

**A STUDY TO ESTABLISH FACTORS THAT LEAD TO NON ADHERENCE TO
ANTI-RETROVIRAL TREATMENT FOR ORPHANS LIVING WITH HIV IN
OKAHANDJA CONSTITUENCY**

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Philosophy (HIV and AIDS Management) at Stellenbosch University



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Declaration

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DEDICATION

This thesis is dedicated to my late sister Mrs Mukelabai Mumbuna Mwape

With lots of love

Abstract

This study sought to establish the factors that lead to the non-adherence of antiretroviral treatment for orphans on treatment in Okahandja constituency. Parents and guardians of orphans and non-orphans who were on ART were interviewed. Professionals who provided services to children on ART were also interviewed to establish more information on the topic. These were nurses, community counsellors, a social worker and a doctor. A structured questionnaire was used to collect data from primary respondents while a semi-structured questionnaire was used to collect data from key informants.

Opsomming

Die doel van die studie was om die faktore te bepaal wat lei tot die ongereelde gebruik van antiretrovirale middels by weeskinders wat op behandeling is in die Okahandja gebied. Daar is onderhoude gevoer met ouers en voogde van die wees- sowel as nie-weeskinders wat op die behandeling is. Verdere onderhoude is ook gevoer met professionele persone wat dienste aan die kinders bied, met die doel om meer inligting oor die onderwerp te bekom. Hulle sluit in verpleegsters, gemeenskapsberaders, 'n maatskaplike werker en 'n dokter. 'n Gestruktureerde vraelys is gebruik om data in te samel van primêre respondente, terwyl 'n semi-gestruktureerde vraelys gebruik is om verder data in te samel.

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List of Acronomys

ART - Anti-retroviral treatment

HAART - Highly active antiretroviral treatment

OVC - Orphans and vulnerable children

PMTCT - Prevention of mother to child transmission

CHAPTER 1

RESEARCH ORIENTATION

1. Background

Most of Namibia's orphans lose their parents due to HIV and AIDS which is one of the most challenging health and developmental issues facing Namibia. In 2007, Namibia's HIV prevalence rate of 20% was ranked among the highest in the world (Namibia plan of action for orphans and vulnerable children, 2007).

According to the national plan of action for orphans and vulnerable children (OVC), "an orphan is a child who has lost one or both parents because of death and is under the age of 18; while a vulnerable child is one in need of care and protection". With the increasing morbidity and mortality rates due to HIV and AIDS, children are left without proper care and it becomes a challenge for extended families to cope with the overwhelming responsibility of taking care of these orphaned children who may also become vulnerable due to their living circumstances.

After the death of parents, it is usual for relatives to take in orphans but households are becoming larger, dependency rates are growing, grandparents especially grandmothers have to take care of an increasing number of children with dwindling resources and household food security is threatened (National plan of action for orphans and vulnerable children, 2007).

For orphans who have a surviving parent, the parent takes over the responsibility to care for the children. As for orphans who are left in the care of extended family members owing to the death of both parents, it is a challenge for these caregivers to meet the needs of these children and their own children. In cases where the orphaned child is infected with HIV, the burden faced by the caregivers is exacerbated by the increasing demands to meet the health care needs of the child and the provision of psycho-social support.

Although orphans may have access to health care and antiretroviral treatment, adhering to the treatment still remains a matter of concern. Adherence to antiretroviral treatment requires a comprehensive care plan and the family plays a vital role as treatment supporters for children who are on treatment.

When children are left without caregivers as the extended family system becomes exhausted, orphans are left to fend for themselves. Older children usually take over the care of the younger siblings and if they are also infected with HIV; the burden is doubled as self care becomes as demanding as that of the siblings.

With the gradual breakdown of extended families due to HIV and AIDS, poverty levels continue to rise and the sheer number of children being orphaned is taking a new meaning. Child headed households are emerging and these children are at a high risk of missing out on schooling, live in households with less food and are at high risk of being abused (Jackson, 2007).

As staggering as the numbers already are, the orphan crisis in sub-Saharan Africa has just started to unfold. Eight out of every 10 children who have lost their parents live in sub-Saharan Africa. With the escalating mortality rates of young adults due to HIV/AIDS, children are left without care and protection (UNICEF; 2007).

The availability of ART is a pharmacological step ahead in the medical fraternity towards the management of HIV/AIDS; however, the extended family system is overburdened with the care of orphans and vulnerable children and providing quality care is not an easy task at all. It could be understood considering the needs of an orphaned child; later on meeting the pressing demands to take care of an orphan whose life depends on this treatment with inadequate resources. This has had an influence on orphans who are on ART to adhere to their treatment as their living circumstances render them vulnerable.

2. The research question

A research problem as an interrogative sentence or statement that asks: what relations exist between two or more variables? (Christensen 2007). There are three criteria that good problems must meet. Firstly, the variables in the problem should express a relationship. The second criterion is that the problem should be stated in a question form. The third criterion and the one that most frequently distinguishes a researchable from a non-researchable problem is that “The problem statement should be such as to imply possibilities of empirical testing (Kerlinger; 1973).

For this study the following question was formulated:

What factors lead to non adherence to anti-retroviral treatment for orphans living with HIV in Okahandja constituency?

3. Significance of the study

Information established by this study would be helpful in the planning, implementation and monitoring of programs and interventions aimed at enhancing the level of treatment response and adherence to ART for children on treatment. It will be useful in strengthening the coping capabilities of the children themselves, the caregivers and health care and other service providers. In addition, this information can be used to support the establishment and strengthening of structures, systems, and policies to support children living with HIV and are on treatment.

4. Definition of the main concepts of the study

For the purpose of this study, adherence and non-adherence were defined as follows:-

4.1 Adherence - The extent to which the patient's behaviour coincides with the prescribed health care regimen as agreed upon through a shared decision making process between the patient and the health care provider (Fomundam, 2008).

4.2 Non adherence – Is patient's failure to take their medication, as prescribed by the health care provider and at the right time (Ministry of Health and Social Services, 2007).

5. Aim and objectives

5.1 Aim

To establish the factors that lead orphans not to adhere to antiretroviral treatment in Okahandja constituency in order to formulate strategies that will address this problem.

5.2 Objectives

- To establish the factors that lead to non-adherence to ART for orphans in Okahandja constituency.
- To establish and recommend possible remedial measures that can support child adherence and positive response to ART.

- To contribute to additional knowledge for the use of doctors, nurses, counsellors, social workers and general communities in the support for orphans on HIV antiretroviral treatment.

6. Research design

A research design refers to an outline, plan, or strategy specifying the procedure to be used in seeking an answer to the research question. It specifies such things as how to collect and analyse data (Christensen, 2007).

The researcher made use of the explorative research design to gain insight into the research phenomenon as there has not been a study conducted on this topic in Okahandja constituency before. For this study, both quantitative and qualitative research methods were used. Quantitative data was collected using a structured questionnaire while qualitative data was collected through in-depth interviews with key informants and the literature review.

6.1 Sampling method

There are two major goals that sampling can achieve; the first is to establish the representativeness of what we are studying conversely to reduce biasness; the second is to be able to make inferences from findings based on a sample to the larger population from which that sample was drawn (Baker, 1999). For the purpose of this study, target sampling was applied and data collected was from Okahandja State hospital.

The researcher selected guardians of orphans who are both adherent and non-adherent to treatment from five different locations of Okahandja. These guardians were the primary respondents in the study. The researcher selected sample groupings to ensure that the results could be generalised and open for scientific interpretation. The key informants in this study were doctors, nurses, social workers and community counsellors who provide services to children on ART. One doctor and two nurses were selected from the ART clinic. A social worker and two community counsellors were included in the selected sample size of key informants.

Target sampling was applied because the primary respondents were identified from records at Okahandja State hospital and all the key informants are employed by the Ministry of Health and Social Services.

7. Data collection methods

Data collection is a specific and systematic activity that seeks to avoid haphazardness and vagueness (Henderson & Thomas, 2005). For this study, a structured questionnaire was used to collect data from primary respondents and a semi-structured questionnaire with questions requiring narrative responses was used to collect data from key informants.

8. Data analysis

Quantitative data that was collected using the questionnaire was analyzed using the statistical package for social sciences (SPSS 18) with results delivered in contingency tables, charts and graphs for easy use and interpretation.

Thematic analysis was used in analysing qualitative data gathered from in-depth interviews. Qualitative data from parts of the questionnaire was grouped into themes and concepts and analysed quantitatively.

Non-parametric and chi-square tests were performed to test associations, relations and independence of variables and hypothesis.

CHAPTER 2

LITERATURE REVIEW

1. Introduction

The HIV and AIDS crisis is one of the greatest humanitarian and developmental challenges facing the global community. In the years and decades ahead, the impact of HIV and AIDS on children, their families and their communities will grow far worse expanding to dimensions difficult to imagine at present (Stine, 2005). To date, the number children orphaned due to HIV and AIDS in sub-Saharan Africa is estimated to be 11,600,000 and the number of children living with HIV and AIDS is estimated at 1,800,000 which constitutes both orphans and non-orphans (UNAIDS, 2009).

Like in many countries in Sub-Saharan Africa, HIV and AIDS remains a critical public health concern in Namibia. The scale of new HIV infections, the mortality rates that will occur in the main productive population, the rising number of orphans and the burden on the productive and social sectors continues to increase. Namibia has a population of approximately 2 million, and an estimated 200,000 people are living with HIV and AIDS. The number of women living with HIV and AIDS is estimated to be about 110,000 while 14,000 children are said to be living with HIV and AIDS. The number of orphans has greatly increased due to HIV related mortalities in Namibia and the extended family system is overstretched due to the epidemic. The number of orphans due to HIV and AIDS in Namibia is estimated by UNAIDS to be 66,000.

Although the HIV and AIDS epidemic has had a severe impact on many countries worldwide, the scale of its impact on sub-Saharan Africa has been immense. An estimated 22.4 million adults and children were living with HIV in sub-Saharan Africa at the end 2008 and an estimated 1,4 million people died from HIV and AIDS (UNAIDS 2009).

With an estimated 2.7 million new infections worldwide and five new people becoming infected with every two put on antiretroviral treatment, it's becoming increasingly clear that major programmes that have worked at the beginning of the epidemic may not have the same effect now (UNAIDS 2009). As the HIV epidemic is evolving, so must the response. One of the major achievements in the medical fraternity which has overwhelmingly responded to the crisis of HIV and AIDS is the introduction of antiretroviral therapy. The course and outcome of HIV and AIDS has been substantially changed by the introduction of antiretroviral

therapy. The effective use of antiretroviral therapy has contributed to the management of HIV and AIDS because it can now be treated as a chronic illness. In resource-rich countries, the prognosis of paediatric HIV infection has undergone a dramatic transformation since the availability of antiretroviral treatment particularly with the advent of highly active antiretroviral therapy (HAART) regimens (Gaur, 2008). As a direct consequence of the availability and use of antiretroviral therapy, marked declines in mortality and morbidity have been reported in recent years (Giacomet et al, 2004)

Antiretroviral therapy for HIV infection in children has dramatically improved their survival and quality of life. However, the effectiveness of antiretroviral therapy is dependent on good adherence (Paterson, 2008). Adherence to treatment can be influenced by a number of factors depending on the circumstances in which a patient finds themselves. Adherence in children may even pose greater challenges especially if children do not have proper care. Sustaining good adherence to ART in children is difficult as it is influenced by factors such as child behaviour, lack of parental care, abuse, poverty, poor access to health services, HIV status of caregivers, their attitudes and beliefs (Powell, 2007). The treatment of children with HIV using antiretroviral treatment has been a major challenge in the fight against HIV and AIDS especially in resource constrained settings.

In many African countries, the shortage of human resources to provide health care is one of the major barriers to achieve universal access to HIV treatment and care of children. In particular, the reliance on doctor and hospital-centred care hampers the ability to scale-up antiretroviral treatment and the process of task shifting, delegation of tasks to health workers with lower qualifications has become a recognised strategy (Johan, 2007).

Although antiretroviral therapy has turned around what was known as an incurable disease to a manageable disease to many including children, providing a glimmer of hope on a continent of gloom, the challenge of ensuring that those on antiretroviral treatment adhere to their treatment still lies ahead. In sub-Saharan Africa, the number of children receiving treatment continues to increase. However, the life saving imperatives of early testing and initiation of treatment are not yet standard in most countries especially in the area of prevention of mother to child transmission (PMTCT) and paediatric care, the number of women and children lost due to a lack of follow-up is tragically high (UNICEF 2009).

Although the programmes to address the plight of orphans and vulnerable children are increasingly funded, it is often constrained by weak systems and poor co-ordination of

services. To date PMTCT, paediatric HIV care and treatment has been uneven, underscoring inequalities of access to HIV testing, counselling and antiretroviral treatment for mothers and their children (UNICEF, 2009).

Adhering to treatment is not just an issue which should be singled out as a responsibility of the person taking treatment because it is coupled with a number of factors that could influence adherence. The HIV and AIDS epidemic is no longer just a health issue but a developmental issue which has largely contributed to the high levels of poverty in many societies, weakening the economic and social capacities of communities and family structures to sustain themselves. In the midst of the devastating and multiple impacts of the HIV and AIDS epidemic, adherence to treatment may be a matter of concern. If we take a closer look at the issue of orphaned children adhering to medication which is the main aim of this study, we can explore a number of factors which could be attributed to the poor adherence of orphans to ART.

To start with, the unfortunate consequence of living in a region ravaged with HIV and AIDS, poverty and economic inequalities is the number of children left without parental care or at the verge of separation with their caregivers. Orphans and other vulnerable children are at a higher risk of missing out on schooling, live in households with food insecurity, suffer anxiety and depression, and are at a higher risk of exposure to HIV. Factors that affect the situation include children's relationship with their caregivers, the poverty levels of their households and community, and for instance HIV prevalence.

HIV and AIDS forces children out of school, makes them more vulnerable to exploitation, abuse, violence, stigma and discrimination. They face the risk of not receiving adequate care, affection and other basic needs, and particularly affected are the orphans and vulnerable children (UNICEF, 2006). Given the combination of diminishing capacity of the education system due to the impact of HIV and AIDS and the increasing number of orphans for extended families to care for, the threat to maintain the positive trends in children having access to basic education, proper health care and a conducive environment for the welfare of these children is a matter of grave concern needing sustained investment. Without the care of parents or an appointed caregiver, children especially orphans are likely to face extraordinary risks of malnutrition, poor health, inadequate schooling, migration, homelessness and abuse (Powell, 2007).

Children orphaned due to HIV and AIDS are robbed of their childhood at a very tender age in their childhood development due to the fact that they have to take care of their sick parents which is emotionally traumatic and later on have to go through another traumatic experience if they are infected themselves. They have to take care of their siblings and take care of themselves at an age when they can hardly manage to cope with all these demands. The phenomenon of child headed households has yet become another pressing issue especially in regions which have been adversely affected by the epidemic. Child headed households are particularly vulnerable to loss of assets, as it often happens that relatives refuse to recognise the children's inheritance rights and they grab the belongings left behind by their parents (Namibia National Plan of Action for orphans and Vulnerable Children 2007).

The situation for children left without a caregiver or with relatives could be worse if these children are also infected themselves. These children have to be accommodated in households which cannot sustain them due to limited resources as the household becomes overcrowded. HIV and AIDS impacts on the economy at every level, but especially at the household level, where economic resources are undermined by the costs associated with sickness and death and exacerbated by the loss of wage earners (National Plan of Action for Orphans and Vulnerable Children, 2007).

Orphans who are infected are also at risk of suffering psychological trauma as some of these children can hardly understand the nature of their health problem especially if their parents do not inform them about their HIV status. The burden faced by orphans and vulnerable children is often exacerbated by high levels of stigma and discrimination associated with HIV and AIDS which remains a significant problem (Namibia Plan of Action for Orphans and Vulnerable Children 2007). Factors that can possibly influence orphans to adhere to antiretroviral treatment may vary depending on their circumstances.

By 2010, HIV and AIDS would have robbed the lives of the parents of over 20 million children under the age of 15 (UNICEF report, 2007). The estimated number of children who will be orphaned or who will themselves become infected by HIV after their parents die is disturbingly high.

As a cause of orphan-hood, HIV and AIDS is exceptional in that if one parent is infected with HIV, the probability that the spouse or partner is infected is quite high. This means that children face a high risk that both their parents could die within a relatively short period of

time. HIV and AIDS will nearly triple the number of orphans living without parents in sub-Saharan Africa by 2010 (UNICEF, 2007).

Namibia like other sub-Saharan Africa countries has felt the effects of the HIV and AIDS epidemic at household, community and national level and the number of orphans has increased over the years. According to the national plan of action for orphans and vulnerable children (2007), the number of orphans and vulnerable children in 2007 was estimated to be 128,000 and that this number would rise considerably the following year and children were already taking care of their sick parents. The Namibian government provides social welfare grants for orphans and according to statistical information from the data base at the Office of the Prime Minister, 105,136 orphans are receiving social welfare grants nationally.

Orphan-hood due to HIV and AIDS sets in numerous challenges that can be devastating. Orphans may suffer damage to their cognitive and emotional development, have less access to education and proper health care, and are subjected to different forms of abuse such as child labour, sexual exploitation, property grabbing, child trafficking and other forms of exploitation.

Apart from the financial hardships that orphaned children suffer after the loss of their parents due to HIV and AIDS, they also suffer psychological distress, anxiety and fear to face the world ahead of them and the trauma becomes extreme if they are also infected. (Jackson 2007). Children orphaned due to HIV and AIDS face a higher risk of suffering as a result of food insecurity and increasing levels of poverty as the extended family system is stretched to a point where available resources at household level cannot cater for all the basic needs.

For orphans who are infected, access and adherence to anti-retroviral therapy could prolong and improve their quality of life. Adhering to anti-viral treatment is a lifelong commitment which is crucial for both the patient and health care providers.

Family and social support systems are viewed as important aspects in ensuring patient adherence to treatment. Having a healthy network of interpersonal support through friends, family and significant others including health care providers can have a positive impact on treatment adherence (www.ncpad.org).

However, as families break down, and extended family systems are overstretched, financial crises, psychological and emotional turmoil endures, adherence to treatment will remain a

matter of great concern. An enabling environment may serve as a backbone to improve adherence to treatment. (UNICEF report, 2007).

2. Factors that lead orphans into non-adherence to antiretroviral treatment in Okahandja constituency.

2.1 Family support and care giving

Antiretroviral treatment of HIV in children has evolved tremendously since the early 1990's and continues to evolve as new drugs targeting new sites are developed and studied in children (Gaur, 2008). For clinicians caring for children, it is crucial for them to understand that for the eventual success of treatment, it is critical to manage the "whole" child within the context of his/her own economic, cultural, psychological, and family environment. The clinician should also understand the complexities of the interaction of chronic illness and child development and develop the sensitivity requisite to manage this very complex and evolving disease (Gaur, 2008).

Family support and care giving plays an integral part in managing treatment in children. It is however unfortunate that the increase in mortality rates due to HIV and AIDS contributes to the number of orphans who are left without proper parental care. Many children in Africa live in homes and in communities racked by the effects of HIV and AIDS and these children often do not live within a loving family environment where they can receive support, nurturing and guidance to help them cope with life's challenges and fulfil their needs (Van Dky, 2005). It has become a common trend as the HIV and AIDS epidemic takes its toll on the family structures that children become vulnerable due to lack of adequate care and support. An increasing number of HIV infected children are being left in hospitals because their HIV-infected parents are unable to care for them and no one else wants them. The hospital therefore becomes their home (Stine 2005).

Although there is little evidence that extended families often reject orphans on any scale, the growing numbers result in increasing reluctance to accept them and difficult in caring for them, motivating non-governmental organisations of all kinds to provide support (Iliffe, 2006). Within the family, there are invariably times when the needs of one child require more attention than another and responding to their needs does not necessarily mean that the other children are loved any less. Rather, the needs of such a child at that particular moment could be more pressing and critical than that of the others. The needs of HIV infected children are

different from those of a child who is HIV negative. The needs of children who are HIV infected and receiving treatment could be more demanding depending on the situation in which they find themselves. In some cases, a child may not be infected themselves but they have to take care for their siblings or parents who are infected without the maturity of parenthood.

As the parent's health begin to deteriorate due to HIV infection, children find their roles changing from child to primary caregivers as they have to take care for their parents and older siblings have to care for younger siblings and the resultant loss of childhood has serious implications for normal childhood development. Children orphaned due to HIV and AIDS and are infected themselves are in most cases in need of care and support by any surviving relatives but the impact of the epidemic has altered the family system to an extent where they may not be able provide care for these children (Van Dky, 2005).

AIDS is generating orphans so quickly that family structures can no longer cope (Barnett & Whiteside, 2002). Traditional safety nets are unravelling as more young adults die of the disease. Families and communities can barely fend for themselves, let alone taking care of orphans. Typically, half of all people with HIV become infected before they turn 25, acquiring AIDS and dying by the time they turn 35, leaving behind a generation of children to be raised by their grandparents or left on their own in child-headed households (UNICEF, 2003).

Becoming an orphan of the epidemic is often a sudden switch in roles. It is slow and painful, and the slowness and pain have to do not only with the loss of a parent but also with the long term care which the parent's failing health may require. In cases where they have to experience so much psychological trauma of taking care of their parents who die or may die at a later stage these children need to be cared for themselves if they are fortunate enough to have relatives who can take on the parental role especially if they are also infected. It is not only in relation to their own parents that children take on new and premature roles, but when they become orphans, they go to their grandparents or another relative, for instance an aunt or uncle who may die of HIV and AIDS or a grandparent of old age (Barnett & Whiteside, 2002).

Many studies indicate that children who are orphaned due to HIV and AIDS may need immediate support as they deal with a host of new difficulties and challenges. However, it is also important to note that in a longer term, their new caregivers may also need such help for

them to care not only for orphaned children but also the arising healthy needs of these children if they are infected and are receiving treatment. Family support and the caregiver's perception and attitude towards HIV and AIDS can have an influence on the quality of care for paediatric patients who are on ART and consequently on their adherence to this treatment (Paterson, 2009).

The stage of the caregivers lifecycle can probably have some influence on their roles as caregivers if they are to meet the needs of an orphaned child who is infected and they have their own children to take care of or whether they have sufficient resources to engage with the needs of both their children and that of the orphaned children (Whiteside, 2002). Resentment could fester where caregivers have their own children of similar age competing for attention. Caregivers often find orphans difficult to manage, because some can be anxious, depressed, moody and occasionally suicidal (Iliffe, 2006).

Although care giving and family support has largely been emphasized on the role of the caregiver towards orphaned children under their care, it is important to note that these caregivers also need support to care for these children. Supportive and affectionate families are an important factor in enabling adherence, however some caregivers choose not to disclose their HIV status to the children they are taking care of to other family members due to the fear of stigma and discrimination. Some caregivers are reluctant to use public healthcare services due to stigma and concerns about confidentiality as ARV clinics are usually situated within a main hospital with other clinical services (Paterson, 2009).

Family support in the care of infected children is a crucial element in HIV and AIDS treatment and care where grandparents, aunts, uncles and cousins characterize the family system known as the extended family, this institution plays a major role to assist caregivers cope with the care giving roles (Makwiza, 2008).

2.2 Psychosocial support

Psychosocial support is an ongoing process of meeting the physical, emotional, social, mental and spiritual needs of children, all of which are essential elements for meaningful and positive human development (Mallman, 2003). It is important to understand the child in a holistic context, within their economic, cultural, psychological and family environments for the eventual success of treatment.

Psychosocial support recognises that providing physical or material support in the form of clothes, food, shelter and money is not enough if the emotional and psychological well-being as well as the social setting in which one lives in is unhealthy. Provision of psychosocial support may require input of money but money does not play the central role rather people or community involvement is paramount. When dealing with issues of love, security, guidance, provision of identity and care there is no expert, rather if you have the eyes to see, the ears to listen to a child's problems, the mouth to speak words of comfort and wisdom, the heart to feel and understand the plight of children and the time to visit and share, then you will be the expert needed to provide psychosocial support (Mallman, 2003). Any support that lacks this component is not holistic and it is not likely to yield desired results, which are to reach out to the children in difficult circumstances and help them deal with negative feelings of anger, self pity and hopelessness.

Children orphaned by HIV and AIDS are disadvantaged in many and often devastating ways. In addition to the trauma of witnessing the sickness and death of one or both parents, they are likely to be poorer and less healthy than non-orphans. They are also more likely to suffer damage to their cognitive and emotional development, to have less access to education, health care and a nurturing environment and can be subjected to the worst forms of child abuse. Survival strategies such as eating less and selling assets are not lasting solutions but instead intensify the vulnerability of both caregivers and the children (UNICEF, 2008).

Orphaned children go through a series of traumatic events after the death of their parents especially if they are also infected themselves and they probably have to separate with their siblings and begin to stay with relatives, in foster care and in residential child care facilities as a way of lessening the burden of care. Orphaned children who lose their parents due to HIV and AIDS start grieving in anticipation long before their parent's actual death. These children often experience multiple losses after death of their parents as they are caught up in inheritance squabbles and experience sibling separation and eventual relocation that might result in separation anxiety (Van Dky, 2005).

Separation from siblings is another source of trauma as orphans may feel even more isolated when one of their routines of normal daily life is disturbed. Psychosocial trauma can continue even when orphans move to foster families, as they may be treated as second class family members, discriminated against in the allocation of food, perhaps, or in the distribution of work (UNICEF, 2006). It is not easy for children to find adequate support when their parents

die. The loss of their parents brings depressive thoughts and feelings among which are sadness, anger and guilt which may be normal feelings during bereavement. However, with the passing of time especially in cases where children do not get help, these feelings can develop into negative emotions when they find themselves beset with many problems, or fear about the situation they may find themselves.

Many of the orphaned children continue to experience emotional problems and little is done in this area of emotional support. There are several reasons. Firstly, there is a lack of adequate information on the nature and magnitude of the problem, secondly, there is a cultural belief that children do not have emotional problems and therefore there is a lack of attention from adults; and thirdly since psychological problems are not always obvious, many adults in charge of orphans are not always able to identify them. Even when the problem is identified, there is always a lack of knowledge of how to handle it appropriately (Nambi, 2001).

Psychosocial support though not viewed as such in many cases often facilitates treatment compliance for children on ART. Psychosocial characteristics of both caregivers and children play a major role in adherence and support that factors associated with adherence tend to be those that are not routinely assessed in clinical practice. Indeed, quality of life, beliefs and expectations act as determinants of adherence. Foster parents who were specifically trained to provide proper care for children under their care showed virtually perfect adherence and established a target of optimal adherence for all HIV infected children on ART. They also suggested that caregivers of HIV infected children should be given strong motivation and clear information to improve and maintain adherence in their children because psychosocial features of these children and their caregivers affects adherence. Nearly perfect adherence rates have been observed in children receiving psycho-social support from foster parents (Giacomet et al, 2004).

Once children are tested positive, the psychosocial emphasis provides effective means for handling and subsequent commencement of ART, though it does not seem like that in many African countries. Preparation of both caregivers and children contributes to good adherence and treatment outcomes; HIV care is more than getting CD4 counts and prescribing ARV's. Addressing the many psychosocial aspects of the illness is crucial to effective treatment programs but the aspect of paediatric ART has not received sufficient attention in decentralised contexts in some hospital based settings especially in low income countries. In

other cases it is becoming difficult for caregivers to provide adequate psychosocial support to HIV infected children due to overwhelming numbers of orphans they may have to take care of in their households after the death of their parents. Caregivers have multiple tasks and the burden of taking care of orphaned children and perhaps their own children means they also have to strive for economic survival (Houghton, 2006).

Many children in Africa who are made orphans and vulnerable by AIDS do not have psychosocial support to fulfil their basic needs, and unless they are helped, these children face a very difficult future. Synergistic psychosocial support should preferably be provided by the child's own empowered community. Children made vulnerable by HIV and AIDS and do not receive psychosocial support to fulfil all their needs may suffer long-term social and emotional impairment and may be at the risk for developing depression, anxiety and behavioural disorders (Van Dky, 2005).

2.3 Treatment support

In Namibia, the social eligibility criteria for ART require that each patient has a designated treatment supporter before starting treatment (MOHSS, 2007). The treatment supporter should be someone at home, in the community, or at the workplace, who can accompany the patient to hospital visits and assist with daily adherence to HAART. This can be a very difficult criterion for some patients to meet, however, the Ministry of Health and Social Services maintains that it is desirable for all patients to have a treatment supporter (MOHSS, 2007).

In most cases, unless the child is old enough to understand the nature of their illness and the importance of taking their medication, the caretaker has a crucial role to play, as a treatment supporter who is responsible in ensuring that the child takes their medication, at the right time and as prescribed by the doctor.

The task of ensuring that the child takes their medication properly could be more than this depending on the circumstances of the child. Starting HAART should always follow the agreement and education of the child's parents or caregivers and time spent educating the child within the knowledge of their disease and developmental abilities is time well spent. It has been shown that difficulties in adhering to HAART occurs most commonly in the first few months of treatment, which supports the need for time spent educating parents,

caregivers and children before commencing treatment (Gibb et al, 2003) as cited in (Houghton, 2006).

Obtaining and maintaining adherence to HIV medication in children remains a challenging area of practice, particularly as this treatment, currently is that once started, it has to be continued for life and many children have no obvious signs of illness. This supports the need for continuing dialogue with children and their parents and or caregivers around the rationale for treatment and education while recognising the child's cognitive, motor, social, emotional and psychological functioning (Houghton, 2006). Discussing HIV with children remains particularly problematic, given the prevailing stigma attached to the diagnosis of HIV and parental anxieties around subsequent disclosure of diagnosis by the child to the extended family, friends and schoolmates.

Apart from the responsibility of parenting an orphaned child who may need a lot of psychosocial support following the death of his/her parents, the caregiver has an additional role of ensuring that the child adheres to their ART which is a lifelong treatment. The child could be fortunate if their caregiver has the knowledge and understands how to handle their needs. At times, the caregiver could also be HIV positive themselves and may need support just as much as the child under their care. In cases where the caregiver is ill with HIV infection and has difficulties adhering to their medication, the chances are slim that they will ensure the child adheres to their treatment because they may have psychosocial or coping problems that result in distraction and forgetfulness (Berrien et al, 2004).

ART may require a child to take many pills or distasteful liquid medications twice on a daily basis and without interruption. Depending on the developmental age of the child, he/she may not be able to swallow pills and may exhibit resistant behaviour, in general, or, as he/she approaches adolescence, may reject the medications completely. The parent, the legal caregiver or the child may have difficulties in appreciating the significance of the disease and the necessity of strict adherence to control the infection and avoid the emergence of viral resistance (Berrien et al, 2004).

Although disclosure of the child's HIV status is important in treatment adherence, a few caregivers do not reveal the status to the child. This is because of the stigma attached to HIV infection and they may also have the fear that the child may want to know more about their illness, and they may not be able to handle the effects that come with such disclosure. The child should however be considered before their status is disclosed to them. Generally,

children are not well prepared when they go for HIV testing; few children knew exactly why they were there, had little knowledge of HIV and rarely knew about their status after the testing (Johan, 2008). It is however important to disclose the child's HIV status so that the counsellor can assist the caregiver to talk openly to the child about their HIV status, find ways of responding to the child's questions and deal with other reactions.

Within child support groups, an environment created by the counsellor can help the children express themselves, raise questions, worries and develop a positive attitude towards life with HIV (Johan, 2008). Most issues discussed in these groups are raised by the children themselves and reflect their deeper feelings about HIV, life and death, sexuality, manipulation in the caregiver-child relationship and discrimination. Involving the child in the treatment process is vital if the child is old enough to comprehend the nature of their illness and what is required of them for a positive treatment outcome. The child's involvement is more likely to reduce the chances of drug resistance as they are well vested with information to manage their own treatment properly. Resistance to HAART is possible if treatment is not taken correctly, or doses are forgotten or refused which is one of the greatest challenges facing the future health of children with HIV (Houghton, 2006).

Resistance to one medicine may correlate with resistance to other medicines within that class and, as such, means that many medications can be rendered ineffective when only one has actually been resisted. This significantly reduces a child's treatment options and often results in having to choose medicines that have a higher rate of unwanted effects or food restrictions associated with them, which makes adherence even more difficult to achieve (Houghton, 2006).

2.4 Socio-economic circumstances

As one can imagine, the loss of a parent or both parents has profound effects on the socio-economic status of a child. The impact of HIV and AIDS has so far been felt at global, national, community and more especially at household level as the morbidity and mortality rates continues to rise, living orphaned children vulnerable to socioeconomic problems such as poverty, food insecurity, lack of proper health care, education, and shelter. HIV and AIDS has a negative impact on the economy at every level but especially at the household, where economic resources are undermined by the costs associated with the sickness and death, and exacerbated by the loss of wage earners (Namibia National Plan of Action for Orphans and Vulnerable Children in Namibia, 2007).

The death of parents due to HIV and AIDS changes the economic patterns and living conditions in a household as children are left without a breadwinner to meet their basic needs.

The loss of parents due to AIDS may cause prolonged economic problems for children because before parents die, they fall sick, stop working, and spend most of the family resources on medical and funeral expenses. It is not uncommon to find relatives who seize key assets from orphaned children, thus leaving them more vulnerable to further exploitation. After the death of parents, children remain at an elevated risk of economic exploitation. Relatives often violate the inheritance rights of orphans by taking possession of their property and not providing support to them (Williamson et al., 2004).

When parents die after a long illness, the lives of the orphaned children gets worse, as they may be evicted by unscrupulous relatives, siblings may split and their lives may suddenly be devoid of continuity, security, regular food and shelter (Jackson, 2002).

The HIV and AIDS epidemic has largely contributed to increased levels of poverty and has left vulnerable even some families not necessarily considered poor. Most of the vulnerable families and communities are as a result of the impact of AIDS on their economic situation. It has become an overwhelming responsibility for families to meet their most basic needs with the economic strain caused by the epidemic let alone meeting the needs of orphaned children who are also infected.

AIDS affected households tend to be poorer, consuming less food and with smaller disposable incomes. It is hardly surprising that children in these households are usually less well nourished and have a greater chance of being stunted and wasted (Barnett & Whiteside, 2002). Caregivers who takeover the responsibility of taking care of orphaned children who are also infected are often forced to split their limited resources, to meet the pressing needs of these children with little or no support all. Families fostering orphans often have problems of their own, such as their large families to care for; therefore taking in more children has severe economic strains on them. At times, the foster parents are too young or too old to properly care for additional children. , Pathetic situations have been observed where grandparents who are expected to be supported by their children had to care for their orphaned grandchildren. These grandparents are usually found to be less able to provide discipline and adequate socialization, and even to address the basic needs for food, clothing, shelter and proper health care (Hunter & Williamson, 1998).

Orphaned children who are adopted or fostered by relatives often receive worse treatment than biological children in the same family. The education, nutrition and health status of children adopted into impoverished families suffer from lack of resources necessary for their basic needs (Nambi, 2001).

In Namibia, most orphaned children in foster care survive on foster care grants which are N\$ 200-00 per child and may not be enough to cater for all the needs of a child. They are 104,438 orphans and vulnerable children on the grant system and 90, 412 of these are receiving maintenance grants while 14, 026 are receiving foster care grants (Office of the Prime Minister OVC Database, 2009).

A high number of these orphans are from the northern-central regions namely Oshana, Ohangwena, Omusati and Oshikoto; and the north-eastern regions which are Kavango and Caprivi regions (Ministry of Gender Equality and Child Welfare, 2008). Most of the orphans in these regions are under the care of their grandparents as the cultural practice of kinship care is still very strong among the inhabitants in these regions. An increasing number of child headed households are observed in these regions generally due to the death of parents due to HIV and AIDS and caregivers in most cases grandparents who eventually grow very old, weak and die.

In the midst of these economic struggles, it can be challenging for a caregiver to ensure that orphaned children who are on treatment receive adequate care for them to adhere to their treatment. The economic status of the family is an important determinant in adherence to ART due to the nature of the illness and the fact that this treatment is lifelong. ART can have different side effects on different people especially when the patient begins with the treatment which may require them to visit the healthcare provider regularly until the side effects disappear. The critical part is that the side effects can cause some serious discomforts to patients to an extent where they may attempt to discontinue with their medication

In cases where patients discontinue their medication, there is a heightened risk that the patient might develop drug resistance because HIV mutates rapidly and can complete a cycle of evolutionary change in the presence of inadequate drug levels (Mullen, 2002). Although the treatment supporter plays a major role in ensuring that the patient adheres to their treatment, this responsibility can be emotionally and financially taxing especially in situations where the caregiver does not have the capacity to provide this kind of support. For most children, orphans in particular, a home-visit is very important before the initiation of ART to

assess the socio-economic situation of the family and to provide support where necessary or refer them to resources within their community which could be of assistance (Johan, 2008).

2.5 Food security

The sustained and long term impact of the HIV and AIDS epidemic is slowly eroding food security, damaging rural livelihoods and exacerbating poverty. The countries with high prevalence are also the countries where the majority of their populations live in rural households and whose livelihoods largely depend on agriculture. The epidemic is plunging communities further into destitution as their labour capacity weakens, incomes dwindle and assets are depleted. Children orphaned by HIV and AIDS face a higher risk of malnutrition and stunting (UNICEF, 2003).

Namibia is a low middle income country with perennial food deficits, recurring droughts, high rates of malnutrition with the sixth highest prevalence rate of HIV and AIDS in the world, (www.wfp.org). While the country's economy heavily depends on the mining sector, roughly half of Namibia's population rely on subsistence agriculture, characterized by low productivity and high variability due to water scarcity, erratic rainfall, poor soils and low capacity to support intensive agricultural methods. Even in years with good rains access to adequate food for the marginalised is a constant challenge contributing to the current levels of malnutrition (www.wfp.org).

The national HIV and AIDS prevalence rate is estimated at 17.8% peaking at approximately 31.7% in the Caprivi region (National sentinel survey report, 2008). The epidemic has contributed to a rapidly growing number of orphans and vulnerable children. In many areas where the OVC live, chronic food insecurity is a fact of life, 24% of children under five are underweight (UNICEF, 2009)

Findings from a surveillance survey conducted by the Ministry of Gender Equality and Child Welfare and the World Food Programme (2006), indicate that vulnerable households hosting OVC in Namibia include those from marginalised communities such as the San and the Ovahimba, and households headed by single women, grandmothers, children and people living with HIV and AIDS. Furthermore, there is a decrease in access to food among vulnerable groups due to lower levels of education, employment and less income which consequently leads to the decrease in the number of meals often consumed, inadequate

amounts of key foods such as starchy staples, animal products, legumes, fruits and vegetables: and many times the food is insufficient for the entire family.

Orphans and vulnerable children are at an elevated risk of malnutrition as their expenditure decreases due to the depletion of household savings when their parents die leaving little financial resources to adequately meet all their basic needs. In Namibia, households affected by the HIV and AIDS pandemic are subjected to the reduction in the number of cattle, compared to the non-affected households. Eighty-nine percent of widow-headed households are reported to have experienced a sharp decline in cattle as a result of the distress sale of cattle to meet their needs and property grabbing (Ministry of Gender Equality and Child Welfare and the World Food programme, 2006).

The HIV and AIDS epidemic affects different households in different ways and produces a variety of coping strategies. Female headed households, those fostering orphans and people living with HIV and AIDS are particularly susceptible to the impacts of the epidemic and their vulnerability often leads to the adoption of risky survival strategies. Affected households especially widows and orphan headed households, have less access to food as a result of decreased production and the depletion of household resources when the breadwinner in the family gets ill. Health and nutrition status decline as less money is available to properly feed the household.

Food insecurity is one of the challenges that is as a result of the epidemic as poverty levels continues to increase. Food security is a widespread problem in Namibia as the country imports most of its food products from South Africa (www.fao.org). Widows and orphan households experience food shortages as they are less able to cope with the levels of food insecurity with minimal financial resources. In the Omusati, Oshana, Ohangwena, Oshikoto Kavango as well as Caprivi regions the number of orphans is particularly high yet these regions experience heavy floods mostly affecting small scale subsistence farming and ultimately threaten food security. In 2009, the floods caused many families to relocate to makeshift camps dispossessing their homes with property as well as gardens completely washed away.

The Ministry of Gender Equality and Child Welfare together with the World Food Program operated a feeding programme in these regions providing food parcels to orphans and vulnerable children and their families. However, the programme came to an end in 2008 and this has had a negative impact on these families particularly those headed by children.

UNICEF provides financial and technical assistance to the Ministry of Gender Equality and Child Welfare to run small projects for the benefit of orphans and vulnerable children (OVC). UNICEF funds these projects on a five year cycle to selected regions per cycle. The current cycle includes funding for Omusati, Ohangwena, Caprivi, Omaheke and Kavango regions. Funding is for income generating and gardening projects, feeding schemes, and kindergartens. Orphans and vulnerable children benefit from soup kitchens in their communities.

In Okahandja, there are three soup kitchens that feed OVC for 3 – 5 days a week; Two other projects provide formula milk and food parcels for HIV positive babies and their mothers. The Church Alliance of Orphans (CAFO) provides financial assistance to some of these projects. Orphans health and nutrition status is often worse than that of non-orphans. Orphans are more likely to have stunted growth and overall poor health, mainly because of unmet nutritional needs (Nyagara, 2004). On the other hand food security is a serious challenge. Female headed households, and in particular those fostering orphans, are more vulnerable to the food crisis than male headed households (www.fao.org) Orphans nutritional health and survival prospects are also worsened by the increasingly weakened state of health care services, which have been overwhelmed by the HIV and AIDS onslaught in many sub-Saharan African countries (UNICEF, 2003).

CHAPTER 3

RESEARCH METHODOLOGY

1. Introduction

The main focus of this chapter was to explain how this study was conducted. It described the procedures that were employed to obtain the results herein.

2. Problem Formulation

Although the introduction of antiretroviral treatment has dramatically changed the lives of many orphaned children who are receiving this treatment, it has been observed that the unfortunate impacts of orphan-hood influences their treatment adherence. This study therefore aimed to establish the factors that influence orphans to adhere to antiretroviral therapy in Okahandja constituency.

3. The research design

A research design is a plan or blue print of how one intends to conduct research (De Vos, 2003). This study was designed based on the exploratory research approach. The choice of this approach was mainly because there were hardly any studies prior to this one for reference about the subject of investigation. The researcher intended to look at patterns, ideas and hypotheses surrounding children's adherence to ART in Okahandja constituency. The researcher focused on gaining insight and familiarity with the research problem and present results which could be used for future detailed investigations.

4. Sampling

A sample is a subject of the whole population, which is being investigated by a researcher, and the characteristics are generalised to the whole population that is represented. A sample should therefore be seen as representative of the population that it is taken from (Bless and Higson Smith, 1995). For this study, the sample consisted of 30 caregivers. Twelve of these caregivers had orphans under their care who were on ART and they were non-adherent to their treatment. On the other hand, 18 of the caregivers had non-orphaned children under the care who were non-adherent to ART. This information was established from the hospital records in comparison with the information that the researcher had established through her case records. The researcher also selected 6 key informants who included one doctor, two

nurses, two community counsellors and a social worker were employees of Ministry of Health and Social Services. The doctor and nurses are based at the ART clinic and are directly involved in the administration of treatment to the children under investigation. The community counsellors work at the clinic and the hospital; the social workers are based at the social welfare office and they provide psycho-social support services that include adherence counselling to the children in this study and their caregivers.

The procedure used for selecting the respondents in this study was non-random. The participants in the study were selected by means of the researcher's personal choice rather than through mathematical chance. The researcher targeted a particular set of respondents namely care providers particularly for orphaned children, living with HIV and on treatment.

5. Validity and Reliability

To ensure validity of the research a pre-test of the questionnaires was done. The purpose of the pre-test was to eliminate vague, ambiguous or unclear questions, identify problems in the structuring or wording of the questions and conduct a mock analysis before actual data collection was undertaken.

Reliability is the accuracy or precision of an instrument. In general, reliability refers to the extent to which the independent administration of the same instrument consistently yields the same results under comparable conditions (De Vos, 2002). Questions were structured in such a way that reliable information could be obtained from the respondents. The questionnaire was simple and the researcher provided immediate support to the respondents when clarifications were required by the respondents. Further, respondents who could not speak English were helped through a translator to understand the concepts in the questionnaire and respond effectively.

6. Methods of data collection

The researcher hand delivered all questionnaires to the primary respondents i.e. the caregivers of the orphans. While completing the questionnaires for this sample group, the researcher was present in person to give necessary support through the process. A translator was on hand for respondents who needed English concepts to be translated and so as respond effectively.

Questionnaires for the key informants were self administered. However the researcher could be contacted if they experienced any problems while completing it.

CHAPTER 4

DATA ANALYSIS AND INTERPRETATION

1. Introduction

This chapter presented the findings of this study. The detailed analysis and interpretation of the findings are transformed into comprehensive descriptions and presentations. The researcher used tables, graphs and charts to convert quantitative findings into readable results. The qualitative findings were translated into meaningful and descriptive information. The number of children receiving ART in Okahandja constituency was 69 at the time of this study. Of these children, 30 of their caregivers were selected to participate in this study.

2. CHARACTERISTICS OF RESPONDENTS AND CHILDREN ON ART

The children studied were male and female on antiretroviral treatment aged between 3 and 15. Each of the children was under the care of a relative or parents aged between 20 and 55 years. The study was conducted in six settlements of Okahandja constituency.

2.1 Gender profiles

Fifty-six percent of the children studied were female while 43% were male as presented in figure 1 below.

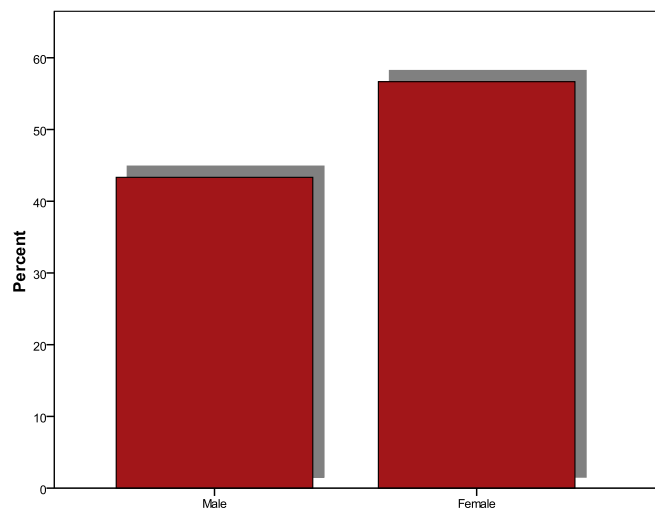


Figure 1 Sex profile of the children

2.2 Age profiles

The youngest child on treatment was aged 3 as the oldest was 15 years old. Over 25% of the children in this study were over 10 years. All these children were under the care of an adult caregiver who was either a surviving parent, primary relative such as sister or brother, grandparent to great grandparents. Some of the caregivers doubled as treatment supporters and in some cases a different treatment supporter was identified should the caregiver be unable as a result of age to perform the role of a treatment supporter. Figure 2 below shows the age groups of the caregivers who were the respondents in this study.

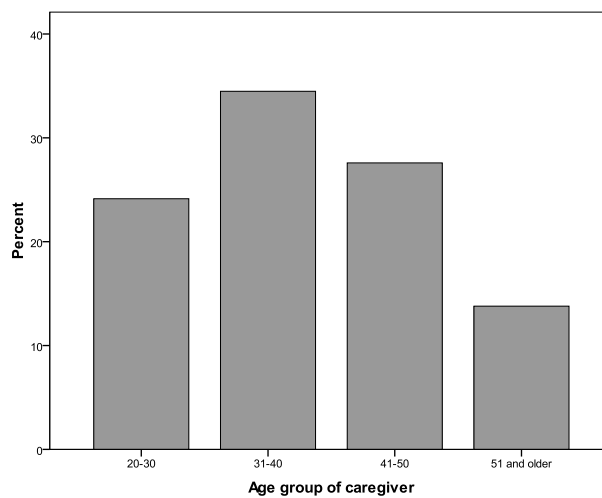


Figure 2 Age groups of the caregivers

While the majority of the caregivers were aged 31-50, it is noticeable that a large number of caregivers were below 30. This age is for various reasons unstable and extremely mobile either due to the search for employment, family life (as most are still unmarried), further study and other forces. The older group aged 51 and above is relatively small. However it is important to note that performing the duties and roles of a caregiver as well as a treatment supporter may demand a lot more than what a 50 year old adult may be able to offer.

2.3 Distribution of respondents by residence

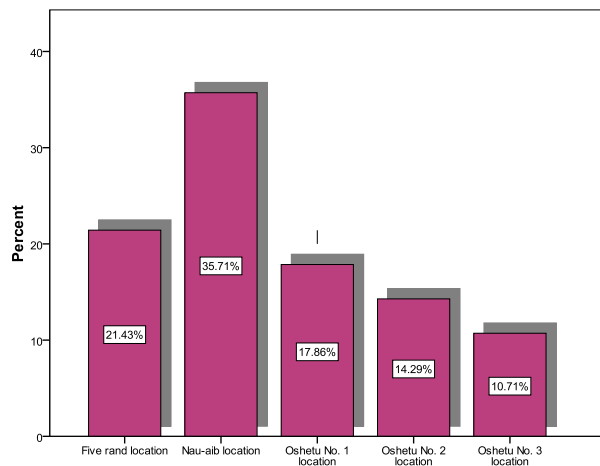


Figure 3 Distribution of respondents by residence

Figure 3 above indicates that the majority of the respondents (over 35%) lived in the Nau-aib location and over 21% from the five rand location. Collectively over 43% of the respondents lived in Oshetu 1-3 locations. Historically these locations were demarcated along tribal lines and the name of a location is usually indicative of a tribe. Oshetu 1-3 are occupied by predominantly Oshiwambo speaking people as Nau-aib is occupied by different tribes. Five-rand location is also predominantly occupied by Oshiwambo speaking people. Community connection and support systems are influenced along tribal lines that are already the basis for the historical demarcations of the locations in the constituency. As such, community support systems are likely to be greater in the Oshetu location compared to Nau-aib and the Five rand locations.

2.4 Marital status of caregiver

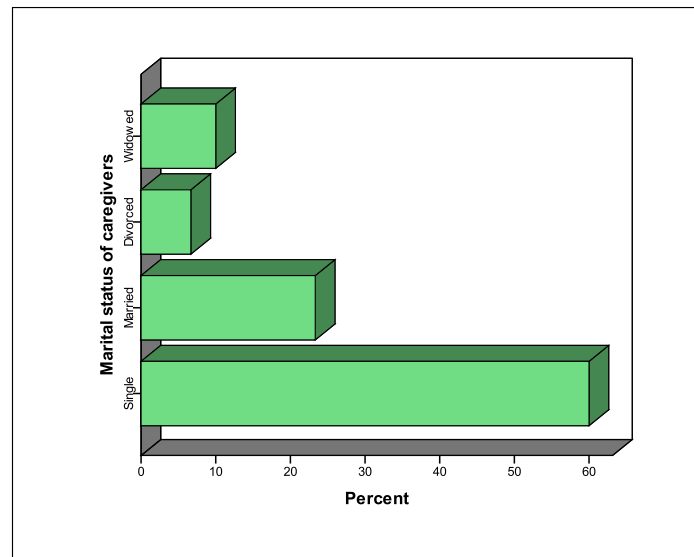


Figure 4 Marital status of caregivers

Figure 4 above indicates that the majority of the caregivers were not married with 60% stating to be single, 10% widowed and just below 10% divorced. Just over 20% of the caregivers reported to be married. In the effectuation of the caregiver roles which may include the added responsibilities of being a treatment supporter, marriage can have an important influence as it increases the likelihood of a caregiver being stable, more supportive and dependable. In some cases marriage may improve financial stability and dependability and division of labour may become easy especially the task of care-giving to a child who is on HIV treatment. It is therefore somewhat unlikely for the children to benefit from the full benefits of treatments in settings other than that of families.

2.5 Employment status for caregivers

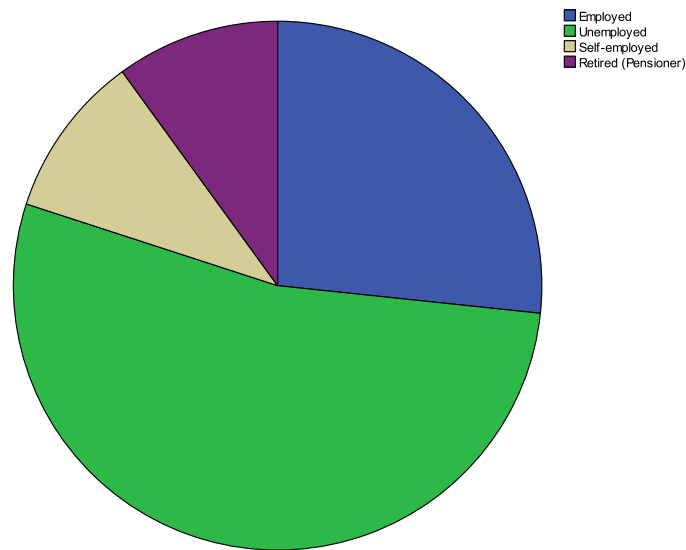


Figure 5 Employment status of caregiver

Figure 5 indicates that over 53% of the caregivers were unemployed. Twenty-six percent of the caregivers were employed with 10% retired pensioners and 10% self employed. Employment is a major source of income; it enhances stability and affordability of added values and needs to treatment. With over half of the caregivers unemployed and therefore not receiving a stable income the care and response to treatment for children under their care can only be achieved with added interventions such as food handouts, government grants and soup kitchens. Self employed persons indicated to be involved in rudimentary businesses such as the sale of meat, wood and casual labour do not earn an effective income. Pensioners receive a government pension fund tailored to meet their needs and as a benefit of their service to the government or other institutions when they retire. It was therefore a financial burden for these pensioners to include the expenses for orphans considering that their pension money was only sufficient for their basic needs.

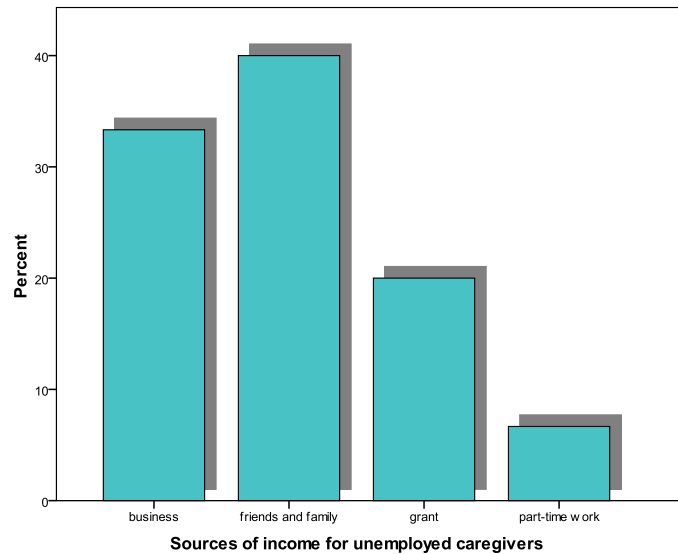


Figure 6 Sources of income for unemployed caregivers

As indicated in the figure above, friends and family play an important role in sustaining the financial lifeline for the caregivers of orphans on antiretroviral therapy. It is important to note that the elasticity of this financial support from friends and family relies heavily on their sources of income and nature of relationship with the financiers. Boyfriends and husbands are for example likely to offer more dependable support just as employed relatives compared to unemployed friends and family. Besides, caregivers who engage in local businesses to gain an income ranging from trading in local brews, wood, meat and meat products locally prepared like biltong may offer a reliable source of support but generally inadequate. Government grants that include maintenance, disability, pension and foster grants are a major source of income for qualifying children and caregivers, this income however is equally variously limited and inadequate. Some caregivers engage in casual part-time labour in especially shops to earn an income. All these forms of ventures can only earn the caregiver income for basic needs limited to hand to mouth expenses and still not meeting that adequately. Therefore the roles of care giving that would have supported adherence were extremely hindered.

2.6 Level of Education of caregivers

Education is an important factor in not only affording the caregivers employable skills but enhancing their chances to access stable forms of income, livelihood including enhanced abilities to care for orphans on antiretroviral therapy. With a higher level of education, chances are that care giving will be easier to understand and undertake than it would be

challenging if a caregiver is less educated. Access and uptake of services linked to the treatment of HIV and AIDS could be linked to the level of education of the patient, the treatment supporter and caregiver.

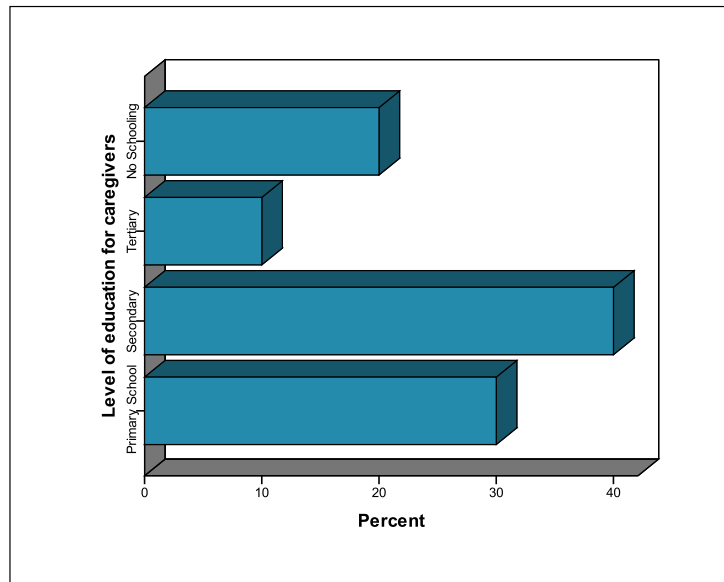


Figure 7 Education levels of caregivers

Figure 7 indicates that only 10% of the caregivers have earned a tertiary education, with the majority (40%) stating to have completed only up-to secondary school education. Only 30% completed primary school education as over 20% did not attend school at all. It is therefore safe to state that the caring roles of over 50% of the caregivers maybe met with challenges resulting from the effects of the low levels of education acquired or no education at all. Further, adherence to antiretroviral treatment can better be achieved if the caregiver is able to articulate how treatment works and how it adds value to the life of the patient. That is only achieved when a caregiver has a level of education to comprehend the explanations involved.

3. FAMILY SUPPORT AND CAREGIVING

Family support enhances the likelihood of adherence to antiretroviral treatment as a result of the constant support and care for the child living within a family setting. The child in a family may enjoy a variety of support sources from family members who from time to time may share the roles of care giving. In non-family settings, the likelihood that a child will depend on the sole care provision of an individual is high and dependent on the fact that such care is only available when the caregiver is available.

3.1 Findings related to the relationship between the caregivers and the children on ART.

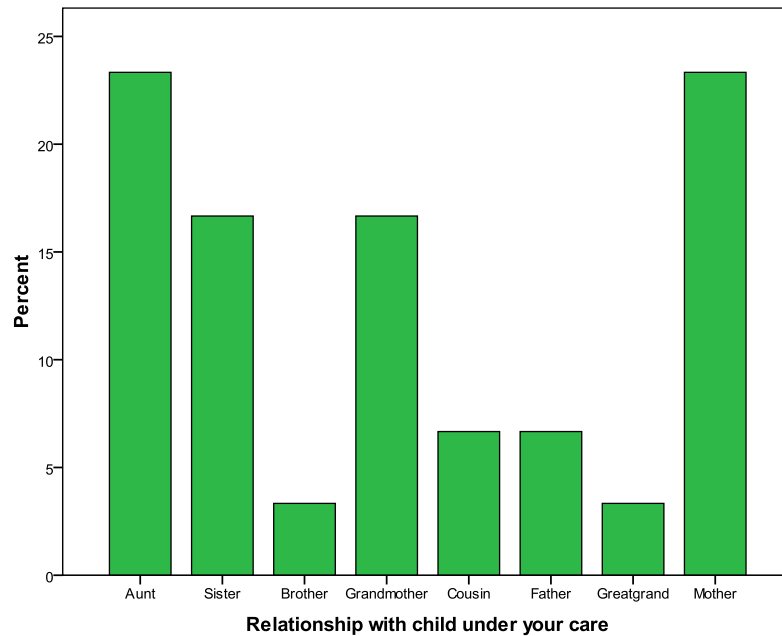


Figure 8 Relationship between child and caregivers

Results of this study indicate that approximately 30% of the children on treatment are cared for and supported by a surviving parent, mother or father – see figure 8 above. More children are however under the care of their aunts – approximately 25% as is the case for sisters (over 15%). Over 15% of the children are under the care of the grandmothers. The extended family system of the community studied affords children the care of relatives which is presumed stronger than if the children were placed with people they are not related to. It is also favoured by communities that relatives takeover the care of orphans than giving them to orphanages and government or private sector establishments that care for orphaned children. While this is true, it is always not easy to care for orphans as they are usually assumed as additional responsibilities considering that caregivers also have their own children. In the case of surviving parents who re-marry, the orphaned child may suffer the same consequences as a child born out of wedlock. Expenditure lines for the family budget including love and care target children born within that marriage primarily.

3.2 Findings as to whether the respondents had their own biological children other than the dependants.

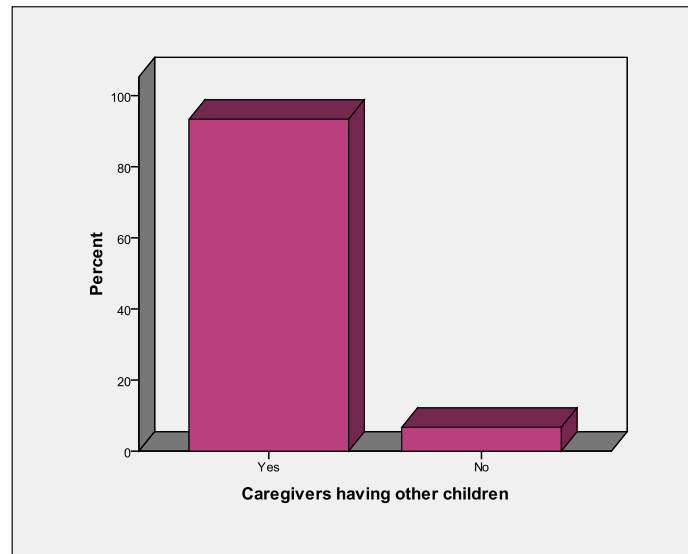


Figure 9 Caregivers having own biological children

Nearly 100% of the caregivers studied reported to have other biological children under their care. Biological children place a huge amount of caring pressure on the caregivers since they should provide the primary and usually all care required for the children they have. This responsibility singularly compromises the efficiency and effectiveness of caring for orphans on antiretroviral therapy. Further it results in over stretched budget expenditures of already meagre incomes, time and other valuable resources necessary in the responsibility of caring for children on HIV treatment.

3.3 Findings on the number of other children that the respondents have.

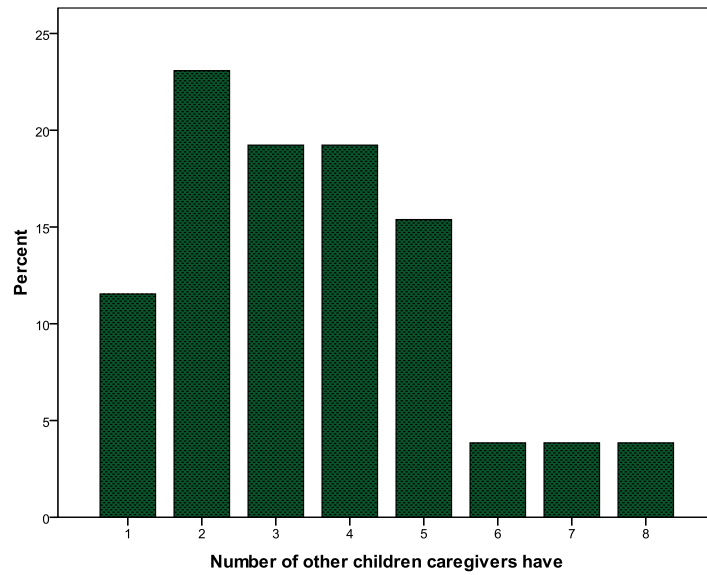


Figure 10 Number of other children that caregivers have

As it can be seen in figure 10, caregivers had varied numbers of other biological children in their care ranging from 1 – 8. The majority of the caregivers had 2 – 5 children. The number of children in an individuals care directly affects the quality of care a child on HIV treatment receives. Families with more children struggle to afford the children the love they may need including a compromised ability to meet children’s needs such as food, clothing, medical care and adequate housing.

3.4 Findings as to whether the respondents had any other dependants apart from their own biological children and the children on ART who are under their care.

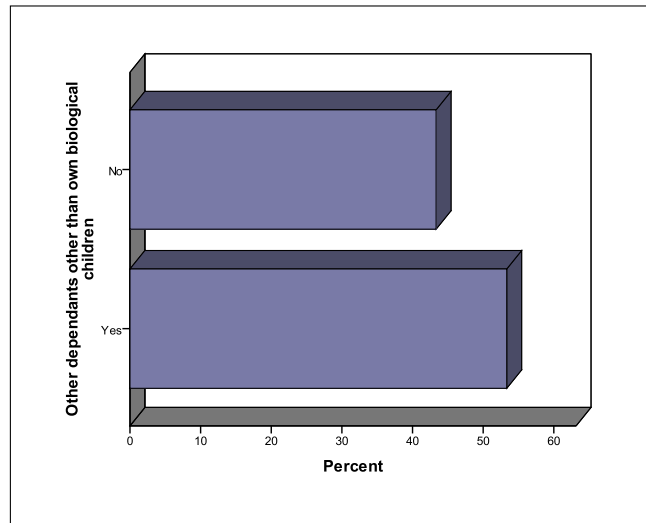


Figure 11 Caregivers with dependants other than their own children

Approximately 55% of the caregivers indicated that they had other dependants in addition to their own children. Dependants are usually children of relatives of the caregiver left in their care for various reasons. Undoubtedly some are orphans although they may not be necessarily living with HIV and on treatment. The added responsibility of these dependants is indicative of the quality of care children may receive which ultimately links to the level of adherence.

3.4.1 Findings related to the number of dependants that the respondents had apart from their own biological children and the children on ART who are under their care.

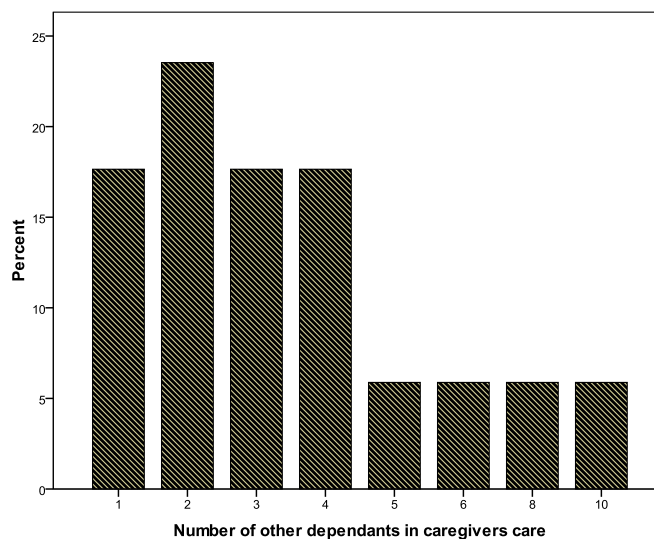


Figure 12 Number of dependants for caregivers

As is the case with own biological children, the number of dependants is crucial in determining the level at which the roles of care giving are fulfilled. The extent to which a child on HIV treatment receives support depends on how stretched the caregiver maybe in providing such care to her own children, other dependants and the orphan on antiretroviral treatment. While most caregivers indicated that they had 1-4 dependants (see table 12 above) added to their own biological children, it is important to note that some caregivers had over 5 and up-to 10 dependants. The burden of care giving was therefore undoubtedly overwhelming for the caregivers in this study, who generally were unemployed and did not have stable income.

3.5 Findings as to whether the respondents were the only persons responsible for their household?

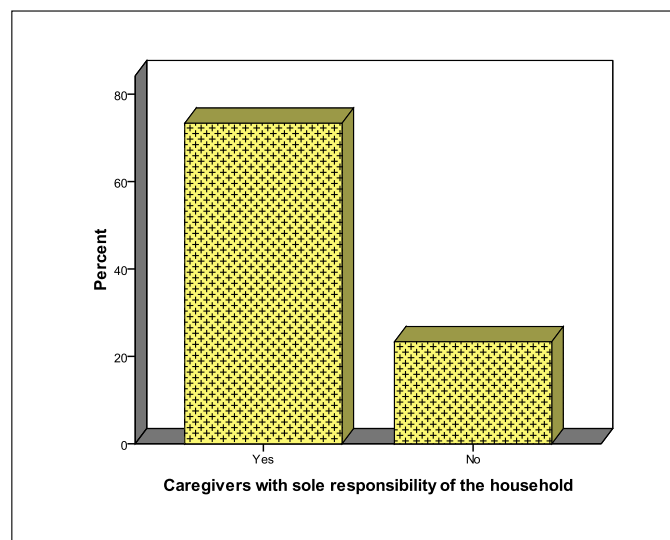


Figure 13 Caregivers with the sole responsibility for the household

The researcher further inquired from the respondents whether they were the only persons responsible for the household. It would be important to determine the level of responsibility of the caregiver to assess how well they may manage to provide the children on HIV treatment with the necessary support that result in good adherence. Figure 13 indicates that approximately 80% of the caregivers had the sole responsibility for their households compared to 20% who were not responsible for the entire household. The caring roles were again seen to be a challenge as caregivers were generally the heads of the households already indicated that they had other children and dependants.

3.5.1 Findings as to who renders assistance to those respondents who stated that they are not the only persons responsible for their household.

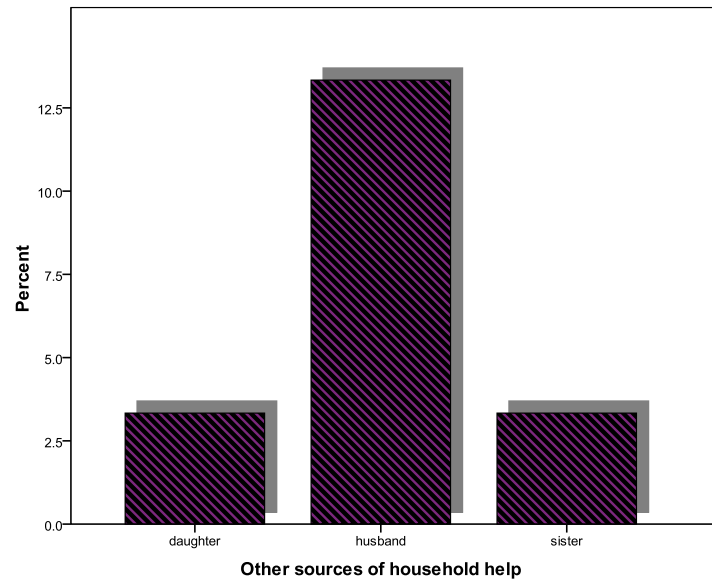


Figure 14 Other sources of support in household

Of the 20% caregivers who indicated they were not the only persons responsible for their household in figure 13, 12.5% stated that their husbands were responsible for the household while 2.5% stated that their daughters and sisters were responsible for the household. It can be noticed that in cases where a husband is responsible for the household, caregivers were to a large extent stable especially if such a husband was employed with a stable income compared to households headed by the brother's or sister's of the children on ART who could be young and unemployed. Noticeable also is that child headed households were a commonplace in communities affected by HIV and AIDS and especially girl children who assumed adult roles and responsibilities over their siblings at a very tender age, let alone an income to meet the needs of their households.

4. PSYCHO-SOCIAL SUPPORT

4.1 Findings as to the nature of psycho-social support that the respondents provide to the children under their care.

Overall all respondents provided a range of physical, emotional, psychological and financial support to the children under their care. However, most caregivers provided both financial and physical support to the orphans. A limited number of caregivers indicated that they were unable to provide proper psychological and emotional support. This could be due to the fact

that such support required the caregivers to have at least basic knowledge necessary to provide this kind of support.

4.2 Findings on the nature of psycho-social support that the respondents find to be the most challenging.

The respondents were asked to indicate the nature of psycho-social support that they found to be challenging. The majority of the caregivers indicated that emotional and psychosocial support was particularly challenging to provide to the orphans under their care. It was earlier indicated that this could be possibly because of the knowledge required to effectively provide this type of care. Caregivers who were not particularly educated or trained to provide this type of support may find it particularly challenging. Further, respondents revealed that family support especially from those members who are trained would help with this challenge.

In addition, respondents also indicated that financial support was challenging. In this study it has been identified that majority of the caregivers of orphaned children were unemployed and they had financial constraints because they were financially unstable.

4.3 Findings as to how the respondents can be assisted to overcome the challenges stated in 4.2

Most caregivers indicated that trainings and skills sharing forums would be helpful in especially focussing on the needs of the child. Other forms of assistance cited to mitigate the impact of the challenges in providing psychosocial support included employment creation, financial grants and cultivation of family support systems.

5. TREATMENT SUPPORT

Treatment support involves helping the child to take their medications as per doctor's prescription, monitoring how the child responds to treatment and keeping appointments for follow up with health care providers. As much as it is important for the children on ART to have treatment supporters, it is also imperative for these treatment supporters to receive adequate support for them to manage with their role of being a treatment supporter.

5.1 Treatment supporter

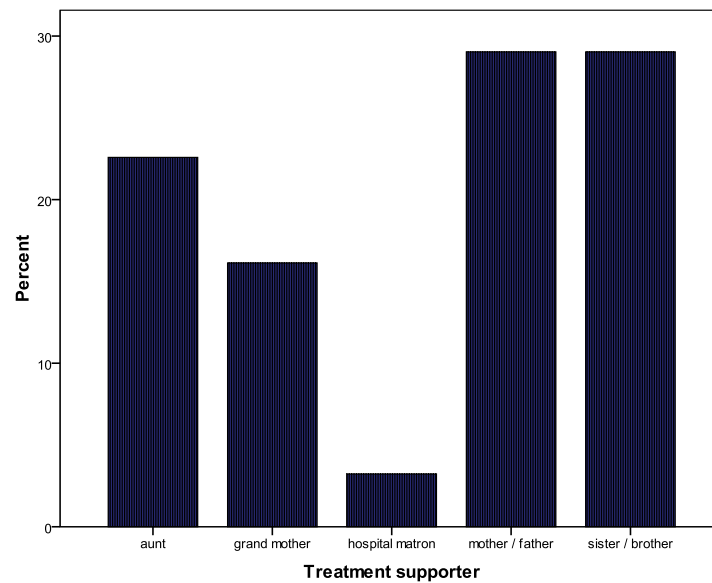


Figure 15 Treatment supporter

The majority of the children on treatment (60% see table 15 above) had their parents or brothers/sisters as their treatment supporters. Approximately 22% are aunts and over 28% grandmothers are treatment supporters. Performing the duties of a treatment supporter may greatly be influenced by the relationship between the treatment supporter and the child as an initial contributing factor to the effectiveness antiretroviral treatment. For instance, children whose treatment supporters are their parents are likely to receive more adequate support than those whose supporters are other relatives.

5.2 Findings as to whether the respondents knew what was required of them to be a treatment supporter.

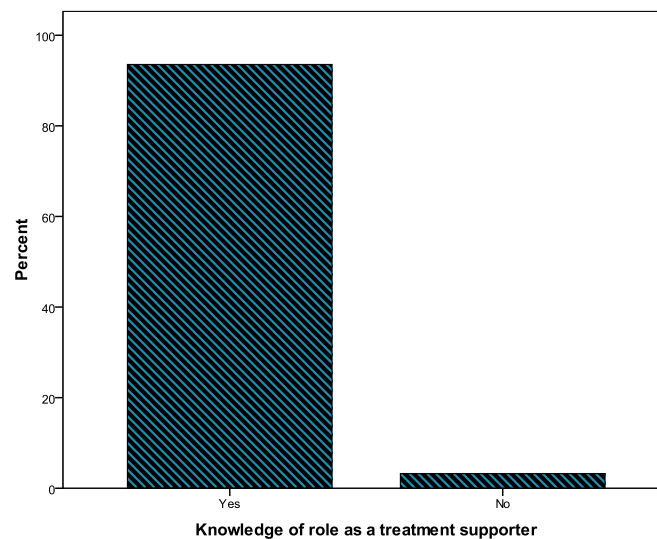


Figure 16 whether treatment supporters know their roles

Treatment supporters attended counselling sessions at the hospital before the children under their care initially started treatment. These sessions equipped caregivers with knowledge and skills required for them to administer the treatment. Figure 16 indicates that over 95% of the treatment supporters contended to be aware of what their roles were. The sessions could therefore be seen as being effective. It is probable that this knowledge should be easily translated into practice given that other circumstances discussed in this study favourably contribute to the identified problem. It was also noted that the involvement of the children in these counselling sessions is minimal even if they were old enough to comprehend the nature of their illness and what is required from them.

5.3 Findings on the respondent's opinion as to whether the health care providers gave them enough information to administer ART.

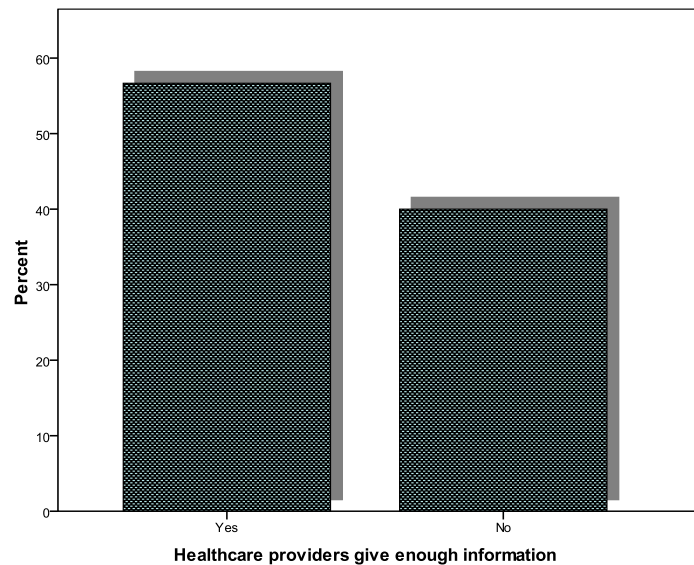


Figure 17 Health care providers given enough information

Approximately 60% of the caregivers rated the healthcare providers as giving adequate information on how to administer antiretroviral treatment to them. However, 40% believed that information provided was inadequate and that they needed more information for them to adequately perform their duties well. This finding is rather contradictory to the previous revelation where respondents stated that they knew what their roles entailed at over 95%. It should however be noted that the counselling sessions were not ongoing and the children on ART changed caregivers or they moved into other households with a new caregiver. While this is true, most caregivers rely on regular training to raise the awareness.

5.4 Findings on the number of years that the children have been on ART.

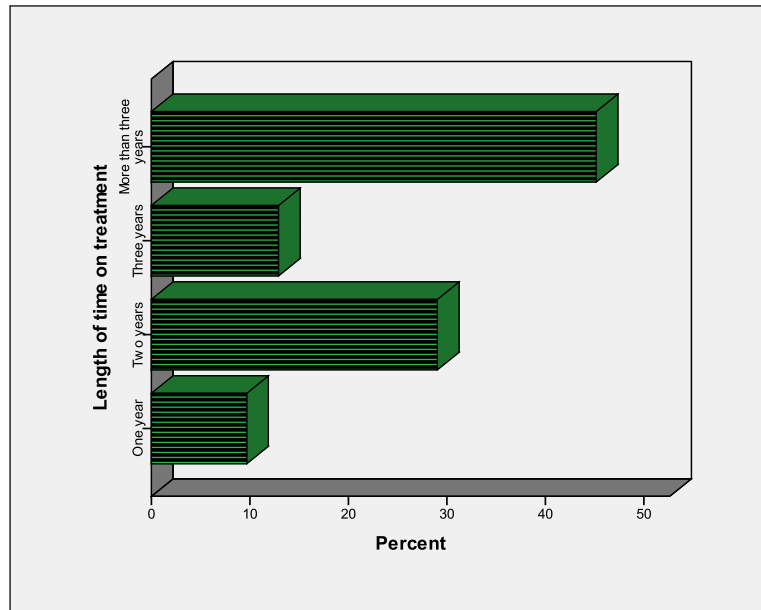


Figure 18 Length of the time the child is on treatment

The length of time a child is on treatment may be indicative of the response to treatment and the level of adherence to treatment. Overall, the children involved in the study were on treatment for at least one year with the majority – nearly 50% having been on treatment for more than three years. Thirty percent of the children were on treatment for two years with over 10% having been on treatment for three years. Approximately 10% of the children were on treatment for one year. Therefore, it can be stated that the children had responded rather positively to their treatment and the degree of adherence was average.

5.5 Findings as to whether the respondents have someone to assist the children to take their medication if they are not at home.

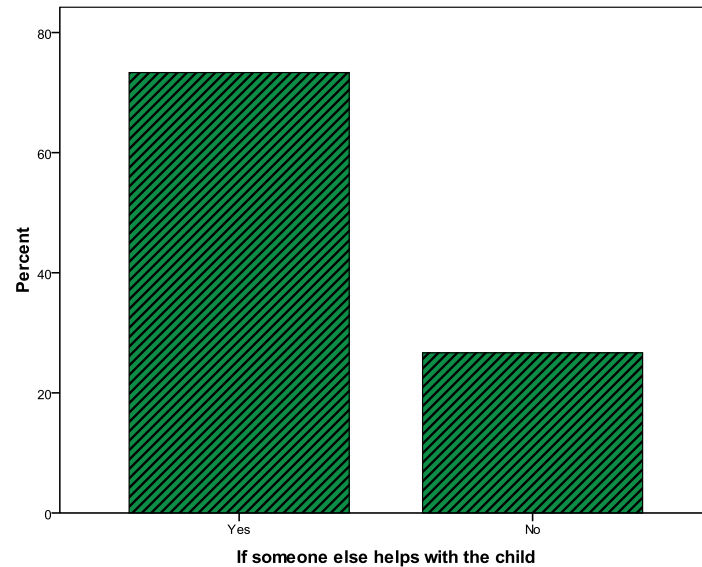


Figure 19 Availability of a helper with children other than caregiver

Seventy-eight percent of the respondents stated that they have someone to assist the children with taking medication while 22% stated that they do not have someone to assist the children take their medication when they are not at home (See figure 19 above). Availability of a helper other than the designated caregiver and/ or treatment supporter increases the likelihood of adherence and positive response to treatment for the children. This is so because in the absence of the caregiver, the helper ensures that the child takes the medication as per prescription. Most of the respondents who stated to had no helper indicated that the children under their care were old enough to take medication without supervision. In submitting this however, further assessments are necessary in determining the level of adherence for such children to treatment. Further, the oldest child in the study was aged only 15 and that could raise questions over the ability to effect self medication at such a young age.

6. ECONOMIC CIRCUMSTANCES

Individual abilities to meet the needs of children on antiretroviral treatment can be greatly influenced by the economic status of the caregiver. This status can be enhanced by the availability of a stable income, employment, and gender and property ownership. The researcher in this section intended to find out the economic status of the caregivers and how that influenced their level of care and ultimately the adherence to treatment of the children under their care.

6.1 Income

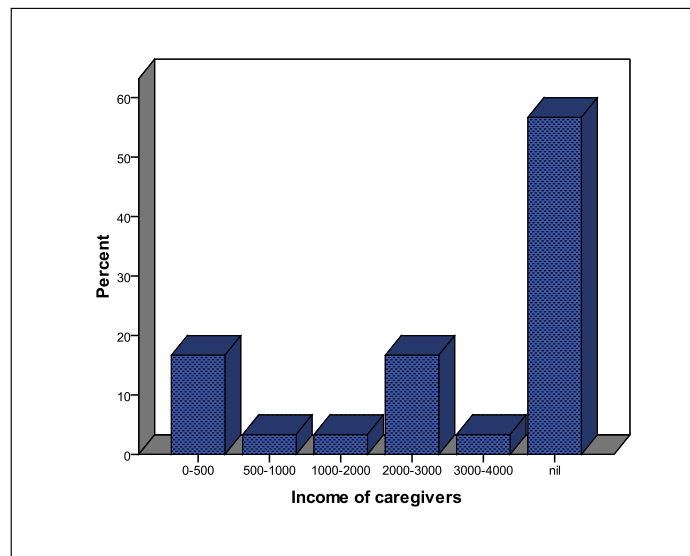


Figure 20 Income levels of caregiver

Figure 20 revealed that the majority of the caregivers (approximately 60%) do not have a monthly income. They were unemployed and had no alternative sources of monthly income like businesses or pensions and grants. Therefore a large number of children were under the care of persons who depended on stipends from other relatives, from people in their communities and goodwill handouts. In effect, this affects the adherence of the children on antiretroviral treatment.

Table 1 : Income as an influence for adherence

| Income in N\$ | | Adherent or not | | Total |
|------------------|------------|-----------------|--------|---------|
| | | Yes | No | |
| Nil | Count | 9 | 8 | 17 |
| | % Adherent | 47.40% | 72.70% | 56.70% |
| | % of Total | 30.00% | 26.70% | 56.70% |
| 1-500 | Count | 2 | 3 | 5 |
| | % Adherent | 10.50% | 27.30% | 16.70% |
| | % of Total | 6.70% | 10.00% | 16.70% |
| 500-1000 | Count | 1 | 0 | 1 |
| | % Adherent | 5.30% | 0.00% | 3.30% |
| | % of Total | 3.30% | 0.00% | 3.30% |
| 1000-2000 | Count | 1 | 0 | 1 |
| | % Adherent | 5.30 % | 0.00% | 3.30% |
| | % of Total | 3.30% | 0.00% | 3.30% |
| 2000-3000 | Count | 5 | 0 | 5 |
| | % Adherent | 26.30% | 0.00% | 16.70% |
| | % of Total | 16.70% | 0.00% | 16.70% |
| 3000-4000 | Count | 1 | 0 | 1 |
| | % Adherent | | | |
| | % of Total | 5.30% | 0.00% | 3.30% |
| Total | Count | 19 | 11 | 30 |
| | % of Total | 63.30% | 36.70% | 100.00% |

Table 1 reveals that the greater the income a caregiver earns the more the chances for adherence of the child under their care. Caregivers with an income above N\$500.00 do not report non-adherence. Caregivers with no income recorded the highest cases on non-adherence with significant cases of non adherence recorded for caregivers earning only up to

N\$ 500.00. There exists therefore a valid association between income and possible adherence to treatment.

6.2 Findings as to whether the respondents were the only breadwinners in their household?

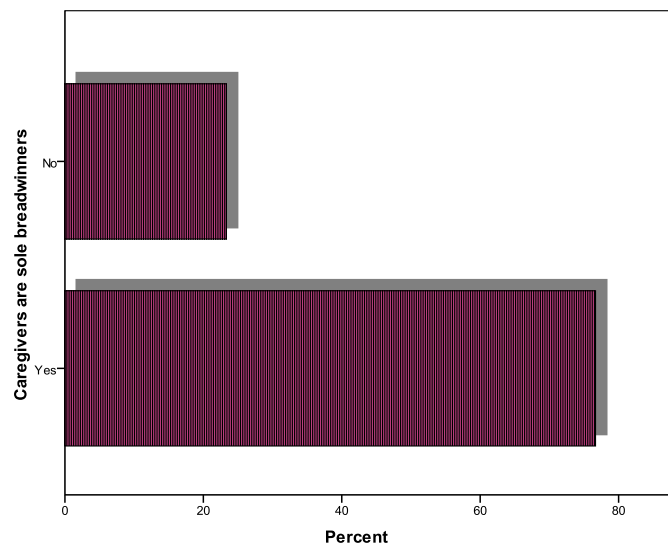


Figure 21 Caregivers are the only breadwinners for the household

While it is true that approximately 60% of the caregivers do not earn a monthly income, figure 21 above reveals that the majority of the caregivers (approximately 80%) remain the sole breadwinners for their households. Essentially this means that most households cannot meet their needs for food, including other housing and healthcare requirements. With an acute deficiency of these needs, adherence and response to antiretroviral treatment for the children is largely and negatively impacted.

6.3 Findings as to whether the income of the respondents was sufficient to meet the needs of the children on ART, their own children and other dependants under their care.

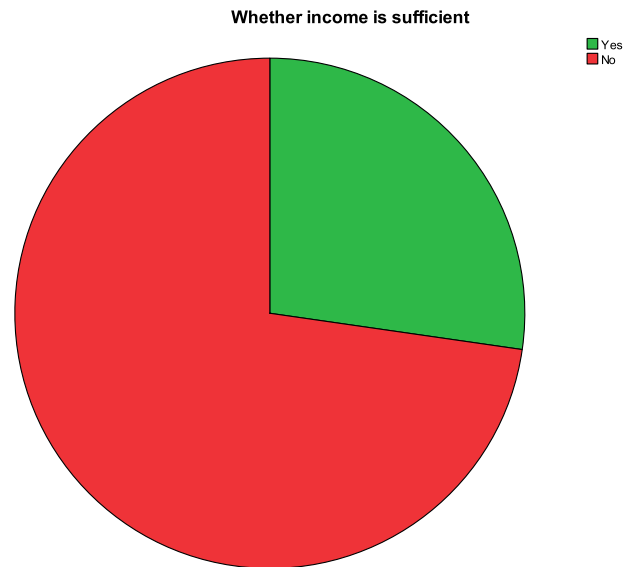


Figure 22 Caregivers income as sufficient from meeting the needs of children

As revealed in this study, only 40% of the respondents indicated to have had an income. Of these, over 72% revealed that their income was insufficient to meet the needs of the children under their care. Only 27% of the respondents who had an income could sufficiently meet the needs of the children under their care. It should be noted that those who indicated that they had an income to earned between 0 - N\$4000.00 with the majority earning 0-N\$500.00 per month.

Only 7% of the total respondents indicated that the deceased parents of the orphaned children under their care left an estate which could assist them with some of the needs of these children. Over 90% of the respondents had no sources of income left by the parents of the children under their care.

6.4 Findings as to how many respondents were receiving a social welfare grant from the government.

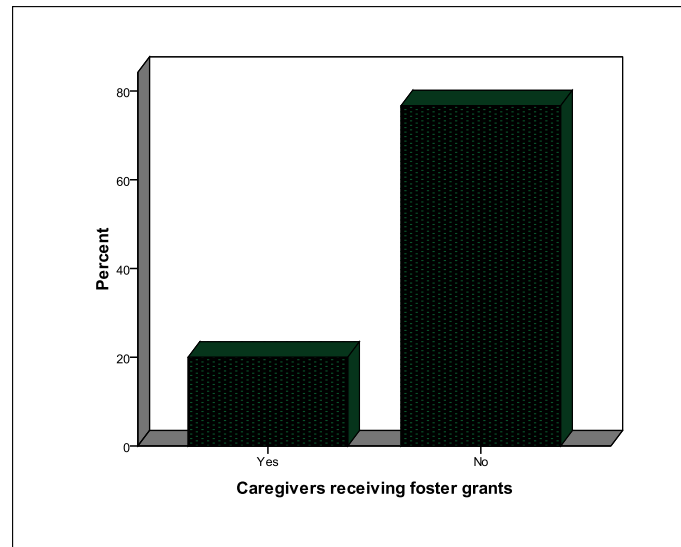


Figure 23 Caregivers receiving foster grants

The government of Namibia provides financial support to orphans and vulnerable children such as disability, maintenance and foster care grants. Of the orphans who were on ART, only 20 % were receiving foster care grants while 80% were not. However, the foster care grant is only N\$ 200-00 per child per month and it is insufficient to meet the needs children on antiretroviral treatment.

7. FOOD SECURITY

The positive response and adherence to HIV treatment is linked to the availability of nutritious food that compliments the treatment. Therefore, food security is essential in ensuring that the children on treatment get the optimal treatment benefits, adhere to their treatment and live longer productive lives. The researcher intended through this section to investigate the level at which caregivers had secure food sources sufficient to meet the nutritional needs of the children under their care.

7.1 Findings as to whether the respondents could afford a meal for at least three times a day for the children on ART.

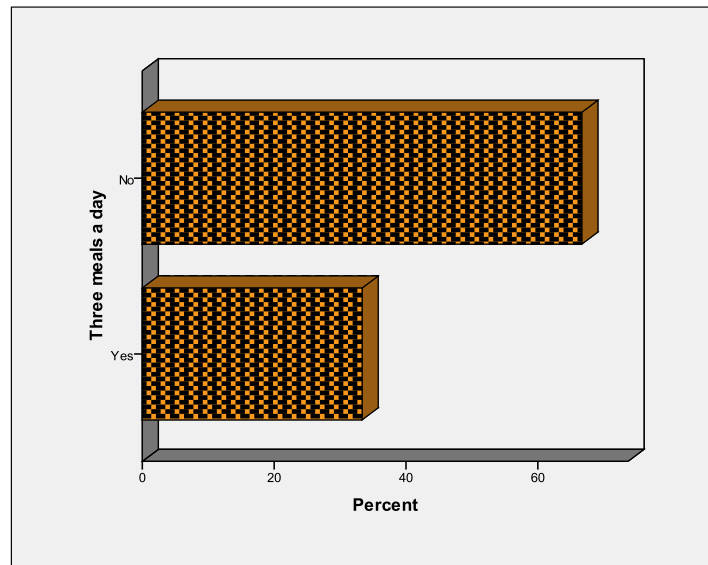


Figure 24 Caregivers can afford meals three times a day

Findings indicate that over 65% of the caregivers could not afford three meals a day for the children under their care. All respondents indicated financial constraints as the main reason why they could not afford three meals a day. Namibia is generally a dry and semi-arid country. Agriculture for subsistence is not common and communities depend on food bought from stores usually imported from South Africa. Therefore, without the money to purchase this food, caregivers ultimately have to depend on alternative sources of food. Respondents revealed that they access food from sources such as soup kitchens, food hampers from non-governmental organisations in their communities and drought relief supplies from the government.

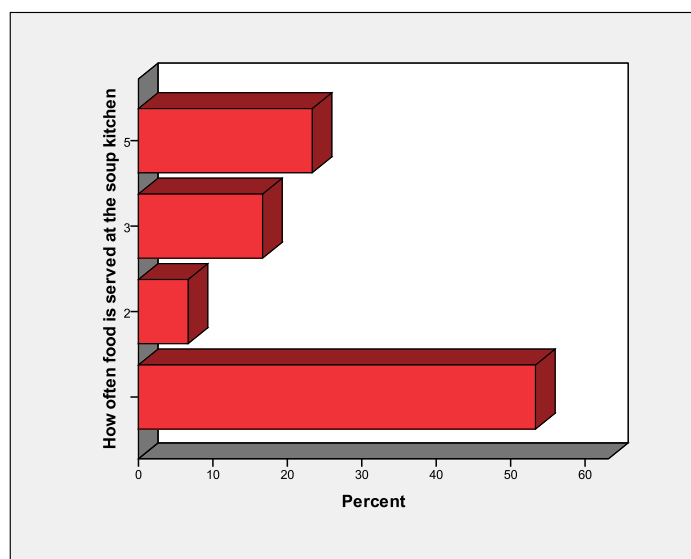


Figure 25 Frequency of food service at soup kitchens

Even with the option of a soup kitchen, figure 25 indicates that over 50% of the children in Okahandja constituency could not only survive on food from soup kitchens. For those who could access this food service it was still limited to a maximum of five days a week. Taking and committing to a lifelong treatment like antiretroviral therapy requires a consistent supply of food which in the end facilitates a positive response to treatment. Soup kitchens, a form of feeding scheme at community level, are operated by non-governmental organisations as an interim intervention to supplement and relieve the dire food needs for most orphans living with and are on HIV treatment. However these interventions meet severe challenges including financial constraints to sustain a constant food supply; and manpower to assist caregivers during the time that the children are at soup kitchens. For this reason, soup kitchens are not entirely a dependable food solution for children living with HIV and on antiretroviral therapy.

7.2 Findings as to whether the children on ART take food at all times before they take their medication.

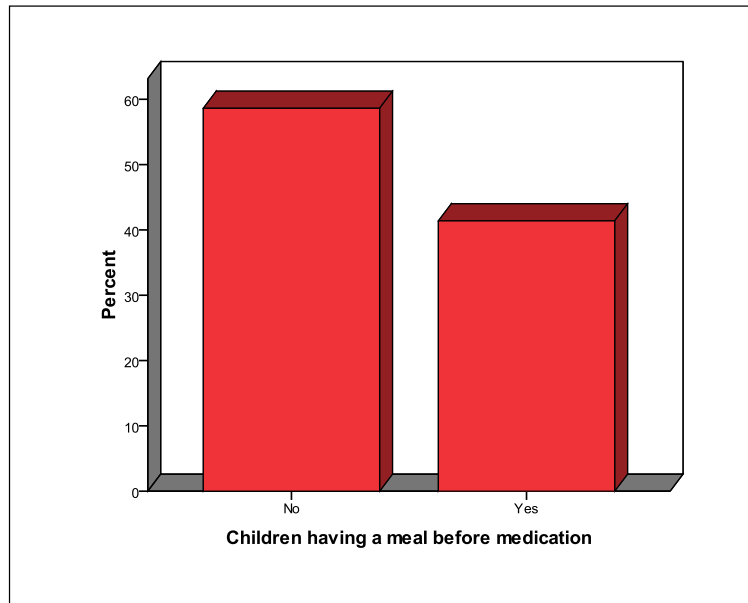


Figure 26 Children having a meal before they take their medication

With an acute scarcity of food and a limited availability of alternative sources of food, only very few children on treatment could afford to have a meal before they took their medication. Figure 26 above reveals that approximately 60% of the children on antiretroviral therapy did not have a meal before they took their medication. Only about 40% had a meal every time before they took their medication. Most of the children who had a meal before they took their medication were from families where the breadwinner was employed and earning a stable income and thus able to buy and maintain a constant supply of food.

8. FINDINGS FROM KEY INFORMANTS

Six key informants were selected for interview in this study. They included a medical doctor, two nurses based at the ART clinic, two community counsellors and a social worker. All key informants were employed by the Ministry of Health and Social Services and directly involved in the management and administration of antiretroviral treatment and wider services that included counselling, nursing and training of caregivers.

The doctor reviews the clinical aspects of the children and provides medication routinely. In cases where the child might have opportunistic infections, the doctor prescribes medication and monitors the progress of the child and watches for any adherence problems. Where necessary the doctor provides adherence counselling. In addition, the doctor provides regular

nutritional and general health assessment of the children and refers children on ART for other necessary support from service organisations in the community.

The nurses are involved with the assessment of the children on before referring them to the doctor. This assessment involves drawing blood to determine the CD4 count which indicative of the progress of the child on ART. They check the child's eligibility for tuberculosis prophylaxis and monitor the weight and growth of the child. They also monitor the side effects that the child on ART might develop or any opportunistic infections and refer them to the doctor for further interventions. Furthermore, they educate the children and their treatment supporters through adherence counselling and provide them with information on nutrition where necessary.

The community counsellors provide adherence counselling to the children on ART and their treatment supporters and refer them to other support organisations in the community.

The social worker provides counselling to the children and their treatment supporters when referred from the hospital. The social worker also conducts home-visits to assess the living circumstances of children specifically those who do not adhere to their treatment and compiles a report to determine the relevant intervention option. The social worker conducts hospital visits when children are admitted in the hospital so as to establish suitable interventions that would support treatment adherence. The social worker also links and refers the children and their treatment supporters to other organisations in the community if necessary for support.

All the key informants stated that the orphans on ART do not receive support necessary for them to adhere to it. The doctor stated that these children lack psychological, emotional, financial and spiritual support hence making it difficult for them to adhere to treatment. He also stated that many of these children do not know about their status and they do not receive counselling in a child friendly language that they would understand. This is in agreement with the earlier finding that psycho-social support is one of the areas where the caregivers of children on ART are lacking.

The nurse revealed that there is lack of proper treatment support for orphans on ART because of the frequent change of caregivers and this has a negative impact on the progress of treatment. The nurses also stated that they develop a relationship with their patients as health care providers and this makes it easier for them to follow-up and monitor the progress of

these patients. However, they observed that it becomes difficult for them to follow-up on orphaned children because they move from one caregiver to another or sometimes relocate without notifying their health care providers. This means that the nurses have to ensure that the new caregiver receives adherence counselling for them to manage and ensure proper progress of the child on ART. The nurses also stated that some caregivers who receive the social welfare grant from the government tend to misuse it and this makes the orphans especially prone to malnutrition because of food insecurity at household level.

One of the community counsellors also agreed that the orphans on ART do not receive adequate support necessary for them to adhere to treatment. The counsellors revealed that they received basic training on adherence counselling and this made them less able to provide their counselling services effectively. Nevertheless, caregivers receive adherence counselling for three weeks before the child is initiated to treatment for them to know how to manage and administer the treatment. The children on ART were less involved in counselling sessions as the counsellors dealt with the caregivers to a larger extent than the children.

The social worker stated that the orphans on lacked adequate support because of the poor support systems within families after the death of their parents. Extended family systems are exhausted with the increasing number of orphans leaving the caregivers with high numbers of dependants in their household to take care of. This makes the caregivers less able to provide emotional and psychological care to the orphans and both the financial and physical care needs which is necessary for them to adhere to their treatment are over burdened.

8.1 Findings on the main contributing factors that the key informants observed to have contributed towards the non adherence of orphans on ART

The doctor stated that the lack of treatment supporters and the frequent change of caregivers contribute to non adherence of orphans to their treatment. Further, communication barriers due the lack of trained and experienced child counsellors contributed to non adherence because most of the children did not know their status. The community counsellors cited lack of proper parental care as a contributing factor to non adherence. The community counsellors stated that the lack of a stable income for the caregivers contributed to non adherence because it had an effect on food security.

The nurses stated that the lack of committed treatment supporters and support from family members contributed to non-adherence. In addition, most of the caregivers were financially

unstable. Therefore they are less able to provide healthy foods to the children on ART. The social worker also cited lack of financial means and poor nutrition as contributing factors to non-adherence. Further, poor family support systems contributed to non-adherence.

8.2 Organisations that provide services to children on ART in Okahandja constituency.

Four referral non- governmental organisations were identified including Ileni Tulikwafeni in Five rand location, Orange babies in the town area, Okahandja Samaritans Network and Okahandja Home-based care in Nau-aib location. Ileni Tulikwafeni, Okahandja Home Based Care and Okahandja Samaritans network provided nutritional and psycho-social support to children. Orange babies only provided nutritional support. The Ministry of Gender Equality and Child Welfare was also identified for the provision of psycho-social support services to children.

Okahandja hospital provided nutritional support and plump nut to HIV positive babies who were underweight until they gained the targeted weight. Although the hospital provided medical support, it was observed that they were lacking in other areas of support to the children on ART such as emotional and psychological support.

The NGO's were sparsely located and could not effectively reach to provide services to children in Okahandja. The hospital played a major role in providing medical support and NGO's were equally highly involved in provision of psycho-social support services to children.

CHAPTER FIVE

CONCLUSION AND RECOMMENDATIONS

1. Conclusions

This chapter presents the conclusions and recommendations based on the data that was collected, analysed and interpreted.

In this study, it has been observed that most orphans on antiretroviral treatment do not adhere to their medication. The availability of antiretroviral treatment is a step ahead towards the management of HIV and AIDS. However, the unfortunate consequence of living in an era ravaged with HIV and AIDS and aggravated poverty levels, has left many children without proper care. This has had an influence on orphans who are on ant-retroviral treatment to adhere to their medication as their poor living conditions render them vulnerable. Okahandja constituency has an increasing number of orphans and vulnerable children due to HIV and AIDS some of whom are infected themselves. The extended families are now overburdened with the care of orphans and vulnerable children and the provision of quality care is not an easy task at all. There is a growing need to strengthen the family system to provide psycho social support so as to ensure that orphans and vulnerable children adhere to their treatment.

The majority of the caregivers of orphans on ART are unemployed and this has a negative effect on the treatment outcome of the children because their caregivers are less able to provide for their families. The poor economic status of these caregivers contributes to food insecurity because of insufficient food to cater for the entire in household. The inadequate supply of food influences non-adherence among children and results in poor nutrition which negatively affects the treatment outcomes. The majority of the orphans on ART either had less to eat or nothing at all.

The majority of the caregivers had a high number of dependants in their household and under their care and it is challenging to cope with the overwhelming responsibility of caring for a large family and at the same meet the needs of the children on ART. Most of the caregivers did not have family support and they were the only persons responsible to provide all the needs of the household. To a large extent, this made the caregivers less able to provide adequate psycho-social support to the children which consequently lead to non-adherence.

There is some a communication barrier because most of the caregivers do not have knowledge on how to use child friendly languages in communicating with the children about

their HIV status. The counsellors were not knowledgeable either in child counselling and as a result the children were less involved in the treatment process.

Health care providers paid more attention to the medical aspects of antiretroviral treatment. The majority of the children and their caregivers received psycho-social support from non-governmental organisations in the community. While this is true, service provision and the referral system was inadequately streamlined.

Caregivers were frequently changed and inconsistent. This resulted in some inconsistency in the treatment process and progress. It had a negative influence on the treatment outcome of the children on ART.

2. Recommendations

Health care providers should look beyond tablets and provide social, psychological, emotional and spiritual support for the children on ART to fully adhere to their treatment. The involvement of health care providers in providing psycho-social support to children is still minimal but can potentially be maximised. Health care and other service providers working with children on treatment should be trained in child and adolescent counselling.

The Ministry of Gender Equality and Child Welfare should be more involved in the provision of psycho-social support to children on ART.

Caregivers should be empowered with the knowledge to give optimal care to the children under their care. The majority of the caregivers did not have sound knowledge in the administration of ART for the children under their care. Implementation of an intensive education programme on adherence for both the child and caregiver prior to starting ART would be beneficial. This would help to identify and address the specific needs of each child and their family.

Child and adolescent adherence counselling deficiencies, nutritional as well educational needs should be provided as rights to children living with HIV.

Peer to peer and group counselling should be introduced among adolescents on ART for a positive treatment outcome.

Children who are on ART and do not receive proper care should be placed in residential child care facilities where care can be guaranteed from dedicated child care workers.

Social workers should ensure that caregivers of children who are on ART and are receiving social welfare grants use these grants to benefit the children.

Community counsellors should be afforded additional skills training in adherence counselling so as to deliver their services effectively and efficiently.

Government should strengthen the capacity of home based caregivers to give optimal care to children on ART including the strengthening of follow-up mechanisms as a way of monitoring the progress of children on ART and the quality of care they receive from their caregivers.

A comprehensive treatment care plan should be adapted by the relevant government ministries and other stakeholders to address the needs of orphans and vulnerable children on ART.

Food insecurity should be addressed by the relevant government and non-governmental organisations to strengthen the coping abilities of orphans and relieve the caregiver's burden of caring for orphans on ART.

The government should strengthen the capacity of community and church based organisations working with children on ART to maximise their service delivery.

The provision and coordination of services by government ministries working with children on ART should be improved.

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www.avert.org/subadults.htm

www.wfp.org

www.fao.org.hiv/aids

APPENDICIES

Appendix 1 - Questionnaire for Primary Respondents.

Appendix 2 - Questionnaire for Key informants.

Appendix 3 - Approval letter from the Permanent Secretary of Ministry of Health and Social Services to conduct the research.

Appendix 4 - Approval letter from the Principal Medical Officer of Okahandja State Hospital to conduct research.

Appendix 1

Questionnaire for primary respondents

PREAMBLE



STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

TITLE OF THE STUDY

What factors influence orphans to non adherence of antiretroviral treatment in Okahandja constituency?

You are kindly requested to participate in a research study conducted by Ms Yetambuyu Mumbuna holder of a Bachelors of Arts Degree in Social work and a Postgraduate graduate diploma in HIV/AIDS management from the Africa centre of HIV/AIDS management, at Stellenbosch University. I am a student at the University of Stellenbosch pursuing a Master of philosophy degree in HIV/AIDS management. You were selected as a possible participant in this study because you are a guardian/parent of orphans/non-orphans who are on antiretroviral treatment.

1. PURPOSE OF THE STUDY

This research study aims to establish the factors that influence orphans to non-adherence of antiretroviral treatment in Okahandja constituency.

2. PROCEDURES

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

- To answer questions relating the topic of this research study which will be in form of a questionnaire?
- The length of time that you will be expected to participate in this research study is 30 minutes.
- A translator will be used if you are of the opinion that you will be able to express yourself better in your own language.
- This exercise will be conducted at your place of residence so that you do not spend on transport and for your convenience.

3. POTENTIAL RISKS AND DISCOMFORTS

They will be no risks involved if you participate in this study. They may be some discomforts if you share some of the information that you consider confidential if the research study requires you to do so in the questionnaire. However, the researcher will explain thoroughly on the importance of sharing such confidential information to minimize or deal with some discomforts.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The findings and recommendations of this research study will benefit you because strategies will be formulated to address the difficulties you are facing in ensuring that the child/ren under your care adhere to their treatment. These strategies will be formulated based on the findings of this research study

Once completed, this research study will help policy makers and programme implementers at government and non-governmental level to design and implement programmes that will enhance antiretroviral treatment compliance of orphans who are on treatment. This will consequently improve the quality of lives of orphans and vulnerable children which is a good community development initiative.

5. PAYMENT FOR PARTICIPATION

You have been selected to participate in this study; however, the researcher would like to kindly inform you that they will be no payment to participate in this study.

6. CONFIDENTIALITY

Any information that will be obtained in this study and that can be identified with you will remain confidential. Information will only be disclosed with your permission or as required by law. Confidentiality will be maintained by means of safe record keeping at the Ministry of Gender Equality and Child Welfare offices. The final thesis will be kept at the ministry's resource centre on the special collection shelves where information can only be obtained on special request and it can only be used at the resource centre.

The information on the research study will only be made available to a third party if such a party wishes to provide support to the subjects in the study.

The names of the research subjects will not be used in the research at any stage or in the publication. The names and addresses of the subjects will be kept separately so that they can be easily contacted if any assistance is to be provided or available.

7. PARTICIPATION AND WITHDRAWAL

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

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact **Ms Yetambuyu Mumbuna** who is the researcher at office number **062- 500676** and at mobile number **081 2014532**, or at email address; **ymumbuna @ yahoo.co.uk** . Her research supervisor **Dr Greg Munro can be contacted at telephone number + 27- 83- 629 2567 or at email address; gregmunro@yahoo.com** .

9. RIGHTS OF RESEARCH SUBJECTS

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

The information above was described to [*me/the subject/the participant*] by [*name of relevant person*] in [*Afrikaans/English/Otjiherero, Oshivambo, Damara-Nama*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] were given the opportunity to ask questions and these questions were answered to [*my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

If you have read and understood the information provided and concede to take part in the study under the conditions outlined kindly tick in the box provided below.

| | |
|-------------------------|---------------|
| Please tick in this box | Date |
|-------------------------|---------------|

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____
[*name of the subject/participant*] and/or [his/her] representative _____
[*name of the representative*]. [He/she] was encouraged and given ample time to ask me any
questions. This conversation was conducted in [*Afrikaans/*English/Otjiherero, Oshivambo,
Damara-nama*] and [*no translator was used/this conversation was translated into*
_____ by _____].

Signature of Investigator

Date

CONFIDENTIAL

QUESTIONNAIRE FOR GUARDIANS/PARENTS OF ORPHANS AND NON ORPHANS WHO ARE ON ANTIRETROVIRAL TREATMENT

My name is Yetambuyu Mumbuna. I am pursuing my Master of philosophy degree in HIV/AIDS management at the University of Stellenbosch.

I am currently conducting a research study to establish the factors that influence orphans not to adhere to antiretroviral treatment in Okahandja constituency. Your kind co-operation to complete this questionnaire will be highly appreciated.

Please note that all information collected will be treated with confidentiality. Your honesty in answering the questions in this questionnaire will play an important role in the findings of this research. To avoid discrimination, orphans will be referred to as “children” in this questionnaire.

Contact details: Yetambuyu Mumbuna

Ministry of Gender Equality and Child Welfare

Tel: 062: 500676/502676

Mobile number: 081-2014532

Email: ymumbuna@yahoo.co.uk

INSTRUCTIONS

Kindly indicate whether the child/ren under your care is/are adherent or non-adherent to antiretroviral treatment by ticking in the box next to the answer that applies to you.

| | |
|---------------------|--|
| Adherent | |
| Non-Adherent | |

Please read the following questions carefully before you answer. Indicate your answer by ticking the answer or answers that apply in the spaces provided, unless otherwise instructed.

SECTION A – IDENTIFYING INFORMATION

1. What is your gender?

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

2. Kindly indicate your answer by ticking the age group in which you fall.

| | |
|---------------------|--|
| 20 – 30 | |
| 31 – 40 | |
| 41 – 50 | |
| 51 and older | |

3. Where do you stay?

| | |
|-------------------------------------|--|
| Five rand location | |
| Nau-aib location | |
| Oshetu number one location | |
| Oshetu number two location | |
| Oshetu number three location | |
| Veddersdal location | |

4. What is your marital status?

| | |
|-----------------|--|
| Single | |
| Married | |
| Divorced | |
| Widowed | |

| | |
|--|--|
| | |
|--|--|

5. What is your employment status?

| | |
|---------------------|--|
| Employed | |
| Unemployed | |
| Self-employed | |
| Retired (pensioner) | |

6. What is the highest level of education you have achieved?

| | |
|--------------------|--|
| Primary school | |
| Secondary | |
| Tertiary | |
| No schooling | |
| Technical training | |
| Other specify | |

SECTION B – FAMILY SUPPORT AND CAREGIVING

7. What is your relationship with the child/ren under your care?

| | | | |
|---------|--|-------------|--|
| Aunt | | Grandmother | |
| Uncle | | Grandfather | |
| Sister | | Mother | |
| Brother | | Father | |

7.1 Other specify in the space provided below

8. Do you have children?

| | |
|-----|--|
| Yes | |
| No | |

8.1 How many children do you have?

Specify the number in the space provided below

9. Do you have any other dependants apart from your own children and the children under your care?

| | |
|------------|--|
| Yes | |
| No | |

9.1 If your answer for question 9 is yes, how many dependants are you taking care of?

Please state the number in the space provided below.

10. Are you the only person responsible for the daily needs of ALL the children in your household?

| | |
|------------|--|
| Yes | |
| No | |

11. If your answer for question 10 is no, who else assists you with the daily care of the children in your household?

Please specify in the space provided below.

SECTION C – PSYCHO –SOCIAL SUPPORT

12. In which way of the following do you provide support to the child/ren under your care? You can have more than one answer in for this question.

| | |
|-------------------------|--|
| Physical | |
| Emotional | |
| Psychological | |
| Financial | |
| All of the above | |

**13. Which of the above-mentioned do you find to be the most challenging?
You can have more than one answer for this question.**

| | |
|-------------------------|--|
| Physical | |
| Emotional | |
| Psychological | |
| Financial | |
| All of the above | |

14. Why do you think it is the most challenging?

You can have more than one answer for this question.

| | |
|---|--|
| Unemployment | |
| Lack of parenting skills | |
| Lack of knowledge/training on the needs of a child | |
| Lack of family support | |

14.1 Other specify in the space provided below.

15. How can you be assisted to overcome this challenge? You can have more than one answer.

| | |
|---------------------------------------|--|
| Family support | |
| Social support networks | |
| Training on needs of the child | |
| Financial support | |

16. Do you receive any kind of support that helps you to meet some the needs of the child/ren under your care in the community where you live?

| | |
|------------|--|
| Yes | |
| No | |

16.1 If your answer for question 16 is yes, what type of support do you receive?

Please specify in the space provided below?

SECTION D – TREATMENT SUPPORT

17. Who is the treatment supporter for the child/ren under your care?

Please specify in the space provided below.

18. Do you know what is required of you to be a treatment supporter?

| | |
|------------|--|
| Yes | |
| No | |

19. For how long has the child/ren under your care been on antiretroviral treatment?

| | |
|------------------------------|--|
| One year | |
| Two years | |
| Three years | |
| More than three years | |

20. Have you been at the hospital or clinic to get some guidance on how you should administer the antiretroviral treatment for the child/ren?

| | |
|------------|--|
| Yes | |
| No | |

21. In your own opinion, do you think the health care provider gave you enough information to administer the ART?

| | |
|------------|--|
| Yes | |
| No | |

21.1 If your answer for question 21 is no? Please explain why in the space provided below

22. Do you go to the ARV clinic for follow-up visits all the time you are expected to do so?

| | |
|-----|--|
| Yes | |
| No | |

23. Do you face any challenges to manage to go for hospital follow-up visits?

| | |
|-----|--|
| Yes | |
| No | |

23.1 If your answer for question 23 is yes, what challenges do you face?

Please explain in the space provided below.

24. Do you have someone to assist the child/ren with taking their medication if you are not at home?

| | |
|-----|--|
| Yes | |
| No | |

25. If the answer to question 24 is no, what happens to the child/ren's treatment routine?

| | |
|--|--|
| The child does not take the medication | |
| The child takes the medication when you are back home | |
| The child is old enough to take the medication without your supervision | |

25.1 Other please specify in the space provided below.

26. Are you of the opinion that education on the administration of ART would assist you to better administer this treatment at home?

| | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

SECTION E - ECONOMIC CIRCUMSTANCES

27. How much is your income? Please indicate your answer by ticking in the space provided below.

| | |
|----------------------------|--------------------------|
| 0 – N\$ 500-00 | <input type="checkbox"/> |
| N\$ 500-00 – N\$ 1000-00 | <input type="checkbox"/> |
| N\$ 1000-00 – N\$ 2000 -00 | <input type="checkbox"/> |
| N\$ 2000-00 - N\$ 3000-00 | <input type="checkbox"/> |
| N\$ 3000-00 - N\$ 4000-00 | <input type="checkbox"/> |
| N\$ 5000-00 and above | <input type="checkbox"/> |

28. Are you the only breadwinner in your household?

| | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

29. Do you have any other income apart from what you have stated above?

| | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

30. Is your income sufficient enough to meet the needs of the children under your care and your own children?

| | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

31. If you do not have any stable income how do you survive? Please explain in the space provided below.

32. Did the parents of the child/ren you are taking care of leave any estate?

| | |
|-----|--|
| Yes | |
| No | |

33. Do you receive a social welfare grant?

| | |
|-----|--|
| Yes | |
| No | |

34. If your answer for question 33 is yes, can you manage to take care of the financial needs of the child/ren under your care with this social welfare grant?

SECTION F – FOOD SECURITY

35. Can you afford to provide at least three meals for the child/re under your care?

| | |
|-----|--|
| Yes | |
| No | |

36. If your answer for question 35 is no, what are the reasons? Please provide your answer in the space provided below.

37. Do the child/ren you are taking care of belong to any soup kitchen in the area where you live?

| | |
|-----|--|
| Yes | |
| No | |

**38. How many times in a week do they benefit from this soup kitchen?
Please state the answer in the space provided below?**

39. Does the child /ren on antiretroviral treatment take food at all times before the take their medication?

| | |
|-----|--|
| Yes | |
| No | |

40. If your answer for question 40 is no, explain why in the space provided below.

THANK YOU FOR YOUR PARTICIPATION!

Appendix 2

Questionnaire for key informants

PREAMBLE

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH



TITLE OF THE STUDY

What factors influence orphans to non adherence of antiretroviral treatment in Okahandja constituency?

You are kindly requested to participate in a research study conducted by Ms Yetambuyu Mumbuna holder of a Bachelors Degree in Social work and a Postgraduate graduate diploma in HIV/AIDS management from the Africa centre of HIV/AIDS management, at Stellenbosch University. I am a student at the University of Stellenbosch pursuing a Master of philosophy degree in HIV/AIDS management. You have been selected as a possible participant in this study because you are a health care provider who provides services to children on ART.

PURPOSE OF THE STUDY

This research study aims to establish the factors that influence orphans to non-adherence of antiretroviral treatment in Okahandja constituency.

PROCEDURES

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

- To answer questions relating the topic of this research study which will be in form of a questionnaire?
- The length of time that you will be expected to participate in this research study is 30 minutes.
- This questionnaire will be self administered; however, the researcher will be available if you may need any clarity.
- This exercise will be conducted at your work place so that the researcher can easily reach you if need any clarifications and for your own convenience.

POTENTIAL RISKS AND DISCOMFORTS

There will be no risks involved if you participate in this study. You may consider it unethical to share some information about your patients if you are of the opinion that such information is highly confidential. The researcher initially obtained permission from the permanent secretary of the Ministry of Health and Social Services and the Principal Medical Officer will be able to enlighten you on the nature of information that you may not reveal to the researcher provided it is on reasonable grounds.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

This research study will benefit you because the findings and recommendations of this study will be used in the strategic formulation of policies that will be used to address challenges that you may be facing in ensuring that the children on ART adhere to their treatment. These strategies will be formulated based on the findings of this study.

Once completed, this research study will help policy makers and programme implementers at government and no-governmental level to design and implement programmes that will enhance antiretroviral treatment compliance of children who are on treatment. This will consequently improve the quality of lives of orphans and vulnerable children which is a good community development initiative.

PAYMENT FOR PARTICIPATION

You have been selected to participate in this study; however, the researcher is kindly informing you that there will be no payment to participate in this study.

CONFIDENTIALITY

Any information that will be obtained in this study and that can be identified with you will remain confidential and will only be disclosed with your permission or as required by law. The final thesis will be kept at the ministry's resource centre on the special collection shelves where information can only be obtained on special request and it can only be used at the resource centre.

The information on the research study will only be released to any other third party if such a party wishes to provide support to the subjects in the study.

The names of the research subjects will not be used in the research at any stage or in the publication. The names and addresses of the subjects will be kept separately so that they can be easily contacted if any assistance is to be provided or available.

PARTICIPATION AND WITHDRAWAL

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

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact **Ms Yetambuyu Mumbuna** who is the researcher at office number **062- 500676/502676** and at mobile number **081 2014532**, or at email address; **ymumbuna @ yahoo.co.uk** . The researcher's supervisor **Dr Greg Munro can be contacted at telephone number + 27- 83- 629 2567 or at email address; gregmunro@yahoo.com .**

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Malenè Fouchè

(mfouche@sun.ac.za; 021 808 4622) at the Division for Research Development, Stellenbosch University.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [*me/the subject/the participant*] by [*name of relevant person*] in [*English*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] were given the opportunity to ask questions and these questions were answered to [*me/my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*] and/or [*his/her*] representative _____ [*name of the representative*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*English*] and [*no translator was used*].

Signature of Investigator

CONFIDENTIAL

QUESTIONNAIRE FOR KEY INFORMANTS TO ASSIST WITH THE DATA COLLECTION ON THE FACTORS THAT INFLUENCE ORPHANS WHO ARE ON ANTIRETROVIRAL TREATMENT AND THEY ARE NOT ADHERING TO THEIR TREATMENT.

My name is Yetambuyu Mumbuna. I am pursuing my Master of philosophy degree in HIV/AIDS management at the University of Stellenbosch.

I am currently conducting a research study to establish the factors that influence orphans not to adhere to antiretroviral treatment in Okahandja constituency. Your kind co-operation to complete this questionnaire will be highly appreciated.

Please note that all information collected will be treated with confidentiality. Your honesty in answering the questions in this questionnaire will play an important role in the findings of this research.

Contact details: Yetambuyu Mumbuna

Ministry of Gender Equality and Child Welfare

Tel: 062: 500676/502676

Mobile number: 081-2014532

Email: ymumbuna@yahoo.co.uk

INSTRUCTIONS

Please complete the questionnaire by marking the appropriate responses with an X in the space provided unless instructed otherwise. Your honesty in answering this questionnaire will play a vital role in the findings of this research. Information gathered will be treated strictly confidential.

1. What is your profession?

| | |
|----------------------|--|
| Community Counsellor | |
| Doctor | |
| Nurse | |
| Social Worker | |

2. What services do you provide to children on antiretro viral therapy? Please explain in the space provided below.

3. In your own opinion, do orphans receive adequate support necessary for them to adhere to their treatment?

4. Which areas do you think the lack support that is important for them to adhere to their treatment?

5. According to your observation and experience, what are the main factors contributing towards the non-adherence of orphans to their treatment? Please explain in the space provide below.

6. Apart from the services that you provide to these children, what other services exist in your area for orphans on antiretroviral treatment that to assist them adhere to their treatment?

7. What recommendations would you make that will assist in ensuring that orphans on antiretroviral treatment adhere to their treatment?

THANK YOU FOR YOUR PARTICIPATION!



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: (061) 2032562

Fax: (061) 272286

E-mail: hilmanangombe@yahoo.com

Enquiries: Ms. H. Nangombe Ref.: 17/3/3/AP

Date: 26 January 2010

OFFICE OF THE PERMANENT SECRETARY

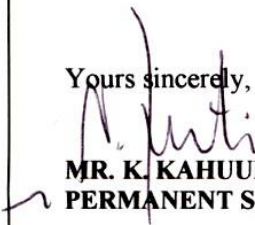
Ms. Yetambuyu Mumbuna
P. O. Box 900
Okahandja
Namibia.

Dear Ms Mumbuna,

RE: What factors influence double orphans to non adherence of antiretroviral treatment in Okahandja Constituency?

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. Kindly be informed that approval has been granted under the following conditions:
 - 3.1 The data collected is only to be used for academic purpose;
 - 3.2 A quarterly progress report is to be submitted to the Ministry's Research Unit;
 - 3.3 Preliminary findings are to be submitted to the Ministry before the final report;
 - 3.4 Final report to be submitted upon completion of the study;
 - 3.5 Separate permission to be sought from the Ministry for the publication of the findings.

Yours sincerely,


MR. K. KAHURE
PERMANENT SECRETARY





REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Attention:

To:

Mr. Sidney Engelbrecht
Division for Research and Development
Stellenbosch University

From:


Dr. L.J.P. Tumba /PMO.
Okahandja State Hospital
Private Bag 2026
Tel: (062) 503030
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Re: Letter to the research ethics committee (Stellenbosch University)

Dear Sir,

Please be advised that **Ms. Yetambuyu Mumbuna** got approval from the Ministry of Health and Social Services for research data collection in Okahandja district and conditions where set in the MOHSS/Permanent Secretary correspondence, **Ref 17/3/3/AP**,

Yours Sincerely


Dr. Tumba
PMO
Okahandja Hospital

"Health for All"