age of five. Another was that one respondent could not be interviewed as he was constantly out of his home and could not be reached by any possible means. With such a small sample size you may not be able to generalise the results beyond this geographic region.

Chapter 5: Recommendations and conclusion

5.1. Recommendations

- 5.1.1. Community members' and some medical personnel's basic level of knowledge, attitude should be enhanced through continuous capacity building so as for them to comprehensively assist others on matters related to HIV and AIDS, especially under-five children.
- 5.1.2. The above point should be coupled with intensive sensitization of community members on behavioural and attitude change, through information, education for communication (IEC) as well as media coverage and documentaries.
- 5.1.3. Being custodians of traditional values and practices, all chiefs and other traditional leaders should be brought on board to fully participate in the fight against this deadly pandemic.
- 5.1.4. More ART centres should be established so as to bring services as close to the people as possible. These centres should be stocked with enough supplies of ARV syrup for under-five HIV positive children.
- 5.1.5. Support groups should be increased so that parents and/or guardians can share ideas, have their capacity build; but also be empowered with income generating activities (IGA).
- 5.1.6. More community based organisations such as CHW, TBA and HBCP should be trained in order to enhance outreach activities to the community members.
- 5.1.7. Overall, there should be an increase in resource mobilisation in general, but funding to the National AIDS Council through the Ministry of Health in order to support paediatric HIV and AIDS.
- 5.1.8. A clear record keeping system should be established by the relevant ministry and its partners so that disaggregated data for under five HIV positive children can be stored efficiently and effectively to allow for easy access.
- 5.1.9. The results of this research should be widely disseminated in order to assist in evidence based programming for under-five HIV positive children.
- 5.1.10. An advocacy strategy should be developed, which will not only stipulate strategies and tactics for raising awareness on identified audiences such as families, outreach workers, medical personnel, but also formulate IEC messages on prevention, early diagnosis, treatment, care,

psych-social support as well as strengthening supporting structures for under-five HIV positive children.

5.2. Conclusion

This study was very interesting as it brought out a lot of useful information for both the researcher as well as the respondents. The findings of this research will go a long way to inform children's health activists and the general public, in order for them to assist in advocating more under-five HIV positive children to access ART. The results of this study, once disseminated, will not only act as a reference check for health personnel and HIV/AIDS activists, but also enable them to source and allocate resources in order to increase the number of under-five HIV positive children's access to ART. The full participation of families and communities is vital for the sustainability of project activities.

References

- Agha, S., Hutchinson, P. & Kusanthan, T (2006). *Journal of Adolescent Health*, Vol. 38 Tulane University, New Orleans/ University of Zambia, Lusaka.
- Bond, V. & Dover, P. (1997). Men, women and the trouble with condoms: Problems associated with condom use by migrant workers in rural Zambia, *Health Transition Review*, Supplement to Volume 7, 377-391), Lusaka.
- Creswell, J.W., (2007), *Mixed Methods Reader*. Sage Publications, Nebraska.
- Christensen, L.B., (2007). *Experimental Methodology*. University of South Alabama.
- Denzin, N.K & Lincoln Y.S., (2005), *Sage Handbook of Qualitative Research*, Third Edition, Sage Publications, California.
- DATF and DHS (2011), Siavonga. District Health Reports, unpublished.
- Dr. Chirwa, (2011), *Presentation to the Annual Review Meeting*, Livingstone, unpublished.
- Dyk, A. V., (2005), *Paediatric HIV Working Group, 1997; Who, 2000a*), Pearson Education, South Africa.
- EGPAF, (2011) *Study brief on Male Involvement in PMTCT: Reaching Men Through Syphilis Testing*, unpublished material.
- Huberman, A.M. & Miles, M.B., (2002). *The Qualitative Researcher's Companion*. SAGE Publications, California.
- Kimuna, S.R. & Djamba, Y.K. (2005). *A study on Wealth and Extramarital Sex Among Men in Zambia*, Volume 31, Number 2, East Carolina University.

MoH Zambia, (2010)– *Guidelines for Antiretroviral Therapy for HIV Infection in Infants and Children in Zambia*, second edition, Government Printers, Lusaka

MOH, (2011), *Presentation to the Partners Meeting, Livingstone*. Unpublished.

Mulenga, M.(2012). Child Defilement Cases in Zambia Rising. Accessed from <http://www.lusakatimes.com/2012/03/05/child-defilement-cases-zambia-rising/> on 12/11/2012 at 01:32 hours.

The Population Council, (2012). Research that makes a difference. Accessed from <http://www.popcouncil.org/pdfs/horizons/sapedsa.pdf> on 12/11/2012, at 01:50 hours.

MedScape, Children and HIV/AIDS: From Research to Policy. Accessed from http://www.medscape.com/viewarticle/575826_4 On 2/02/2013 at 12:10 hours.

NAC, (2009), *National AIDS Strategic Framework 2010 to 2015*, Government Printers, Lusaka.

NAC Zambia, (2009, 2010) *Country Report to UNGASS*. Government Printers, Lusaka.

NAC Zambia, (2002). Kara Counselling, TvT Associates Inc./Synergy and FHI - *HIV/AIDS Care and Support Capacity and Needs in Zambia: An Assessment of Four Districts*. Government Printers, Lusaka.

NAC Zambia, (2009). *Securing Zambia's Future*, National HIV Prevention Convention Report, 3-5, Government Printers, Lusaka.

NAC Zambia, (2010). *National HIV/AIDS/STI/TB Research Framework*. Government Printers, Lusaka.

NAC – *National HIV and AIDS Strategic Framework, 2006-2010*. Government Printers, Lusaka.

Orr, N.M. & Patient, D. *Positive Health*. University of Stellenbosch (Lecture material).
Post Newspaper of Friday November 9, 2012, pg 6, Lusaka.

Save the Children, (2011). *Sponsorship: Impact Area Presence Plan for Lufwanyama district – Copper belt*, 2012- 2017. Unpublished.

SAAIDS, (2009). Implementation of regional and international HIV prevention, treatment, care and support: Conventions and Declarations in Swaziland and Zambia. Unpublished.

SAFAIDS (2009). News 1 - Researching Sex. Vol. 15. Unpublished.

Save the Children Norway – Zambia, (2012), Public Relations Report 2009 – 2011, Lusaka.

Silverman, D., (2005). *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. SAGE Publications, London.

Southern African AIDS Trust. Guidelines for Counselling on ARV Treatment. No. 12, unpublished.

Southern African AIDS Trust. Guidelines for Counselling around HIV and Pregnancy, No. 13. Unpublished.

Stratten, K., ‘Zambia Could Be First Country to Distribute Pratt Pouch Nationally.’
http://www.intrahealth.org/blog/zambia-could-be-first-country-distribute-pratt-pouch-nationally#.VNv73_39mYM re-accessed on 12/02/2015 at 03:39 hours.

Stover, J., & Johnston, A., (1999) ‘The Art of Policy Formulation: Experiences from Africa in Developing National HIV/AIDS Policies’

Stringer, E.M., Chi, B.H., Chintu, N., Creek, T.L., Ekouevi, D.K., Coetzee, D., Tih, P., Boulle, A., Dabis, F., Shaffer, N., Wilfert, C.M. & Stringer, J.S.A. (2008) *Monitoring effectiveness of programmes to prevent mother-to-child HIV transmission in lower-income countries*. WHO Bulletin, Geneva.

The Joint Learning Initiative on Children and HIV/AIDS (2008) – Final synthesis report. Unpublished.

The Population Council, (2012). Research that makes a difference. Accessed from <http://www.popcouncil.org/pdfs/horizons/sapedsa.pdf> on 12/11/2012, at 01:50 hours.

Tindyebwa, D., Kayita, J., Musoke, P., Eley, B., Nduati, R., Coovadia, H., Bobart, R., Mbori-Ngacha, D. & Kieffer, M.P. (2005). *Handbook on Paediatric AIDS in Africa*, ANECCA Secretariat, Kampala.

UNDP, (2012), ‘*Progress Report on Millennium Development Goals*’ accessed from www.undp.org/content/undp/en/home/librarypage/mdg/the-millennium-development-goals-report-2012/ at 23:00 hours.

UNICEF (2010). *Progress for Children, Achieving the MDGs with Equity*, Number 9. UNICEF.

UNICEF (2008) – *Zambia Situation Analysis of Children and Women*. Lusaka

United Nations, (1989) *United Nations Convention on the Rights of the Child*. Geneva.

Wheeldon. J., (2010), ‘Mapping Mixed Methods Research: Methods, Measures, and Meaning’. *Journal of Mixed Methods Research*, Volume 4: 87, Sage Publications, London.

Zambia Central Statistical Office, (1984). *Zambia HIV/AIDS Epidemiological Projection*. Government Printers, Lusaka.

Zambia Media reports, (2012). '*Three Children Sexually Abused by Grandfather*'. Post Newspaper of Friday November 9, Lusaka.

Zambia National HIV/STI/TB Council (2009). *Zambia, HIV Prevention Response and Modes of Transmission Analysis*, Government Printers, Lusaka.

Addendum A

Some Facts about Zambia

Population of country 13,460,305 people

Area of Zambia 752,614 sq. kilometres

Located on the continent Africa (AF)

Capital of Zambia Lusaka

Currency at Zambia Kwacha (ZMK)

Domain Zone .zm

Phone country code 260

FIPS code of Zambia

Climate of Zambia:

- tropical
- modified by altitude
- rainy season (October to April)

Terrain of Zambia: •mostly high plateau with some hills and mountains

Zambia also has such useful resources as: copper, cobalt, zinc, lead, coal, emeralds, gold, silver, uranium, hydropower

Source: DS World's Lands @ <http://ds-lands.com/zambia/> accessed online on 06/10/2014 at 22:04 hours

Statistics about Zambia

Addendum B

Other Information about Zambia

- In Zambia HIV sero prevalence is 14%
- 16.1% in females
- 12.3% in males
- According to UNDP Report (2012) About 1, 327, 995 are estimated to be living with HIV in Zambia.
- 535, 828 adults > 15 years of age require ART
(90 % are on ART)
- 107, 592 children < 14 years require ART
(28% are on ART)

New infections

- Estimated at 82,000 people/year
 - Translates into:
 - 226 new adult infections per day
 - 25 new paediatric infections due to MTCT per day
- Out of the 1.3 million orphans 50% are due to impact of AIDS.

**Source: Dr. Mwiya (2014), Presentation to the workshop on Paediatric HIV and AIDS.
Centre of Excellence, UTH, Lusaka. Unpublished**

Addendum C



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

To investigate the extent to which under-five HIV positive children access antiretroviral therapy (ART) – A case of Siavonga District, Southern Province of Zambia

You are asked to participate in a research study conducted by Lontia Chinkubala, a student from the Africa Centre for HIV and AIDS and the Management Sciences Faculty at Stellenbosch University. The results of this study will anonymously be processed into the study report on *Why there is a smaller number of under-five HIV positive children accessing ART in Siavonga district?*

You were selected as a possible participant in this study as a result of you being connected to the SCN supported District AIDS Task Force (DATF) project – Community Response to HIV and AIDS, but also your being a resident of Siavonga district, the location for the study in question.

1. PURPOSE OF THE STUDY

To find out the extent to which under-five HIV positive children access ART in Siavonga district, in order to advocate the scaling up of appropriate interventions for this category of the population.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do one of the following activities:

Interview

A short Interview with the researcher will be conducted with Ministry of Health staff, Community Health Workers (CHW), Home Based Care Providers (HBCP) and members of the District AIDS Task Force (DATF). This is to understand the reasons for the smaller number of under-five HIV positive children accessing ART in Siavonga district. This will take approximately one hour of your time at a time this has been identified as convenient.

3. POTENTIAL RISKS AND DISCOMFORTS

Information required by the interviewer may cause some discomfort of unease on the part of the participant as some of it may be sensitive or denote some form of stigma and discrimination e.g. when talking about families who have under – five children who are HIV positive and why they are not accessing ART. However, the intention of the study is to assist the people of Siavonga district in particular and Zambia as a nation; but also Save the Children as an organization for evidence based programming. Further reassurances will be provided if needed.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

It is envisioned that the research can assist the district and eventually the people of Zambia to advocate the promotion of an increase in the number of under-five HIV positive children accessing ART so as to prolong the lives of such children and contribute towards a productive population. In addition, as there isn't adequate information about the topic under study, the results will add value to the data bank for both the district and the country as a whole.

5. PAYMENT FOR PARTICIPATION

There will be no payment for participation. This is a voluntary exercise that is contingent on your participation.

6. CONFIDENTIALITY

Confidentiality will be maintained at all times. As no personal details will be collected from the participants, there is no direct threat to the participants. The communities will be identifiable and as such all documentation of these communities will be kept on my personal computer which is

password locked and also in a closed location not accessible by the public. The information might also be inspected by the University of Stellenbosch, Human Research Ethics Committee. The records will only be utilized by them in carrying out their obligations relating to this study.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether or not to participate in this study. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant so doing.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Lontia Chinkubala: +260211252080, Cell: +260965721354/+260977750339, email: Ichinkubala@gmail.com or Dr. Thozi Qubuda (Study Supervisor) on tqubuda@sun.ac.za

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT

The information above was described to me.....by Lontia Chinkubala. A translator Godfrey Kalaluka – District AIDS Coordinating Advisor, was asked to explain in my own language sections that I could not understand. I am in command of this language Chitonga and where necessary it was satisfactorily translated to me.

I.....was given the opportunity to ask questions and these questions were answered to my satisfaction. I am aware that the results of the study

will anonymously be processed into a study report and that at any stage I can withdraw my consent and participation in the study.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Signature of Subject/Participant

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____
_____. He/she was encouraged and given ample time to ask me any questions.
This conversation was conducted in _____ and *a/no* translator was used in
this conversation. The conversation was translated into _____ by
_____.

Signature of Investigator

Date

Addendum D

SIAVONGA DISTRICT MEDICAL OFFICE

24th August, 2011.

Centre in charge
Chipepo RHC
.....



Dear Sir/Madam,

INTRODUCTION – MS LONTIA CHINKUBALA

This serves to introduce Ms Lontia to you as having been granted permission by the District Medical Office to carry out a research on Low Percentage of Under Five HIV Positive Children Accessing Antiretroviral Therapy.

Kindly render the necessary help and guidance that she may need during her research.

Thanking you in anticipation.

Yours faithfully

A handwritten signature in blue ink, appearing to read 'Dr. Mwaba Phallon'.

Dr Mwaba Phallon

Acting – Medical Officer In Charge

For/District Medical Officer

Siavonga

Addendum E

Interview Schedules

Interview schedule for Community Health Workers, Home-based Care Providers, staff of the Ministry of Health and District AIDS Task Force (DATF)

A. General knowledge on HIV and AIDS

1. How much do you know about HIV and AIDS?
2. What is your attitude towards people, especially under-five children who are HIV positive or have AIDS?
3. What kind of challenges do you think they face?

B. Services

4. What interventions has your institution put in place to address issues related to under-five HIV positive children in your catchment area?
5. What kind of antiretroviral therapy services are available for this category of people?
6. How accessible and affordable are these services?

C. Practice

7. What do you think is the number of under-five children who are infected by HIV in your catchment area?
8. How many of these access antiretroviral therapy?
9. For those who do not access ART, what could be the reasons?
10. What could be done to ensure that more under-five HIV positive children access ART?
11. How is your institution addressing HIV and AIDS related stigma and discrimination? How is the community responding to this?
12. Who else can assist these children and in what ways?

D. Closing

13. Are there any other comments that you want to share?

Interview Schedule for Community Members 1.e. Parents, Guardians, Care takers

A. General knowledge on HIV and AIDS

1. What do you know about HIV and AIDS?
2. What causes HIV/AIDS
3. Modes of transmission
4. Stages of the disease
5. Treatment
6. Care
7. Prevention
8. What is your attitude towards people, especially under-five children who are HIV positive or have AIDS? What kind of challenges do you think they face?

B. Services

9. Where do people in your community seek medical attention?
10. What services are available for HIV positive members of your community especially under-five HIV positive children?
11. What do you know about Antiretroviral Therapy (ART)?
12. What is your opinion about under-five HIV positive children accessing ART?
13. How can more of these children access ART?

C. Practice

14. Has any of your family members, including children under the age of five years been counselled or tested for HIV?
15. If yes, do you know any under-five child that is HIV positive? How are they related to you if at all?
16. What kind of support do you or others give to under-five HIV positive children who need or are on ART?
17. What do you think about on the stigma and discrimination attached to under-five HIV positive children? What can families and the communities do about it?

D. Closing

18. Are there any other comments that you want to share? Do you have any questions?