

**An investigation of living conditions of children living
with terminally ill parents due to HIV and AIDS: A case
study in Havana Informal Settlement – Windhoek,
Namibia**

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Declaration

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ABSTRACT

This study was conducted as an inquiry into the living conditions of children living with terminally ill parents due to HIV and AIDS. It examined possible support systems that such children can access from general communities in which they live. The study was also purposed to identify specific needs related to the fact of living with terminally ill parents due to HIV and AIDS.

Both qualitative and quantitative research methods were employed in conducting the study. These included interviews, focus group discussions and questionnaires. Social workers, class teachers and parents were the main respondents in the study.

The study revealed that children living with terminally ill parents suffer multidimensional effects that are social, economic and psychological. Children assume adult responsibilities at a very early stage including that of fending for the family. In an effort to meet family needs, older children resort to a host of activities in an attempt to earn money for self and family survival from temporary paid labor, sex work to rudimentary trade. In effect, children become prone to abuse, exploitation and are exposed to crime.

OPSOMMING

Hierdie studie was gedoen om inligting te verkry oor die lewensstandard van kinders wat saam met hul ouers woon wat terminal siek is weens MIV/VIGS. Die beskikbare ondersteunings sisteme in hul gemeenskap was ondersoek. Die navorsingsstudie het ook daarop gefokus om die kinders wat as gevolg van MIV/VIGS saam met hul terminale siek ouers woon se spesifieke behoeftes te identifiseer.

Tydens die norsingsstudie was kwalitatiewe en kwantitatiewe navorsingsmetodes gevolg. Onderhoud focus groep besprekings en vraelyste was benut. Maatsplike werkers, onderwysers en terminal siek ouers was die hoof respondenete in die navorsingstudie.

Die navorsingsstudie het bewys dat kinders wat saam met hul terminale siek ouers woon, multidimensionele gevolge ervaar waat sosiaal-ekonomies en psigologies van aard is. Kinders neem ouers se verantwoordelikhede op 'n vroeë ouderdom aan. Om vir die gesin te voorsien, gaan die ouer kinders tot die ekstreem en raak betrokke in seks werk en smous vir 'n tydelike inkomste. Die gevolg is dat die kinders blootgestel word aan mishandeling, en moontlike misdaad. Die addisionele verantwoordlikhede dwing hulle om te oorleef deur gebruik te maak van misdaad, prostitusie en kinderarbeid. Al die kondisies dra by daartoe dat kinders blootgestel word.

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ACRONYMS

AIDS-	Acquired Immune Deficiency Syndrome
ARV-	Antiretroviral
CAFO-	Church Alliance for Orphans
ELCIN-	Evangelical Lutheran Church in Namibia
HIV-	Human Immune-deficiency Virus
ILO-	International Labour Office
MGECW-	Ministry of Gender Equality and Child Welfare
N-	Number
N\$-	Namibian Dollar
NGO-	None Governmental Organization
NPA-	National Plan of Action
OVC-	Orphans and vulnerable Children
TV-	Television
UN-	United Nations
UNICEF-	United Nations Children's Fund
UNAIDS-	Joint United Nations Programs on HIV/AIDS

CHAPTER 1: Introduction

1.1 Background and rationale

Namibia is one of the ten countries most affected by HIV and AIDS, in the world, with one in five adults infected. The pandemic affects children in various ways. Single and double orphan rates have risen, child headed households have increased as well as infant and child mortality. The vulnerability of children due to HIV and AIDS begins well before the death of their parents. The effects often begin with the onset of a parent's illness and may consist of impoverishment, emotional suffering, neglect and the increased burden of responsibility associated with a parent's illness, stigma and discrimination associated with HIV and AIDS that breaks down and humiliates children (Hunters & Williamson, 2000; UNAIDS, 2004).

The purpose of this study was to investigate children's needs that are a result of living with terminally ill parents due to HIV and AIDS. Children living with ill parents are faced with difficult circumstances and they are a vulnerable population. They do not only bear the emotional burdens of watching their parents suffer and die, but they also experience the trauma of the family unit collapsing, the stigma of HIV and AIDS associated with parental death, diminishing attention and affection, and a harsh decrease in the family's economic power (Foster, 2000).

Children living with terminally ill parents take over many adult tasks and responsibilities at a very early stage. While both girls and boys suffer, girls are most vulnerable. They usually drop out of school to become caregivers of their young siblings, and take over other adult and motherly responsibilities including all forms of household chores such as cooking, gardening, laundry and general house keeping (Foster, 2000).

Furthermore, orphaned female children have a higher probability of HIV infection compared to their male counterparts. If withdrawn from school it is possible that their children will have higher mortality rates, as female education is associated with infant and child mortality rates. It is an even more worrying trend in high HIV and AIDS

prevalence countries in Africa regarding the myth that sleeping with a virgin girl cures AIDS (Barnett & Whiteside, 2002).

There is a knowledge gap on the nature of effects on households of children living with terminally ill parents. There are no direct policies in place in Namibia that particularly focus on the protection of these children. The Ministry of Gender Equality and Child Welfare is mandated through the Directorate of Child Welfare Services to ensure appropriate care and services to all children in Namibia and implementation is guided by the Children's Act, (No.33 of 1960).

While this is true, there is no evidence as to whether children for whom care and services are most needed know of the existence of the Act and the fact that they can source support from the Ministry of Gender Equality and Child Welfare. No previous studies have been conducted to assess awareness or better still access to services for the children living with terminally ill parents.

The Ministry of Gender Equality and Child Welfare, through their child allowance division, supports approximately 250,000 children to date, generally categorized as Orphans and Vulnerable Children (OVC) with monthly grants. The (NPA) Namibia National Plan of Action for Orphans and Vulnerable Children 2006-2010 predicted the number of children to need support to be 117,000 by 2010. As such the number of children receiving support grants is a lot higher than the estimates and will most likely impact on planned resources and ultimately the final goal of total care for orphans and vulnerable children.

Being a social worker, also employed by the Ministry of Gender Equality and Child Welfare, investigative home visits to identify orphans and vulnerable children is part of my routine work. During these visits I observed that children living with terminally ill parents face challenges that manifest forms of exploitation and abuse all in the search for food and livelihood.

A 12 year old boy explained that he operates a makeshift car wash under a tree for which he earns N\$ 1.00 for every car washed. He spends the earnings to buy food for his family as the parents are ill, weak and unable to work. Children from families where parents can no longer work to afford basic needs for their family would do anything in exchange for social favors, money and basic needs as a result. This ranges from typical child labor (for most boys) to sex work especially in the case of girls.

Working with community leaders and constituency counselors during the research process intended to possibly create some form of community awareness about these challenges and possibly link it to promotion and protection of children's rights. Therefore, the research zeroed into Havana, an informal settlement on the outskirts of Windhoek, Namibia's administrative and commercial capital.

Increasing numbers of children are being traumatized by the experience of witnessing or having to nurse one or both parents through terminal illness, often in conditions of extreme poverty and neglect, low self esteem, lack of hope for the future and direct depression which characterizes many orphans. These children by nature of these circumstances become vulnerable to abuse, exploitation, improper care and quite easily drop out of school and yet risk of contracting HIV is real (Foster & Jiwli, 2001).

Due to HIV and AIDS the family structure and the roles within the families gradually change. In many cases this basic human structure gets completely disintegrated and destroyed. With the increase in mortality among adults, older people are under increasing pressure to care for children as well as the sick adults. These grandparents already experience economic setbacks because of an initial fact that they are mostly unemployed and secondly, the loss of support from their children which makes burden of care only worse (Foster & Jiwli 2001).

1.2 Research Question

To gain an understanding of the different needs and challenges that children living with terminally ill parents face, the research questions formulated for this study were:

- What are the category-specific needs of children living with terminally ill parents due to HIV and AIDS?
- What challenges do children living with terminally ill parents due to HIV and AIDS face?
- What support systems are available for children living with terminally ill parents due to HIV and AIDS?
- What challenges do service providers face in the delivery of services to children living with terminally ill parents?
- What service gaps can be identified in meeting the needs of children living with terminally ill parents?
- What can be done to improve the livelihood of children living with terminally ill parents due to HIV and AIDS?

1.3 Objective of the Study

The objectives of this study were:

- To identify the needs and challenges faced by children living with terminally ill parents.
- To identify existing support system for children living with terminally ill parents.
- To identify challenges faced by service providers in delivering support services for children living with terminally ill parents.
- To identify service gaps in meeting the needs of children living with terminally ill parents and suggest means of resource.
- To develop intervention strategies based on findings to better meet the needs and mitigate the impact of the challenges faced by children living with terminally ill parents.

1.4 Significance of the Study

Information generated by this study is helpful in the planning, implementing and monitoring of programs that target and reach-out to children living with terminally ill

parents due to HIV and AIDS. It is useful in strengthening the coping capabilities of the children themselves and general communities. Additional use of the information is envisaged to support the establishment of structures, systems, laws and policies to support children living with terminally ill parents due to HIV and AIDS.

1.5 Structure of the Thesis

Chapter one reveals the research question and provides the basis for the study. The aims and objectives of this study are outlined and the procedure is explained.

Chapter 2 provides literature on the variables that influence the problem, the existing living conditions of children living with terminally ill parents due to HIV and AIDS. The chapter outlines the needs and challenges that children living with terminally ill parents due to HIV and AIDS face. Relevant coping mechanisms were identified and discussed.

Chapter 3 describes the research methodology and research approach used during the study. Special attention was paid to clarify the concept of “household needs and challenges of children who live with terminally ill parents”. The three tools were used in collecting data are discussed and explained as well as the data analysis plan.

Chapter 4 deals with the presentation, discussion, theoretical framework and interpretation of the results. It attempted to answer the set out objectives in chapter one.

Chapter 5 gives the conclusions based on findings, recommendations and suggestions for areas that need further research.

CHAPTER 2: Literature Review.

2.1 Introduction.

According to the monitoring and evaluation report for the National Plan of Action 2006-2010 for orphans and vulnerable children in Namibia it was estimated that the number of orphans in 2007 would be 117,000. However, the Ministry of Gender Equality and Child Welfare currently supports a registered 250,000 children. The number is far more than it was predicted by the National Plan of Action. The rights of most these children to health, education, a caring family environment and full participation in society may be under threat (Ministry of Gender Equality and Child Welfare National OVC Data warehouse 2010).

Since independence, Namibia has enacted several laws and policies aimed at providing child protection especially for orphans and vulnerable children in various ways. Examples include the Combating of Rape Act 2000 that provides a stronger framework for addressing sexual abuse among children, giving increased protection to children, both girls and boys. The maintenance Act of 2003, allows for monthly grants to sustain the livelihood of orphans and vulnerable children in absence of parental support.

This study paid particular attention to children who endured additional responsibilities as a result of their parent's illness and or death. The study purposely kept the topic open ended and broad to effectively engage target respondents, primarily the children. For the purpose of defining a child: A child is a person below the age of 18 (MGECW, 2009). This is consistent with the UN convention on the Rights of the Child and the African Charter.

For the purpose of this research, the respondents were children between the age of 10 to 18 both in and out of school.

2.2 The impact of HIV and AIDS on the Household.

Although there is no part of the population in Africa which is unaffected by HIV and AIDS, it is usually the poorest areas of society that are most susceptible to the illness and consequences of this are always worse. This puts tension on the household and it is very uncomfortable. It is sad as most of the time it causes the household to gradually disintegrate. This is specifically because parents die and children are forced away or sent somewhere else for protection and care (Greener et al., 2004).

In many places, community groups and religious organizations fill the gap through spontaneous and determined outreach, to vulnerable children and orphans. Volunteers, mainly women, visit the sick people and raise funds to feed vulnerable and orphaned children and enroll them in schools, with impetus and good leadership. These groups of volunteers become community facilitators and advocates. Some go as far as offering savings and credit schemes for the affected families, formal and vocational training for orphans and vulnerable children and a variety of other services (Gailborn, 2008).

A number of program principals and models have blossomed from the cumulative experiences of African and international groups working with children affected by AIDS. The first priority is to strengthen the community capacity to support orphans and vulnerable children. However, it is costly and ineffective for institutions to ensure a nurturing environment where abandoned and desperate children are cared for. Special attention should be paid to vulnerability of girls and to the needs of older children for skills to support and protect themselves (Gailborn, 2008).

The girl children are usually the first to drop out of school to take care of the sick parent. The argument is that girls' issues should not be bunched together with those of women or other children, but should be dealt with as a separate group that needs special attention and support. This is particularly important in the presence of HIV and AIDS which is taking an excessive toll on African girls (Mbugua, 2006).

All organizations must be guided by the fundamental rights of children to families, communities and their culture to education and play to health, safety, and most

importantly to voice the issues that affect them. The huge challenge that remains is to deliver protection and services to all children affected and infected by HIV and AIDS. The best thing that can be done for children is to keep their parents alive not only with access to sound medical care but through a relentless effort towards the ultimate goal which is prevention (Gailborn, 2008).

2.3 The Impact of HIV/AIDS on Children in Africa.

The impact on children affected by HIV and AIDS is very dramatic and more than a child should have to bear. This illness can not only cause children to lose their parents or guardians, but it can also cause children to lose their childhood years as well. Many times children often have to take on a huge amount of responsibility to care for the sick parents, produce food and earn an income for the family. It is often hard too for the children to find adequate food, housing and clothing. Due to the huge cost of illness children also give up on their education because the parents are unable to send them to school (Greener et al, 2004).

However, Wilfert et al., (1999) believe that health care professionals caring for children of parents who are chronically or terminally ill with HIV and AIDS, should consider raising the issue of planning for the future of these children, at an appropriate time. For parents who face worsening illness and impending death, one of the most painful things to witness is the inability to care for their children, planning for their children's future and see them grow to maturity.

In the context of HIV infection, both parents are most likely to be infected and possibly ill or dying. The mother might be quite isolated and may not have assistance from the father of the children. The father might have died or he is unavailable. Future planning for the children can create a peace of mind for parents by making sure that their children will be cared for according to their parent's wishes concerning their future (Wilfert et al., 1999).

Because of the increasing number of children orphaned due to HIV and AIDS, health care professionals should assist chronically ill and dying parents to plan for the future of their

children. “Creating loving and nurturing environments, for such children by providing the legal framework, the counseling and other social and financial services; and the stability of a clear, consistent family structure which enhances the outcome for children while assuring that chronically ill parents participate vigorously in the planning process.” Wilfert, et al (1999).

Further, health care professionals caring for the children of chronically and terminally ill parents with AIDS should help families to create a plan for the future care and custody of their children. The discussion should be initiated in a responsive manner early in the course of parental illness, and take place over a suitable period consistent with disease severity, and the course of the parents’ illness. Pediatricians should refer families for help with planning for future well-being of their children to social services agencies that offer these services. Parents often are reluctant to initiate such planning due to guilt, denial of the seriousness of the illness and fear that others may learn about their diagnosis. Planning for the future of a child who will be orphaned includes creating a steady nurturing environment and belonging. This could include an environment that provides love, stability, as well as paving a legal framework and social intervention, to enable the children to better cope with the loss of their parents (UNAIDS, 2004).

Fear of discrimination leads parents not to disclose their HIV status to their families. However, others seek help but they are rejected or abandoned even by their family members after revealing the nature of illness. In addition to overwhelming demands on caring for adults children are left in tears with their grief and suffering while they watch their parents die and their family languish. The impact of HIV and AIDS on families is devastating. In many parts of the world, it is not divorce that creates single parent and step families, but parental death and orphanhood due to the HIV and AIDS pandemic (UNAIDS, 2004).

2.4 Advantages of planning for children before their parents die.

Parents do not plan for their children because the planning process is painful, it is a reminder of death. However, mothers with AIDS identified several advantages of

planning. During Mason's study in 1998 on custody planning with HIV-affected families some of the advantages were:

- It lessens stress on them as parents ensuring a normal life for their children including a smooth shift to a new home.
- It provides sick parents and their children with a choice of where the children will live after their parent's death.
- Children will know that their parents cared enough to plan for them and will know where they are going to live after the death of their parents.
- Planning has a potential positive psychological impact on the parents and their children (Mason, 1998).

2.5 How school age children manage stress of their dying parent.

Children are not only affected by the death of a parent but the constant reminder and anxiety of the looming death of the parent is traumatic. People dealing with children should not only have an emphasis on grief counseling, but also on dealing with the trauma associated with the time before death. The chronic nature of an illness intensifies traumatic stress by causing ongoing anxiety (Saldinger et al., 2003).

A child's immature ego makes him or her less able to cope with stressful situations. The death of the parent involves the loss of a person who plays an important role in the child's emotional support. Parental loss may include the feelings of desertion and the development of scary thoughts in the child. Children and adults who anticipated deaths were more adversely affected than those who lost loved ones suddenly (Saldinger et al., 2003).

2.6 Social and economic aspects of children living with terminally ill parents.

Children affected by HIV and AIDS lose their childhood, it limits their choices and opportunities. In order to develop appropriate means of enabling and protecting children against infection and the effects of HIV and AIDS, attention needs to be given to the rights and realities of the children's childhood (Lyons, 1998).

HIV and AIDS close on children from all sides in the hard-hit regions of East and Southern Africa. Children nurse their parents during prolonged illness and essentially watch them suffer and die. Serious illness puts households under enormous financial stress. Ill parents incur huge medical expenses. They are unable to farm or work so they find it difficult to get funds to pay off the expenses. Children find it hard to get money to buy food, pay school fees, health care, and clothes. The family of the deceased is left to struggle to pay off funeral expenses, widows and orphans stand to lose their land, homes and possessions if their rights to property and inheritance are neglected (Gilborn et al, 2008).

2.7 Psychosocial aspects of HIV/AIDS in infected parents and children.

Infected mothers with HIV place a great importance on their role as parents. The first question that they face when they find out they are HIV positive is “What will happen to my children?” (Mason, 1998). Finding someone to care for their children can be an intimidating process. Parents would like someone who can take all of the children and meet the special needs of each child.

Most parents will only trust someone whom they have watched with their children over a long period of time. Mothers infected with HIV also fear that even if they identify a potential caregiver, that person may change her or his mind about the caring of the children after the mother’s death (Mason, 1998).

Parents of children in care may bring a sense of urgency to the child welfare bureaucracy. However, if reunification is the goal, the mother may want it to happen very fast so that she has more time with her children, and if adoption is the goal, the mother may want the legal arrangements in place before she becomes terminally ill or die. With the prospect of early death the role of a parent and the importance of children are amplified (Evans et al., 1994).

The end of life is about taking stock of what one has accomplished (Manson, 1995). For many parents seeing their children healthy and happy provides proof that the parents were

successful in up bringing of the children. Their children are seen as their legacy to the world. Children have some important questions when they find out that a parent has HIV. The questions vary from child to child. Some themes are common, as they ask (Evans et al. 1994):

- ❖ When will my parents die?
- ❖ What is going to happen to me?
- ❖ Who can I tell about this?
- ❖ What should I tell them?
- ❖ Did I cause this?
- ❖ Will something happen to me?

The child's experience is that of worry, fear, anger, sadness and confusion. Children get confused as soon as they get to know that their parent or parents are HIV positive (McKelvy, 1993).

They often cannot discuss their feelings directly but show their feelings through problems at school and or at home. For example, they fight, they withdraw themselves or they experience difficulties in sleeping. When the parent's illness or future is not talked about with the children, young children especially make up their own answers to these questions, answers that contribute to their fear and misunderstanding. Children who escape HIV infection, however, do not escape the impact of the disease. They may suffer the pain of the death of the parents. They may serve as caregivers to their ill parents including washing and feeding bedridden mothers or fathers and often assume adult responsibilities for household maintenance (Foster et al., 2005).

2.8 The impact of HIV/AIDS and child labor.

HIV and AIDS is neither the only nor the principal cause of child labor. Poverty is the primary cause of child labour and it is probably the impoverishment caused by AIDS, that has intensified the need for girls and boys to work (ILO, 2007). Due to the growing convergence of poverty and HIV many working children are living in households affected by HIV or are orphaned due to AIDS. Older children may look for paid

employment to support their family when no adult is well enough to work, and raise their younger siblings in the place of their parents (Foster et al., 2005).

The rapid assessment and thematic studies of working children carried out between 2002 and 2004 by the ILO in Cameroon, Malawi, South Africa, Tanzania, Uganda, Zambia and Zimbabwe have confirmed the strong impact of HIV and AIDS on child labor in particular following the loss of one or both parents as a result of AIDS. In Cameroon 47% of working children started to work after the death of a parent or foster parent, in most cases due to AIDS.

A 2004 survey conducted by the ILO in Uganda found out that 58% of the children affected by HIV and AIDS were orphans who were working to sustain themselves. These studies have generally discovered that children in AIDS affected families are more likely than other children to be engaged in child labor, commercial agriculture, domestic services, prostitution and street vending in return for cash, in-kind remuneration or food (ILO, 2007).

Leaving school makes it more likely that children will stay uneducated, and grow up to know poverty as adults which increases their general level of exposure to the danger of HIV. Lack of schooling means they will in turn face more difficulties in accessing decent work when they become adults.

This way, poverty, lack of education and children's exposure to exploitation including the worst forms of child labor, all lower the probability of access to HIV prevention, while raising the probability of exposure to HIV in the short or long term. The HIV epidemic has greatly increased the social cost of caring for sick people and orphaned children for households and communities. In many HIV and AIDS affected families in developing countries, some children and non orphans carry out household chores in other people's homes – domestic work such as cooking or laundry, nursing the sick parents, caring for young children, and older persons, home construction and agricultural tasks (ILO, 2007).

Domestic chores can be excessive or exploitive and may comprise a form of child abuse. All children who work are at some level of risk of HIV basically because work draws them into the adult work, whereas they belong in the world of children at school or at play. Furthermore, being outside school robs children of the personal growth and access to information that would help them to protect themselves as children and adults. It denies them access to skills that would enable them to climb out of poverty and protect themselves as adults (ILO, 2007).

The Namibian Child Activities Survey conducted in 1999 revealed that children between the age of 6-18 years who were working or looking for work comprised 16.3% of the 445,007 children in that age group. This meant that 72,405 children were working or looking for work with no less than 40,000 being under the minimum working age of 14 years. The majority of these children lived in rural areas with about two-thirds working on communal farms (Mapaure in Ruppel, 2009).

The research process that paved the way for the Namibian Action Programme on the elimination of child labor 2008-2012 recognized that many of the worst forms of child labor were being experienced in Namibia. It was predicted that between 10 to 30 children in conflict with the law were forced by adults to work (Mapaure in Ruppel 2009). The commercial sex exploitation of children occurred both in terms of children being prostituted and in terms of adults taking advantage of needy children by providing basic needs in return for sex. It looks like this situation is mainly attributed to the high incidences of poverty, some cultural practices, child labor, lack of proper guidance for children, lack of resources in schools and many other things (Mupaure in Ruppel, 2009).

2.9 Sexual exploitation of children.

When children are impoverished by the illness of one or both parents, they may get involved in sexual exploitation even at a very young age as first or last resort to obtain immediate cash earnings and food (ILO, 2007). Among the numerous hazards these children are exposed to, the exposure to HIV is one of the most life threatening. Poverty, lack of schooling, orphanhood and lack of marketable skills create the conditions that may favor the sexual exploitation of children. Other conditions that may contribute to this

exploitation include cultural factors, such as the low status of girls and women, the weak enforcement of laws and social unrest, disturbance and conflicts that lead to economic hardships, displacement and migration (ILO, 2007).

2.10 Conclusion.

It is evident that HIV and AIDS have a great effect on children living with terminally ill parents. It is usually the poorest areas in society that are the most susceptible. The illness and consequences are always worse. The illness does not only orphan children but it robs them of their childhood years. Children take up huge responsibilities to care for their sick parents. Emphasis should be put on planning for the children would to know where to go after the death of their parents. Parents who are HIV positive should consider planning for their children at an appropriate time which is before they get terminally ill.

Households with terminally ill parents may be less able to pay for their children's education. Orphaned children might have to engage themselves in income-earning work. Sick parents may have reduced expectations of the returns of investing in their children's education, as they do not expect to live long enough to recover the investment. When a child goes to live with another household after his or her parent's deaths, the obstacles becomes greater as the child is not their own (Barnett & Whiteside, 2002).

CHAPTER 3: Methodology.

3.1 Introduction.

In conducting this research, quantitative and qualitative study methods were used with semi-structured questionnaires and structured interviews administered as main components for data gathering.

3.2 Target population.

This study targeted children living with terminally ill parents due to HIV and AIDS. These children were aged 10-18 and would express and verbalize their feelings. The study sample size was 20 children residing in Havana informal settlement and 20 terminally ill parents from the same locality. The researcher worked with different organizations in Windhoek who knew these families well. More time was spent at AIDS Care Trust in Okuryangava an informal settlement neighboring Havana. Experienced personnel of the AIDS Care Trust helped with the screening of children who lived with terminally ill parents.

3.3 Qualitative research.

The research intended to study the living conditions of children living with terminally ill parents with a particular focus on the different needs and challenges they faced. The qualitative approach was used to gain a reliable interpretive result while investigating people in their natural environment (Kumar, 2005). The use of both qualitative and quantitative approaches was to achieve a holistic view of the living conditions of children living with terminally ill parents during the investigations. The researcher recognized the limitations of quantitative and qualitative methods and felt that the biases inherent in any single method could neutralize the biases of the other method. The mixed methods approach built a stronger research design and more valid and reliable findings were realized.

The respondents were selected at AIDS Care Trust where they regularly met for psychosocial support and other child services. Questionnaires were self administered in a single day activity with guidance from the children's counselor whom they were familiar

with. The counselor's guidance focused on clarifying the questionnaire for the children who found it difficult to understand.

3.4 Naturalistic inquiry.

Naturalism is the philosophical view that strives to remain true in the nature of the phenomenon under study (Bryman, 2004). It is based on aptitude of humans to create their own experience. Children living with terminally ill parents were able to explain their own experience and came up with suggestions as to how they could be assisted by the government.

Data was collected in naturalistic surroundings of children's environment at the AIDS Care Trust where children spent most of their time for counseling and other services. Focus group discussions with parents as well as the children were held in the same surroundings. For the benefit of most responding parents who could not speak or understand English, counselors assisted with the translations into vernacular the interview questions as well as responses to the researcher. Observations meticulously followed all forms of verbal and non-verbal communication during the data collection process.

3.5 Holistic Perspective.

The holistic perspective looked at children living with terminally ill parents. Data was collected from the children themselves, the parents, the teachers as well as the social workers. All the four different dimensions gave meaningful information to the study. The integration of the different data collection methods, the interview, focus group discussions as well as the questionnaires helped to expand information sources in the achievement of the objectives of the study.

3.6 Quantitative research.

Quantitative data is derived from interviews or respondents observations and naturally takes the form of a large quantity of unstructured texture material (Bryman, 2004). It is a descriptive type of study that collects quantitative data to explain the variables of interest (Christensen, 2007). It seeks to establish fundamental relationships between two or more

variables, using the statistical methods to test the variables. The researcher used the attitudinal questionnaires as a measuring instrument in identifying needs and challenges that children living with terminally ill parents due to HIV and AIDS faced.

3.7 Sampling criteria.

Sampling is an important step in a research process as you need to decide on the population, its individuals, groups or institutions (Bryman, 2004). The selection criteria of the study was based on the four populations of the following.

3.7.1 Sampling criteria for the children.

The main respondents of the research were children living with terminally ill parents. The researcher worked from the AIDS Care Trust Centre where these children met for psychosocial support services. The counselor at the centre assisted with the screening of children living with terminally ill parents as the main respondents. The sample was twenty children. They were divided into four manageable groups of five. Respondents were asked to give consent to participate in the study. The questionnaires were handed over to the children for self-administration and handed back to the researcher the same day. After handing in the questionnaires, the same children participated in the focus group discussions. They shared with others their experiences and views about living with terminally ill parents. Data collection took four days but the researcher met participants on several occasions to get clarity of what they had answered in the questionnaire.

3.7.2 Sampling criteria for the terminally ill parents.

It was challenging to find the parents in one place. Some were in hospital and others in their homes unable to come to the AIDS Care Trust.

Only seven parents were available at AIDS Care Trust. Due to the sensitivity of the topic, the risk of stigmatization on the parents, information shared by children that would imply blame and guilt for parents, was evened out by way of counseling. The parents were counseled by the senior counselor of the AIDS Care Trust who they were familiar with and trusted. During the interview it was revealed that some parents disclosed to their children their HIV positive status.

3.8 Validity and reliability of quantitative findings.

Questions were constructed in such a manner that reliable information could be obtained from the respondents. The questionnaires were simple and straight forward, and administered with the assistance of the researcher and the counselor from the AIDS Care Trust, making it even easier and helped maintain consistency in understanding the concepts of the questionnaire.

Validity entails whether the instrument deployed by the researcher is doing what is intended to do (De Vos et al. 2005). The validity of this study was enhanced by children living with terminally ill parents in Havana and receiving psychosocial support from the AIDS Care Trust. The threat to internal validity was the circumstances related to abuse of children living with terminally ill parents. Children and their terminally ill parents were assured of confidentiality and anonymity of the questionnaire as well as their responses. The researcher met the children more than once to get the clear and meaningful follow-up feedback on responses they had made in the questionnaires.

3.9 Pre-testing of the questionnaires.

A pretest was done to determine the reliability of the research instrument. It was administered on a representative sample from the population for which the instrument was intended. A pretest was done at the AIDS Care Trust centre in Okuryangava to determine whether the measuring tool was clear and accurate. It was carried out by a counselor who checked the terminology used in the questionnaire and if respondents would understand the terms and the language the researcher used. The time interval between the two administrations did not take too long to prevent real and permanent changes from taking place in the attribute being measured.

3.10 Application of ethical issues.

Various research ethics during the entire process of investigation were put into consideration. Considering the fact that the topic under investigation was sensitive, consent forms were attached to each questionnaire and respondents were advised to read the consent forms first and sign it before they could proceed to answer the questionnaires.

The consent forms were in three different languages to give provision to those who did not understand English. The issue of confidentiality was addressed in the consent form and that enabled respondents to feel comfortable when filling in the questionnaire. The purpose of the study, the procedures, as well as the right to withdraw was covered in the consent form. Respondents were informed about anonymity, their identities were not to be disclosed. They were able to participate freely in the study, as no body was forced to participate.

CHAPTER 4: Data Analysis and Findings.

4.1 Introduction.

This chapter takes care of conclusions of the investigations with a view of transforming it into comprehensive information. Figures, tables and graphs are used to indicate the responses of the structured interview. Data analysis involved breaking down data into manageable themes, patterns, trends and relationships to make correlations and draw conclusions.

Twenty children between the ages of 10-18 living with terminally ill parents were interviewed, twenty parents who live with their children were interviewed as well as two social workers and two teachers were involved in the study. Firstly, the researcher analyzed and interpreted data on the questionnaires which were answered by the children. Secondly, the group discussions on children living with terminally ill parents were analyzed and interpreted. Thirdly, the researcher also analyzed and interpreted questionnaires that were answered by the parents. Fourthly, the researcher interpreted and analyzed the group discussion with the parents as well as two teachers from Havana primary school and two social workers from the Ministry of Gender equality and Child Welfare.

The researcher concentrated on getting a clear picture of children living with terminally ill parents how they directly experienced life. The investigations of children living with terminally ill parents focused on challenges such as abuse, and tried to describe how children experienced life and how they understood their circumstances and how they interpreted events.

The researcher used the non-probability sampling method, for purposive or judgmental sampling. The strategy in this investigation was to select the units that were judged by the researcher to be representative of the population under investigation.

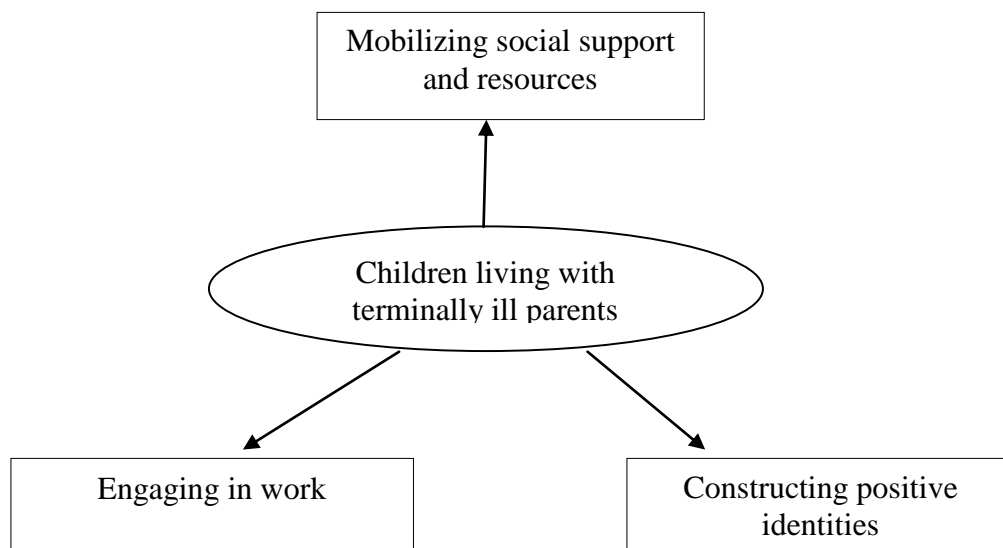


Figure 1: Diagram explaining children responsibilities (Skovdal, et al, 2009)

The diagram shows children living with terminally ill parents, their strength and challenges that make them vulnerable to related abuse. HIV and AIDS can affect children in many ways such as having to cope with sick parents which brings both practical and psychological pressures. Dealing with death of the parents, trauma, grief of bereavement and resulting psychological problems, such as depression, guilt, anger and fear with lack of support. Having to cope with severe economic hardships and lack of livelihood opportunities.

4.2 Demographic information of the findings on children.

The study focused on children's experiences associated with living with terminally ill parents. Twenty questionnaires were distributed to children who live with terminally ill parents. Twenty five percent 25% (n=5) were male and they were between the age group of 10-13 while 15% (n=3) were female and were in the same age group of 10-13. Forty percent 40% (n=8) female being the highest percentage fell in the age group of between 13-15. Ten percent 10% (n=2) were male and 10% (n=2) were female and they fell in the age group of 13-15.

The majority of respondents were female 40% (n=8) between the age group of 13-15 while, the least percentage were 10% (n=2) between the same age group of 13 -15.

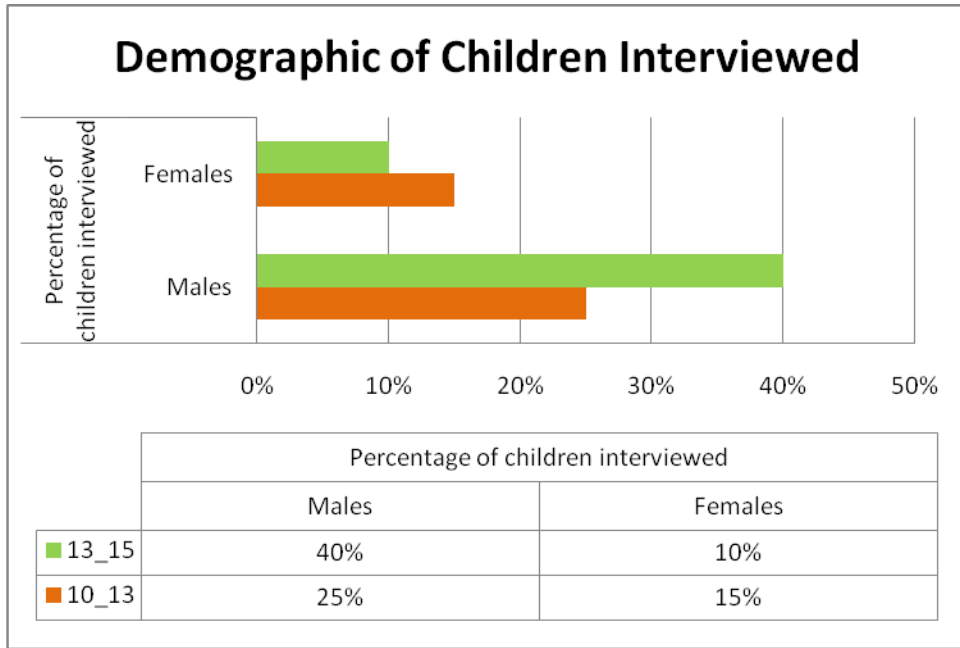


Figure 2: Demographics of Children Interviewed.

There was also need to know where the parents of the children lived at the time of the study. Ten percent 10% (n=2) of the children indicated that their fathers were currently admitted in hospitals. Ninety percent 90% (n=18) indicated that their fathers were at home. None of the respondents indicated that their fathers were taken to their home villages or are living with relatives. However, 20% (n=4) of the respondents indicated that their mothers were admitted in hospitals; and 35% (n=7) stated that their mothers were at home bedridden while 45% (n=9) of the respondents stated that their mothers were taken by their relatives for care and support at their birth places.

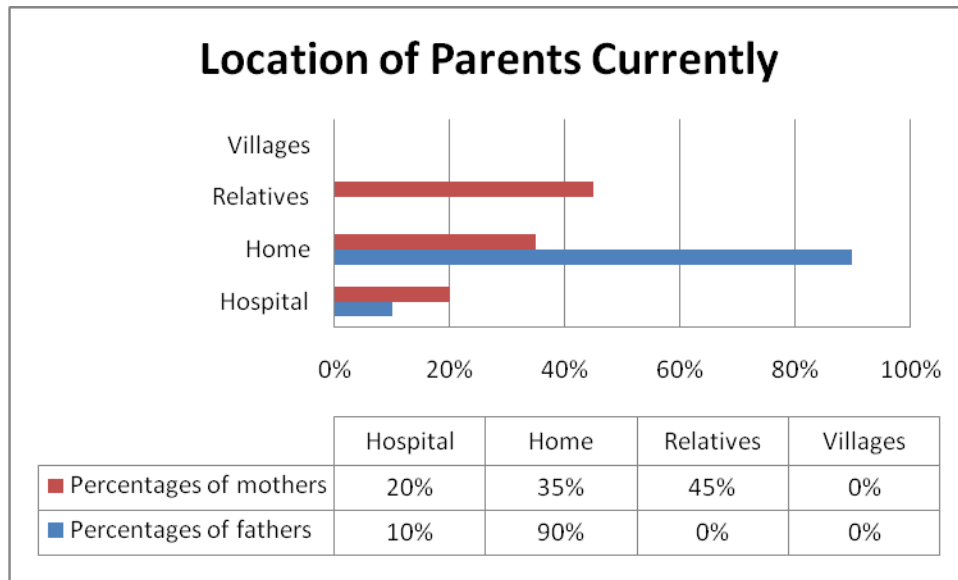


Figure 3: Location of Parents at time of study.

4.3 Findings on how long has the parents been terminally ill

Children who are not themselves living with HIV and AIDS still may be affected by HIV in many ways. When a parent has a chronic and ultimately terminal illness, children's basic needs for love, trust, security and parenting are threatened and they are unlikely to experience anything like a normal childhood (Foster, et al 2005).

Findings on how long the parents of the children had been terminally ill revealed that forty five percent 45% (n=9) of the respondents' mothers had been sick for one and a half years. Fifteen percent 15% (n=3) of the respondents' mothers had been sick for two and five months. Thirty five 35% (n=7) of the respondents indicated that their mother's had been terminally ill for five to ten months. Ten percent 10% (n=2) of the respondents stated that, their mothers had been terminally ill for two to three years.

As for the fathers, twenty five percent 25% (n=5) of the respondents indicated that, their fathers had been sick for two to five months while 25% (n=5) indicated that their fathers had been sick for five to ten months. Forty five percent 45% (n=9) stated that their fathers had been terminally sick for one year while 5% (n=1) stated that their fathers had been terminally sick for two to three years.

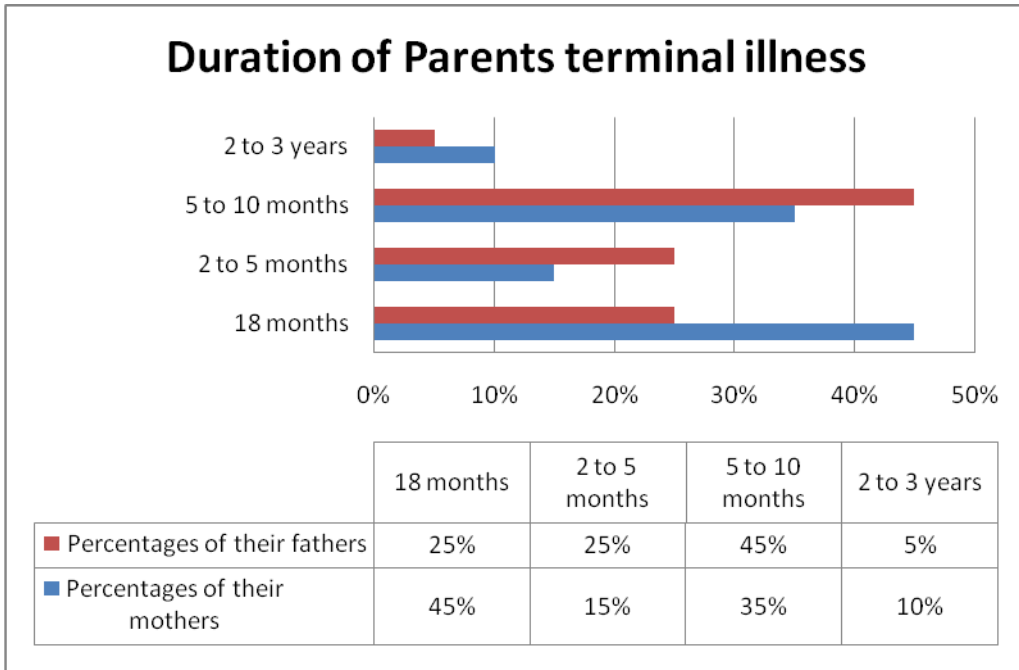


Figure 4: Duration of Parents terminal illness.

4.4 Findings on where the children go for assistance regarding household needs.

Thirty five percent 35% (n=7) of the respondents indicated that they go for assistance at CAFO. This is a National interfaith organization dedicated to the development and sustainability of support programmes for orphans and other vulnerable children. Ten percent 10% (n=2) of the respondents indicated that they go for assistance at ELCIN. This is a Church “Evangelical Lutheran Church in Namibia”. Five percent 5% (n=1) go for assistance at the Anglican Church. Twenty five percent 25% (n=5) indicated that they go for assistance at the Ministry of Gender Equality and Child welfare (MGECW) while 45% (n=9) indicated that they go for assistance at the AIDS Care Trust.

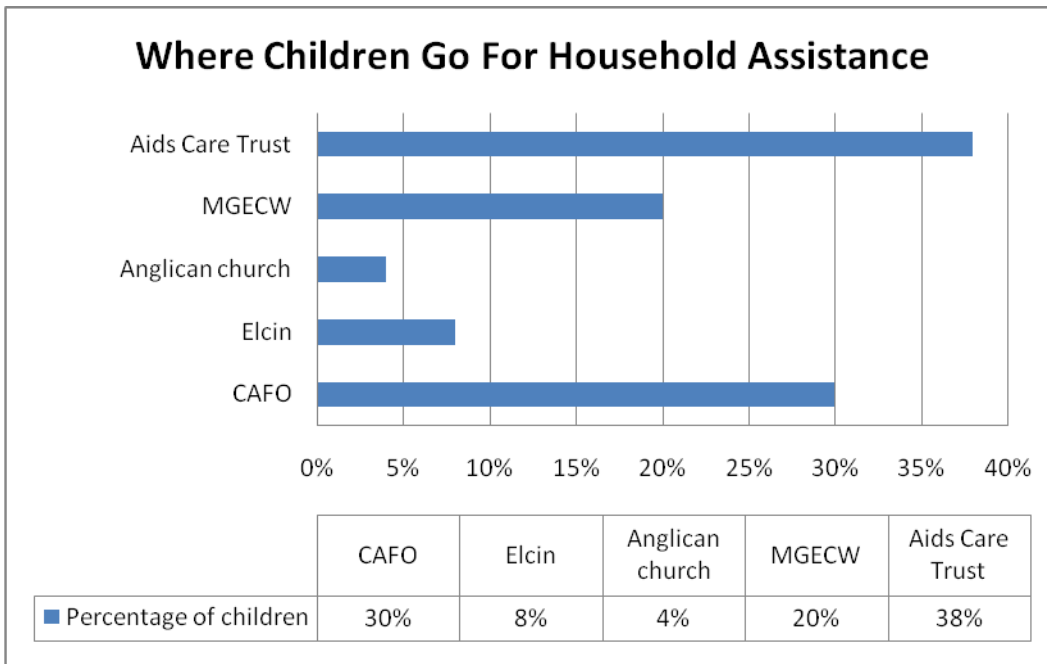


Figure 5: Where Children Go For Household Assistance.

The majority of the respondents indicated that they receive assistance from the AIDS Care Trust. Since the organization provides food to children after school there is no doubt that the percentage was high. The Ministry of Gender Equality and Child Welfare came second with 25% (n=5). The Ministry does not provide food to children living with terminally ill parents, but it has a once-off assistance which is used for emergency purposes. It also provides other assistance to children who are orphaned by providing maintenance grants, foster care grants, special maintenance grants also known as disability grants.

There was a need to know if respondents have knowledge on HIV and AIDS. Eighty percent 80% (n=16) of the respondents indicated that yes they knew about HIV and AIDS while, 20% (n=4) showed that they did not know about HIV and AIDS. A 10-12 year old boy who knew about the disease stated that, “HIV and AIDS is a bad virus it kills people and it has no cure”. Respondents who indicated that they knew about the disease explained that they heard it at school in a drama and within the community, and over the radio.

4.5 Statement rating on programs in the community to support children living with terminally ill parents.

The statement rating was to particularly find out, if it is best to have programs in the community to support children living with terminally ill parents due to HIV and AIDS. Forty five percent 45% (n=9) of the participants strongly agreed while 40% (n=8) agreed with the statement. Ten percent 10% (n=2) disagreed. Five percent 5% (n=1) don't know if the programs in the community would support the children living with terminally ill parents. No participant strongly disagreed to the statement.

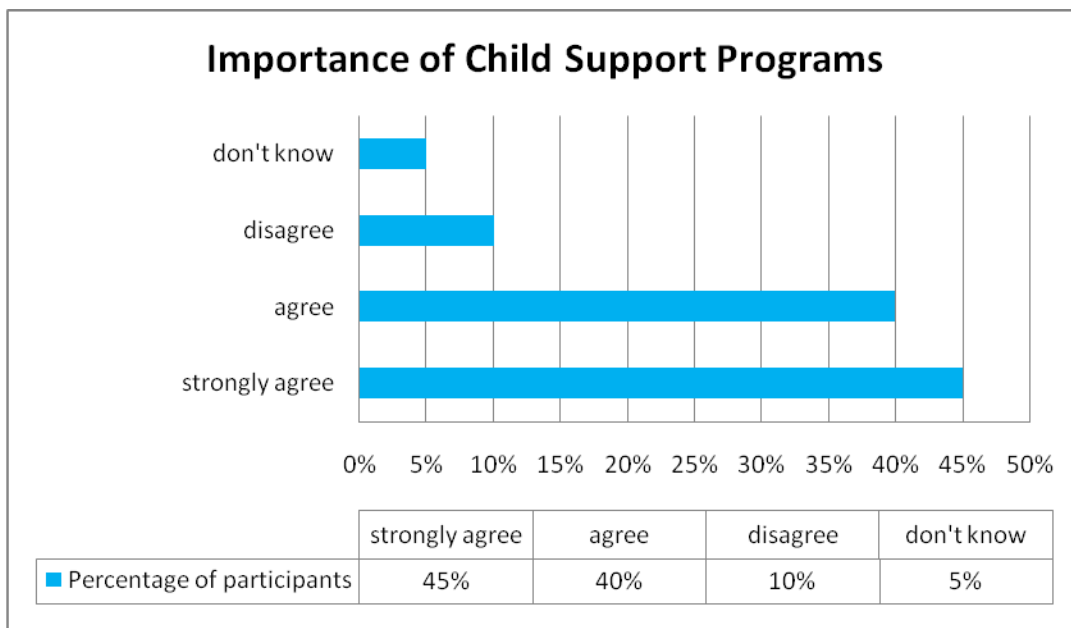


Figure 6: Importance of Child Support Programs.

4.6 Programs that will strengthen the capacity of the community to support children living with terminally ill parents.

The statement aimed to find out if participants are in support of having programs in the community to strengthen their capacity to support children living with terminally ill parents. Forty percent 40% (n=8) of the participants strongly agreed while another 40% (n=8) agreed that programs will strengthen the capacity of the community. Ten percent 10% (n=2) of the participants strongly disagreed while 5% (n=1) disagreed and 5% (n=1) of the participants did not know if the programs in the community will strengthen the capacity of the community to support children living with terminally ill parents due to

HIV and AIDS. The five percent of the participants who disagreed with the statement are in the age group 10-15 years old boys. It could be that their mental capacity of reasoning is slow or not fully developed.

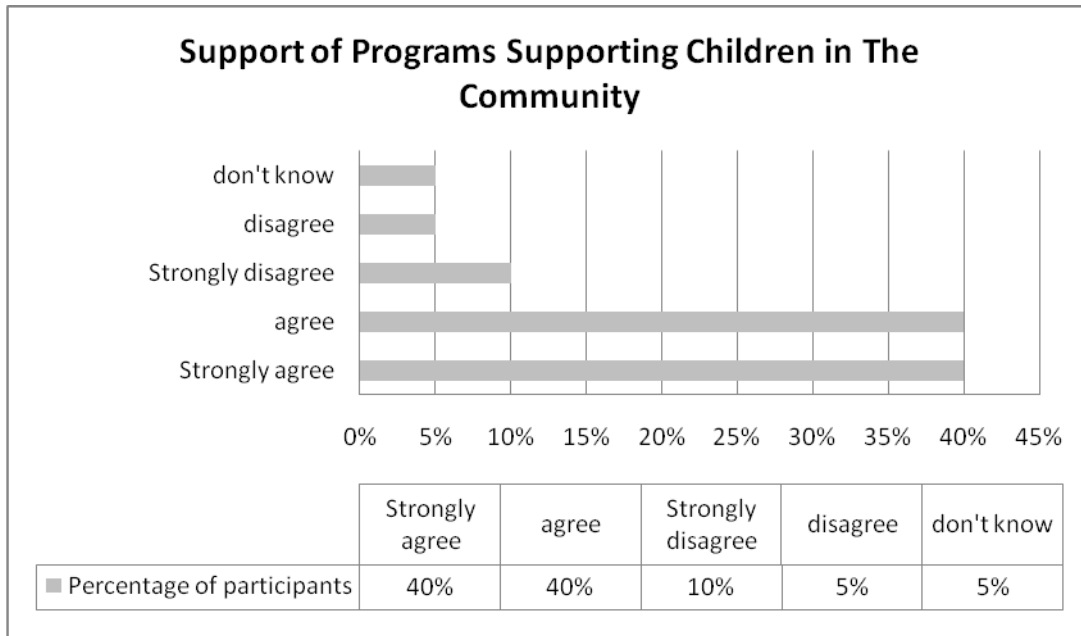


Figure 7: Support of Programs Supporting Children in the Community.

During the group discussion it came out clearly that having interventions in the community like after school programs would assist children in the community with school assignments such as home work. This could possibly reduce the level of school dropouts of children in Namibia. The balance here is to find ways to support families and communities more adequately meet children’s needs and to protect children from being exploited.

4.7 Needs of the girl children should be more seriously considered.

The majority of the respondents 60% (n=12) strongly agreed that needs of girls should be more seriously considered, while 35% (n=7) agreed and 5% (n=1) disagreed with the statement. In chapter two in the literature review it was revealed that girls are the first to drop out of school to take care of a sick parent. In some cultures girls are got out of school to be married off, sometimes to a man old enough to be her grandfather (Mbugua, 2006).

4.8 Development of skills for older children should be taken into consideration to support and protect themselves.

Fifty five 55% (n=11) of the respondents strongly agreed while 45% (n=9) agreed. The response to the statement showed that respondents are in favor of development of skills for older children as they may support and protect themselves. To effectively support children living with terminally ill parents, there is need to fulfill their potential for growth and development and a number of approaches are needed. For example, economic, educational, psychosocial as well as health care along with the community mobilization. Children must acquire skills to reduce their risks of becoming infected and to support themselves prematurely if their parents die (Foster et al., 2005).

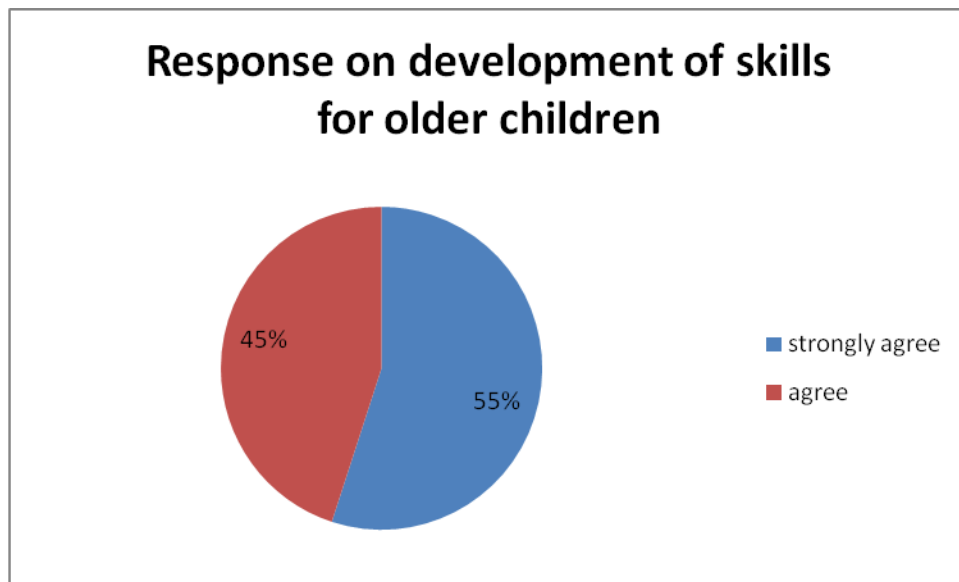


Figure 8: Response on development of skills for older children.

4.9 Children should be guided regarding their Culture and Rights

The statement intended to find out if children should be guided regarding their culture and rights. Forty five 45% (n=9) of the respondents strongly agreed while 40% (n=8) agreed. Ten percent 10% (n=2) of the respondents strongly disagreed. To fulfill children's rights is directly relevant to reduce their risk of HIV infection, as well as to better the long-term impact of HIV on their lives, their families and their communities (Gruskin & Tarantola in Foster, 2005).

In reality differences in sex, age, and social, economic, cultural, and political context in which children live must be taken into account in any policy or programmatic response to HIV and AIDS epidemic. From a children’s rights perspective, Gruskin and Tarantola asserted that HIV and AIDS illustrates how cultural norms and legal precept constrain the capacity of the children to decide on issues central to their health and wellbeing (Foster et al., 2005).

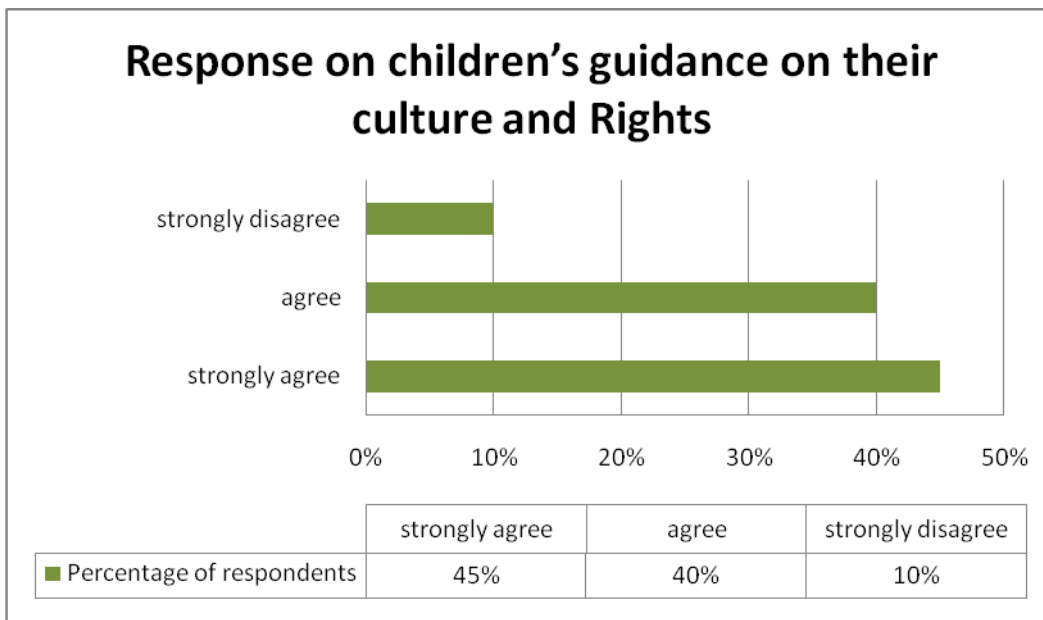


Figure 9: Response on children’s guidance on their culture and Rights.

4.10 All schools must have a feeding scheme to motivate children to attend school

The statement meant to find out if feeding schemes at schools would motivate children to attend school. Fifty percent 50% (n=10) of the respondents strongly agreed while 40% (n=8) agreed and 5% (n=1) disagreed and 5% (n=1) did not know if feeding schemes in schools would motivate children to attend school.

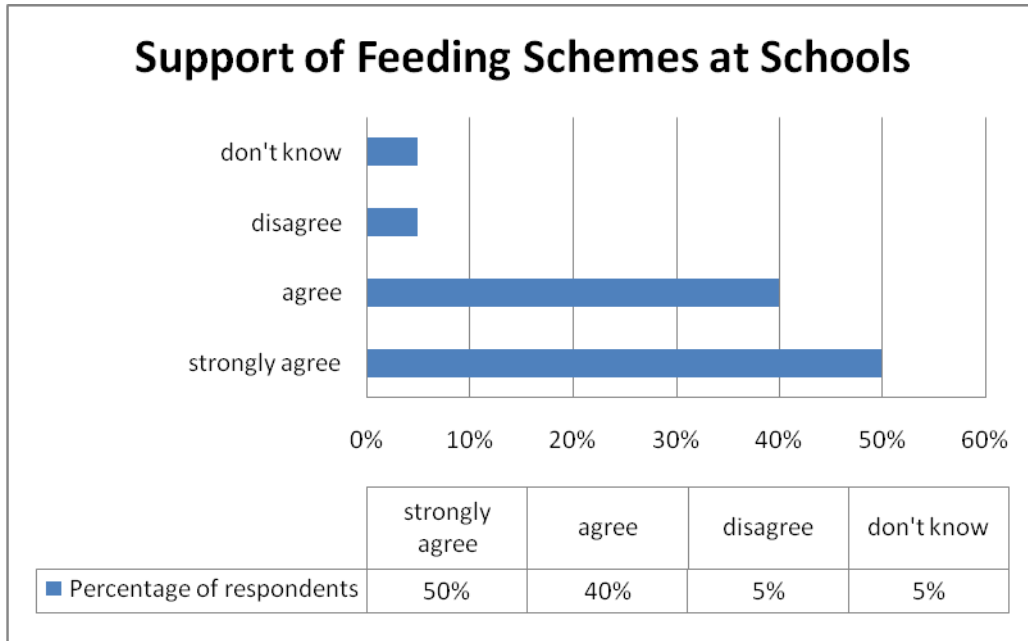


Figure 10: Support of Feeding Schemes at Schools.

4.11 What are the problems you face since your parents got sick?

All the respondents indicated that they face health problems, education problems, financial problems, housing problems, stigmatization problems as well as isolation problems. HIV can reduce income by 40-60%. As the health of parent with HIV deteriorates, households struggle to pay for increased expenditure on healthcare, while simultaneously having to deal with reduced productivity and loss of income of parents and other relatives who are ill or involved in care giving (Evan & Becker, 2009).

4.12 What are the main risks of children living with such problems?

Sixty percent 60% (n=12) of the respondents indicated that they experienced child labour while 20% (n= 4) indicated that they are at risk of committing crime. Ten percent 10% (n=2) indicated a risk of rape and 10% indicated emotional strain. During the discussion with the children 20% (n=4) of the respondents stated that, they face a risk of getting sick themselves as they collected and ate food from garbage bins. A 10 year old boy stated that his sister got a job in the bar, where she gets paid N\$ 15.00 a day. She walks alone in the night to come back home, when she gets paid she buys food for the house, but sometimes she works and does not get paid. “My father goes to drink when he is well and forgets his medication, he also sold the TV” a 12 year old respondent explained.

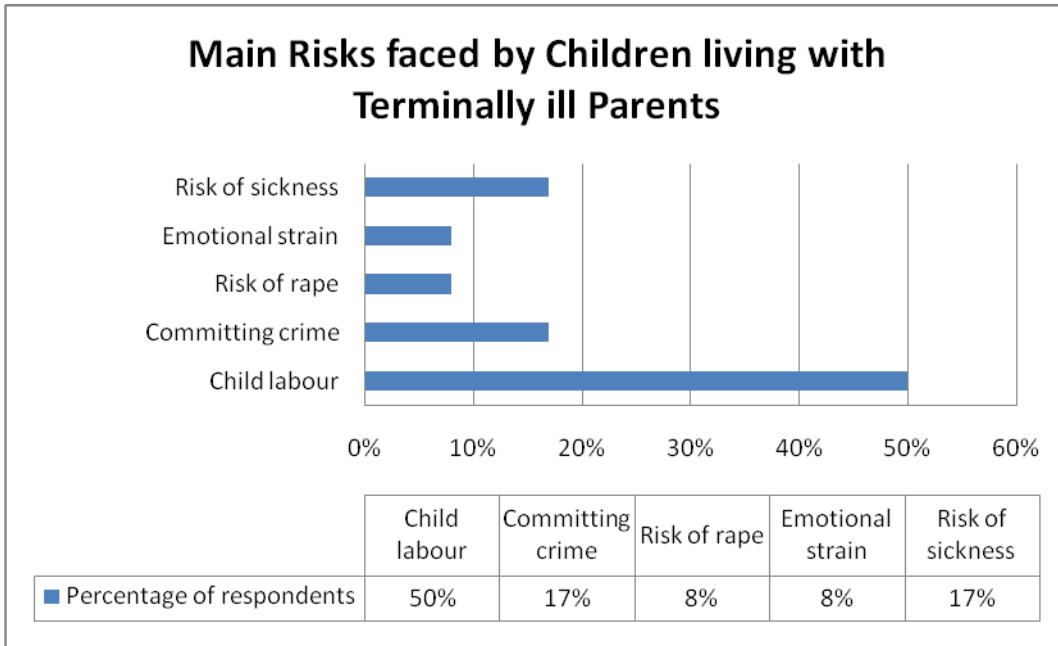


Figure 11: Main Risks faced by Children living with Terminally ill Parents.

4.13 What difficulties do you go through while nursing your parents?

With this open ended question it was intended to allow the respondents to express themselves on events that could have been hidden. It provided a possibility of exploring matters in depth with difficulties children living with terminally ill parents go through while nursing their parents. “Washing my mother, changing the bed sheets when my mother messes them up, and lifting her is a heavy job”. “Sometimes my mother refuses me to touch her” Johannes, a 15 year old respondent revealed. Other respondents explained that they have no access to running water, as their cards have been blocked from accessing water. In the Havana settlement all residents are issued with cards by the municipality to access water from the common tap, residents pay N\$20.00 every month for water. If holders of these cards don’t pay for three months consecutively the card is blocked. Terminally ill parents are usually unable to pay water bills and their families cannot access water. Respondents further explained that they did not have food in the houses and yet ill parents are required to eat before taking treatment. Children walk long distances to fetch firewood to prepare any food that could have been secured for the day.

Forty percent 40% (n=8) of the respondents between the age group of 13- 15 years old revealed that there is always no food in the house and their parents are not in a position to get them food, so they “*zula*” to survive. The word *zula* is a common street slang in Namibia that means “discover how”. What came out clearly in this question was that children do not have proper facilities to nurse their parents. They need toiletries, water, disinfectants and gloves to properly nurse their parents.

4.14 In what ways do you think children living with terminally ill parents can be assisted?

Forty five 45% (n=9) of the respondents indicated that they need assistance with food, the government should give food handouts to children living with terminally ill parents. They need toiletries, school uniforms, school shoes and stationeries and bed sheets. Respondents indicated that they want the municipality to exempt them from paying utility bills. Ten percent 10% (n=2) of the respondents said that sick people should not be discharged from hospitals as it is a lot of work to the children at home. A 10-15 year old girl (Nancy) added that she feared that the mother was going to die in the house.

4.15 Did your parents plan for you?

This open question intended to find out if the children have any idea if their parents had any plan for them. Eighty percent 80% (n=16) of the respondents responded no. They did not know if their parents had planned for them while 20% (n=4) knew that their parents had planned for them. They know whom they will stay with if their parents died.

4.16 Before my parents got sick they could have planned who will take care of me.

The statement intended to find out the children’s attitude on planning. How children living with terminally ill parents felt about the whole issue of planning. Fifty five percent 55% (n=11) of the respondents strongly agreed that their parents should have planned for them. Twenty percent 20% (n=4) of the respondents by agreeing while 10% (n= 2) strongly disagree. Ten percent 10% disagree while, 5% (n=1) did not know if planning could make things different or better.

4.17 I get very worried when I see my mother in bed all the time.

The statement intended to find out how respondents felt when they saw their parents in bed. Forty five 45% (n=9) of the respondents strongly agreed that they get very worried when they see their mothers in bed. Fifty five percent 55% (n=11) agreed to the statement.

4.18 Now I do not know who will pay for my school fees.

There was need to find out if the respondents knew who will be responsible for paying their school fees after the death of their parents. Forty five percent 45% (n=9) of the respondents indicated that they strongly agreed that they did not know who would be responsible for paying their school fees if they lost their parents. Thirty percent 30% (n=3) agreed while 15% (n= 3) percent disagreed. Five percent 5% (n=1) strongly disagreed followed by another 5% (n=1) who did not know.

4.19 My mother does not trust anybody to take care of me.

It was necessary to know from the respondents if their terminally ill parents trust anybody to take care of them when they died. Forty five percent 45% (n=9) of the respondents strongly agreed that their parents did not trust anybody to take care of them. Thirty percent 30% (n=6) of the respondents agreed while 15% (n=3) disagreed. Five percent 5% (n=1) strongly disagreed and another five percent 5% (n=1) did not know if their mothers did not trust anybody to take care them.

4.20 Now I started working to earn some money.

The statement intended to find out if respondents are employed or engaged in some form of labor to receive an income. Thirty five percent 35% (n=7) strongly agreed that they started working to earn some money. Forty percent 40% (n=8) respondents agreed, 15% (n=3) disagreed while 10% (n=2) strongly disagreed.

4.21 I buy food for the house.

As terminally ill parents lay in bed unable to work and provide for their children, it is possible that there is no other income for the household. As children indicated that they started working, there was need to know if they bought food for the household. Forty percent 40% (n=8) of the respondents strongly agreed that they buy food for the household. Fifty five percent 55% (n=11) agreed while 15% (n=3) strongly disagreed that they do not buy food for the household.

4.22 I have a boyfriend in the neighborhood.

The majority of the respondents aged of 15- 18 indicated that, they have boyfriends in the neighborhood. Respondents were later approached if having boy friends made a difference in their lives. A 15 year old girl explained that, “nobody likes me, they think I have HIV.” Another 17 year old girl said “My boyfriend gives me money and I buy soap and *cool aid* (powdered drink) for my little brother”. Thirty percent 30% (n=6) of respondents strongly agreed that they have boyfriends. Twenty five percent 25% (n=5) agreed that they have boyfriends in the neighborhood while 20% (n=4) indicated none, meaning they do not have boyfriends – these were in age group of 10- 13. Twenty percent 20% (n=4) strongly disagreed to the statements.

4.23 I do not attend school, I take care of my sick parents.

The majority of the respondents disagreed with the statement. Forty five percent 45% (n=9) responded by disagreeing to the statement. Thirty percent 30% (n=6) agreed, while 20% (n=4) strongly agreed and 5% (n=1) strongly disagreed. Most of the respondents in Havana, attended school at Havana primary school. This school is one of the few schools in Windhoek that has a feeding scheme. It could be possible that children are motivated to attend school because of the feeding scheme. None of the children indicated that, they stay home to take care of the sick parents.

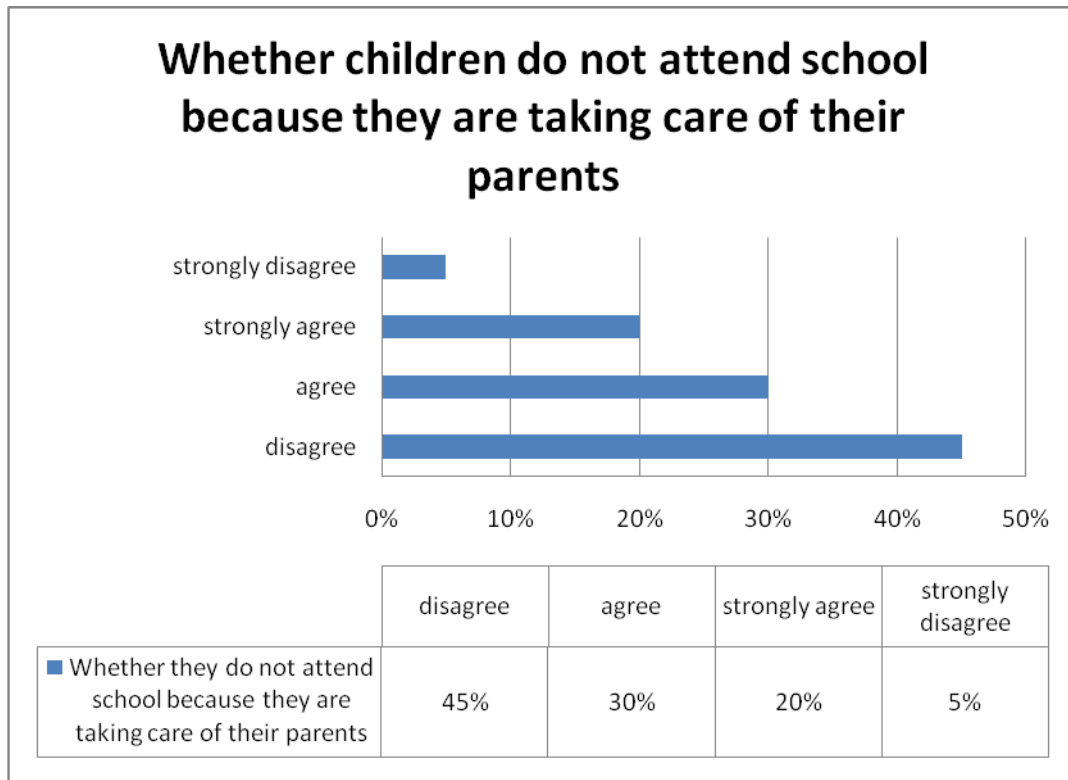


Figure 12: Whether children do not attend school because they are taking care of their parents.

4.24 When I go to school I do not want to play with my friends anymore.

The statement intended to find out the respondent’s feelings at school. It was mentioned by the teachers that children who live with sick parents are withdrawn at school, they do not want to mingle with other children.

A 15-18 year old girl said “I don’t want to play with my friends because I am worried of my mother. I am afraid my mother is maybe dead”. A 10-12 year old girl said “I don’t want to play with my friends at school because, I am worried about my mother at home.” The majority of respondents (70%) indicated that they do not want to play with their friends at school because they feel worried about their parents who are sick at home. A 10-13 year old boy (Tom) said “I do not want to play with my friends at school because I do not know if my mother is having help from the neighbour”. The boy explained that sometimes the neighbour goes to sell food and she forgets to check on his mother.

A 10 year old boy explained that he does not feel happy at school because his mother is admitted in the hospital. When his mother got admitted in the hospital she left a small baby of five months old. The father who was left at home also got very sick and he was taken to their home village 700km away from Windhoek. The boy was left in the house alone with three siblings including a baby, five months old. The boy who narrated the story was the oldest. This boy stopped school and started taking care of his siblings and it was the neighbour who noticed that the boy frequently fetched water from the common tap. He was doing the laundry, cooking and baby sitting his little sister. It came to be known that the father of the children died on the way to their home village.

A 12-15 year old girl suffers discrimination at school, her friends do not want to play with her, and they do not want to touch her books because they know the her parents have AIDS. The teacher is actively counseling the children in an attempt to stop this discrimination.

4.25 Focus group discussions introduction.

The focus group presents the researcher the opportunity to study the ways in which individuals jointly make sense of the phenomenon and create meaning around it (Bryman, 2004). There were two focus group discussions; one with children living with terminally ill parents, and one with the ill parents.

The focus group with children was held at the Aids Care Trust in Okuryangava 10km away from Windhoek. The center is near Havana settlement where children gather to receive psychosocial support, assistance with home work and feeding. The focus group discussion for the parents was held in two places; one, at the Aids Care Trust with four parents, and another one at the church within Havana location with five parents. This was because some of the parents could not walk to the centre.

4.26 Focus group proceedings with the children.

A counselor from the AIDS Care Trust was assigned to the researcher to assist with translation from English to vernacular and help with trust building between the children and the researcher. This was because the children were familiar with the counselor. The

objectives of the focus group discussions were laid down and consent explained. The consent forms were written in the local language (Oshiwambo) and distributed to the participants to read, understand and sign.

Although the participants were used to this kind of group discussion at the AIDS Care Trust, there was need to observe the rules of the group: Respect for each other, listening to other's ideas, letting one person talk at a time, talking louder so that other people could hear and confidentiality.

The focus group discussion stretched to two hours as there were translations for clarity. It emphasized specifically the problems and difficulties children living with terminally ill parents experienced. It explored attitudes, perceptions, feelings and ideas about the topic. However, there were some participants who were reluctant to disclose their thoughts possibly due to the sensitivity of the matter.

Grants from the Ministry of Gender Equality and Child Welfare can only be accessed by children who have lost one or both parents. During the discussion participants mentioned that, although the Ministry of Gender Equality and Child Welfare is responsible for orphans and vulnerable children, the intended recipients do not directly benefit. Despite being classified as "vulnerable" children who are not orphans, but live with terminally ill parents who are unable to work and support their children do not receive these grants.

Children look for employment to support their households as their parents are no longer fit to work due to ill health. Girls get employment in nearby bars (*Shebeens*) so as to support their siblings at home. Boys are used by shop owners to sell cell-phone recharge vouchers on the streets while others sell empty bottles which they collect from the surroundings and in the garbage bins. Children have no time for home work as they are thinking and planning what to do to get the next meal.

Some of the group members reported that when fathers got better as a result of ARV treatment, they started drinking excessively. They forgot to take their treatment going out and coming back late in the night. They started to sell household properties such as

television sets, radios, as the fear of death intensified. Some children mentioned that their water supply had been disconnected by the municipality due to non-payment. They did not have any means of preparing food as firewood was sold and they did not have money to pay. Neighborhood support has gradually diminished and dried out.

The issue of planning was discussed by the group and they were of the opinion that planning would be a good idea. Currently very few children knew who will be their guardian after the death of their parents.

After school programs were discussed as they would be helpful in assisting children with home work. The group decided that after school programs should include feeding schemes as food is a big problem for the children living with ill parents. The parents should also be assisted with food parcels for example every week a household should receive food. This would lessen the burden on the side of the children as they struggle to get food for the household. Children would concentrate on their school work and not worrying about what they will eat at home.

It was mentioned in the focus group discussion that children as young as three are found looking for food along streets. Children experienced food shortages, most of the time depending on handouts from people of good will, churches, non government organizations and families. Even then, what they get does not last them long. It was mentioned that sometimes children sell the donated clothes or exchange them for food. The group mentioned a friend they know who dropped out school to enter into business of selling bones. The group elaborated that bones are sold to Bokomo factory who make salt out of them.

It was further discussed that many boys on the street in Katutura, come from households with sick parents. The parents have no supervision over them because they are sick and very weak. They grab people's handbags, cell-phones and sell them to buy food for their households. The community has come to know about these children and whatever gets missing in the community they get suspected.

The group mentioned the issue of discharging sick people from the hospital. Patients are discharged when they are still very sick and unable to help themselves. They felt doctors could take time interviewing sick people to find out if there is any adult at home to support the patient. The group expressed concern that sick parents are released in their care, lifting them is a big problem as they are heavy and unable to support themselves.

4.27 The demographic information on terminally ill parents.

The terminally ill parents were interviewed. “Terminally ill parents” are defined as parents who are frail and unable to work or provide for their children due to the advanced HIV and AIDS disease.

The researcher intended to find out in what age groups the terminally ill respondents belonged. The majority of the respondents were in the age group of 20-25 at 45% (n=9). Forty percent 40% (n=8) respondents were in the age group of 17-20 while 10% (n=2) were between the age group of 30- 45. The least were in the age group of 25-30 and they were 5% (n=1)

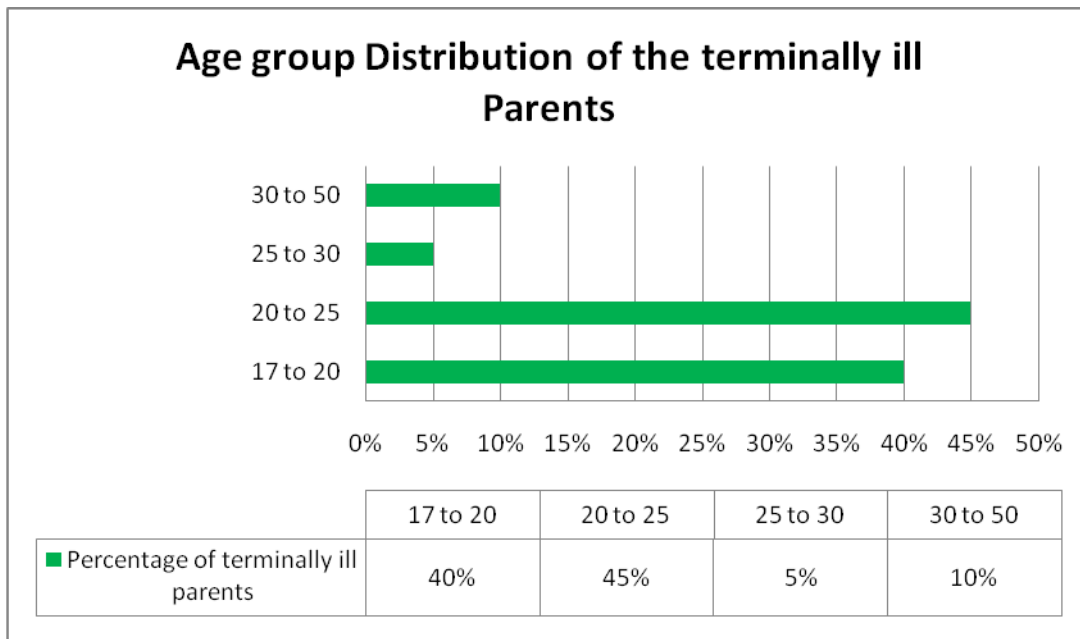


Figure 13: Age group Distribution of the terminally ill Parents.

4.28 How long have you been terminally ill?

Seventy percent 70% (n=14) of the respondents were terminally ill for more than a year. Ten percent 10% (n=2) were terminally ill for one year. Another ten percent 10% (n=2) were terminally ill for six months while 10% (n=2) were terminally ill for three months.

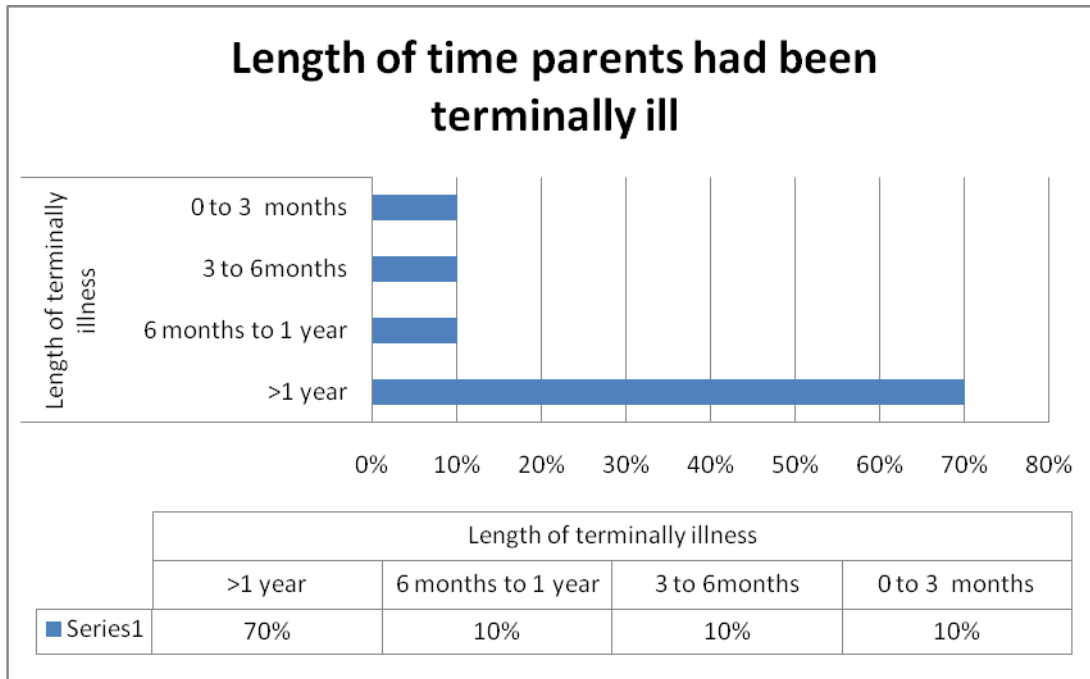


Figure 14: Length of time parents had been terminally ill.

4.29 Do you live with your spouse or boyfriend?

Eighty five percent 85% (n=17) of the respondents indicated that they did not live with their boyfriends while 15% (n=3) percent lived with their boyfriends. A follow up question was raised to the 85% respondents as to why they do not live with their boyfriends. Respondents had this to say:

“My husband left me for another woman,” a 45 year old woman explained.

“My first boyfriend passed away in 2006. Now I am seeing another one,” a 25-40 year old woman explained.

Five respondents indicated that they were just friends but not married.

A 20-25 year old woman indicated that, when she started getting sick, her boyfriend thought that she was just lazy. He thought that she did not want to work in the field. So the boyfriend left her for another woman.

“We were married traditionally but we separated due to HIV and AIDS. He thinks that I am the one who infected him,” a 20-25 year old woman explained.

A 20-25 year old woman revealed that when she lost her baby, her boyfriend left her and claimed that she was to kill him with HIV/AIDS.

4.30 Where do you go for assistance when you fail to provide for your children?

Twenty five percent 25% (n=5) indicated that they went to church organizations, CAFO, ELCIN, Baptism church, Anglican church, and Catholic church for assistance. Fifteen percent 40% (n=8) indicated that they got assistance from AIDS Care Trust. Ten percent 10% (n=2) indicated that they go to the Ministry of Gender Equality and Child Welfare. Another 10% (n=2) indicated that they ask their neighbors for assistance. Ten percent 10% (n=2) indicated that, they asked their family for assistance. One of the respondents explained that she had a disabled child who received a monthly disability grant of N\$ 450.00, the money she received is used to support the family.

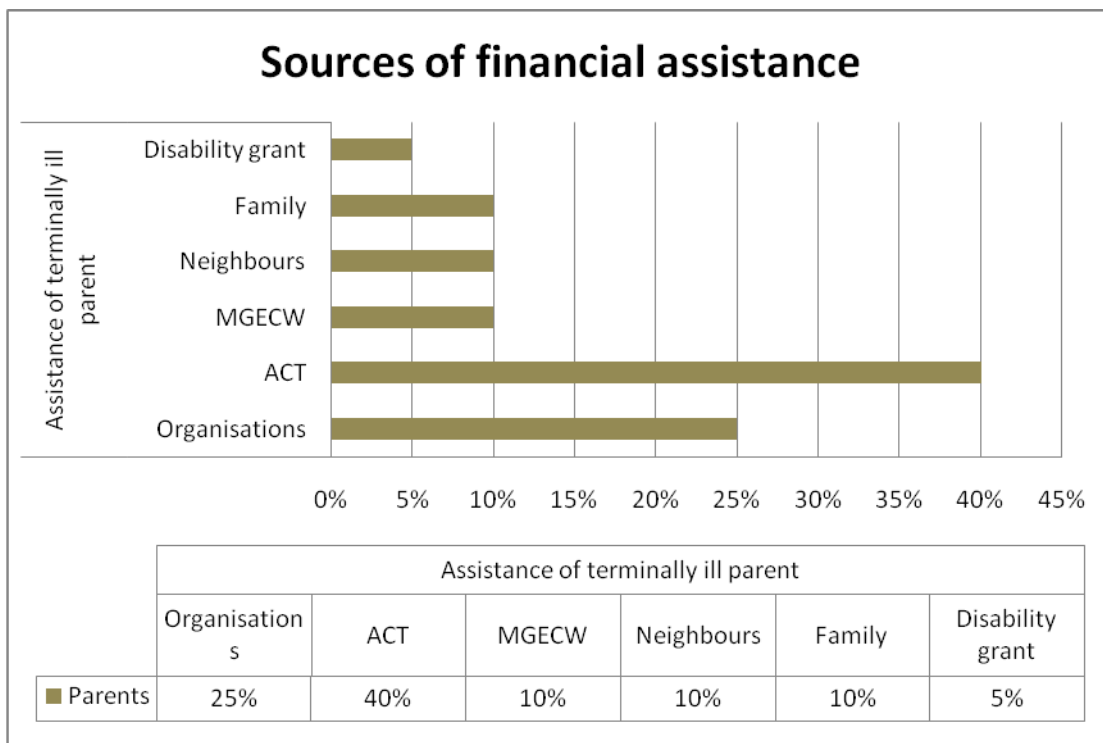


Figure 15: Sources of financial assistance.

4.31 Are you both terminally ill?

With this open ended question, sixty percent 60% (n=12) of the respondents said they were not terminally ill while 40% percent indicated that they are terminally ill. They both receive treatment. One of the respondents indicated that she is taking ARVs but her boyfriend refused to take the treatment. The girlfriend is terminally ill and she is unable to walk to the clinic to get her medication. She sends her 13 year old son to the clinic to get her the medication. Another respondent indicated that she no longer lives together with her boyfriend so she does not know if her boyfriend is also as ill as she is. Another respondent indicated that her boyfriend passed away in 2005, she started getting sick in 2009, and she is now unable to work. She lives with her children. A 35 year old woman indicated that they are both terminally ill but a few times her husband gets better, and when he is better he goes drinking and forgets to take his medication. He gets sick again.

4.32 What are the problems you face since you fell sick?

There was need to know what problems terminally ill parents experienced. All the twenty respondents indicated problems like inability to support their children due to the sickness. They experienced emotional problems, housing problems, health problems stigmatization and isolation. Thirty five percent 35% (n=7) mentioned that they experience housing problems, they live in a single room house made out of old corrugated iron sheets. This type of house demands constant repair. However, due to diminished income they no longer afford these repairs. “When it rains, the water destroys our property” a twenty year old woman explained. Forty five percent 45% (n=9) explained that they are stigmatized by their families more than any other person around them. This results in isolation from their own relatives. In focus group discussions, issues of loneliness were discussed, one respondent explained that her family threw her out when they discovered that she was HIV positive. They are not concerned about her.

4.33 What are the main risks of children living with terminally ill parents?

The majority of the respondents 45% (n=9) indicated that children face a risk of child labor when living with terminally ill parents. Thirty five 35% (n=7) indicated that children face a risk of crime involving especially petty crimes such as stealing from neighbors and shoplifting. Fifteen percent 15% (n=3) indicated that children face a risk of involving themselves in sexual activities for pay and other petty crimes.

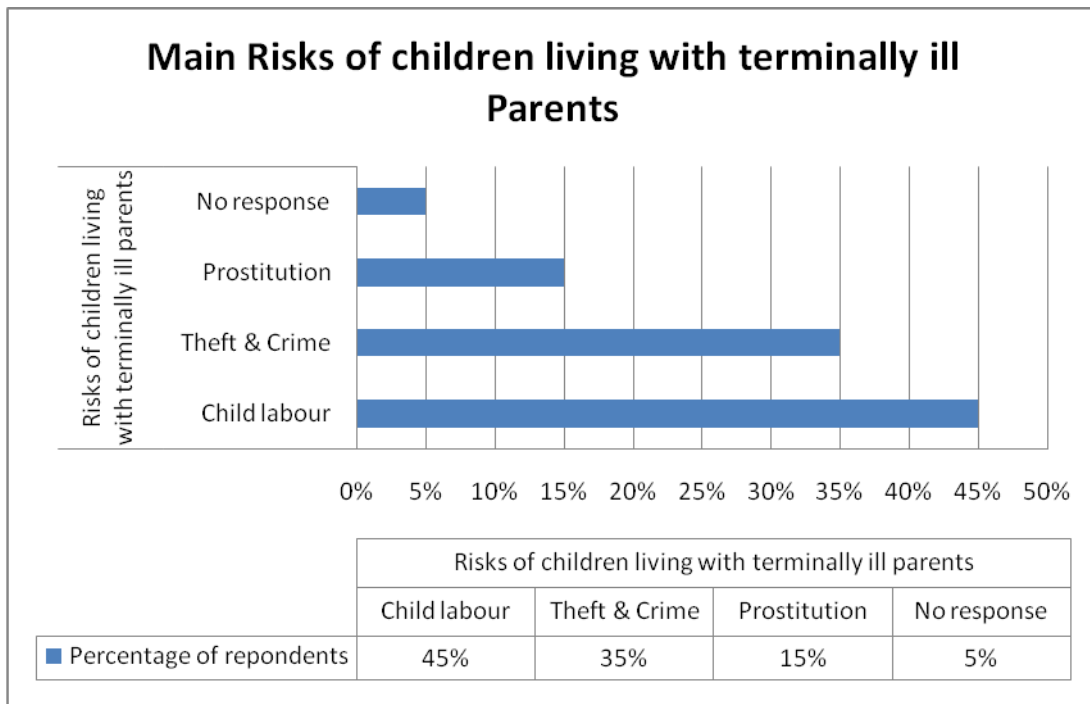


Figure 16: Main Risks of children living with terminally ill Parents.

4.34 It is best to have programs in the community to support children living with terminally ill parents.

The statement on programs intended to find out from the terminally ill parents feelings and opinion if it would be best to have programs in the community to support children living with terminally ill parents. Eighty five percent 85% (n=17) strongly agreed with the statement. Ten percent 10% (n=2) did not know if having programs in the community would support children living with terminally ill parents, while five percent 5% (n=1) disagreed with the statement.

4.35 These programs will strengthen the capacity of the community to support children living with terminally ill parents.

The majority of the respondents 85% (n=17) strongly agreed with the statement that programs will strengthen the capacity of the community to support children living with terminally ill parents. Fifteen percent 15% (n=3) did not know if programs will strengthen the capacity of the community to support children living with terminally ill parents.

4.36 Development of skills for older children should be taken into consideration to support and protect themselves from exploitation.

Ninety percent 90% (n=18) of the respondents strongly agreed with the statement that development of skills for older children would support and protect them from being exploited. Ten percent 10% (n=2) of the respondents did not know if development of skills for older children would support and protect them from being exploitation.

4.37 Children should be guided regarding their culture and their rights.

The statement intended to find out from the terminally ill parents if children should be guided regarding their culture and their rights. Seventy five 75% (n=15) of the respondents strongly agreed to the statement while, 25% (n=5) did not know if children should be guided regarding their culture and their rights.

4.38 Planning is a way of preparing for anything that could happen in future, for example death. Have you done any preparation for the children in the event of death?

The purpose for this question was to find out from the respondents if they had made any arrangements for their children in case they died. One respondent indicated that she has never thought of it. A 45 year old parent stated that she has no estate to leave for her children but she talks to them especially regarding protecting themselves when having sex. She further indicated that she tells her children to respect their guardians when she is dead. She tells them to study hard so that they help each other.

Another 25 year old woman indicated that she does not work and has no source of income. She lives with a friend, her family threw her out and she lives with someone who is HIV positive and they met at the support group meetings. Therefore she owns nothing in life.

The researcher intervened when it was identified that participants understood that one had to have assets in order to plan for children. It was made clear that, children needed to know who would take care of them should their parents die.

Three respondents indicated that their sisters will take care of their children, while four indicated that the government will take over care for their children. However, it was obvious that most terminally ill parents had not made any planning for their children.

4.39 All schools must have a feeding scheme to motivate children to attend school.

The majority of the respondents 75% (n=15) responded by strongly agreeing that schools must have a feeding scheme to motivate children to attend school. Twenty five percent 25% (n=5) disagreed with the statement. If children are provided with meals at school there would be less pressure on them to leave their studies in order to look for means to look for money to get food or scavenge rubbish heaps. The respondents feel that schools should employ a more “hands on” approach to address absenteeism.

4.40 Have you thought of a foster parent that will take care of your children if you died?

A 45 year old woman stated that she had told her oldest son to take care of his siblings when she died. Three women indicated that they have not gathered courage to say anything regarding foster homes. One woman indicated that her family cursed her, and she did not trust anyone in the family. Five respondents indicated that yes the children will go to foster homes when they died, but the children have not been told yet. Another older woman mentioned that she has eight children, six of them are divided among the relatives because she was unable to support and care for them. She lives with two who in turn take care of her. It was evident that most of the parents had not thought of foster homes for their children in the possible event of their death.

4.41 What do you think the government should do about the children living with terminally ill parents?

The reason for asking this question was to find out the parents' opinion regarding assistance from the government. The majority of the parents were of the opinion that the government should take care of the children living with terminally ill parents. They should also benefit from the government grants. Another option was that children living with terminally ill parents should be taken to the children's homes because if they remain with their sick parents they hardly concentrate on their school work and are prone to dropping out of school. Another suggestion that came to light was that government could distribute food parcels to households of ill parents.

The parents further added that the government should build more children's homes as the ones existing are already full to capacity. If not, more children will end up on the streets due to lack of supervision as the parents are weak to properly supervise the children. Children are prone to committing petty crimes and could end in prison instead.

4.42 I would have planned for my children before I got terminally ill.

The statement intended to find out from the terminally ill parents if planning for their children before they got terminally ill would have made a difference. Eighty percent 80% (n=16) of the respondents strongly agreed. Ten percent 10% (n=2) agreed while 10% (n=2) disagreed with the statement. The researcher is of the opinion that the respondents would not have planned for their children, had they not received a "wake-up-call" reminding them of their mortality.

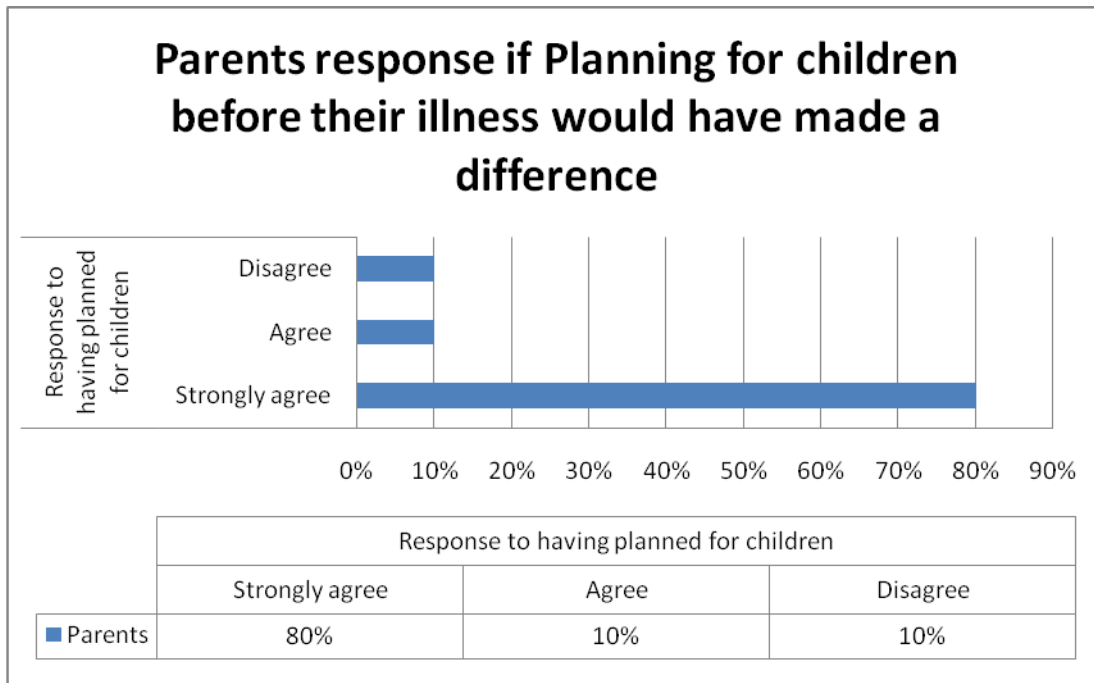


Figure 17: Parents response if Planning for children before their illness would have made a difference.

4.43 My children would know where to go when I die.

Seventy five percent 75% (n=15) of the respondents strongly agreed with the statement that if they had planned for their children before they got terminally ill, their children would know where to go if the parent died. Ten percent 10% (n=2) agreed while 10% (n=2) disagreed and 5% (n=1) strongly disagreed. Most terminally ill parents agreed to the importance of planning with regards to who would look after their children and where their children would live after their death.

4.44 I get very worried when my children see me very ill.

The statement intended to find out the feelings of the terminally ill parents when their children see them ill and unable to care for and supervise them. Seventy five percent 75% (n=15) of the respondents strongly agreed with the statement while 10% (n=2) agreed and 10% (n=2) strongly disagreed and 10% (n=2) did not know. The parents are clearly worried when their children see them in a fragile state. This may be due to anxiety generated as a result of parents' knowledge of their own mortality and their helplessness as they go through this traumatic experience.

4.45 I have not had an income ever since I fell sick.

The majority of the respondents strongly agreed with the statement that they have not had an income ever since they got ill. Seventy five percent 75% (n=15) strongly agreed while 15% (n=3) agreed and 5% (n=1) strongly disagreed and 5% (n=1) disagreed. The circumstances in the households of children living with terminally ill parents who no longer earn an income induce the children to look for work. Children working in the home of a third party are extremely vulnerable to exploitation and abuse. Terminal illness means that parents are unable to work. The majority of people living in Havana are paid wages based on the hours or days that they work. Simply put, no work means no income. The average person in the Havana settlement does not have access to private schemes or funds that pay people out when they are ill. There is no government grant paid out to terminally ill people due to HIV and AIDS.

4.46 My children bring food at home because I am unable to work any more.

The intention of the statement was to find out if the children are the ones who bring food at home since the parents are unable to work. Sixty percent 60% (n=12) of the terminally ill parents strongly agreed while 35% (n=7) disagreed with the statement. Five percent 5% (n=1) agreed. The fact that a parent is terminally ill means that the onus falls on the children to find means of providing nourishment for themselves and their families. This is as a direct result of the parent's terminal illness and inability to work.

4.47 Planning for children is good but it is a reminder of death.

The statement intended to find out from the respondents if they considered planning as a reminder of death. Sixty five percent 65% (n=13) strongly agreed while fifteen percent 15% (n=3) disagreed with the statement. Ten percent of the respondents 10% (n=2) agreed with the statement and 10% (n= 2) did not know. The majority of the respondents feel that planning is a responsibility that they have to undertake, despite the reminder of mortality.

4.48 I am not sure if planning would provide love and stability for my children.

Fifty five percent 55% (n= 11) of the respondents strongly disagreed with the statement while 11% (n=5) did not know. Fifteen percent 15% (n=5) disagreed with the statement. Five percent 5% (n=1) agreed with the statement but they are not sure that planning would provide love and stability for the children. Most respondents are confident that the planning measures that they put in place will ensure that their children shall be looked after in a loving and caring environment.

4.49 My children attend school except the girl.

The statement intended to find out if girls dropped out of school to take care of their terminally ill parents. Sixty percent 60% (n=12) strongly agreed with the statement while 40% (n=8) do not have girl children or possibly their girl children attend school. However, referring to the first question for the children on gender and sex, it revealed that girls were 40% (n=8) between the age group of 13 to 15. Nevertheless, expanding children's knowledge and empowerment is crucial particularly for girls (United Nations Children's Fund, 2006). Most parents sacrifice the girl child's education in order for them to assume the role of the primary caregiver. This is because of their strict adherence to gender roles.

4.50 My daughter decided to stop school to take care of the household.

There was a need to know from the participants if girl children stopped attending school to take care of the household as the parents are unable to help themselves and to take care of the household. According to the findings, it revealed that sixty percent 60% (n=12) of the girls in Havana settlement do not attend school while 40% (n=8) strongly agreed to the statement that their girl children stopped school to take care of their sick parents.

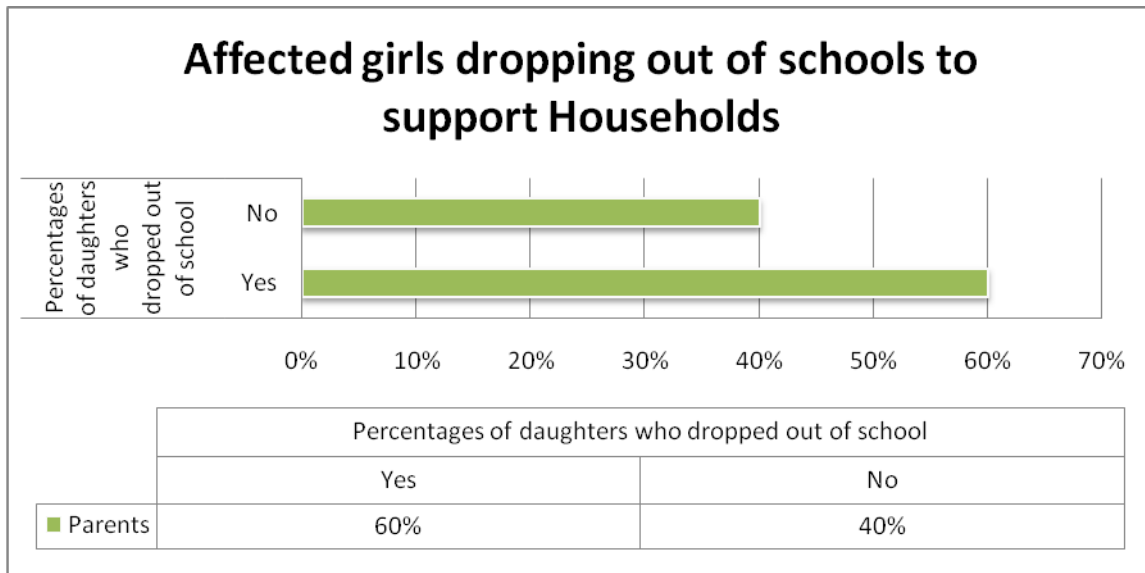


Figure 18: Affected girls dropping out of schools to support Households.

4.51 Focus group discussion with the terminally ill parents.

The focus group discussion was done in two groups, one at the AIDS Care Trust and another one at Okuryangava church with those parents who could not manage to reach the centre. The Okuryangava Church was the nearest place to those sick parents who did not manage to reach the centre. The group at AIDS Care Trust consisted of four terminally ill parents while the one at Okuryangava Church had eight terminally ill parents. The purpose of the focus group discussion was to obtain as much information from the terminally ill parents themselves as they share the same common problem.

Both groups discussed problems and challenges that children living with terminally ill parents experienced. If both parents are terminally ill, children get confused and they lack love, attention, as well as supervision. The group mentioned that children lack supervision, guidance as well as support they previously used to receive from their parents. Children leave the house in search for food, in garbage bins, on the streets begging for a dollar, the older ones engage themselves in business for example, selling cell-phone recharge vouchers collecting empty bottles and selling them, others washing cars.

4.52. Interview with the Social Worker at court.

The social worker at the Magistrates court screens children who are in conflict with the law. Children who have been arrested for stealing, rape, assault and other crimes. They are screened to find out their age, if they are under the age of 18 they are then recommended for life skills optional programs. The social worker recommends children under the age of 18 not to be charged under normal trials.

During the interview, the social worker explained that it is not common for the children to open up easily that they were found stealing food in a shop because their parents were terminally ill or unable to buy food. However, many times children are arrested for stealing due to the circumstances at home. When a home visit is conducted, this is when its revealed that there is a terminally ill caregiver in the household. The social worker mentioned one case of a juvenile who told him that he cannot go for life skills programs due to his grandmother who is terminally ill at home. There was nobody taking care of the grandmother if he had to go for this program. So yes some children steal for the sake of survival as their parents are unable to provide food.

The social worker added that out of seven children screened a day, about two or three are from a household where there is at least one family member who stopped working due to AIDS, and this family member was the bread winner.

Most of the children screened live with their grandparents who are in most cases pensioners. These grandparents depend on pension money, now if their children get terminally ill, they are brought to them because there is that little income from pension. The grandparents begin to support the terminally ill son or daughter together with grandchildren. The pension money of course is just a drop in the ocean, the grandparents would never be able to adequately finance their family. The grandchildren resort to committing crimes and get into conflict with the law.

There are number of factors that contribute to the children living with terminally ill parents to get into conflict with the law. Unemployment that leads to lack of income at home, peer pressure when children see their friends smoking and they also want to

practice it, insufficient supervision at home, when parents are down with AIDS they no longer raise their voices to their children.

The social worker at court continued explaining that children living with terminally ill parents are faced with many responsibilities because they are doing adult duties which are not meant for them. These added duties appear to be the ones that force children living with terminally ill parents to enter into child labor, drop out of school, enter into prostitution, rape, housebreaking, as well as murder. In chapter two, during the literature review it was revealed that this terrible illness can not only cause children to lose their parents or guardians but it can also cause children to lose their childhood years (Greener et al., 2004).

Children living with terminally ill parents should be included in the financial grants to assist them through during the time of their sick parents. These children once identified by the social workers, of the Ministry of Gender Equality and Child Welfare, should be provided with ongoing counseling as they are going through a difficult stage of life. However, several efforts are undertaken by non-governmental organizations, faith based organizations and community based groups which are making sustained and substantial attempts to address the needs of vulnerable children (National Plan of Action, 2006-2010).

4.53. Interview with the School teachers at Havana Primary school.

Havana school is one of the new schools in Windhoek. It is situated in Havana location where the research was conducted. The researcher worked closely with Havana school teachers as most of the vulnerable children are from this area. Two class teachers were interviewed from Havana School.

One of the questions posed to the teachers was, to elaborate if they see any difference between children living in terminally ill households and other healthy households. They responded by saying that it is not easy at all because children are overprotective. They do not want other people to know what is happening at their homes. Teachers might suspect

that their might be something wrong at home but they may not point a finger at it. Children suffer silently on their own maybe for fear of stigma and discrimination.

The second question was whether coming from a family with terminally ill parents affects a child's school performance. Teachers replied by saying that yes, difficult circumstances at home do affect a child's performance at school as sometimes a child may miss coming to school. They stay home to look after their sick parents or they are sent to fetch medication from the clinic for their sick parents. It becomes a burden for the children to live with sick parents.

Teachers went on explaining that 50% of teaching is daily conversation which leads to overall continuous assessment. If a child's participation in class is low, then it might contribute to the child's assessment. Teachers may not be able to tell that the child is living in a terminally ill household, but will notice that there is a difference in the child. In teaching the attendance is very important that is why there is a class attendance register. Teachers explained that there are measures taken if a child misses school longer than a week, then the school writes a letter to the parents or caregivers. If there is no response, then the class teacher pays home visit.

Teachers explained that if they find out that the family lacks assistance, the school has a mother body group that looks after the children, they do counseling and they give soup. If it gets tough like rape cases involved, they refer those cases to the police and the police take them to Women and Child Protection Unit for further investigations.

4.54. Interviews with the Social Worker from the Ministry of Gender Equality and Child Welfare.

The Ministry of Gender Equality and Child Welfare is mandated to watch over all children in Namibia. It is the focal Ministry that provides social grants for the children who are in need of care. The social worker's day to day activities includes among many, including intake of case work from the public. This involves investigations and home visits and compiling of professional reports to the Commissioner of Child Welfare for children who are in need of care. Social workers compile custody and control reports for

children born out of wedlock according to the Children Status Act, (No. 6 of 2006). Social workers attend meetings and they are involved in planning of meetings.

Social workers explained that children living with terminally ill parents do not benefit much from the Ministry of Gender Equality and Child Welfare in terms of social grants. The few assistance children living with terminally ill parents get from the Ministry is the assistance of school exemption letters which are written to the school board requesting the board for exemption, they also get a once off food aid assistance after the home visit and circumstances are found to be not conducive.

Regarding assistance offered to children living with terminally ill parents, these children are left uncared for in most cases. Although the term orphans and vulnerable children covers all children in need of care, including those living with terminally ill parents, when it comes to assistance to such children, they fall out of the safety net as they do not have documents to access social grants. Since their parents are still alive, this restricts them, and they are excluded from benefiting from the grant which is provided by the Ministry of Gender Equality and Child Welfare.

Since children living with terminally ill parents do not qualify for any grant provided by the ministry, the first intervention that social workers undertake is to solicit for the once off emergency fund to buy food for these children who are in dire need. The social workers do a home visit to find out how the living circumstances are, and compile a report to the Department of Child Allowance recommending food aid. Once the children are assisted with food the first time, they are not allowed to access such assistance again. The emergency fund is once off assistance.

4.55 Conclusion.

Chapter four took care of interpretation of findings. It interpreted the findings on children's experiences of living with terminally ill parents. It mapped out the daily efforts and achievement of children living with terminally ill parents. The results revealed that children nursed their sick parents in very difficult circumstances and in most cases their water was disconnected due to unpaid bills of municipality, and children walk long

distances to fetch firewood to prepare meals. Some of them indicated that they fetched ARVs from the clinics as their parents sometimes were too weak to walk. Older children displayed entrepreneurial aptitudes as they organized activities such as collecting empty bottle for resale. Girl children were hired to work in bars to earn an income for the household. Findings also revealed that children living with terminally ill parents experienced insufficient food supply in the households. The majority, 45%, of the children in Havana attended school despite the circumstances at home while 30% stayed home to take care of their terminally ill parents.

It was further revealed that 45% of the children in Havana seek assistance at AIDS Care Trust, while 35% go for assistance at CAFO which is a national interfaith organization. Having programs in the community to strengthen the capacity of the community to support children living with terminally ill parents was agreed to. Children would be occupied with these programs in the community, and they would reduce exploitation children. The issue of planning was discussed both in focus group discussion and in the interview. It was revealed that most parents did not make any planning or any provision for the children in case the terminally ill parents die.

The majority of respondents supported the idea of developing skills for older children to support and protect themselves, as older children would be skilled and productive to support their siblings.

It was revealed that when terminally ill parents get well after using ARVs they go and drink and they forget to take their medication. The cycle repeats as the parents get sick again. Children continued living in the same difficult circumstance as their parents do not adhere to the treatment. The issue of schools having feeding schemes to motivate children to attend school was discussed and it was highly recommended by the participants.

CHAPTER 5: Conclusion and Recommendations.

5.1 Conclusion

The impression drawn from the results is that the majority of children living with terminally ill parents, lacked support from their relatives. Children took up adult responsibilities at very early ages including temporally paid labor to support themselves and their families.

For a child living with a terminally ill parent due to HIV and AIDS there are multidimensional effects and challenges. The child endures life experiences associated with the HIV disease that deteriorates and increases in intensity as the disease advances with the parent. The needs of the children increase and the ability to meet them diminishes severely as the parent endures a weak and ill health, unable to work and earn an income.

As a reciprocal result, children assume all kinds of adult responsibilities which in turn exert tremendous pressure on them to earn money and mend the stricken financial state of individual families, an act that increases their vulnerability and exposure to abuse, exploitation, crime and worse of all HIV infection.

Children face uncertainties ranging from food insecurity to lack of education and ultimately an undefined future. The sense of hopelessness is highly prevalent among children living with terminally ill parents just as in the parents themselves. It is evident that the eventual death of the parents sets in motion and cements all these and more qualms thereby getting the children into extreme vulnerability and the fact of a desolate future.

Children as well as parents understand the importance of planning during the currency of the HIV disease but struggle to implement it because it awakens the fear of an imminent death. In another tone, parents overly assume that planning would involve the distribution of property and personal riches which most of the respondents reported not to have.

Organizations and Government agencies have developed responses to lessen the impact of ill health and death of parents due to HIV and AIDS for the child but more could be done. Most approaches are designed to render help and support to orphans and little is in place for the child that struggles with an ailing parent long before they die.

5.2 Recommendations.

Government and the private sector could do more to respond to the needs of children living with terminally ill parents. The provision of grants and food rations could be more evened out and targeted to increase child security in terms of food and sustainability. Current policies and grant procedures could be reviewed to become more inclusive and responsive especially of the vulnerable children.

Education should be prioritized for vulnerable children. All efforts should be made by government through local government structures such as constituency councils and local private sector agencies to maintain the children in school. Education will not only ensure an aware and exposed adult life for the children but will help reignite a sense of hope for the future and deliver the children from lifes obstacles associated with a lack of education such as early pregnancies or marriage, disease and extreme poverty.

Counseling services should be decentralized to schools where the children attend classes. While its important to host after school programs at the different NGO settings, segregating counseling from schools may in itself contribute to the widening of the disparities between children and continued discrimination against the children who live with infected parents which they suffer at schools. Counseling services should include the important aspect of planning.

Education, teaching and learning techniques should target to equip learners with practical life skills that can help children respond to the short, medium and long term life challenges as a result of living with ill parents and orphanhood when the parents eventually die. Such skills would include gardening towards food security, entrepreneurship, business skills, health and hygiene.

5.3 FUTURE RECOMMENDATION.

In future if similar research is to be done, I would recommend the following.

It is important for the researcher to identify with the target population, their language and cultural settings to help interpret the research question more effectively, as some relevant information could have been missed in the translation process. It is a fact that language as a major tool of communication is of great value to any form of understanding.

The target population could be expanded and clustered to reveal the difference and or similarities in experiences of other social-economic groups such as the middle class, the well to do and the poor. While these segregations can occur, the subject matter of children living with terminally ill parents remains relevant.

Researchers need to be trained in counseling skills so as to remain sensitive to the respondents as the subject of HIV and AIDS remains rigidly sensitive to general communities. The values of openness, confidentiality, impartiality, patience and honesty with ones own experiences and that of the others are vital in the entire process.

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Appendices

Appendix 1 - Questionnaire for the children

My name is Margaret N. Kizza I am a student at the University of Stellenbosch in South Africa. I 'am carrying a study for my thesis entitled: *An investigation of living conditions of children living with terminally ill parents due to HIV and AIDS: A case study in Havana Informal Settlement – Windhoek, Namibia.*

I would like to interview children from the age of 10-18 years old. Please be assured that all the information gathered during the research will be confidential and will only be used for the purpose of this research.

The questionnaire is anonymous and I would like you to answer all questions as honestly as possible. I thank you for taking your time to answer these questions.

1. How long has your mother/ father/ been very sick?

2 – 5 months		5 – 10 months		1 year – and a half		2 – 3 years	
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2. Which age group and gender are you?

7 – 10		10 -15		15 -18
Male		Female		

3. Is there any organization/ Church in the community that assists you with household needs?

Yes		No	
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4. If yes what is the name of the organization

CAFO		ELCIN		CAA		Anglican Church	
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5. Do you have any knowledge on HIV/AIDS?

Yes		No	
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6. If your answer to question 5 was yes please elaborate

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Please tick a column that you think is right.	Strongly agree	Agree	I don't know	Disagree	Strongly agree
7. Its best to have programs in the community to support children living with terminally ill parents.					
8. These programs will strengthen the capacity of the community to support children living with terminally ill parents.					
9. Needs of girl should be seriously considered.					
10. Development of skills for older children should be taken into consideration to support and protect themselves					
11. Children should be guided regarding their culture and rights					
12. All schools must have a feeding scheme to motivate the children to attend school.					

13 What are the problems you face since your parents/ parent got sick?

Education problem	
Emotional problem	
Financial problem	
Housing problem	
Health problem	
Stigmatization	
Isolation	
Others	

14. If you marked others on the above question please specify.

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15. What are main risks of children living with such problems?

Child labor	
Crime stealing	
Rape	
Prostitution / commercial sex	
Others	

16. If your answer to question 14 is others please specify.

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17. What can you say about the sickness your parent/parents?

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18. What do you think the government should do about the children living with sick parents?

.....

19. Do you think it should have been best if your parents had planned for you before he/she got very sick?
 Please specify

.....

Please tick the relevant box you feel is the best	Strongly agree	Agree	I don't know	Disagree	Strongly disagree
20. My mother should have planned before she got very sick.					
21. I would know where to go after my mother is unable to care for me.					
22. I get very worried when I see my mother in bed all the time.					
23. Now I do not know who will pay for my school fees.					
24. My mother does not trust anybody to take care of me.					
25. Now I started working to earn some money.					
26. I buy food for the house.					
27. I have a boyfriend in the neighborhood.					
28. I do not attend school I take care of my sick					

mother / father.					
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29. When I go to school I do not want to play with my friends anymore. Please elaborate why?

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Appendix 2 - Questionnaire for terminally ill parents

My name is Margaret N. Kizza I am a student at the University of Stellenbosch in South Africa. I ma carrying a study for my thesis entitled: *An investigation of living conditions of children living with terminally ill parents due to HIV and AIDS: A case study in Havana Informal Settlement –Windhoek, Namibia.*

I would like to interview sick parents due to HIV/AIDS, and they live with their children between the age of 12-18. Please be assured that all the information gathered during the research will be confidential and will only be used for the purpose of this research. The questionnaire is anonymous and I would like you to answer all questions as honestly as possible. I thank you for taking your time to answer these questions.

1. How old are you?

17-20 years old		20 – 25 years old		25- 40 years old	45-50 years old

2. How long have you been terminally ill?

3 months		6 months		One year		More than a year	

3. Do you live with your spouse?

Yes		No	
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4. If your answer to question 3 was no, Please specify

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5. Where do you go for assistance when you fail to provide for your children?
6. I go to my church CAFO, ELCIN, Baptism church, Anglican church, Catholic church.
7. I go to the Ministry of Gender Equality & child Welfare to assist me
8. I go to my counselor in my village.
9. I ask my neighbour for assistance

6. Are you both terminally ill ?

Yes		No	
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Please elaborate

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6. What are the problems you face since you fell terminally ill ?

Unable to support my children	
Emotional problem	
Financial problem	
Housing problem	
Health problem	
Stigmatization	
Isolation	
Others	

7. If you marked others on the above question please specify.

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8. What are the main risks of children living with terminally ill parents?

Child labour	
Crime stealing	
Rape	
Prostitution / commercial sex	
Others	

9. If your answer to question 8 is others please specify.

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Please tick a column that you think is right.	Strongly agree	Agree	I don't know	Disagree	Strongly agree
10. Its best to have programs in the community to support children living with terminally ill parents.					
11. These programs will strengthen the capacity of the community to support children living with terminally ill parents.					
12. Needs of girl children should be seriously considered.					
13. Development of skills for older children should be taken into consideration to support and protect themselves					
14. Children should be guided regarding their					

culture and their rights					
15. All schools must have a feeding scheme to motivate children to attend school.					

16. Planning is a way of preparing for anything that could happen in future, for example death. Have you done any preparation for the children? Please elaborate

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17. Have you thought of any foster parent that will take care of your children if you die?

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18. What do you think the government should do about the children living with sick parents?

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Please tick the relevant box you feel is the best	Strongly agree	Agree	I don't know	Disagree	Strongly disagree
19. I would have planned for my children before I got terminally ill					
20. My children would know where to go if die.					
21. I get very worried when my children see me very ill.					
22. I have not had an income ever since I fell sick.					
23. My children bring food at home because I am unable to work anymore.					
24. Planning for the children is good but it is a reminder of death.					
25. Planning takes things at another level.					
26. I am not very sure if planning would provide love and stability for my children.					
27. My children attend school except the girl.					
28. My daughter decided to stop school to take care of her siblings.					

Appendix 3- Permission to carry out research



REPUBLIC OF NAMIBIA

MINISTRY OF GENDER EQUALITY AND CHILD WELFARE

Tel: + 264 61 283 3111
Fax: +264 61 238941/240 898
Email: genderequality@mgcew.gov.na

Private Bag 13359
Windhoek
Namibia

Our Ref:
Your Ref: **Mrs. C. Feris**
Inquiries:

26/10/2009

Mrs. Margaret N.Kizza
P.O. Box 80528
Olympia
Windhoek- Namibia

Dear Mrs. Kizza

**RE: PERMISSION TO CARRY OUT RESEARCH ON CHILDREN LIVING WITH
TERMINALLY ILL PARENTS DUE TO HIV/AIDS IN KHOMAS REGION**


The Ministry of Gender Equality and Child Welfare has a pleasure to inform you that you have been accepted to carry out your research on vulnerable children who live with terminally ill parents due to HIV/AIDS in Khomas region.

Please be informed that after your research investigations, you must share your research findings with the Ministry. This will enable us with future planning purposes.

Thank you for your interest you have shown working with the children, all the best

Yours sincerely


Ms. Sirkka Vuolteenaho


PERMANENT SECRETARY

Appendix 4 – Interview with the Social Worker at MGECW

An investigation of living conditions of children living with terminally ill parents due to HIV and AIDS: A case study in Havana Informal Settlement – Windhoek, Namibia.

Interview with the Social Worker at the Ministry of Gender Equality and Child Welfare.

Discussion Guide

1. What are your day to day activities at the Ministry of Gender Equality and Child Welfare?
2. What services do you provide to children living with terminally ill parents due to HIV and AIDS?
3. In your opinion where do you see the gaps regarding assistance offered to children living with terminally ill parents?
4. These children are faced with added responsibilities like, nursing their sick parents, cleaning the house, looking for food, taking care of their siblings and sometimes these children are infected with HIV and AIDS. What intervention measures do you under take for such a case?
5. How are the children living with terminally ill parents being assisted by the Ministry of Gender Equality and Child Welfare?
6. Children who lost one parent are offered maintenance grants and those who lost both parents are offered foster care grants. In your opinion what can be done about children living with terminally ill parents.
7. You as a Professional Social Worker caring for children, what would you recommend in terms of planning for children living with terminally ill parents?
8. What can the Ministry of Gender Equality and Child Welfare do to help children living with terminally ill parents due to HIV and AIDS?

Appendix 5- Interview with a School Teacher at Havana Primary School.

Interview with a School Teacher at Havana Primary School

My name is Margaret Kizza, I am a student at the University of Stellenbosch in South Africa.

I am carrying out a study on my thesis entitled **An investigation of living conditions of children living with terminally ill parents due to HIV and AIDS: A case study in Havana Informal Settlement Windhoek, Namibia.**

The purpose of the study is to find out children's experiences and challenges they face while living with terminally ill parents.

Questions

1. As a Teacher do you notice any difference between children living in terminally ill household and others in health households?
2. Does coming from a family with terminally ill parents affect a child's school performance?
3. As a teacher do you notice a difference in behaviour of children coming from homes with terminally ill parents as compared to other classmates?
4. It is known that children living with terminally ill parents have to skip classes to take care of their parents. This affects the school performance and attendance. Have you experienced this as a teacher? If so can you highlight how this affects the child?
5. What measures does your school have in place to assist children living with terminally ill parents?

Appendix 6– Focus group discussion with the children living with terminally ill parents.

An investigation of living circumstances of children living with terminally ill parents due to HIV and AIDS: A case study in Havana Informal Settlement Windhoek, Namibia.

Focus group discussion with the children living with terminally ill parents.

DISCUSSION GUIDE.

1. It is believed that children living with terminally ill parents due to HIV and AIDS experience a lot of difficulties. What are these difficulties?
2. What are most pressing needs that must be immediately attended to?
3. How do you want the government to assist you in this regard?
4. Developing programs for children that live with terminally ill parents in the communities is a good. Why do you think it is good?
5. How do you feel about schools having feeding schemes?
6. Planning is a way of preparing for the future. Do you think that your parents have adequately planned for your future?
7. Why is it that in most cases girls are the first ones to drop out of school?
8. What other responsibilities do you face when living with sick parents?
9. Do you think that you are being exploited by the situation?
10. How do you think the exploitation can stop?

Appendix 7 - Focus group discussion with terminally ill parents.

An investigation of living circumstances of children living with terminally ill parents due to HIV and AIDS: A case study in Havana Informal settlement – Windhoek, Namibia.

FOCUS GROUP DISCUSSION WITH TERMINALLY ILL PARENTS IN HAVANA SETTLEMENT IN WINDHOEK

1. In your opinion how can children living with terminally ill parents be assisted by the government?
2. What do you think that can be done to avoid exploitation of children living terminally ill parents?
3. Do you think planning for children before parents get terminally ill would prevent child exploitation?
4. If the government is to come up with programs in the communities what do you think the focus should be.
5. How should the government assist sick parents before they get terminally ill to minimize the abuse of children in the community?
6. Do you think foster homes could be a good option for the children to live for the duration of the parent's illness and after the parent's death?
7. What kind of assistance could be given to girls who drop out of school first to support their siblings and parents?
8. What could be done to avoid child labour?
9. What would you like to say about the exploitation of children due to HIV and AIDS?
10. Children lack supervision during the time when their parents are terminally sick. What do you think should be done to the children during this stage?

Appendix 8 – Consent to participate in the research

CONSENT TO PARTICIPATE IN RESEARCH.

PRIMARY INVESTIGATOR.

MARGARET NTABADDE KIZZA.

Contact cell. No. 0812769727.

Office No. 061 2833176.

The purpose of the research is to investigate household circumstances of the children living with terminally ill parents in Havana settlement due to HIV and AIDS in Windhoek-Namibia.

Children living with terminally ill parents are requested to participate in this research to determine their needs that are related to abuse when living with sick parents. The participation of the children in this research is entirely voluntary. The information you provide will remain anonymous and names of participants will not be used for any reason.

All information collected will be treated confidential and will only be used for the purpose of this research.

I.....have read the consent form request and understand the purpose of the research. I have had the opportunity to ask questions and I understand that I can change my mind or choose to withdraw from the research at any time. I agree voluntarily to participate in the research.

Name/ Signature.....

Date.....

Signature of researcher.....

Appendix 9 - Translated consent form in Oshiwambo.

UUTHEMBA WOKUKUTHA OMBINGA MOMAKONAKONO (Oshiwambo)

Omukonakoni

Margaret Ntabadde Kizza

Ongodhi yomekwamo: 0812769727

Onomola yomombelewa: 2833176

Elalakano lo makonakono, olokumona eenkalo dhomo magumbo, dhuunona mbu hawu kala naakuluntu, nenge gumwe gwo maakuluntu,taya ehama unene omolwa omukithi gwo HIV and AIDS molukanda Iwa Havana mo Venduka mo Namibia. Omakonakono ogii kolelela kuunona.

Uunona mbu hawukala naakuluntu taya ehama, otawu indilwa wukuthe ombinga mo makonakono ngoka, omolwa oku shiwa oompumbwe dhawo, dhii kolelela kominyonena dhi haya ningilwa sho haya kala naakuluntu taya ehama.

Oma wuyelele ageshe otaga kakala iiholekwa, no tagaka longithwa owala omolwa omakonakono ngaka.

Ngame.....ondalesha ombapila ye indilo lyuuthemba, no nduviteko elalakano lyomakonakono. Onda mona ompito yokupula omapulo, nonduviteko kutya otandi vulu okulundulula omadhiladhilo gandje, nenge okwii kuthamo omakonakono ngaka.

Edhina.....

Esiku.....

Omukonakoni a shayina.....

Appendix 10 - Translated consent form in Afrikaans

TOESTEMMING OM IN DIE NAVOORSING DEEL TE NEEM (Afrikaans)

Oorspronklike ondersoeker.

Margaret Ntabadde Kizza.

Kontakt No: 0812769727

Kantoor: 061 2833176

Die doel van die navoorsing is om die huishoudlike omstandighede van die wat met of albei ouers lewe wat baie erensting siek is van HIV and AIDS in Windhoek- Namibia, in Havana woonbuurt.

Kinder swat met siek ouers lewe word versoek om deel te neem in ide navoorsing on hul nodighede te bepaal in verband met die mishandeling wanneer hulle met siek ouers lewe. Die deelmeeming van kinders in die ondersoek in heeltemaal vrywilig. Die inligting wat gegee word sal namloos waees, en name van deelnemers sal om geen rede gebruik word nie.

All die inligting wat versamel word sal vertroulik gehanteer, en sal net vir doel van die navoorsing gebruik word.

Ek.....het toestemmings gelees, en verstaan die doel van die navoorsing. Ek het die geleentheid gehad om vrae te ek verstaan date k my besluite kan vernder of besluit om terug te trek van die ondersoek enige tyd. Ek stem vrywilling in om deel in die ondersoek.

Naam/ Handtekening.....

Datum.....

Handtekening van ondersoeker.....

Appendix 11- Interview with Social worker at Court

Interview with the Social Worker who works at court, who screens children who are in conflict with the law.

My name is Margaret N. Kizza, I am a student at the University of Stellenbosch in South Africa. As part of completion of my masters degree, I am carrying out a study entitled **“An investigation of living conditions of children living with terminally ill parents due to HIV and AIDS: A case study in Havana Informal Settlement – Windhoek, Namibia.”**

We are all aware of the high rate of HIV and AIDS in Namibia which has caused children to live with terminally ill parents. As the parents become terminally ill due to aids, they become unable to provide in the basic needs of their children, the children end up committing crimes while trying to survive, as a result they get into conflict with the law.

1. Approximately how many child-offenders do you screen a day?
2. Approximately how many children living with terminally ill parents do you screen a day?
3. What circumstances do children living with terminally ill parents live in? What kind of shelter, adequate food, do these children receive?
4. What is their source of income?
5. Amongst the child offenders living with terminally ill parents, what are those factors that contribute to them getting in conflict with the law?
6. What are the problems faced by children living with terminally ill parents due to aids?
7. In your opinion how do you think the Ministry of Gender Equality and Child Welfare would assist children that live with terminally ill parents?