

**Factors contributing to the failure by parents and care givers to disclose the
status of children who are HIV positive**

By

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Declaration

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Abstract

HIV and AIDS are developmental challenges the world for Africa, businesses, family and individuals are facing. No single person is immune from the effects of the deadly epidemic. Efforts to fight the pandemic are finally paying off as in many countries the morbidity and the mortality rates are falling; however, the worrying factor is infection rates are increasing particularly among young people. The discovery of Antiretroviral Treatment has brought hope and relief to those infected and nations of the world as people can now live longer as they continue to support their families while contributing to the development of their countries by paying rates and taxes.

While efforts to fight off the epidemic are rewarding in some areas, HIV is opening yet other avenues which could potentially undermine the battle against the deadly virus. Due to the availability of ARVs an increasing number of children are being born to HIV positive parents despite the availability of PMTCT programs. The danger is most of these children born to HIV parents are unaware of their own positive status and they are not informed of their infection. Some of these children are sexually active within certain sexual contextual behaviour in Namibia namely early sexual debut, multiple concurrent sexual partners, intergenerational sex, transactional sex, alcohol and substance abuse, low condom use, low risk perception of HIV among young people and low male circumcision.

The study objective was to establish why parents are failing to disclose to their children they are HIV positive; parents were facing challenges in telling the truth about their status. Often parents keep HIV as far as possible from these children where they tell them instead they are suffering from some ailments other than the infection. Sadly most children trust the words of their parents and guardians. However, some of the children establish their status from external sources and this is creating problems in the families with some giving up on ARVs, while there are incidences of them taking their own lives.

The study found often parents even if they want to disclose they do not have the skills and knowledge. Sadly most parents are not aware of the dangers of their failure to disclose to their children. Their focus is based on the narrow interest of keeping the child in the dark not knowing the young person could be spreading HIV or defaulting on treatment since they do not fully understand why they are taking such medication.

As the way forward guidelines on disclosure should be made available to help parents and guardians act responsible. In addition instead of training limited personnel in the public and NGO sector the attention should focus on the care giving role. In addition the topic on disclosure should be extended to the media to keep the debate going in view of limited resources.

Opsomming

MIV en vigs hou ernstige ontwikkelingsuitdagings in wat die wêreld, besighede, familie en individue in die gesig staar. Geen enkele persoon is immuun teen die gevolge van die dodelike epidemie nie. Pogings om die epidemie te beveg is uiteindelik besig om positiewe uitslae te wys aangesien die sterftesyfer in baie lande daal, maar die kommerwekkende faktor is dat die infeksiekoers veral onder jong mense styg.

Die ontdekking van anti-retrovirale behandeling het hoop en verligting gebring aan diegene wat ge-infekteer is, mense kan nou langer leef en voortgaan om hul families te ondersteun en bydra tot die ontwikkeling van hul lande deur die betaling van belasting en tariewe.

Terwyl pogings om die epidemie te beveg dividende werp in sommige gebiede, is MIV besig om ander moontlikhede, wat die stryd teen die dodelike virus potensieel kon ondermyn, te ontbloot.

As gevolg van die beskikbaarheid van ARVs skenk meer en meer MIV-positiewe ouers geboorte aan kinders ten spyte van die beskikbaarheid van voorkoming van ma-tot-kind infeksie-programme. Die gevaar is dat die meeste van hierdie kinders wat van MIV-positiewe ouers gebore is, is onbewus van hul eie MIV-positiewe status as hul ouers of voogde nie vir hulle die waarheid vertel nie.

Sommige van hierdie kinders is reeds seksueel aktief met inagneming van die feit dat daar sekere seksuele gedrag in Namibië geobserveer kan word, naamlik vroeë seksuele debuut, verskeie gelyktydige seksmaats, intergenerasie seks, transaksionele seks, alkohol en dwelmmisbruik, lae gebruik van kondome, lae risiko persepsie van MIV onder jong mense en 'n lae voorkoms van manlike besnyding.

Die studie se doel was om uit te vind waarom ouers nie hulle kinders vertel dat hulle MIV-positief is nie. Dikwels hou ouers MIV so ver as moontlik van hierdie kinders dat hulle sê hulle ly aan 'n ander siekte as MIV. Ongelukkig vertrou die meeste kinders die woorde van hul ouers of voogde. Maar 'n paar van die kinders vind uit oor hul status van eksterne bronne, en dit skep probleme in die families met 'n paar wat ARVs opgegee het, ander neem hul eie lewens.

Die studie het gevind dat baie ouers, selfs as hulle wil bekend maak het hulle nie die vaardighede en kennis om dit te doen nie. Ongelukkig is die meeste ouers nie bewus van die gevare van hulle versuim om hulle status te openbaar aan hul kinders. Hul fokus is gebaseer om die kind vir so lank as moontlik in die duister te hou, nie wetend dat hierdie kind kan MIV versprei of nie sy medikasie gereeld neem nie.

Vir die pad vorentoe moet riglyne oor die bekendmaking beskikbaar gestel word om ouers en voogde te help. Daarbenewens, in plaas van om 'n beperkte hoeveelheid personeel in die openbare en regeringsektor op te lei, moet die bekendmaking uitgerol word aan almal.

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

The study will focus on establishing the factors contributing to the failure by parents and care givers to disclose the status of children who are HIV positive. Namibia is experiencing a growing number of children who are HIV positive the majority of whom are being infected prenatally, some of these children are getting into their adolescent stage and yet their parents or guardians have not yet disclosed to them their status. Some are even on anti-retroviral treatment and yet they have not been told the truth about their situation.

1.2 Background of the study

Sub-Sahara Africa (SSA) remains the epicentre of the HIV epidemic with 12% of the world's population hence it remains heavily affected. While the rate of new infections has decreased the total number of people living with HIV is on the increase due to life prolonging drugs. The 2012 Joint United Nations Programme on HIV and AIDS (UNAIDS) reported 68% of all the infected persons globally live in SSA. In the same year the report says an estimated 1.9 million people in the region became newly infected accounting for 70% of all the global infections among adults and children.

Namibia is of the country which is severely affected by HIV. This is a country with 2.1 million people it is among the top ten countries in the world with the highest prevalence rate along which currently stands at 18.8 %. The others in the region are Botswana, Lesotho, Swaziland and South Africa according to the 2011/2012 Estimates and Projections of the Impact of HIV and AIDS in Namibia Report.

The country was classified as an upper income country by the World Bank. It is one of the most unequal societies in the world with the highest income inequality (Gini Coefficient 0.74) the problem has been found as one of the key drivers of HIV in Namibia.

The impact of HIV and AIDS on Namibia has been significant that since the first case detected in 1986 it is estimated about 120 000 people have died from AIDS (2011/2012 Estimates and Projections of the Impact of HIV and AIDS in Namibia).

The impact of the virus is being felt across all sectors of the economy such as mining, agriculture, tourism, fisheries and transport sector. According to the 2011/2012 Estimates and Projections of the Impact of HIV and AIDS in Namibia currently indicated 193 000 adults and children are living and this figure is likely to increase to 196, 000 in 2015/2016. During the financial year 2011/12 alone an estimated 5000 adults and children died as a result of AIDS.

In the 2011/2012 Estimates and Projections of the Impact of HIV and AIDS in Namibia report approximately 8000 people were infected with the virus with approximately 22 new infections per day. Windhoek the capital city of Namibia recorded 3.5 new infections on a daily basis. The infection rates are higher in the informal sector where the prevalence rate is also high. Overall HIV and AIDS has increased related cases, decreased life expectancy and an increase in the number of orphans and vulnerable children with the number of orphans stand at 74, 748.

According to the Report on the 2012 National Sentinel Survey the prevalence rate is starting to stabilise after a sharp increase when the first case was dictated in 1986 until it reached its peak in 2002 with 22.0% prevalence. This is due to a number of efforts the Government of Namibia has put in place to mitigate the impact of HIV and AIDS such as the provision of free ARVs. Currently Namibia has over 107 000 people on ARVs both adults and children, this medication is available for free in the public hospitals and clinics. The Government has so far developed four multi-sectoral strategic plans and the current one is the National Strategic Framework (NSF) all aimed at mitigation the impact of HIV and AIDS.

The introduction of free ARVs in the public hospitals and clinics was hailed as a step in the right direction. Namibia enjoys significant recognition as one of the countries to take bold steps to make these lifesaving drugs accessible to even the poorest of the poor to access treatment across the breadth and length of the country. The introduction of the Electronic Distribution System has improved the monitoring and distribution of drugs.

Children have not been spared from the scourge of HIV and AIDS, most of them living with the infection prenatally through Mother-to-Child Transmission (MTCT). HIV has also been ranked

at the number one leading cause of death (20%) among the children under the age of five. As results of the impact of HIV there is a growing concern of adolescences living with HIV and AIDS (ALHV) some have despite their conditions graduated from university.

As results of the impact of HIV there is a growing concern of adolescences living in their societies with HIV and AIDS (ALHV). Some of these children are already on ART but they have not been told of their condition by being HIV positive and they are on medication, they are often lied to that they are taking medication which is not linked to HIV. As a result some of these children are getting into the adolescence stage when dating and sex is likely to take place.

According to the 2011/2012 Estimates and Projections of the Impact of HIV and AIDS in Namibia it is estimated there are 16,000 adolescences living with HIV and AIDS. In Namibia according to the National Strategic Framework eleven key drivers of the epidemic are namely: Multiple and Concurrent sexual partnerships, intergenerational sex, transactional sex, low and inconsistent condom use, low perceptions of risk of HIV infection, low levels of male circumcision, alcohol abuse, people mobility and migration in and outside the country, income inequality and early sexual debut.

Sooner or later these adolescences are likely to find themselves in sexual relationships which are driven by some of these factors. According to the National Guidelines on Adolescents Living with HIV the figures for sexual behaviours of adolescents are not available but the trends and findings from the Namibian demographic Health Survey of 2006/7 indicate twelve percent of men and women reported having had sexual intercourse by the age 15.

In some cases children have already found out about their status, however, they will be waiting to get the necessary information from their own parents and guardians. Such silence has created mistrust between the children and the parents this is building resentment which often lead to antisocial behaviours characterised by teenagers only to infect their sexual partners in the process. The failure of parents and guardians to disclose the HIV status has the potential of undermining prevention efforts and more so should these children fail to adhere to treatment there is a strong likelihood of passing the resistant strain to their sexual partners thus fuelling another wave of HIV infection which can be difficult to treat and thus making the management of HIV difficult to manage.

1.3 Motivation of the research project

The study is fundamental in the sense a large number of people will stand to benefit. These people include the children on ARVs, the parents or guardians, the health care workers to include nurses, doctors, psychologists, social workers, HIV counsellors and generic counsellors.

There are many who will benefit such as children on ARVs will at least know what is really happening in their lives thus relieving them from the psychological burden of living in the dark about that status. Some have knowledge after finding out from other sources but they are still waiting to be told officially by their care givers. The parents and guardians will be empowered with guidelines which will give them the ability and direction to initiate conversations on how they can disclose to their children or those in their care. Often the inability or failure to disclose has created conflict within the family as children demand answers as to why they are taking medication. The parents and guardians it will keep them away from lying to their children as they are evasive around the reality of what is happening to these children and why they are taking medication. Health care workers too will have a tool kit in which they will then use to equip parents and guardians on how they can go about empowering them to face the truth in disclosing at the appropriate time the HIV status and the real reason they are taking medication.

Overall as Namibia is putting all measure into place to prevent new infection by 50 percent in the National Strategic Plan 2010/11-2015/2016, through this intervention it is a potential way of preventing HIV infections, thus contributing to the national goals of preventing new infections in Namibia.

Academic perspective have introduced the incidences of HIV and AIDS in Namibia, however, what remains identified are the gaps which more often go unnoticed while creating a significant contribution in the spread of the infection. Moreover there is a growing number of adolescents living with HIV and AIDS and given their many challenges they face in that stage of development, often the focus has been on adults and sexually mature adolescences but this

findings will stimulate interest in shifting focus and paying attention in doing more research in that area.

1.4 Problem statement

There is a need to establish the factors contributing to the failure by parents and care givers to disclose the status of children who are HIV positive and on ARVs as this has serious impact in combating HIV and AIDS in terms of prevention, care, treatment and support. These findings are key as it will eventually influence the formulation of guidelines on how parents and guardians should handle the issue of the disclosure of HIV to children. It has thus far not been established what the factors are causing the parents to fail the disclosure of the HIV status to these children.

HIV has generated a serious problem in Namibia and more so there is a growing number of Adolescents Living with HIV and AIDS. In fighting against HIV certain gaps do emerge, if they are not taken care of and taken into serious consideration they create channels through which the virus continue to be spread and issues of non-disclosure of HIV to children is a potential way through which the virus will continue to be silently in the midst of key drivers of HIV epidemic in Namibia.

If children are not aware of their HIV positive status it is difficult for them to protect themselves from infecting their partners as well re-infecting themselves. Issues such as early sexual debut, unprotected sex, multiple concurrent partnerships and alcohol abuse are common among adolescents given the significant proportion of ALWH who currently are estimated at 16,000 there is need to look into the factors holding back parents and guardians from disclosing their status.

The prevention perspective is aimed at young people that the future workforce will be derived from; however, if ALWHA are not taken into consideration the future work force will be compromised.

The research question for this study is: What are the factors holding back the parents or guardians from disclosing information from their children which in the long run may have an impact on the prevention efforts in the fight against HIV and AIDS in Namibia?

1.5 Objectives of the study

The objectives of the study are:

- To investigate the challenges parents/guardians face in disclosing the children's HIV status
- To establish the factors hindering parents from disclosing
- To identify the gaps and the present needs of the parents and guardians
- To analyse the needs and the present needs of public health system
- To recommend the formulation of guidelines to support parents and guardians

1.6 Research methodology

The research will focus on using a qualitative research method to provide an answer to the formulated problem. Chiromo (2009) describes qualitative research as a way that produces findings not arrived at by means of statistical procedures or other means of quantification. In addition qualitative research is a systematic, interactive and subjective approach used to describe life experiences and give them meaning.

In this survey the target population will be parents and or guardians, with children who are on ARVs, the nurses, doctors, psychologists, social workers, generic counsellors and HIV and AIDS Counsellors.

The sample of this research should have at least 20 respondents; to include key respondents, social workers, psychologists, nurses, HIV counsellors, generic counsellors, parents or guardians with children living with HIV. The respondents will be drawn from Windhoek the capital city, Ondangwa Town in Oshana Region in Oshana Region and Rundu in Kavango Region.

Structured questionnaires will be administered to the chosen sample to elicit responses. Chiromo (2009) says a questionnaire is the most used as well as abused instrument for gathering data.

Hunter (2009) outlines several advantages of questions among them it produces reliable information, that it collects data in an organised manner and it can be completed immediately as the project progresses. There is a possibility some people do not complete questionnaires care should be taken to ensure accurate responses.

The other tool is face to face interviews particularly with the counsellors and parents or guardians who are taking care of children who are HIV positive. The questions formulated for these interviews will be both structured and semi-structured. The in-depth interviews allows for flexibility in administering questions to the respondents thus will assist to get more understanding and depth of underlying matters.

The research will utilise document review with information derived from the Ministry of Health and Social Services, and other bodies working with the ministry.

The use of key informants from the Ministry of Health, gender and I-Tech will form part of the selected individuals to acquire data.

1.7 Ethical consideration

The researcher is aware of the code of conduct and will therefore adhere to such during the research. To this the behaviour will be underpinned by two fundamental ethical principles namely informed consent and confidentiality.

As for the former the researcher will inform the people to participate in the study. The researcher will seek respondent's consent which includes the purpose of research, the explanation on the procedure of the research process and the rationale why they have been selected to participate in the research.

As for confidentiality the researcher will assure the interviewees all the information gathered will be treated with strictest confidentiality and will not be disclosed to anyone who is not part of the research.

1.8 Limitations of the study

This research due to ethical reasons will only focus on people who are in the caring profession mainly nurses, generic counsellors, HIV and AIDS counsellors, psychologists, social workers and field workers working in home based care setting. Parents or guardians and the children who are living with HIV and AIDS will not be interviewed in this study.

1.9 Outline of chapters

Chapter one: Introduction

The introductory chapter will provide the overview of the research and focuses on the background of the research, problem statement, research methodology and limitations of the research.

Chapter two: Literature review and Theoretical framework

This chapter will provide a rationale for conducting the research topic this is because any research should show its lineage to the existing knowledge previous investigations. This section will then involve a thorough review of related literature from sources such as the internet, library books, journals, publications. The literature is meant to help me to put my study in proper perspective. More importantly the literature aims to help me to add credibility and justification of my research.

Chapter 3: Description of research methodology

This chapter has a number of sub headings which help to detail specific account of how the researcher intends to test their hypothesis and answer for my research questions. This chapter will entail tools the researcher will use to collect data, the researcher will also identify the population to be sampled, the research procedure and partial data analysis.

Chapter 4: Research presentation, Analysis of results and discussion

This will entail I will analyse the data to arrive at a point where I can detect the differences. I will apply all known techniques of data analysis discussion and interpretation thereof. And I will have to demonstrate if I found the solution.

Chapter 5: Summary and conclusions

This will basically rounding off and highlighting the key findings of the research and proving if the research indeed unpacked all the issues at hand while giving conclusion and recommendations for the way forward.

1.10 Conclusion

The HIV and AIDS epidemic is a very serious problem which is confronting humanity and hence the role of research cannot be over emphasised in helping the management of this multi-faceted problem which is becoming elusive time and again. The following chapter on literature review further confirms the magnitude of HIV and AIDS that more need to be done.

CHAPTER TWO

LITERATURE SURVEY

2.1 Introduction

HIV is an acronym which stands for Human immunodeficiency virus or HIV, AIDS is caused by the human immunodeficiency virus. When this virus enters the human body from outside and gradually destroys the body's immune system which consequently wears down the body's ability to defend its self against infection or diseases.

Once the body's immune system has been weakened especially the final stages then a person develops what is commonly known as AIDS which is short for Acquired Immune Deficiency Syndrome. According to Dyk (2011) AIDS is a syndrome of opportunistic diseases, infections and certain cancers, each or all of which has the ability to kill the infected person in the final stages of the disease.

The discovery of antiretroviral drugs has had a significant impact of AIDS related deaths as taking the medication reverses the AIDS stage to HIV infection thus prolonging individuals to live longer.

2.2 The beginning

Two viruses are associated with AIDS thus HIV-1 and HIV-2. HIV-1 one is mostly found in and is associated with infections in Central, East, and southern Africa, North and South America, Europe and the rest of the world. Under HIV-1 they are different sub types emanating from the replication process of the virus as it reproduces itself. HIV-1 is virulent and often leads to a

quicker progression to AIDS. HIV-2 is mostly found is confined in West Africa including Cape Verde Islands, Guinea Bissau and Senegal. HIV-2 is associated with longer latency period which translates to slower progression to the AIDS stage, in addition it is associated with slower transmission and lower rates of transmission.

The theories of the origins of AIDS are associated with a number of myths. According to Dyk (2011) they are two main theories about the origin, firstly that AIDS is a centuries old disease of Africa and secondly it crossed the species barrier from primates to human beings. Overall according to Dyk (2011) the AIDS epidemic began in human beings in the late seventies and early eighties but the spread was only confined to a limited number of isolated communities in Africa who had little contact with the outside world. However, given the magnitude of the widespread other factors might have contributed to the virus being spread all over the world. These factors include but not limited to, *inter alia*, improved transport networks, migration, tourism, multiple concurrent partnerships, prostitution and socio-economic instability.

2.3 The global impact

Globally according to the UNAIDS (2013) report it is estimated an estimated 35.3 million people are living with HIV. Adults constitute 32.1 million, women 17.7 million and it is estimated that around 3.3 million children below the age of 15 are living with HIV. The same reports indicated a total of 2.3 million were newly infected, despite the stabilisation of the death rate, the rate of new infections is of concern; adults account for 2.0 million while children less than 15 years accounted for 260 000. AIDS related death stand at 1.6 million and of these adults estimates are 1.4 million.

The UNAIDS (2013) report confirms previous reports sub-Saharan Africa is the worst affected and so far it is estimated that 25.0 million adults and children are living with HIV and AIDS. It is also estimated adults and children who are newly infected account for 1.6 million while the average prevalence is at 4.7% the prevalence of cause varies in different countries in sub-Saharan Africa.

These estimates indicate while considerable efforts has been made to mitigate the impact of HIV and AIDS, the reality is the HIV and AIDS epidemic is a big challenge and unfinished business and still stands as a serious contemporal health challenge. Part of the Millennium Development Goals particularly goal 6 relays: Combat HIV and AIDS, malaria and other diseases, come 2015 it will be time to evaluate the extent to which the fight against HIV and AIDS has been rolled back.

The reduction in the death rate in AIDS related cases is testimony that the use of ARVs has brought some relief and improved the quality of the people's lives. The initiation of the Prevention of Mother to Child Transmission in addition has been successful in most cases it has reduced the infection by 50%. Current campaigns to roll out male circumcision are all efforts aimed at containing the impact of HIV and AIDS. However, some disturbing sexual behaviours are worrying as they are likely to increase the rate of infection thus giving way to a new wave of infection. AIDS related deaths in sub-Sahara both adults and children is estimated to be around 1.2 million. Children who are newly infected is estimated at 230 000 below the age of 15.

2.4 Impact in Namibia

Namibia according to the 2011 population census Namibia Statistical Agency (2011) has a total population of 2.1 million. This constitutes a female population of 1,083,600 while the male population is at 1,021,300. The majority of Namibians live in the rural areas thus making a population of 1,219,400, while the urban populations currently stand at 885,500. The country besides concerted efforts is severely affected by HIV and AIDS.

The current prevalence rate according to the 2012 HIV Sentinel Survey (MoHSS 2012) the total ANC prevalence rate is at 18.2%. Namibia is ranked among the top five countries in the world with the highest prevalence. According to MoHSS (2013) an average of 40 Namibians are infected every day, Windhoek's informal settlement account for 3.5 infections every day alone. The total number of people living with HIV and AIDS (PLHHA) according to MoHSS (2012) is 194,137 of this figure females account for 103,713, males 71,670, children are at 18,754 and female children are at 9,881. The incident rate for Namibia is at 0.70% according to the HIV incidence rate and new infections (2012/13) the new infections estimates are at 6,738. It is

estimated that the age group of 15-24 account for 43 infections and children between (0-14) are at 473.

The annual death rate according to (MoHSS 2012/13) the total annual deaths is 4, 570 of these figures adults make up the largest figure of up to 4,038, children are at 532 and new deaths between the ages (14-24) are at 282. But according to the MoHSS the annual death rate is on the decline due to the use of ARVs which are prolonging the lives of PLHA thus reducing the morbidity and mortality rate.

Namibia has been hailed as a shining example in HIV and AIDS intervention as the country currently has a national coverage of 84% of ART roll out, adults who are above the age of 15 are at 96,563 while those who need ART are at 110,814, the coverage in this area is 87%, the children who are currently on ART are 10,528 while those who need ART are 16,105 and the coverage in this area is 65%.

According to the Ministry of Gender Equality and Child Welfare (2012) Namibia has 71, 941 AIDS orphans while none AIDS orphans are at 43, 635. In Namibia, the growing number of children who are HIV positive is steadily increasing. The 2011/2012 Estimates and Projections of the Impact of HIV and AIDS in Namibia reports there are 19,564 children between the ages 0-14 who are living with HIV.

While most of the children are infected prenatally, the National Guidelines on Adolescents Living with HIV say the some of the ALHV are infected through early sex debut or behavioural sexual transmission and a few through sexual abuse and violence. The growing number of children living with HIV is due to the success of the introduction of HIV treatment and care. The 2011/2012 Estimates and Projections of the Impact of HIV and AIDS in Namibia reports the roll out of ARVs has been successful in Namibia for example 107 000 adults and children are on ART. However, the biggest problem in Namibia is the majority of children do not know they are HIV positive even if they are on treatment since parents and guardians have not yet disclosed to them what is happening in their life.

Part of the problem emanates from the notion that, “children should be seen but not heard”, what it means often children are seen as objects and often their thoughts, feelings and behaviours are not consulted nor taken into consideration. This approach does not end here but in situations when children are exposed to HIV the principle still applies.

Research shows children who have been exposed to difficult situations are not passive instead they have acquired knowledge and skills to help themselves and others. Shielding the children from their knowledge about their status is therefore holding them back from participating in matters to help them cope with their situation given that such circumstances allow them to be passive and helpless.

This is a challenge to prevention efforts in the sense that sooner or later they will have to engage in romantic relationships as is common among adolescents like any other peers and they are likely to engage in unprotected sex with their partners. According to the National Guidelines on Adolescents Living with HIV in Namibia says that 4 in 10 women (36%) and half of men (49%) have had sexual intercourse by the age of 18.

In addition the National Coordination Framework for HIV and AIDS Response in Namibia 2010/11-2015/16 identified eleven key drivers of HIV in Namibia and among children early sexual debut was identified as a factor something these children are likely to find themselves. As a result non-disclosure is limiting the children from taking necessary precautions in sexual and reproductive needs. In the process they are infecting themselves and their partners and in the event they get pregnant there are chances of passing the virus to the unborn child.

There is strong emphasis in HIV counselling and testing as an entry point to prevention, care support and treatment, equally these children are already infected and some on medication knowing their status. The failure of parents and guardians to disclose the status is preventing these children from fully accessing and participating in their own care and support effort. Lack of care is seen by Johnson (2002) as a recipe for disaster for increased spread of HIV infection in the future, and for increased social instability.

Johnson (2002) brings in another dimension which parents are probably aware that these children are suffering from stress coming out of witness their loved ones suffering from HIV related sickness and eventually death and this is creating a sense of insecurity. Dyk (2011) supports the challenges that children often go through that children suffer a lot from the silence around HIV. Some children as mentioned elsewhere may have known from somewhere about their HIV positive status and hence this silence makes them feel angry, confused and hurt by the time they are finally told about their HIV positive status. As a result this is creating children growing with low self-esteem with poor social skills. Johnson (2002) adds this will likely increase instability and other problems in the society and consequently the cycle of high risk of HIV is likely to repeat itself and eventually having an uninfected adult will no longer be present.

When children continue to infect each other in the long term the future will be bleak and insecure. The statistics have shown in 2000, 600,000 children younger than 15 were newly infected with HIV and 1.4 million were living with HIV. Furthermore 500,000 children died of AIDS and the majority of them were in sub-Saharan Africa; worrisome trends which create challenges in the prevention efforts of HIV.

Johnson (2002) stresses the importance of the role of parents can play by taking care of their HIV positive children to assist in managing their own grief and have their family around for longer periods of time. Parents may want to hide their HIV status; however, they will have to inform their family of their status and the progression of the disease. The emotions of a child are often ignored; however, they establish their HIV status from an outside source instead of from their parents. This is because some societies disregard or devalue the feelings of the children and any signs of withdrawal are often punished. Unknown to parents' caregivers have been pushing children to engage in more antisocial behaviours; creating an opportunity to spread HIV to partners. Due to most children not expressing their feelings about their status (those who already know) are waiting for their parent to inform them officially. There are possibilities where some children have become aggressive demanding answers and if the truth is not revealed there could be a defaulting on treatment which will not only compromise their own health but become resistant to strains of the virus further complicating the treatment efforts for other people when the need arises.

This view is supported by the Report on National Guidelines on Adolescents Living with HIV that adherence is important in maintaining long terms virological suppression and untimely death. In Namibia for example the first line ART regimen of the non-nucleoside reverse transcriptase inhibitor (NNRTI) requires strict adherence to avoid the development of a resistant virus. Therefore maintaining these levels of adherence becomes a challenge for adolescents who are transitioning from childhood to adulthood in circumstances where they are not clear why they are taking the medication.

Personal and structural aspect of young peoples' lives makes it difficult to manage adherence. Children attend school and live in hostels and following the prescribed regime of medication becomes difficult to control without the supervision of parents and caregivers. The incidence of stigma further complicated adherence to medication as these children could face rejection and alienation from groups.

Dyk (2011) list some of the advantages of children knowing their status and these includes:

- Children will understand the medical care better
- Children may feel empowered to participate in their own health care
- The knowledge may impact positively in their adherence to medication
- It may prevent high-risk sexual behaviours (in case of sexually active adolescents)
- It may bring the family closer and
- It communicates respect for children

Most parents and guardians are possibly aware of the benefits of disclosing the HIV status than remaining silent. The benefits have negative ripple effects beyond an individual to family and the entire country at large. Most of the time parents or guardians and the health systems often focus on giving information and instruction only when it comes to children. Other ailments such as asthma is supported with knowledge based education, written treatment plans in psychological treatment did not have an effect on self-management, in contrast with interventions that focused on building knowledge, skills and the sense of self control. Caregivers should come to a level of appreciating and understanding if efforts to fight the epidemic will have the desired effect by involving those infected by the virus.

Resilience in children is important to acknowledge given the HIV risk these children find themselves. Resilience is defined as the “ability to spring back in the face of adversity”. Most parents and guardians often know best what is good for a child and their approach is often prescriptive rather than facilitative to enable the child to pick up and start their own life once news of their status has been disclosed. Children once they understand what their status is lowers their fears as they have their own understanding of situations; they actively attach a meaning to situations far from what parents and guardians think.

Often children depend on their caregivers namely their parents or guardians to explain significant moments in their lives such as death and HIV but unfortunately the parents and guardians are not making a contribution thus sowing seeds of mistrust. It is comprehensible often parents and guardians are going through their own set of difficulties and fear their children may not have the coping mechanism to help them handle difficult situations in their own lives. Sometimes parents are living in their own fear, shame and place for bringing the virus in the family and for passing it to their children thus often some of them are not ready to give answers when asked by their children.

Dyk (2012) found parents struggle to tell their children about their own HIV status hence it becomes even more challenging to tell their children they are HIV positive; parent is disclosing to a child a life threatening disease.

It is due to these complexities or difficulties encountered which need to be established in order to assist parents and guardians to disclose the status to their children. Namibia has more than 16,000 children living with HIV there is a need for disclosure to come in the centre of HIV prevention, care, treatment and support. Failure to support these children creates gaps through which the virus finds itself and sustaining itself in different stages. The worrisome factor is with 107, 000 adults and children, there is certain degree that not all of them for various reasons they will not adhere to treatment and this may lead to the new wave of infection.

Namibia has just been upgraded to a upper middle income country and this has seen the reduction of donor funding. Most of the Community Based Organisation, Faith Based Organisation and NGOs have either scaled down their service or closed their facilities. There are now gaps in the quality of care as volunteers who have been helping at community level are no longer employed as services are now restricted to the main centres. The upper middle income

status of Namibia contains one of the highest levels of inequality in its society is a fertile breeding ground of an increase in the infection rate and hence efforts should be made to enhance the improvement in terms of service in facilitating disclosure.

In HIV prevention, care, treatment and support there is an element of psychosocial support to enhance the quality of care and support. Some of these children are orphans they have lost a parent or both, they are therefore either living in a child headed household or they are under the care of extended family members. Whichever the case psychosocial support comes in handy through disclosure right at household level. Often there is dependence on counsellors to facilitate disclosure but then if parents and guardians are empowered to take the initiative at the home setting it will go a long way in helping these children deal with the powerful emotions and also create new opportunities to take control of their lives in managing their HIV status.

Disclosure though difficult has numerous benefits, more so with the growing number of children as well as adolescents who are living with HIV.

2.5 Conclusion

HIV and AIDS is a serious challenge and the face is changing and the number of children living with the deadly epidemic faces a challenge as their parents and guardians are holding back information which is crucial in determining the quality of their lives. The silence around their status is compromising the quality of life for those children who sooner or later they will find in relationships with thus posing the risk of unknowingly spreading the virus.

A situation arises when parents and guardians keep this information from these children sooner or later they will find out from their friends or peers that they are on ARVs and this alone has consequences of deepening mistrust which could create rebellion either passive or active. This could lead to careless and risky behaviours only for these children to stop medication or go out of their way infecting their sexual partners.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

The background of the research on the reasons why parents and guardians are withholding information of the HIV positive status of the children under their care by either parents or guardians was placed in context. In chapter two the literature supporting the topic of the project on the subject under study was presented and provided a platform for the investigation. In this chapter the choice for the methodology is presented to support the process of gathering information from the chosen respondents.

Research methodology considers and explains the logic behind the mode of conducting an investigation and gathering of data to be manipulated. Research methods refer to various means to which the data is collected and analysed and gives effects to how it was collected.

3.2 Problem statement

While the Prevention of Mother to Child Transmission has been hailed as a success in Namibia unfortunately some children continue to be infected with the deadly virus. According to the Ministry of Health and Social Services (2012) Namibia has a total number of 194,137 people living with HIV and AIDS, of this figure female figure account for 103,713 while those for males is at 71,670. The children account for 18,754 and of these the female statistics is 9,881. Most of these children do not know they are HIV positive even if some of them are on Antiretroviral Therapy (ART).

Namibia has done well in the provision of ART where according to MOHSS the national coverage for the provision of these lifesaving drugs is at 84%. This means adults above the age of 15 on ART are 96,563 while those who need ART are 110,814. The children who are on ART are 10,528 while those who need ART are 16,105; this brings the total coverage on a national basis on children to 65%.

These figures confirm HIV is not only confined to adults alone but a significant number of children are living with the virus. The unfortunate part is most of them are not aware they are HIV positive. Some of them are on ART and their parents or guardians have been not been telling them the truth that they are on ARV instead they are told they are taking medication for something else for tuberculosis or heart problems.

Namibia has certain contextual behavioural problems such as early sexual debut, multiple concurrent sexual partnerships, alcohol abuse, intergenerational sex, transactional sex, low condom use and low circumcision. Chances are particularly young people will soon start to engage in relationships and among teenagers there is often a low perception of HIV infections. Young people may not think of using protection which can lead to the other person being infected at that age. This as mentioned operating in all the above contextual behaviours is likely to increase the HIV prevalence rate which is already high.

The failure to disclose the HIV status is a potential concern for new infections in this country which is likely to increase the prevalence effort of HIV which is already high given the small population of this country.

The aim of the research is to establish what is holding back these guardians and parents to tell their children the truth of their condition. Efforts can be made to provide parents develop coping mechanisms and have a functional family. In addition these children when they reach a point of engaging in relationships they will take the initiative to disclose their true status to their partners so they can in the process minimise the risk of exposing their partners to HIV infection.

Should these challenges which are holding them back be identified, it is imperative that guidelines be developed so these parents or guardians are empowered to facilitate the disclosure process. The research question for this study is: What are the factors holding back the parents or

guardians from disclosing information from their children which in the long run may have an impact on the prevention efforts in the fight against HIV and AIDS in Namibia?

3.3 Objectives of the study

The research has the following objectives;

- To investigate the challenges parents/guardians face in disclosing the children's HIV status
- To establish the factors hindering parents from disclosing
- To identify the gaps and the present needs of the parents and guardians
- To analyse the needs and the present needs of public health system
- To recommend the formulation of guidelines to support parents and guardians

The challenge is that most of these children do not know they are HIV positive and they are on ARVs. This is a serious problem as it likely to increase the infection of HIV among young people which in the short and long term is likely to complicate and defeat the efforts to fight HIV and AIDS in Namibia.

3.4 Research approach

Quantitative and qualitative are the common methods which are used in most research projects, the former deals with absolute figures while the former looks at non-numerical data collection which often brings the human element in research. Depending on the demands and researcher at times they are used in isolations while at times they are combined in a process called triangulation. Each of these research methods has its own advantages and disadvantages, however, if combined these methods complement each other thus enriching the research.

In this study the qualitative method has been selected to elicit responses from the chosen respondents. Chiromo (2009) describes qualitative research as that which produces findings not arrived at by means of statistical procedures or other means of quantification. Qualitative

research involves in-depth information as it allows respondents to tell how they feel about the situation and how they do certain things.

Information is acquired by observing, asking direct questions in response to open ended statements. In addition qualitative research is a systematic, interactive and subjective approach used to describe life experiences and give them meaning. The definition it is the description and understanding of individuals and groups with a common identity such as the study being investigated to ascertain the reasons making parents and guardians find it hard to disclose the HIV status of their children who are living with the virus. Christensen, Johnson and Turner (2011) define qualitative research as an interpretative research approach relying on subjective data and investigation of people in particular a situation in their natural environment.

The sample population was mainly based on people who are working in the caring profession thus counsellors, HIV counsellors, nurses, social workers to name but a few. Parents, guardians as well as their children were not part of the sample for ethical reasons. These people (in the sample) deal directly with HIV and AIDS disclosure issues on a regular basis and their subjective reality means how they experience events from where they are standing is important in enabling the gathering of data which will give insight into what is going on in the lives of these parents and guardians.

According to Christensen et al. (2011) qualitative research during and after data collection a researcher tries to understand the data (responses) from the participants' subjective perspectives. In addition during data collection because qualitative research consists of words, picture, clothing, documents and non-numerical information, when it comes to words for example questions by the interviewer are allowed to revolve or change during the study to further explore a phenomenon unlike in the quantitative research.

Advantages of qualitative research play an important role when a researcher wants to understand and describing situations. During the process of interviewing respondents are not restricted in providing responses unlike in quantitative research but they can be guided in real time to get as much information as possible often giving the opportunity for new insights or as new developments emerge. Data on human being experiences which is powerful is obtained in the process of facilitating an interview more compelling than what would from a quantitative

research approach. Qualitative research is useful for understanding and describing situations also makes it an ideal for theory generation, it is thus useful for what is known as ‘the logic of discovery’ contrary to quantitative research which is ideal for hypothesis testing.

The other important aspect of qualitative research is that it uses multi methods for collecting data in the form of introspection analysis, interviews with individuals on their account, written document to name but a few. The use of various methods is called triangulation and it helps to gain a better understanding of the subject which is being studied. Qualitative research also has the advantage that it takes the researcher right there where the respondents are in their own natural settings thus allowing them to get more than they possibly could have imagined or thought. The other advantage of qualitative research is it requires a small sample and this translates in to low costs in the effort to collect, clean and analyse the data; contrary to the quantitative research which requires a large sample.

However, qualitative research has its own limitations, according to Christensen et al. (2011) cites the limitations it is difficult to generalise because the data is based on the local settings and therefore it is not pluralistic data. The other limitation of qualitative research is the lack of coherence in the findings as different researchers are likely to provide interpretations of the phenomena which are the subject of the study. Qualitative research does not generate statistical data (unlike the quantitative approach) but it complements quantitative research by giving insight into the human element. Furthermore the qualitative approach is usually based on the skills of the researcher and can influence the findings by being bias when interpreting responses.

The presence of the researcher can also affect data collection during the interview process as interviewees may feel like they want to answer in a way that they feel will meet the interests and needs of the interviewer.

Qualitative research comes with anonymity and confidentiality issues due to ethical reasons. When it comes to verification and processing at times this becomes a problem as the source of the response cannot be revisited. In the last instance qualitative research is objective procedures for testing are not used particularly due to the subjective nature of the qualitative approach.

The method used in qualitative methods includes interviews, focus groups, discussions, reviews and observations.

According to Hunter (2009) quantitative methods seek to answer the questions ‘how much’ or ‘how many’ expressed in absolute numbers. Data is analysed through different statistical formulas to generate information which can be used to produce meaningful information for interpretation. The main purpose of quantitative research method is to produce reliable data for example in a national census or the sentinel survey to determine the HIV prevalence rate of a country. The reliability of quantitative results provides a basis for recommendations and directions of thinking of solutions.

Quantitative research methods has a number of advantages one of them being that it plays a central role when large numbers of data has to be collected such as census. Census results are the backbone of the development of a country and as such the trends, the averages and so forth are much anticipated by various users. A strong element of objectivity is strength of quantitative research due to the large size of the sample which is numerically quantifiable. In addition quantitative research paves way for generalisation and is often seen as representative of the population due to the large sample. The large sample also works in favour of quantitative research methods as it allows changes to be seen over time, this often leads to the development of indicators which are critical in measuring trends over time.

Quantitative research allows presenting findings in graphical formats through the use of SPSS programmes.

One of the down sides of quantitative research method is time consuming, expensive and the use of human resources. Quantitative research has several cost implications where resources including finance have to be committed to see the process through.

Since quantitative research focuses primarily on absolute figures it often overlooks the important aspect of human aspect. The thoughts, feelings and behaviours are often ignored, however, using a combination of methods known as triangulation can close gap.

3.5 Sampling

Sampling is an important part of research (Christensen et al., 2011) and is defined as a process of drawing a group of individuals from a population. A sample therefore helps to narrow the number of respondents and thereby making the data collection more manageable and affordable.

Non random sampling specifically convenience sampling was selected as being the most appropriate for the research project. Christensen et al. (2011) sees convenience sampling as a method of drawing data by simply asking who are mostly available or these to be easily selected to participate in a study. The respondents usually avail them self to participate in a study on a voluntary basis and cannot be placed under obligation to remain part of the project.

The sample in this study targeted people who are working in the HIV and AIDS field including nurses, doctors, psychologists, social workers, generic counsellors and HIV and AIDS Counsellors. Twenty individuals have been randomly selected to participate in the study with consent from heads of NGOs dealing mainly with HIV issues namely LifeLine/ChildLine Namibia, Red Cross Namibia, UNICEF, Penduka and Positive Vibes Namibia.

The respondents were drawn from Windhoek the capital city, Ondangwa Town in Oshana Region in Oshana Region and Rundu in Kavango Region. The interviews will be conducted on a face to face basis and in some cases telephonically.

3.6 Conclusion

This chapter focuses on the research methodology which the researcher used to collect data for the study. The qualitative research method was used to collect and this method focuses mainly at data collection which is arrived at using non numerical means. Questionnaires and interviews were used to collect data from the population sample which was selected using convenience sampling. The population was unique in the sense that it involved mainly people who work on a day to day basis with HIV and AIDS matters on a daily basis especially on disclosure issues.

The respondents participated on a voluntary basis thus enabling easy access to data collection as well the turnaround time given the pressing deadlines. The sample was a combination of married, single as well as men and women drawn from across the country.

Some of the respondents were interviewed on a face to face basis with the researcher while some were interviewed telephonically. The responses were captured on the questionnaire while a voice recorder was also used both in the face to face interview as well as telephonically.

CHAPTER 4

REPORTING OF RESULTS

4.1 Introduction

This chapter is a presentation of the findings of the study after interviewing respondents who shared their experiences and feeling on the reasons holding back parents and guardians from disclosing the HIV positive status of their children and those under their care.

The research used a qualitative approach and focused mainly on respondents who are in the care giving role in both the NGO and the public sector. These included social workers, nurses, HIV and AIDS counsellors, community counsellors and programme managers working in the HIV and AIDS field.

Even if it was a qualitative research, the findings were quantified using word excel in order to present pie charts, graphs and percentages to add colour to the presentation.

The findings confirmed that indeed there are factors which hold back parents and guardians from disclosing the HIV positive status of their children and those under their care. Even if these parents and guardians have challenges there is a need to ensure they eventually disclose to their children if HIV and AIDS is to be managed in the Namibian space not among the youth but adults as well.

4.2 Problem statement

The fight against HIV and AIDS is now entering the third decade. Over years great efforts and strides have been taken to contain and manage the deadly virus. In most countries there are clear indications the prevalence rates and death rates are beginning to drop as for the latter is attributed

to the introduction of ARVs with has had an impact on the morbidity and mortality rates for both adults and children.

Managing HIV and AIDS is a slippery and unpredictable journey. No sooner have individuals managed to deal with one component only to realise that something even more demanding has to be attended to as all the efforts are likely to be undone. The dilemma facing Namibia and the rest of the world in the fight against HIV is the issue of disclosure. The prevailing dilemma is why are parents and guardians failing to disclose the HIV positive status of their children and those under their care.

Most of these children are not being told the truth about what medication they are taking and why. Some are already teenagers and they are in relationships where they are likely to be passing the virus to their sexual partners and possibly with a resistant viral strain since they are not fully taking their medication accordingly.

The study will seek to investigate the challenges parents and guardians facing to disclose their children are HIV positive and they are currently on medication. This research is aimed at looking into another findings which will shape the way HIV and AIDS is emerging as a growing challenge and what can be done to manage the epidemic. The research question for this study is: What are the factors holding back the parents or guardians from disclosing information from their children which in the long run may have an impact on the prevention efforts in the fight against HIV and AIDS in Namibia?

4.3 Objectives of the study

The research has the following objectives;

- To investigate the challenges parents/guardians face in disclosing the children's HIV status
- To establish the factors hindering parents from disclosing
- To identify the gaps and the present needs of the parents and guardians
- To analyse the needs and the present needs of public health system
- To recommend the formulation of guidelines to support parents and guardians

4.5 Results from the interviewing procedure

The study confirmed non-disclosure of the HIV positive status by parents or guardians is a serious problem. The problem is so deep in the society that some guardians go to the extent where they can conceal the death of a parent to HIV and pretend to be the biological parent of that particular child. The children found the truth through their friends who took them to the mother's grave and showed where the mother had been laid to rest.

Thus some guardians are prepared to holding back the truth about the HIV positive status of the children under their care. The common practice among parents and guardians is they are not telling the truth about the actual reason behind their sickness for which they are taking medication. Instead they invent some sickness such as TB, asthma and some other chronic diseases and HIV is never mentioned at all.

There are a number of reasons parents are doing all this and one of the biggest challenges is stigma and discrimination from both internal and external to their environment. Most parents who are also positive are often afraid once they tell their child of their status they will not keep it to themselves instead they will inform their friends. Once this happens then the knowledge of the status of not only this child but the parents will be known to the public hence the stigma and discrimination.

The study also found out that most parents feel that HIV is a very heavy problem a child cannot deal with. Therefore non-disclosure is seen as a shield to protect the child from the bad news which they perceive will be hard to be taken by a child.

During the interviews it came out clearly HIV is a difficult and complex subject because it is linked to sex most parents is not ready to face questions. Neither are parents willing to answer questions due to their share for being responsible for bringing the deadly disease into the family. As a result keeping quiet is seen as a way of buying time and it is believed to ensure there will be peace in the house.

How the child will react to the news is something they are not prepared to handle and hence they will rather keep silent and defer the matter to the future but unfortunately that moment never arrives even when a child is in their adolescent stage and even engaged in relationships.

The biggest fear is if children are not told the truth there is a possibility they could be passing the virus to their unsuspecting partners since young people often have a low risk perception of HIV as they think it is only for adults. Those who are on medication often do not take it seriously because it is something being imposed on them and could develop resistance and hence posing the risk of passing on a resistant viral strain while compromising their own health according to the treatment plan.

Respondents indicated most parents are not aware of the risks they are engaging in by failing to disclose to their child. Interestingly most respondents recommended even though it is difficult to talk about parents and guardians should take the lead in disclosing the HIV status to the child.

Even if there are institutions both in the NGOs and public sector there is no uniformity in the manner disclosure as most people use what they have which is not very sensitive to deal with HIV disclosure. In the public sector unfortunately only doctors and nurses are allowed to facilitate the disclosure of HIV which often leaves community counsellor to deal with parents and children.

There is no single solution towards the problem but education and training strongly came forward as means to ensuring parents are in a position to control the discussions on their own and those who are not able should be placed in a position to approach institutions which are equally equipped to handle the process. The following is the presentation of findings.

4.6 Presentation of findings of the research

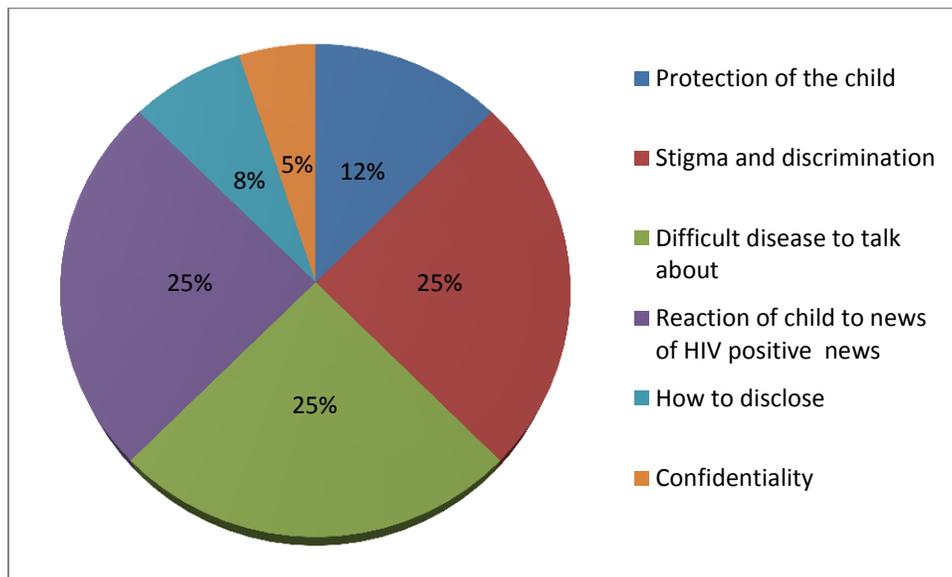
The following is the presentation of the findings which followed a summary of the questions used in the research during the interviews.

- Why parents/children are not disclosing the HIV status of their children

Stigma and discrimination came out as one the leading cause holding back parents and guardians from disclosing the HIV positive status from the children. It is clear society is still dominated by stigma and discrimination as indicated in figure 4.1.

Figure 4.1

Disclosing the HIV status



Most parents are afraid once they tell their child they are infected with the virus the information will not be held confidential. Consequently the status of this child will be linked to that of their parents. Due to linkage of HIV to sex it can eventually lead to the isolation of the family.

Most parents also indicated HIV is a difficult disease to talk about. Traditionally parents do not have good communication contact and skills with their children on day to day issues. Then when it comes to HIV they do not have the knowledge of the subject matter nor the confidence to talk about HIV and hence they prefer to remain quiet and not engage. Coming close to difficulty of the subject matter is most parents are afraid of the reaction of the children to the news. Some parents often reason they are protecting the children as they cannot process the news they are HIV positive.

Some parents are therefore afraid of the aftermath of the disclosure that questions such as “how did I get the virus” are likely and these are questions most parents are not ready to answer. This is because HIV is linked to sex and it may reflect that the parents were sleeping around.

The parents are afraid of a number of things such as the child committing suicide, in addition parents are afraid their children will no longer concentrate on their school work and some may even fail to understand their parents. In order to keep the peace in the family parents often keep quiet.

Those children who are on treatment, parents are afraid their children may stop their treatment and run away from home thus further exposing what the family was trying to conceal all this time. Parents are also afraid they will be blamed by their children for their condition of which they are not prepared to handle the emotions around such dynamics.

Most parents also indicated holding back the knowledge of the child’s HIV status as some form of protection and hence they see it as though they are doing a child a favour. Some parents are afraid the child may not have the ability to handle the magnitude of the problem and therefore keeping quiet is seen as a way of protecting the child from the potential harm of knowing about a serious disease which they are carrying in their body.

Most parents also consider the maturity factor where their children are not yet mature enough to handle the challenges and complexities of the virus. However, even if the child is now grown up parents often find it still hard to tell the child they are HIV positive.

Even if parents feel this is probably the right time to communicate the news. Often they question of how to disclose if affecting people from doing so. Hence they end up holding back and postpone the disclosure process.

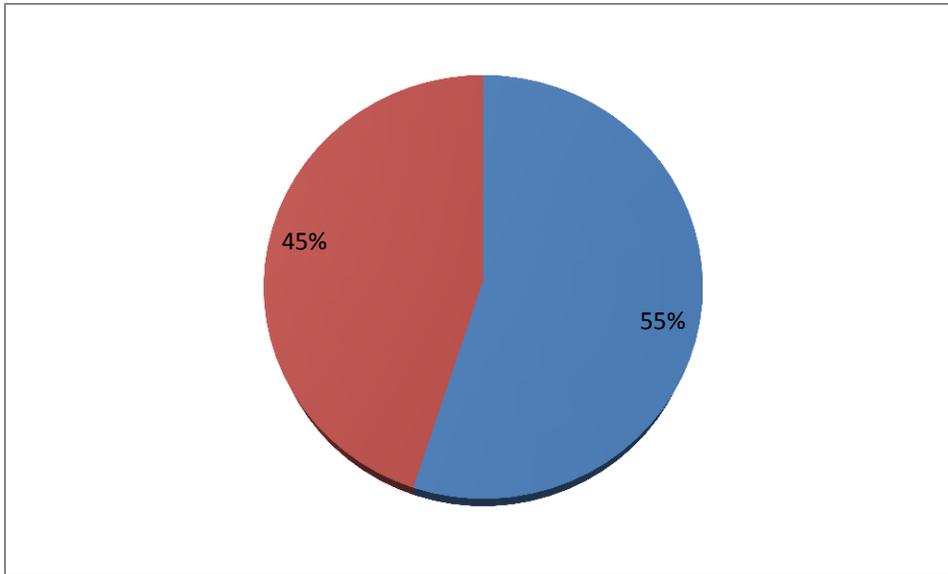
- **Are children aware they are HIV positive?**

Most of the parents indicated most of the children do not know they are HIV positive. Most children are told they are on medication of some diseases such as asthma and often children trust the information given by their parents and hence they continue to take the medication without questioning what is happening to them.

One sign children do not know they are HIV positive is when they finally learn about the truth they often reacting aggressively to the news. Some of the children only find out upon the death of their parents or parents there is HVI present in their bodies (figure 4.2).

Figure 4.2

Awareness of HIV



Some children often find themselves getting tired taking medication asking questions around when they will get healed. Sometimes because they can read this is when they start to find out the truth about the medication they are taking.

Parents often keep the HIV positive status as a family top secret to such an extent they only learn about it from the streets or from friends but verification often become a challenge. A respondent narrated an incident where a guardian kept the secret of not only the paternity but the HIV status of the children she was living with whose mother died and hence she assumed parental role. The friends of that girl was taken to her late mother's grave and told her the truth. When she went home she confronted her foster parent and their relationship was severely damaged.

Some indicated most children know even without being told they are HIV positive and they are on medication since they are learning things from school and are beginning to ask questions and at times confront their parents and their guardians to tell them the truth.

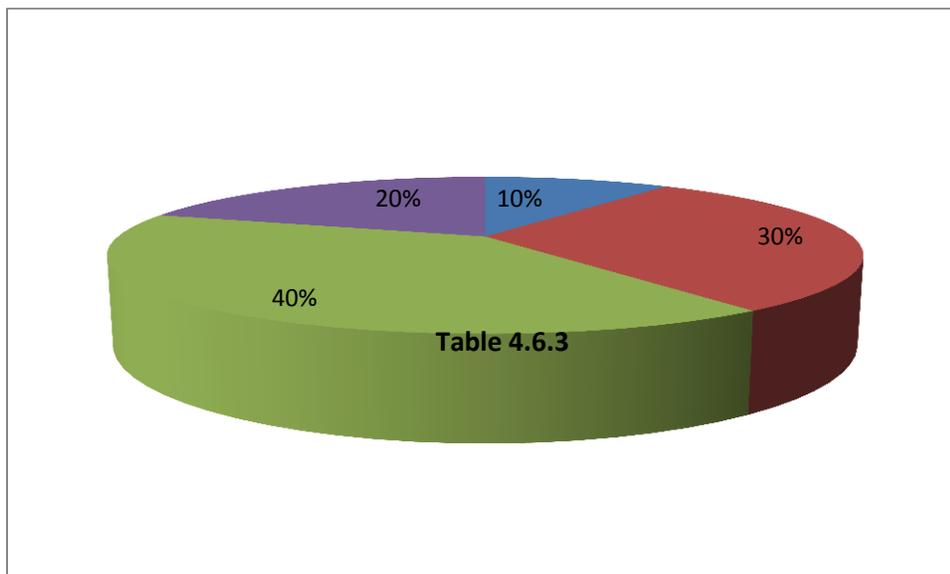
During the interview one respondent gave an example of how an HIV child confronted her grandmother to tell her everything about her status after her friends had told her.

- **Reasons parents bring forward for failing to disclosing the HIV positive status of the children under their care?**

Stigma and discrimination emerged as the main reason parents often bring forward for failing to disclose the HIV positive status of their status. Parents and guardians often bring the same concerns just as the challenge holding them back from disclosing the status of their children that they are they are prefer keeping the status as a secret for fear that their children will tell others in the process their status will become known too (figure 4.3).

Figure 4.3

Failure to disclose



Other parents often fear once other family members find out about the HIV positive status. What follow is family disputes where they start to blame one another and eventually the family become divided; however, they will rather keep quiet to avoid such dissensions.

The perception that these parents are protecting the child from stigma and discrimination since they know their status is one of the reason for failing to tell their child they are living with the virus and are on medication. Often they think in terms of “The less you know the better.” Part of

the reasons is also parents often fear rejection and blame by their children who will want to know how they ended up with the deadly virus which is causing all the hardships they are experiencing.

Some parents often fear the reason why their children are born with virus is due to their risky behaviours. As such they will rather keep it as a secret from their family members for fear they will be accused for not listening to the advice from their elders and finally they 'got what they have been looking for'.

Some parents often justify their action by saying they do not want their children to know, however, if they are infected their children will start to hate them; they postpone the disclosure which never takes place. Some parents often advance the reason they fear losing respect in the eyes of their children as a result of the shame and stigma associated with HIV and AIDS.

The issue of protecting the child came out strongly as one of the reasons parents often give for not disclosing the HIV positive status of the children under their care. When parents do not tell their child they are positive it is seen as a protection strategy and hence they are doing a favour.

Most parents are of the opinion once the child knows about their status they will ask these parents difficult questions related to how they got the virus. They often feel they are not ready to face such questions and at the same time they feel their child is not yet at a stage they can understand the complexities of the diseases.

As indicated in the challenges facing parents or guardians from disclosing, part of the reasons for holding back from telling their children is that experience has shown they might not take it and some may even kill themselves upon hearing the truth about their health.

Helplessness also comes in as another reason parents are failing to disclose the HIV positive status to their children. Parents are afraid they do not know what will happen as a child may react to the news with actions such as suicide, crying and becoming arrogant and uncontrollable something which could point to a main issue which is HIV detected in the family.

The age of the child also puts parents in a helpless position as they are not really sure when it is appropriate to tell the child they are HIV positive. What compounds the problem is they do not know how to disclose to the child.

The research indicated most parents are in denial about their own HIV status. Disclosing their HIV positive status of their child and their reaction means an increased burden of care of handling not only their emotions but extending to helping their child.

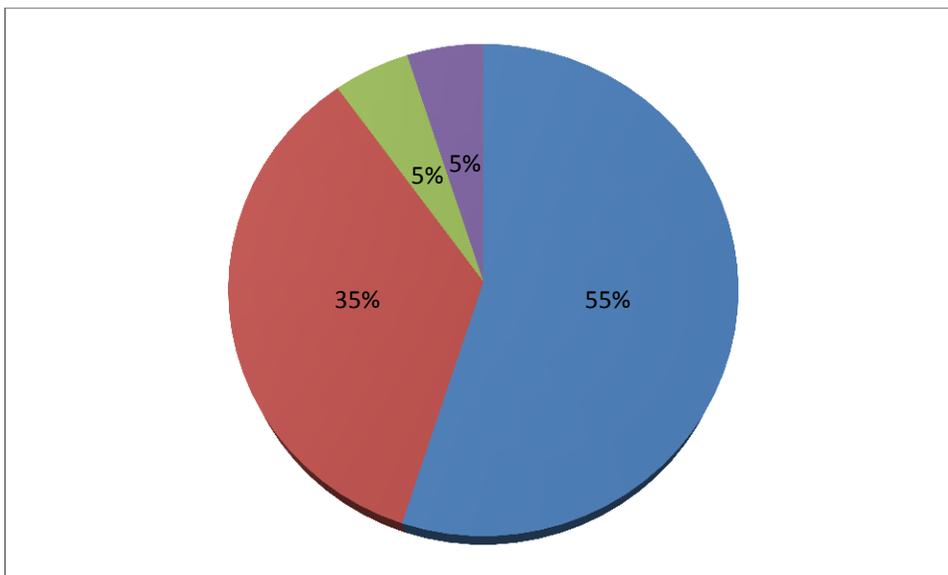
Often parents are forced to invent stories for the reason why this child is taking medication after being questioned. This is the reason some parents come up with diseases such as asthma, TB or some heart condition for fear if they tell the child the truth it may create all types of problems in the family.

- **Are Parents aware of the consequences of lack of disclosure?**

Over 55% of the parents are not aware of the consequences of lack of disclosure of HIV to their children. Some of the findings indicated that parents often do not weigh the advantages and disadvantages of non-disclosure as they believe that they are the protector of their children from the world (figure 4.4).

Figure 4.4

Consequences of lack of disclosure



Since these parents are HIV positive themselves, they are not aware of their own consequences it therefore difficult to know the consequences for their own children. However it is easier for the guardian to disclose since they do not have that attachment to the child.

The thinking around, “what you don’t know does not kill you” is common among parents and guardians as they dedicate their efforts towards protecting their image and reputation. This attitude often holds them back from finding out more about what are the consequences.

The other finding is most parents do not know of the consequences, in addition what they do not know is their children are learning about HIV and AIDS in schools. Out of curiosity some children often approach people who are educating them about HIV and AIDS, especially LifeLine/ChildLine facilitators to get more information on issues they are dealing with or suspect about their being and in most cases they confirm they are indeed on medication.

The use of tactics such as telling the child they are suffering from other diseases instead of HIV infection is a sign that parents are not aware of consequence and the harm they are causing. Such actions are only narrowed to the child without looking broadly at the impact of HIV and AIDS beyond a single individual. If they knew the consequences parents would have communicated to the child the reality they are living with and hence it will be easy for them to take medication without being coerced.

As long as the child does not complain or are in the dark the parents are fine with that. This is attitude among many parents or guardians a sign that they do not fully comprehend the full effects of HIV in a child and the wider society.

Some parents are not aware of the serious consequences of HIV as they just focus only on keeping that secret to their child. In instances when they are confronted by their children they often run to social workers or counsellors for help as a sign that they have run out of depth on the way forward.

One respondent indicated most parents are not aware of the consequences as in most cases these system around HIV and AIDS issues often exclude children for example until a certain age they are not allowed to go for testing. Parents often are not aware when their children become adolescence they engage in sexual relationships with their peers and often they do not use protection based on the perception they are negative. Besides when children play on the streets children may get cuts and often children end up touching each other’s blood resulting in infection on the streets. These incidents could have been prevented had parents informed their children well ahead of time.

About 35% of the parents are aware of the consequences but they are concerned about only protecting their own images and reputation in the eyes of the public. More over they are concerned about protecting the status of not only themselves but that of their children.

Due to post-test counselling as well as the presence of treatment supporters some parents are aware of the consequences but the challenge is they often find it difficult to confront their child about the truth going on their lives.

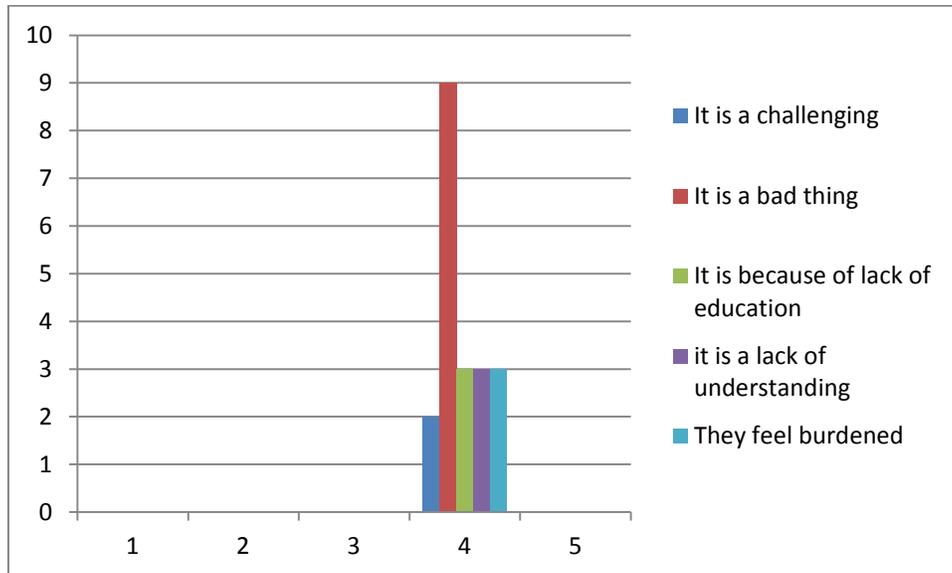
Those who said they do not know whether parents know about the consequence and those who said it depends shared the similar percentage of 5%. HIV is cross cutting and some parents live in the remote parts of the country where getting assistance from helpers is difficult to come by as they rarely come to centres where services are readily available. Therefore such gaps leaves room for parents to find themselves clueless on how do go about.

- **How do you feel about the inability of parents to disclose to their children?**

About 45% of respondents indicated it is a bad thing that parents are not disclosing to their children their HIV positive status. Some respondents indicated it is disappointing parents and guardians are failing to disclose. In most cases when the children who are ARV treatment find out they want to drop the treatment and most of them will not believe it unless they get tested (figure 4.5).

Figure 4.5

Inability of parents to disclose to children



Some respondents indicated it is not in the best interest of the child, “It is not a good thing, I feel bad it is not in the best interest of the child.” While some indicated while it all depends on people’s understanding it remained a bad thing for a child not to be told about their HIV positive status.

The child is HIV positive and it on medication and yet they do not know what is happening in their life was described as bad by some respondents. Concerns were some of these children may not even take their medication seriously which are likely to compromise the quality of their treatment by failing to adhere to medication thus limiting their options for treatment.

In some cases these children are in secondary schools in hostels and unknowingly they are spreading the virus to their fellow learners thus increasing the HIV prevalence rate of the deadly virus among young people. In instances where there is a resistant viral strain it is mostly likely that all the fellow learners’ treatment at one time will already be compromised.

It is important parents should be able to tell their children from 8 years and above because if they are 7 years and younger they are likely to forget said one respondent. There is a general feeling

no matter the consequences, parents and guardians should tell the truth about their HIV positive status. This they believe will bring relief to both parents and the child and should they be on medication it will be taken properly. According to respondents children cope well with bad news compared to adults.

Some respondents likened the failure of parents to disclose the HIV status to child abuse, “They are abusing their children, some will soon find out sooner or later then fights will begin and some will even stop taking medication.” Some children upon learning at a later stage about their condition they have stopped medication and said they want to die the way their parents died. This is how serious lack of disclosure can have on a child and those around them if things are not done accordingly and on time.

There was a tie on the percentages on the issues of a lack of education and the burden of care all at 15%. As for the former respondents felt a lack of information on the emphasis of disclosure as well as a lack of information on how to go about it is one of the problems which should be attended to inform of education.

Some see a lack of education as a big disadvantage as they feel parents need knowledge how they should go about for their own benefit as well as that of their children. One respondent remarked: “The problem is that parents are not aware of the dangers of lack of disclosure. We need to conduct workshops as they have no skills. We need to strengthen the issue of knowledge and skills.”

The burden of care accounted for 15% and some parents are afraid and they feel pity for the child. They are afraid if the child find out they are likely to feel bad about the parents. This is because they are not in a position to explain how the child got infected in the first place as HIV and AIDS are seen as very complex issues.

The burden of care was summed up only as “it is really painful.” Some respondents indicated that even as care givers they are also touched when they hear these things. Often they indicated that in some cases they are better off dealing with clients whom they don’t know but once it is their own family members they feel touched. A respondent recalled an incident how deeply she was affected when the uncle disclosed to them they are HIV positive.

In some cases parents feel they have a burden to take care of, this include a whole host of emotions, attrition between acceptance and denial. Lack of coping mechanisms often come in as a hindrance. The majority of these people often come from economically depressed backgrounds while they battle with the medical condition created by HIV they find themselves with yet other challenges on how to meet their daily needs which are difficult to control as a result of poverty and high unemployment.

In addition some respondents felt HIV is a big challenge as it brings about a double burden to the family. They find themselves dealing with a non-curable disease and at the same they are dealing with their children; some parents keep quiet for fear of being labelled.

Lack of understanding of HIV and AIDS as a disease is one aspect respondents feel parents are not fully aware of the situation. In addition there is a feeling parents are not aware their children are sexually active and they could be spreading HIV to their partners.

- **How your institution is helping with disclosure?**

Reponses on this question were varied as each institution gives its own programme and therefore there is no uniformity in the approach.

LifeLine/ChildLine offers a whole range of services which are readily available for use by clients. These include generic counselling, HIV pre- and post-test counselling, parenting skills and Social Behaviour Change Communication skills courses to name but a few, but these address issues indirectly and it is up to an affected individual to come forward and seek personal attention when they feel they have a need.

LL/CL has strengths that allow people to access various platforms to use some of first aid towards disclosure and can be seen as an entry point for various services people. However, the challenge is there are no specific people who are skilled in facilitating the disclosure process. Respondents indicated particularly generic counselling was not strong or sufficient enough to enable counsellors to handle the HIV disclosure process smoothly and therefore they feel a lot more needs to be done.

Most respondents from LL/CL hailed courses such as positive parenting, the second child counselling module and SBCC as strategic courses in helping parents to disclose from a

community mobilisation perspective. But there is strong feeling HIV and AIDS related and disclosure to create that depth which will eventually help the counsellor, the parents or guardians and the child who is involved.

HIV and AIDS counsellors working in public while they handle a large number of clients when they are doing pre and post-test counselling are not allowed to handle disclosure matters. They had this to say: “As counsellors we are not allowed to disclose, it is nurses and doctors who do it.”

Some organisations often use materials from Positive Vibes training to help them get ideas how they can facilitate the disclosure process as the material is very specific on disclosure matters. There were suggestions that platforms created where learners are tested could be used to facilitate disclosure matters much easier.

- **What areas do you feel you need help in order to better assist parents to disclose?**

Responses to this question were quiet varied providing a wide array of issues which if addressed can make it easier for the care givers to do their utmost best in helping parents handle disclosure matters in a more effective manner.

Empowerment in building communication skills between parents and children has been cited as being naturally weak and the presence of HIV excreates matters, “Everyone should be equipped with good communication skills, lack of communication skills on HIV is a very serious problem.” Some view HIV as part of the problem but there was a feeling parents on issues of sex and sexuality and that helpers need assistance in such communication to be better enablers of parent to do so.

Respondents indicated they need to be empowered broadly to help them bring both parents together in parental roles as it will help to understand their lives better. This is due that often mothers bear the brunt of all this. This is because often they are struggling to tell their husbands or the fathers of their babies how then can they disclose to their children.

Dealing with stigma and discrimination which is seen at being at the centre of non-disclosure by helpers they feel this matter still need more attention in order to remove some of the barriers they are facing. One respondent had this to say: “HIV is a very sensitive subject which touches very

sensitive areas, they are too many dynamics you cannot get used to. One size does not fit here people start to blame each as to who brought it here.” Until today some people see being HIV positive as a death sentence.

Sensitisation of both parents and guardians on the value of disclosing is what some helpers feel will bring them closer to helping both parties; helpers need to be trained to be equipped. One respondent said: “We need to empower parents with information and the importance of disclosing their status and to cope with their feelings.”

Helpers feel information on matters on transmission, how children get infected is what they need the most. In turn this will help them to educate and give correct information to both parents and children.

Those working in the public health system feel the Ministry of Health and Social Services particularly the HIV and AIDS counsellor should extend the training on disclosing to parents and guardians to them since they are the ones who talk to parents and their children a lot more than nurses and doctors.

Some helpers feel that they need training on how to disclose and when to disclose to the child and when and finding that suitable time to do so. The focus of the training should focus on how go about the process: “Care givers need skills on how to go about these challenges, sometimes we come across challenges, parents come crying, I need skills.”

A respondent suggested a closer working relationship should be forged between the Centre for Disease Control and the ARV clinics with other players in HIV and AIDS. Since they have all the data it is therefore easier to get the latest information and developments thus keeping updated with what is going on. This is envisaged will help collaborative efforts on disclosure efforts instead of working as islands.

- **Are there any issues you struggle with when it comes to HIV and disclosure?**

While the battle against HIV and AIDS has been going on for close to three decades it is important to find out if there are still challenges care givers are encountering as a potential hindrance in carrying out their duties. This question was aimed at finding out if there are challenges which they face particularly when it comes to HIV and disclosure.

One of the issues is that of parents who are stuck in denial. They are on medication but they have not yet accepted the fact that they are living with the virus. This brings the notion that people are still far from understanding HIV which makes it hard to imagine how they can open up that discussion with their children if they themselves are struggling.

Part of the issue care givers confront is the fact that stigma and discrimination is the underlying cause inhibiting people from coming forward when it comes to HIV. The system within which people living with HIV are treated in hospitals and clinics whereby they have their own corners is entrenching stigma and discrimination. To make matters worse the treatment they receive at the hands of health care workers where they are treated as second rate citizens often deters people from coming forward and disclose.

Clients often when they come for help they expect counsellors to do it on their behalf. Since most of the caregivers are not fully equipped to deal with such matters they are forced to dig deeper to do what they can to help these parents and the child seated in front of them. "I did in once, it was a bit difficult, it's very emotional, I spoke to them separately and then brought them together," remarked a respondent.

Caregivers are human beings too and often they are touched with what is happening even if they deal with numerous cases, "you have this sorry thing, why did it happen to this person."

Dealing with a child who has defaulted on their treatment is one of the issues which some caregivers struggle. This comes against the back ground if one is defaulting on treatment they are minimising their chances for treatment

Issues where a child is suicidal after learning that they are HIV positive is one of the issues caregivers are struggling with, especially when a child has already made up their minds that they want to end their lives. The skilling of caregivers often does not have a suicide prevention component as how the caregiver can respond to the newest challenge of suicide prevention thus leaving the helper helpless while there is an expectation that they have to help in this situation.

The lack of knowledge on the appropriate time a child can disclose to the child often leaves most caregivers struggling. Often some parents argue that it is a child and should learn about the truth they are likely to end their lives.

At times caregivers often find issues around helping people to understand that being HIV positive is on the end of their lives, that there is treatment if they need it. Therefore a lack of knowledge about the services available for people living with HIV and AIDS often makes the work of caregivers rather difficult.

Some indicated in support group settings they do not have the skills on how they can go about helping the child and parent deal with various issues they bring to the fore. “It is feels fragile to work in a support group, I don’t feel that I am equipped to do so, people know about their status but they have not disclosed to their partners.”

However, some respondent indicated they have never had problems working around disclosure issues with children as children are good people to work with unlike adults.

- **Any comment you might have?**

Respondents brought to the fore a number of issues they feel need to be attended to, one of them is early sexual debut among children which they feel need to be addressed through early related education in schools which will teach these children to be responsible about their life in terms of sex and sexuality.

Children have to be told they are HIV positive, in addition to their parents and caregivers should be empowered. A child needs to know what is happening in their lives and hence they need to have a lot of support to help them through.

Stigma and discrimination came out strongly with recommendations that it needs to be attended to while emphasising on disclosure to benefit all other people, “You are dying slowly if you are not disclosing,” remarked a respondent.

Some suggested it is the responsibility of parents and guardians to ensure the truth about their lives and the best is to open up to avoid the current situation where there is resistance on medication as well as aggressive children after they have learnt from other sources they are HIV positive and are on medication. Those who fail to disclose should be able to approach institutions to assist.

It is important parents learn and understand for themselves what HIV and AIDS is all about so they can talk about it at family level and be free about the subject. Once they do so it becomes easy to communicate with their children about the deadly virus.

Parents and guardians do not know anything about medication and treatment. They collect the medication but beyond that they do not know anything and therefore there were suggestions they should be involved in group discussions to improve their knowledge about the issue they are involved.

The other recommendation stressed the importance of caregivers need to be trained in disclosure through the Ministry of Health and Social Services beyond only nurses and doctors who have already been trained. This will be of great help to counsellors since they are the ones who engage with parents and children thus making their careers much easier to handle.

Some stressed it is important parents should learn and know to disclose when kids are still young. Since they are young it will help them to deal with problem around HIV and AIDS as they grow and more so it will help them to deal with suicidal tendencies which are common if they learn about their status at a later stage especially when they learn they have been told untruths all along.

Others stressed the importance of education of parents and guardians to be able to disclose to their children, “It is really helpful to educate parents, we are losing children, even if they are on medication they are not adhering, we should not get tired of HIV as some parents do not understand, we do not know the concept of Mother to Child Transmission (MTCT) as we assume that they are all negative, a lot has happened we need new information about HIV and AIDS.”

The other dimension was media where there is a need to talk about HIV and use it as a health platform to debate issues of this subject against the background of resources which are increasing growing limited due to increases in demand for other challenges.

4.7 Conclusion

The study confirmed that indeed there are factors which are holding back parents and guardians from disclosing the HIV positive status of their children, mainly is it due to stigma and

discrimination as parents often fear that once they tell their child about their status they are likely to tell their friends and in doing so it will link the HIV to the family. Some think they are protecting the child as they feel the issues of HIV are too advanced for a child to comprehend given their age, unfortunately they keep on postponing even if the child has reached their adolescent stage.

Lack of knowledge of when to do it and how is one of the reasons parents are not telling the child they are living with HIV. The other finding is most parents are not aware of the consequences of not disclosing to their children while some are aware but they do not know how to do it.

While there are institutions both NGOs and public there seem to be a lack of coherence on how disclosure should be done. The MoHSS whose mandate HIV and AIDS fall under seem not be the leading force either as they have trained only doctors and nurses to do so while we have a number of community counsellors who could be trained to facilitate the disclosure process. As a result there were strong suggestions that MoHSS should train all counsellors to ensure uniformity in the manner in which disclosure issues are handled.

It was emphasised keeping knowledge from the child as a secret is not a good thing at all. Therefore parents and parents should be educated to be in that position where they can tell the child the truth. If this is done it will alleviate problems such as the spread of HIV among young people who often have a low risk perception towards its infection. In some cases it will improve the levels of adherence to medication as children will know the exact reason for taking medication instead of being lied.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The previous chapter looked at the presentation of data which came from data collection for the study on investigating the reasons holding back parents and guardians from disclosing the HIV positive status of their children and those under their care. This chapter will focus on the conclusions as well as recommendations based on the findings from the data collected from respondents who were interviewed during the study. The chapter will also look at the limitations and how to overcome them for future research

5.2 Conclusion

- **Objective one: To investigate the challenges parents/guardians face in disclosing the children's HIV status:**

The study confirmed parents are facing challenges when it comes to disclosing to them they are HIV positive and that they are on medication. Parents invent or create other diseases such as asthma, TB or some unspecified sickness they are suffering, for example to keep a distance from mentioning HIV.

The study also established most children 'trust' the words of their parents and often believe what their parents say is the correct version of the reason for their sickness or why they are taking. It is perhaps the reason why some of these children become aggressive towards their parents when they find out their parents were not telling them the truth.

Parents or guardians can keep the secrecy of HIV from a child up to a certain time. Sooner or later children find from other sources for example at school where information about HIV is being shared to school children by various NGOs. These organisations often go to schools at times with bottles of medication which means if a child is on medication they can see the bottles and link to what they are taking at home.

In some cases children learn from their friends they are HIV positive. While parents or guardians may keep everything under wraps, this is not the case with the neighbours who may have information about the HIV status of them who will unknowingly pass on the information to their children without realising and these will in turn tell others of what they have heard. Another scenario how these children learn about their status is when this guardian presented herself as the biological parent to this girl whose mother died while she was an infant.

This girl only learnt from her friends her mother has long passed on and the one taking care of her was a mere guardians. Because these girls knew it all about her death they took her to the grave yard where they showed her, where her mother was buried. Upon getting home she confronted her guardian and the relationship was damaged to the extent she stopped medication and later on she passed on.

As the children grow older some parents find themselves disclosing to their children in heated moments. It came out some parents fearing for the worst their child may spread the virus to their partners they will engage in arguments where they cannot go out at night for parties. The children will become rebellious and want to find out why that is the case. It is then where some parents are cornered into telling them the truth that they are positive and hence they cannot go due to their sickness.

These scenarios indicate parents are having serious challenges disclosing the HIV positive status to their children and those under their care. Often when parents do this they are merely focusing on their children. They are not taking into consideration the risk of how their child or children have in spreading the virus to other people mainly their partners. Namibia is characterised by several behavioural aspects which are driving the rapid spread mainly: Early sexual debut, multiple-concurrent sexual partnerships, low condom use, low male circumcision, low risk perception of HIV and AIDS, intergenerational sex and transactional sex.

The other factor is because these children do not understand the reason why they are taking this medication, chances are that their level of their adherence may not be that high. It is most likely because they are engaging in sexual encounters mostly unprotected since most young people have a low perception of HIV among themselves. There is a danger they are passing on the resistant viral strain of HIV to their partners which already not only compromises their treatment plan but that of their partners as well.

It came out during data collection most parents are not aware of the danger of not disclosing to their children and the impact it has on a wider population beyond their child. According to some responses from respondents, had parents been aware of the effects of their non-disclosure they would have taken appropriate measures to do so. This is probably why some respondents suggested parents should take the lead in disclosing to their children for they can know the truth so they can grow knowing what is happening in their lives as this will help them to deal with the problem.

▪ **Objective two: To establish the factors hindering parents from disclosing:**

The study revealed parents are faced with a number of challenges which are holding them from telling their children they are HIV positive. One of the biggest challenges is that of stigma and discrimination, most parents are afraid once they tell their child the truth about their health, this child will not keep it confidential as they will tell their friends who will spread the message around. Once people know the status of this child, then it equally means the status of their parents will be known. This is something parents do not want to happen and hence the decision to keep it a secret.

The other challenge is HIV is a difficult disease to talk about. This is because of its linkage to sex, therefore most parents are afraid of confrontations from their children for their responsibility in bringing about a disease which is creating all types of problems in their lives, sex is a taboo subject which is rarely discussed between parents and children. Since most of them do not even know where to start and which words to use thus becoming a challenge to address the matter. Moreover the subject is technical for most

people and they do not have the vocabulary to start when it comes to trying to explain what HIV is and how people get infected as well as how does a child.

The level of education for most parents or guardians is low to nothing at all and hence they have to talk about such a complex issue. Out of the fear of exposing themselves for their shortcoming to their children they opt to keep quiet.

The reaction of the child if they learn they are HIV positive has been found to be one of the reasons holding back from telling their children they are HIV positive. The study revealed in most cases children often react aggressively to the news by taking their lives through suicide, some who are on ARVs often stop the medication and opt rather to die. These are some of the reactions parents want to keep at bay for as long as possible.

Some parents often think they are protecting the child by withholding the knowledge of their HIV positive status. Most parents have not have accepted their own status as some are caught up in denial as they fail to comprehend what they are going through. It then becomes a challenge how they can tell their child as they also facing the magnitude of the disease which will have a lasting effect in their lives. Hence it becomes difficult for parents to communicate the truth as they are clueless on where to begin and end.

▪ **Objective three: To identify the gaps and the present needs of the parents and guardians:**

Lack of the full knowledge and the impact of HIV and AIDS as well the way medication works was found to be a limitation most parents have around disclosure. Communication skills often do not exist on general issues and when it comes to HIV it becomes even more difficult for these parents. It was also found women find themselves in a difficult situation since most men are not participating in the raising of their children. Some suggestions were the subject of parenting should be revisited with the aim of bringing men to participate in raising children.

- **Objective four: To analyse the needs and the present needs of public health system:**
In its current form the public sector is not helping in facilitating disclosure between parents and children. The Ministry of Health and Social Services has done little in ensuring the process is systematically undertaken. Currently only the doctors and nurses are only allowed to facilitate the disclosure process leaving out community counsellors who are spread all over the country out of the system.

Namibia has a number of NGOs which deal with HIV and AIDS matters; for them they are using their own initiatives. This means there is lack of uniformity and coordination of the disclosure from the centre and that is the MoHSS. These gaps are making it difficult for most people who are working in the NGOs to have the depth in handling disclosure matters.

- **Objective five: To recommend the formulation of guidelines to support parents and guardians:**
Guidelines are important to initiate the process of disclosure when needs arises. Most parents are naive when it comes to disclosure as when to engage in the process. Disclosure of HIV should be part of the agenda on a broader scale. Resources are limited but the use of platforms such as media can pave way for people to know about disclosure and gain knowledge on how they can do it appropriately when their circumstances arises.

5.3 Recommendations

The following are some of the recommendations which can assist in solving the disclosure of HIV parents to their children.

- **Information and education:** It is too early to close the topic on HIV and AIDS based on the achievements countries have achieved. The time has come to address different components of HIV at both national and grassroots level so there is a thorough understanding about the complex subject becomes a shared subject to create shared understanding on HIV and AIDS, the facts and figures, the anatomy of the virus, the

transmission, how the virus replicates itself in the body, how treatment, works, how ARVs work in the body, the importance adherence, how children get infected and when to disclose and why

- **Disclosure guidelines:** The MoHSS has over years generated various documents and guidelines for example on ARVs and it important they consider facilitating the writing up of such guidelines nationally with standard guidelines on disclosure unlike the current scenario where there are no strategy. Each organisation is doing what they can based on the immediate situation or using generic counselling which do not really address HIV disclosure matters appropriately thus leaving the process half done or not done at all
- **Training:** All care givers should be trained in disclosing the HIV positive status of children after certification. Until rapid testing was introduced, HIV identification and counselling was a preserve for nurses and doctors. However the situation changed when rapid testing was introduced as more care givers mostly community counsellors where trained. At the end it helped in rolling out testing and counselling services thus reaching a wider majority. Equally the same principle can be applied in respect of disclosure. Namibia with such a high HIV prevalence rate the country cannot afford to have yet another stumbling block which could potentially increase the spread of HIV in the population. The role of NGOs cannot be overemphasised and hence they need to be part of the process, the personnel involved in counselling must be trained and be updated with the latest developments so they can offer quality service to their clients. Most parents it has been noted they are often held back by the fear of the reaction of their children, the guidelines must include subjects such as suicide so they can not only provide help to deal with possible suicide or its prevention.
- **Stigma and discrimination:** The Namibian society is generally a stigmatising and discrimination one. The system at the CDC clinics as well as the hospitals where HIV positive people can be easily be identified with their health passports and queues entrenches stigma and discrimination and hence should be systematically be addressed. In communities, families and institutions stigma and discrimination should be addressed.
- **Parenting skills:** HIV and AIDS have exposed the weaknesses of some of the traditional parenting practices which cannot stand the demands of HIV among others. Therefore as per the recommendations and suggestions by respondents are parents should be exposed

to training such as parenting skills so they can develop communication skills which will help them to communicate better by being assertive and confident.

- **Empowerment of parents and guardians:** Often parents have unrealistic expectations where care givers will disclose on their behalf. Instead parents must be empowered in a way they should be able to have enough courage to tell their children they are HIV positive and be empowered enough on how to handle the reaction even though it may be difficult. This will help to build trust and create new opportunities for growth in the parent/s and child relationship. This in the long run helps parents and children reach mutual understanding in coping with HIV and AIDS.

5.4 Revisit the limitations and make recommendations how to overcome them

The limitations which parents face in disclosing include stigma and discrimination, fear of the reaction of the child to the news of being HIV positive, confidentiality, not knowing how to disclose, they are protecting the child from the difficult of HIV and AIDS.

These are real challenges parents are facing parents which are preventing them from disclosing to them that they are HIV positive. In order to overcome these challenges, broadly the subject of HIV and AIDS should not be taken out of the agenda as yet, instead HIV should be seen as a very serious challenge which society need to be aware and be in a position to deal with as different challenge arise from the time when one discovers they are HIV positive.

As for parents and guardians the knowledge holding back the knowledge of the child status should not be seen as a favour they are doing the child but rather more harm than good is done when the truth is withheld.

All guidelines for disclosure guidelines should be made available by the MoHSS so that care givers can help parents and guardians in facilitating disclosure in a standard and uniform way. The guidelines should involve community counsellors so they have the necessary skills and knowledge on how to disclose instead of them relying on doctors and nurses, this scenario on works for public health settings where there are doctors and nurses but in the NGOs it is not the case often leaving caregivers in the NGOs to use whatever tool they have to facilitate the process.

The challenge is for doctors and nurses where they are not trained counsellors and the quality of the way of disclosing has not been tested, tools being used in the NGO world have not been tested to find if it has the strength which is required to bring that difference in disclosure process which will be of benefit to both the child and parents.

5.5 Conclusion

The study investigated the reasons holding back parents and guardians from disclosing to their children who are HIV positive. The study was composed of 20 respondents who are care givers in the field of HIV and AIDS. The data collection confirmed that indeed parents and guardians were having numerous challenges in disclosing the HIV status of the children under their care.

Some of the challenges include stigma and discrimination, not knowing how to disclose, the fear of the reaction of the child, confidentiality and they are protecting the child by not telling them the truth about their health. Parents are not aware of the dangers of not disclosing to their children. That the child is sexually active and could potentially infect other or default on treatment is something they are not aware of.

The way forward is disclosure guidelines must be provided for caregivers to be equipped with requisite skills to facilitate the process professionally. Currently only doctors and nurses are allowed to facilitate the disclosure process thus leaving out care givers mostly counsellor who handle most of the cases.

Therefore if guidelines are available community counsellors must undergo the training so they too can help in the HIV disclosure process. The guidelines will create a uniform and structured way of disclosing HIV thus making it easier to monitor and evaluate the process for the purpose of improving the quality of service.

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Addendum A: Research Questionnaire

Place of interview:.....

District:.....**Region:**.....

Interviewer's code:.....

Date:.....

The questionnaire is completed anonymously and will take approximately 20 minutes of your time. Thank you kindly for your cooperation.

1. Sex

| | |
|------|--------|
| Male | Female |
| | |

2. Marital Status

- a) Single
- b) Married
- c) Divorced

3. Age:

| | | |
|-------|-------|-------|
| 15-25 | 26-35 | 36-45 |
| | | |

4. What are some of the challenges are parents and guardians facing in disclosing the HIV positive status to their children?

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5. Are their children aware that they are HIV positive?

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6. What are the reasons they bring forward for failing to disclose the HIV status of their children?

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7. Are the parents and guardians aware of the consequences of not disclosing to their children?

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8. How do you feel about their inability to disclose the status of the child?

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9. How is your institution helping you in disclosing the status?

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10. Which areas do you feel you need help to help the parents to disclose their status?

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11. Are there any issues you struggle with when it comes to HIV and disclosure?

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12. Any other comment

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Addendum B: Permission to conduct research from the Ethics Committee

Approval Notice

Stipulated documents/requirements

27-Sep-2013

Dube, Sibangani S

Dear Mr Sibangani Dube,

Your **Stipulated documents/requirements** received on **27-Sep-2013**, was reviewed by members of the **Research Ethics Committee:**

Human Research

(Humanities) via Expedited review procedures on **27-Sep-2013** and was approved.

Sincerely,

Susara Oberholzer

REC Coordinator

Research Ethics Committee: Human Research (Humanities)

Addendum C: Permission to conduct research from LifeLine/ChildLine Namibia



11 September 2013

The Ethics Committee
University of Stellenbosch

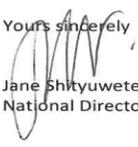
Re: M. Phil in HIV and AIDS Management research proposal, Mr Sibangani Dube

Dear Sirs

This is to confirm that LifeLine/ChildLine is happy to allow Sibangani Dube to interview our counsellors and other staff in relation to his research: *To assess the reasons holding back parents and guardians from disclosing the HIV positive status to children under their care.*

This is an important topic, which LifeLine/ChildLine will benefit from understanding better.

Yours sincerely


Jane Shityuwete
National Director

P O Box 5477, Windhoek
45 Bismarck Street

Tel: +264 61 226889
Fax: +264 61 226894

email: janes@lifeline.org.na



From: 19 September 2013

Penduka TB Control Program

PO Box 7635, Namibia

To:

MR. Sibangani Dube

P.O. Box 5477

Windhoek

Cell: 0812948891

Dear Sir

Ref: permission to conduct research

With regards to your letter requesting our programme for your research regarding your study at Stellenbosch University on HIV and AIDS Management with our field promoters, we therefore hereby informing you that your request has been agreed on, you can plan on the day and inform our office for organizing the field promoters to be ready for the interview.

We congratulate you once again in your career and you are requested to report to our offices before you start with your research with all their necessary Original identification documents. After the interview you are requested to feedback our office with write a report.

We appreciate your decision of choosing our TB/HIV program as the first step for your career and we assure you that with the information that you will get from our field promoter, you will be able to complete your master degree.

We wish them all the best for their career.

Sincerely,

Tannay Shilikha

Program Manager

E-mail: admin@penduka.org Tel -061-309859

PENDUKA TB PROGRAMME
P.O. BOX 7635, WHK
TEL: 061-309859
FAX 061-309186