AN EDUCATIONAL PROGRAMME TO SUPPORT THE CAREGIVERS OF ADOLESCENTS LIVING WITH HIV REGARDING DISCLOSURE IN OSHIKOTO REGION, NAMIBIA.

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ABSTRACT

In 2017 about 1.8 million adolescents, between the ages of 10 and 19, were living with human immunodeficiency virus (HIV) worldwide, accounting for about 5% of all people living with HIV and about 16% of new adult HIV infections. Adolescents living with HIV (ALHIV) present a significant proportion of new infections of HIV in Namibia as well. The caregivers of ALHIV are faced will the difficult decision of when, and how to inform their children of their HIV status.

The purpose of this study was to explore and describe the experiences of caregivers of ALHIV regarding disclosure in Oshikoto region, Namibia. The study included the development of an educational programme to support such caregivers and to facilitate their disclosure practices.

This was a qualitative, descriptive study with an explorative and contextual design. The findings were that caregivers of ALHIV experienced barriers to disclose HIV status to ALHIV; they experienced emotional trauma, and experienced mixed feelings related to adolescents' diagnosis with HIV. Caregivers experienced resistance from ALHIV to take antiretroviral therapy (ART). However, the study found that non- biological parents are at ease to care for ALHIV, because they are probably less emotionally attached to the child.

The findings were used to develop an educational programme to support the caregivers of ALHIV regarding disclosure. The educational programme was implemented and evaluated in the final phase of the study and indicated that the educational programme has a potential to help caregivers of ALHIV regarding disclosure of their status.

Recommendations from the findings are that there are needs for a more large scale introduction of healthcare workers to support caregivers regarding disclosure of HIV status to ALHIV for healthy living of adolescents concerned. Additionally, the study recommended further studies on evaluation of the effectiveness of the educational programme and the role of the family characteristics in disclosure practices.

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AIDS:	Acquired immunodeficiency syndrome
ALHIV:	Adolescents living with HIV
ART:	Anti-retroviral therapy
CDC:	Centre for disease control and prevention
HIV:	Human immunodeficiency virus
FGD:	Focus group Discussion
IEC:	Information, education and communication
MoHSS:	Ministry of Health and Social Services
NIMART:	Nurse Initiated Management of Antiretroviral Therapy
NSA:	Namibia Statistics Agency
PHC:	Primary healthcare
UNAIDS:	Joint United Nations Programme on AIDS
UNICEF:	United Nations Children's Emergency Fund
WHO:	World Health Organisation

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This study is dedicated to the loving memories of my beloved parents meme Ester Nakangula Asser and tate Nikanor Mbonge yaMvula yaKambonde kaMpingana, who remain a source of inspiration, and were both generous of heart and constant in faith. Thank you for teaching me to face life with enthusiasm and the fear of God.

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DECLARATION

I, Ottilie Tangeni Omuwa Ikeakanam, hereby declare that this study titled: *An educational programme to support the caregivers of adolescents living with HIV regarding disclosure in Oshikoto region, Namibia,* is the true reflection of my own research work. This work has not been submitted for a degree in any other institution of higher learning. No part of this dissertation may be reproduced, stored in any retrieval system, or transmitted in any form, or by means of mechanical, electronic, photocopying, recording or otherwise without the prior permission of the author, or the University of Namibia on her behalf.

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CHAPTER 1

INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 INTRODUCTION

There were about 1.8 million adolescents, between the ages of 10 and 19 years old, living with human immunodeficiency virus (HIV) worldwide in 2017. Adolescents account for about 5% of all people living with HIV and about 16% of new adult HIV infection (WHO.2017). The regions with the highest numbers of HIV positive adolescents are sub-Saharan Africa and South Asia. Of the 1.8 million adolescents living with HIV (ALHIV), about 1.5 million (85%) live in sub-Saharan Africa. Worldwide adolescents and young people represent a growing share of people living with HIV (United Nations Children Emergency Fund and Joint United Nations Programme on AIDS (UNICEF & UNAIDS, 2017).

Due to the success continuum of HIV care, and antiretroviral treatment (ART), a growing number of children become adolescents; as the latter grow older the issue of informing them of their HIV status arises (WHO, 2016). Caregivers are faced with the difficult decision of when, and how to inform their child of his/her HIV status (Ministry of Health and Social Services [MOHSS], 2012).

Namibia remains one of the countries with the highest HIV prevalence in the world, namely, a prevalence rate of 18.8%. Adolescents represent 23% of the total population of Namibia. The total number of Namibian ALHIV is estimated as 11 035: 6 087 girls and 4 948 boys (Namibia Statistics Agency [NSA], 2013).

Amaambo (2018) reported that in Namibia 5161 children aged between 10 and 14 years old are on ART, as are 6107 children aged 15 to 19 years old.

Adolescents living with HIV (ALHIV) continue to present a significant proportion of new infections of HIV in Namibia. They represent a new generation, which were not considered in the early days of the epidemic in the country. The majority of Namibian adolescents currently living with HIV have been positive since they were born or contracted HIV as infants via breastfeeding. A few were infected through early sex debut or behavioral sexual transmission or through sexual abuse (National Guidelines on Adolescents Living with HIV, 2012).

Adolescence is a transitional period from childhood to adulthood and poses challenges that have to be handled with care. Adolescents living with HIV (ALHIV) are not exceptional; therefore their caregivers need to have sufficient knowledge and skills to cope with the situation. HIV not only touches the lives of those infected, but also has negative impacts on the lives of caregivers especially in the area of disclosure of the HIV status to the adolescents. Many children in Namibia who are living with HIV and started on ART are at age when they would know their HIV status. Caring of ALHIV regarding disclosure by their caregivers has received little or no attention in the Oshikoto region.

According to the United Nations Children Fund (2015) most caregivers of ALHIV are living in fear that their respective child's health and nutrition are compromised due to HIV; therefore have concerns over treatment failure, treatment adherence and consequences of disclosing the HIV status to their respective children. Both negative and positive social, psychological, and behavioral impacts of disclosure to children have been reported, including improved adherence to medication regimens. A study done in Uganda found that parents/caregivers may be concerned about possible stigma and discrimination and may also experience internalised stigma and negative feelings, including shame, guilt and fear (Lorenz, Grant, Muyindike, Maling, Card, Henry & Nazarali, 2016). Many parents/caregivers feel challenged to disclose their own or the child's HIV status because they often are concerned about possible adverse consequences of the disclosure, uncertain about the disclosure process and not confident that they can handle children's reactions to HIV status disclosure (Li, De Wit, Qiao & Sherr, 2015).

Additionally, there is a need for focused research on caregivers of ALHIV that explores the experiences, disclosing the HIV status to adolescents, challenges, parenting behaviors, mental wellbeing, family support, social networking and coping mechanism in their daily life context (McHugh, Simms, Chikwira, Majuru, Nathoo, Chonzi, Munyati, Dauya, Bandason, Busza & Ferrand, 2018).

In sub-Saharan African countries, as well as in most parts of Namibia, parents, extended families, grandparents, aunts, cousins and other family members care for most orphans including those living with HIV. These caregivers are often elderly women who take care of the children after the death of their parents (Britto, Mehta, Thomas & Shet, 2016) Many caregivers have unresolved grief stemming from fear of the loss of a child if their child finds out she or he is living with HIV (Hayfron-benjamin, Obiri-Yeboah, Ayisi-Addo, Siakwa & Mupepi, 2018).

Many caregivers of ALHIV lack disclosure skills because they have not been trained on how to tell the child about their HIV status (Madiba & Mokwena, 2016). The caregivers have also fear to be confronted by the ALHIV if they ask them their own HIV status.

Age-disaggregated data was not available to determine the exact number of adolescents receiving ART in Namibia in 2012. According to the 2008/09 reports of the Ministry of Health and Social Services (MOHSS), it was estimated that the impact of HIV was that approximately 14000 Namibian children aged 0-4 years, and 6100 adolescents aged 10-19 years, were living with HIV (National Guidelines on Adolescents Living with HIV, 2012).

Namibia has made remarkable progress since rolling out ART in 2003. About 93% of patients who enrolled in the programme are alive; their health status has improved and they are leading productive lives (MOHSS, 2014). With the availability of an ART programme in Namibia, and throughout the world, many children living with HIV have access to care and treatment services: they are now surviving and entering into adolescence. This population of adolescents is now older, healthier and living with HIV as a chronic illness. Therefore proper strategies should be in place to support the caregivers of ALHIV in Namibia, specifically in the Oshikoto region. Such strategies are necessary for them to deal with the challenges they are facing regarding HIV disclosure to avoid accidental disclosure to their respective adolescent or the latter overhearing conversation over their status.

Namibia is a country in south-western Africa that covers approximately 824,000 square kilometres. It is bordered by the Atlantic Ocean in the west, Angola and

Zambia in the north, Botswana in the east, and South Africa in the south and east. The country's population in 2011 was 2,113,077 (Namibia Population and Housing Census, 2011).

Namibia is divided into 14 regions: Erongo, Hardap \\Karas, Kavango East, Kavango West, Khomas, Kunene, Ohangwena, Omaheke, Omusati, Oshana, Oshikoto, Otjozondjupa, and Zambezi (see Figure 1.1). Seven regions, namely, Zambezi, Kavango East and West, Omusati, Otjozondjupa, Khomas, and Erongo, were identified as the high burden regions that are mostly in need of support to address HIV among adolescents (Report on Phase 1 of THE NAMIBIA "ALL IN" country assessment, 2015). Although the Oshikoto region was not among them it recorded about 1,350 adolescents living with HIV; 796 adolescents are on ART. About 75% of ALHIV are orphans; they live with the caregivers, such as grandparents, aunts, cousins or uncles. The remaining 25% of ALHIV live with one or both biological parents. In terms of the number of ALHIV the immediate neighboring region of Oshana recorded 400 and the Ohangwena region recorded 527. This high number of ALHIV in the Oshikoto region indicates that there are many caregivers who take care of more than one adolescent in the community.

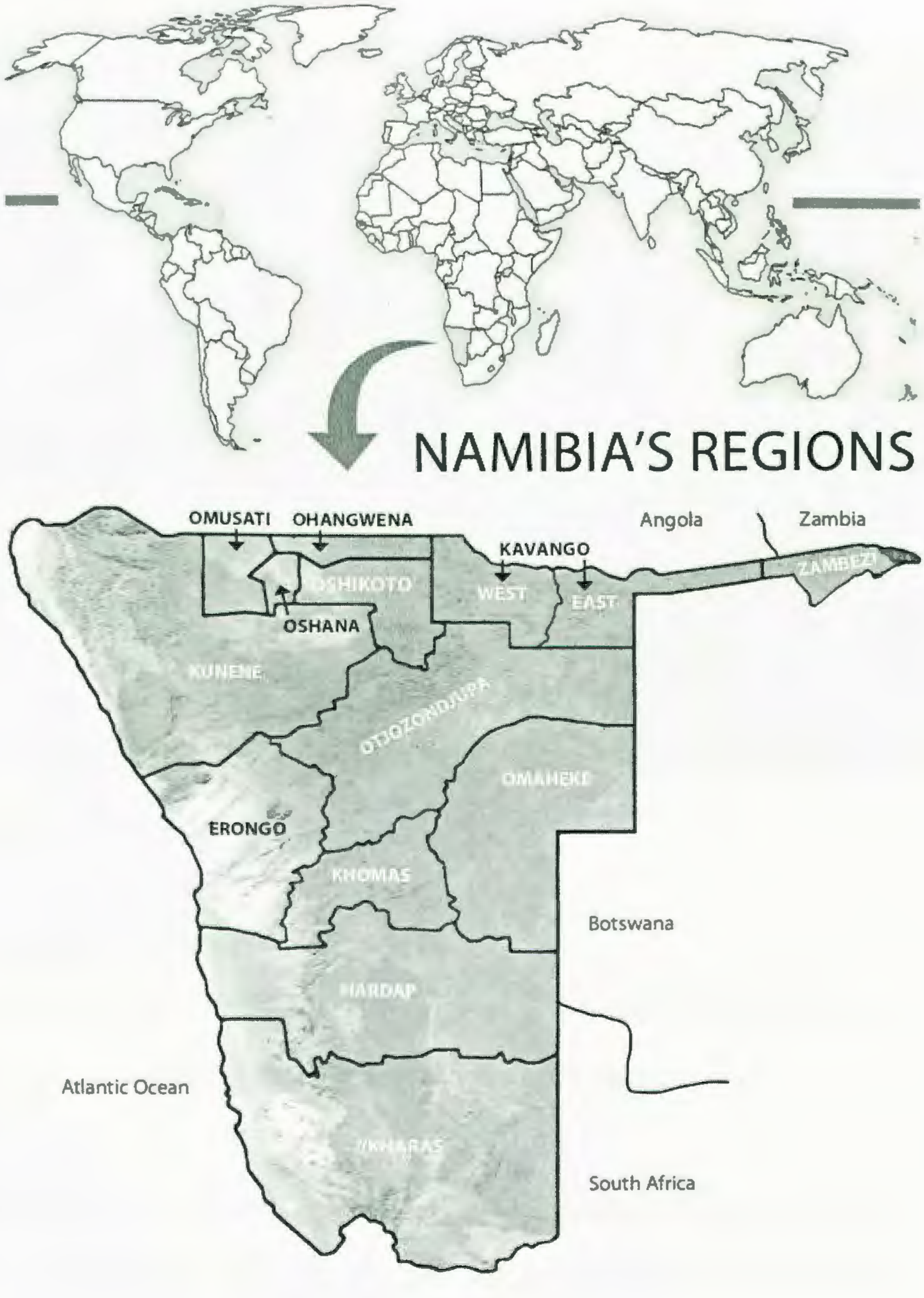


Figure 1.1: Regions of Namibia.

The Oshikoto region is one of Namibia’s 14 regions. It is named after Otjikoto Lake (see Figure 1.2) and means “deep hole.”

Figure 1.2: Otjikoto Lake.

1.2 BACKGROUND TO THE PROBLEM

Adolescents represent 23% of the total Namibian population. The total number of ALHIV was 11 035: 6 087 girls and 4 948 boys (MOHSS, 2012).

Many HIV infected children that were not expected to survive childhood are entering adolescence and young adulthood. The prospect of a longer lifespan brings new challenges related to the impact of HIV infection on their physical and mental health, as well as on normative developmental processes such as growth, peer relationships, puberty, and sexuality (Havens, Mellins & Hunter, 2012).

Many ALHIV are likely to be at an early phase of the disease and require treatment; they will thus need care and support by their caregivers, including disclosing their HIV status and to be prepared for treatment (UNICEF & UNAIDS, 2017). Disclosing HIV to children living with disease is described as one of the main challenges for parents or caregivers. Many caregivers of such children do not disclose their disease status because they do not know how to do so (Qiao, Li & Stantom, 2011). The main reasons for caregivers failing to disclose the HIV status to adolescents are that they: may incur a negative reaction; fear that the infected adolescent may disclose their status to others which may lead to stigmatisation towards them and their family; do not know when and how to tell adolescents that are living with HIV; lack of knowledge about HIV and its treatments; and think the infected child is too young to understand their HIV status (Baker, Bayer, Kolevic, Najaro & Viani, 2018). A Nigerian study found, that despite the availability of anti-retroviral drugs and treatment, the caregivers of children living with HIV have continued to face major challenges especially on how and when to tell their child who is living with HIV. The burdens associated with caregivers often result in a high level of stress amongst them; usually manifesting as anxiety and/or depression (Okechukwu, Offiong & Ekop, 2018).

A South African study indicated that caregivers living with HIV are frequently reluctant to disclose their own sero-status to adolescents, and they often delay informing the adolescents about the latter's HIV infection (Moodley, Myer, Michaels & Cotton, 2016). According to study done in the Democratic Republic of Congo, one-third of caregivers of HIV positive children aged 5–17 years saw no benefit in informing ALHIV that they were infected with HIV (Vaz, Maman, Eng, Barbarin, Tshikandu & Behets, 2010).

During the early 1980's in New York and California, HIV disclosure was assumed to advocate (Land & Poindexter, 2010). However, because of the HIV epidemic these days, the task of HIV disclosure is the responsibility of anyone who is caring for someone living with HIV including ALHIV. In addition most of caregivers of ALHIV reported that they often or always felt negative feelings such as sadness, despair, anxiety and depression regarding HIV status disclosure (Alemu, Berhanu & Emishaw, 2013).

Caregivers while providing care for people living with HIV may experience problems such as lack of knowledge and skills regarding disclosure, sleep deprivation, anxiety, depression, stress, feeling of inferiority, hopelessness, restricted freedom, rejection, a loss of income as well as stigma and discrimination (Bejane, Havenga & Aswegen, 2013). It is well documented in a study, done in Burkina Faso among the mothers of children living with HIV, that the caregivers faced many challenges. These ranged from asking questions about health or treatment, HIV/AIDS, stigma, and the burden of care. These concerns led to the caregivers not disclosing the HIV status of the children (Hejoaka, 2009). Many caregivers had unresolved grief stemming from fear of the loss of their child if the latter were to find out she or he is living with HIV (Hayfron-benjamin, Obiri-Yeboah, Ayisi-Addo, Siakwa & Mupepi, 2018).

Caregivers of ALHIV often lack disclosure skills because they have not been trained on how to tell their child about the diagnosis (Madiba & Mokwena, 2016). Aside from challenges facing the caregivers of ALHIV, caregivers experienced that when ALHIV know their HIV status they were more likely to cooperate with the steps to manage their health and the risk of transmitting HIV to others (Jemmott, Heeren, Sidloyi, Marange, Tyler & Ngwane, 2014). Some caregivers may plan to disclose the HIV status to the adolescents at some point in the future, but delaying to disclose the HIV status to the adolescents should be discouraged by all means to avoid accidental disclosure (Brown, Oladokun, Osinusi, Ochigbo, Adewole & Kanki, 2011). Several studies suggest that disclosure of HIV status to children and adolescents have a positive impact on their lives, compared to keeping their status secret. Therefore, caregivers are encouraged to disclose HIV status to adolescents (Jemmott, Heeren, Sidloyi, Marange, Tyler & Ngwane, 2014).

HIV is one of the health challenges facing Namibia with a large number of ALHIV. It is also known that HIV has no cure. Given the large number of orphans including ALHIV, means this may be a problem to those who are caring for them. HIV not only touches the lives of those infected but also impacts the lives of the caregivers. Therefore, it is very rare to find a family that has not been affected or infected by the HIV pandemic. In sub-Saharan African countries, as well as in most parts of Namibia, extended families, grandparents, aunts, cousins and other family members care for many orphans including those living with HIV. This situation is not unique to Namibia because a study done in the town of Chiang Mai in Thailand, found that primary caregivers are often elderly women who take care of the children after the death of their parents (Hawkins, 2013).

In the Oshikoto region, based on the high number of ALHIV, it is obvious that a large numbers of these ALHIV are cared for by their relatives; often grandmothers and aunts. Some of these caregivers have reported that they often or always felt negative feelings such as sadness, despair, anxiety and depression regarding disclosing the HIV status to the adolescents (Onandjokwe Lutheran Medical Services, 2015). Little is known about the real experiences of these caregivers of ALHIV regarding disclosure of the HIV status to the adolescents.

1.2.1 The context of the study

This study was conducted in the Oshikoto region that covers 38,685 square kilometers in northern central Namibia. Its borders are the Otjozondjupa region to the southeast, the Ohangwena region to the north, the Oshana region to the west, and the Kavango region to the east. The total population is 181600, with mostly a youthful population and an annual population growth rate of 2% (Namibia Statistic Agency, 2011). The region is largely rural with 87% of the population living in rural areas. There are 11 political constituencies and three towns: Tsumeb, Omuthiya and Oniipa. There are 18700 single parent households and 12466 child-headed households. The Oshikoto region has three state hospitals: Intermediate Hospital Onandjokwe, Omuthiya District Hospital, and Tsumeb District Hospital. There is one private hospital in Tsumeb. There are three health centres, namely, Onayena, Okankolo and Onyaanya, 24 primary health care (PHC) clinics, 128 outreach points, and eight ART outreach centres (MOHSS, 2016a).The HIV prevalence varies in different parts of the region: 14.5% prevalence rate in Tsumeb, 18.1% in Omuthiya, and 22.6% in Onandjokwe (MOHSS, 2016b). Out of an estimated 6087 Namibian adolescent girls living with HIV, 5% are in the Oshikoto region (UNICEF, 2015). Health-related problems form one of the top 10 social problems in the region. There are a number of non-governmental and community-based organisations active in the region providing social services; the SOS Children's village in Tsumeb provides family strengthening services; the Sr. Leoni's Care Centre in Tsumeb provides services targeting orphans and vulnerable children, HIV infected children and adults. Agriculture and mining are the main economic activities and subsistence for the people in the Oshikoto region. The region has a high literacy rate of 84%; unemployment is high at 40% (MOHSS, 2016a).

1.3 PROBLEM STATEMENT

Globally, caregivers of ALHIV experience challenges to disclose the HIV status to adolescents. Disclosing HIV to a child is a controversial and emotionally charged issue among the healthcare workers, parents and caregivers of the adolescents. Disclosure of HIV is often characterised as a dilemma by caregivers, but on the other hand it can promote health in the adolescents. Most of the time disclosure is delayed because the caregivers lack disclosure skills (Madiba & Mokwena, 2016).

Stigma, discrimination and disclosure are special issues in parenting and HIV. It is not surprising that in the face of such discrimination many caregivers choose to keep the HIV status of the adolescents in their care secret despite that disclosure of HIV status to children gives them the opportunity to gain full access to care and support services.

Despite the availability of a tool for disclosure of HIV status for children by healthcare workers, which was rolled out in Namibia (MOHSS, 2012), little has been done to assist and support the caregivers of ALHIV regarding disclosure. Some of the caregivers in the Oshikoto region do not disclose the HIV status to the adolescents; they just provide them with ART. The caregivers have doubts of poor adherence if the adolescents know their status, because of stigma and discrimination by others. They also think that their HIV positive child is too young to know their status. Additionally, worries about the adolescent's future in the context of HIV and their reproductive health also appear to concern the caregivers. Investigation of the experience of caregivers of ALHIV regarding disclosure has not been widely assessed in the Oshikoto region where many of the ALHIV live.

There are about 1,350 adolescents that are known to be living with HIV (Oshikoto Region Annual HIV report, 2014). Adolescence presents a phase of intense physical, cognitive and social growth. It is the period of increasing knowledge of individual rights, developing personal opinions and complicated emotions including romantic and sexual feelings. Disclosure to ALHIV is an unavoidable entry point to their full involvement in care and other group specific support services.

Although consequences of non-disclosure are evident in Namibia and elsewhere, little is known about what coping mechanisms are available to caregivers of ALHIV in the Oshikoto region. It is against this background that the researcher set out to investigate the experiences of caregivers of ALHIV regarding disclosure in the Oshikoto region in order to develop educational educational programme to support the caregivers in caring for adolescents living with HIV in the Oshikoto region.

1.4 AIM OF THE STUDY

The purpose of this study was to develop, implement and evaluate an educational programme to support the caregivers of ALHIV regarding disclosure in Oshikoto region, Namibia.

1.5 OBJECTIVES OF THE STUDY

The specific objectives focused on the following.

- Conducting a situational analysis through investigations and describing experiences of caregivers of ALHIV regarding disclosure. For this objective, data were collected through focus group discussions (FGDs).
- Developing a conceptual framework to support the caregivers of ALHIV regarding disclosure. In order to accomplish this objective, the researcher used the six elements of the practice-oriented theory of Dickoff, James and Wiedenbach (1968).
- Developing, implementing and evaluating an educational programme to support the caregivers of ALHIV regarding disclosure.

1.6 SIGNIFICANCE OF THE STUDY

The study was underpinned by the following in terms of its significance.

- The developed educational programme can be used to support the caregivers of ALHIV regarding disclosure and should facilitate their disclosure practices.

- Disclosure of HIV status to ALHIV should be part of routine health education sessions given at all health facilities to enhance the knowledge of caregivers regarding disclosures.
- The developed educational programme can support caregivers in terms of them being able to join available support groups in their respective community to help them cope with the effects of HIV.
- The MOHSS would involve the stakeholders to address the challenges facing the caregivers of ALHIV regarding disclosure by educating them through workshops and training.

1.7 PARADIGMATIC PERSPECTIVES

According to Bowling (2002) a paradigm is defined as a set of ideas (hypothesis) about the phenomena under inquiry. Baker (2003), as cited by De Vos (2011), defines paradigm as a pattern containing a set of legitimated assumptions and a design for collecting and interpreting data. A paradigm is defined as world interpretation, a common viewpoint on complexities of the world. Paradigms for social review are characterised by the way in which they respond to simple logical questions (Polit & Beck, 2012).

For this study the paradigm consists of assumptions on which the research is founded and the theoretical basis for the study. The constructivist paradigm was adopted for this current study. According to Polit and Beck (2012), a constructivist paradigm is applied to obtain reality about experiences of caregivers of ALHIV regarding disclosure in a region. By means of this paradigm, people construct their knowledge and understanding of the world through experiencing things and reflecting on their experiences (Educational Broadcasting Cooperation, 2004).

In this study the researcher explored the experience of caregivers of ALHIV regarding disclosure in order to understand the reality of what they faced. The assumptions applied in this study are ontological or nature of reality, epistemological or relationship of researcher and participants, axiological assumption or role of values in the study, methodological assumption or process of research study and rhetoric or language and voice of reporting. These assumptions are explained below.

1.7.1 ASSUMPTIONS ON WHICH RESEARCH IS FOUNDED

This research is anchored on five assumptions: ontological, epistemological, axiological, methodological, and rhetoric.

According to Rohan (n.d) ontological refers to a question of what is reality and understanding the existence of reality; epistemological refers to the nature of knowledge; axiological refers to the nature of values; methodological is about the nature and structure of a study; rhetoric refers to how best researchers can share their studies with others.

1.7.1.1 Ontological assumptions

Ontological refers to the nature of reality. Researchers embrace the idea of multiple realities and report on them by exploring multiple forms of evidence from different individuals' perspectives and experiences (Creswell, 2014). According to Edmonds and Kennedy (2013) "reality" arises out of each individual's perception of his/her experiences. Reality may be more or less well informed within the context of participants` lives (Rohan, n.d). In this study the reality in question was: What are the experiences of caregivers of ALHIV regarding disclosure? It was assumed that each caregiver has different experience on when and how to disclosure the HIV status to ALHIV. In this study the researcher used verbatim quotations and observations obtained during data collection to identify themes and sub-themes regarding disclosure in terms of the experience of caregivers of adolescents living with HIV.

1.7.1.2 Epistemological assumption

According to Wagner, Kawulich and Garner (2012), an epistemological assumption is the nature of knowledge, objective and independent of the values, interests and feelings of a researcher. These constitute a view of the world. This assumption is concerned with deep meaning of knowledge and science of the content of truth and rerated ideas. Epistemology deals with how a researcher acquired the information from participants. In order to get answers to research questions a researcher interacts with the participants. In this study the researcher used FGDs to collect the data from the caregivers. It was assumed that the collected data from the caregivers of ALHIV would enable the researcher to gain evidence on what experiences the caregivers had regarding disclosure of HIV status to adolescents.

1.7.1.3 Axiological assumptions

Polit and Beck (2012) define axiological assumption as the voice and interpretation of a study's participants. Researchers should be aware of their values and how these influence a study (Nassar-McMillan & Niles, 2011). Axiology influences how people view themselves in relation to others. In this study the caregivers and the researcher brought their own values. The researcher assumed that the developed educational programme would support the caregivers of ALHIV regarding disclosure.

These assumptions are crucial in order to understand the phenomenon of interest; an objective interaction would be the primary way to access potential influences. This is about the values that a researcher brings to a study and the acknowledgement of biases. The researcher in this study aimed to eliminate and control bias by capturing and revealing the true data. Any influences that could mislead the result of the study were reduced in order to retain subjectivity.

1.7.1.4 Methodological assumption

According to Babbie and Mouton (2009) a methodological assumption refers to the description of methods and techniques that are used to conduct a study. This study comprised four phases.

Phase 1 was about the situational analysis where the experience of the caregivers of ALHIV regarding disclosure was investigated and described. Based on the data from this phase a conceptual framework was developed in phase 2. Phases 3 and 4 covered the development and implementation of an educational programme to support the caregivers of ALHIV regarding disclosure.

1.7.1. 5 Rhetoric assumption

Rhetoric assumption examines the language used, and the writing approach of a researcher (Peterson, 2014). A rhetorical approach was used in this study to interpret the results. Some researchers are of the opinion that a research report needs to be written in the first person indicating the participation of a passionate agent (Rohan, n.d). In this study the researcher reports the findings in a logical way supported with some verbatim quotations from the participants to buttress the points.

1.7.2 THEORETICAL BASIS OF THE STUDY

The study was based on the following theories.

- Dickoff, James and Wiedenbach's (1968) practice oriented theory
- Kolb's experiential learning cycle
- Knowles' model of andragogy

Theoretical assumptions are important; they are the setting of a study; they guide the process of argumentation, evidence generation and conclusion (Nkwake, 2013). According to Dickoff, James and Wiedenbach (1968) a conceptual framework provides a rationale or structure that guides the development of a study and thus constitutes an understanding on which a study is based.

1.7.2.1 Dickoff, James and Wiedenbach's (1968) practice oriented theory

Dickoff, James and Wiedenbach's (1968) practice oriented theory was adopted to guide the development of the conceptual framework of this study. A survey list that related to six questions by Dickoff et al. (1968) was used in this study. These six elements in this study included

(i) an agent, namely the researcher had to perform the activity

(ii) the recipient, namely, the caregivers of ALHIV who would receive the activity

(iii) the context in which the activities would be performed

(iv) the dynamic challenges' finding during situational analysis

(v) the procedure was an educational programme to support the caregivers of ALHIV regarding disclosure

(vi) terminus was the end that can be achieved.

The application of the conceptual framework that guided the development of the educational programme to support the caregivers of ALHIV regarding disclosure in a region is described in chapter 4. The use of a conceptual framework enables a researcher to relate the results of a study to the existing body of knowledge.

1.7.2.2 Kolb's experiential learning cycle

Kolb's experiential learning theory was adopted by the researcher in the implementation of an educational programme of this study. Kolb's experiential learning cycle has four stages of learning. A concrete experience pertains to experiences; reflective observation is where a person has to reflect on experience; abstract conceptualisation is when a person learns from experience; and active experimentation is where a person tries out what has been learned (Macleod, 2013). The application of Kolb's experiential learning cycle in this study is discussed in chapter 5.

1.7.2.3 Knowles' model of andragogy

The implementation of an educational programme in the current study was guided by Knowles' model of andragogy. This model has five assumptions, which differentiate adult learning from child learning (Knowles, 1984). These assumptions identified adult learning principles. There is a need to explain to an adult the reasons why specific things are taught; instruction should be task-oriented; and adult learners are self-directed. In this study all the activities that were used in the educational programme had to be explained. To achieve the objectives of the programme the participants needed to evaluate their learning activities. The application of Knowles' model of andragogy in this study is discussed in chapter 5.

1. 8 Definition of concepts

For the purpose of this study the following key concepts covered in the discourse pertaining to an educational programme to support the caregivers of ALHIV in the Oshikoto region are clarified.

1.8.1 Caregiver

Caregiver is defined as a person who provides formal or informal support and assistance, with various activities to persons with disabilities or long-term conditions. Such a person may provide emotional or financial support, as well as hands-on help with different tasks including activities of daily living (WHO, 2014). In this study the caregivers were taken to represent anyone who was taking care of ALHIV ranging from biological parents, grandparents, cousins, aunts, brothers or sisters.

1.8.2 Adolescent

The World Health Organisation (2014) defines adolescents as young people between the ages of 10-19 years. It is a period in human growth and development that occurs after childhood and before adulthood. In this study adolescents were therefore taken to refer to those within the age of 10-19 years. Those who provided care to those living with HIV in this age bracket were included as participants in this study.

1.8.3 Disclosure

Disclosure refers to a person gaining knowledge of his/her HIV status or health condition. Disclosing the HIV status to a child is a controversial and emotionally charged issue amongst both healthcare workers and caregivers of the children (UNAIDS, 2013). In this study disclosure refers to ALHIV gaining knowledge of their HIV status from their caregivers.

1.8.4 HIV

HIV is the acronym for human immunodeficiency virus (WHO, 2017). It is the infection caused by the virus that has become a pandemic over the last 30 years.

1.8.5 Programme

Programme refers to planned series of future events or performances (Concise Oxford English Dictionary, 2016). Programme in this study refers to performances or activities to support the caregivers of ALHIV.

1.9 ARRANGEMENT OF THE REPORT CHAPTERS

The chapters of this study are as follows.

Chapter 1: Introduction to the study, which covers the background, the statement of the problem, the objectives and aims of the research.

Chapter 2: The research design and methodology.

Chapter 3: The data analysis and literature control that explains the finding of the data.

Chapter 4: Conceptual framework that explains the development of an educational programme.

Chapter 5: Development of an educational programme, which describes the intervention programme to support the caregivers of ALHIV regarding disclosure.

Chapter 6: Implementation and evaluation of the educational programme in terms of how the programme was implemented and evaluated.

Chapter 7: Conclusion, recommendations and limitations of the study.

1.10 SUMMARY

In this chapter an introduction to the study was presented. The background to the study, the statement of the problem, the objectives and aims of the research, as well the significance of the study, were discussed. The paradigmatic perspective and assumptions on which the research was based were also outlined. Important concepts covered in the research were explained. The outline of each chapter was listed. Research design and methods are covered in the next chapter.

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

The introduction and background of the study, as well as the statement of the problem and the objectives of the research, were presented in the previous chapter. Research design, and methods of this study, which was carried out in four phases, is presented in this chapter. The purpose of this study was to develop, implement and evaluate an educational programme to support the caregivers of ALHIV regarding disclosure in Oshikoto region.

The specific objectives focused on the following.

- Conducting a situational analysis through investigation and describing experiences of caregivers of adolescents living with HIV regarding disclosure. For this objective, data was collected through the FGDs.
- Developing a conceptual framework to support the caregivers of the adolescents living with HIV regarding disclosure. In order to accomplish this objective, the researcher used the six elements of practice-oriented theory of Dickoff, James and Wiedenbach (1968).
- Developing, implementing and evaluating an educational programme to support the caregivers of adolescents living with HIV regarding disclosure in Oshikoto region.

2.2 RESEARCH DESIGN

According to Babbie (2007), as cited by De Vos (2011), research design involves a set of decisions regarding what topic is to be studied among what population, with what research methods, and for what purpose. The design for this study was based on the qualitative approach.

2.2.1 Qualitative approach

A qualitative enquiry is a way of exploring and understanding the meaning of individuals or group in which a researcher studies a certain phenomenon in a natural setting and tries to make sense out of such phenomenon (Creswell, 2007). For this study a qualitative approach was implemented to assist the researcher to explore and to describe the experiences of caregivers of ALHIV regarding disclosure.

A qualitative approach is regarded as a systematic one. In this study it enabled the researcher to gain an in-depth understanding the caregivers of ALHIV regarding disclosure in Oshikoto region. This qualitative approach allowed the researcher to understand the experiences of caregivers of ALHIV during interactions with them by means of FGDs.

2.3 REASONING STRATEGIES

Reasoning strategies refer to the processing and organising of ideas in order to reach conclusions. Through reasoning people can create logic of their views (Grove, Burns & Gray, 2013). For this study the following reasoning strategies were used: inductive, deductive, inferences, bracketing and reflecting.

These reasoning strategies helped the researcher to investigate and describe the experience of caregivers of ALHIV regarding disclosure, and to organise the data during the analysis process of the theoretical concepts. These strategies were useful to describe the conclusions and the recommendations that emanated from data analysis.

2.3.1 Inductive reasoning

Inductive reasoning is the process of developing generalisations from specific observations (Brink, 2010). In this study it was applied in Phase 1 (situational analysis); namely, the investigation of the experiences of caregivers of ALHIV regarding disclosure. It was used in Phases 2 and 3 (development of conceptual framework and development of an educational programme) to identify themes and sub-themes and for developing a conceptual framework. The latter was used to develop an educational programme to support the caregivers of ALHIV. Inductive data analysis was used by the researcher to work back and forth between the themes and the data in order to establish a set of complete themes (Creswell, 2007).

2.3.2 Deductive reasoning

Deductive reasoning refers to the process of developing specific predictions from general principles (Polit & Beck, 2012). In this study the researcher used deductive reasoning for the development of the conceptual framework, as well as in the development and evaluation of the educational programme. The survey list of the practice-oriented theory of Dickoff et al. (1968) was used deductively as it included the agent, recipient, context, procedure, dynamics, and terminus. Their survey list was used: to conceptualise and define the central concepts; to classify and establish the relationship among these concepts. Kolb's experiential learning cycle, and Knowles' model of andragogy, was used in the development and implementation of an educational programme.

2.3.3 Inference reasoning

An inference is a conclusion drawn from a study's evidence, taking into account the method used to generate that evidence. Inference is an attempt to come to a conclusion based on limited information (Polit & Beck, 2012). According to Grove, Burns and Gray (2013), inference is the use of inductive reasoning to move from a specific case to a general truth. Researchers use inferences to infer from the sample in their study to the larger population. In this study the conceptualisation and development of an educational programme relied on inferences to explore the literature and to clarify the experiences of caregivers of ALHIV regarding disclosure.

2.3.4 Bracketing

Bracketing refers to a research technique of suspending or laying aside what is known about an experience being studied (Grove, Burns & Gray, 2013). Researcher identifies and set aside any preconceived beliefs and opinions that they might have about a phenomenon under investigation. In this study the researcher bracketed preconceived ideas from those previously observed in the course of duties and garnered from the literature review to consider every available perspective on the participants' experiences on disclosure of HIV status to ALHIV (Brink, 2010). Bracketing was applied during data collection and analysis as well as in the development and implementation of educational intervention for the caregivers.

2.3.5 Synthesis

Burns and Groves (2013) defines synthesis as a scientific process that deals with abstracts, or pulling together concepts and statements from data. In this study synthesis was used during analysis of data and in the development of themes and sub-themes. It was also during the development of an educational programme. The four phases of the study are shown in Figure 2.1.

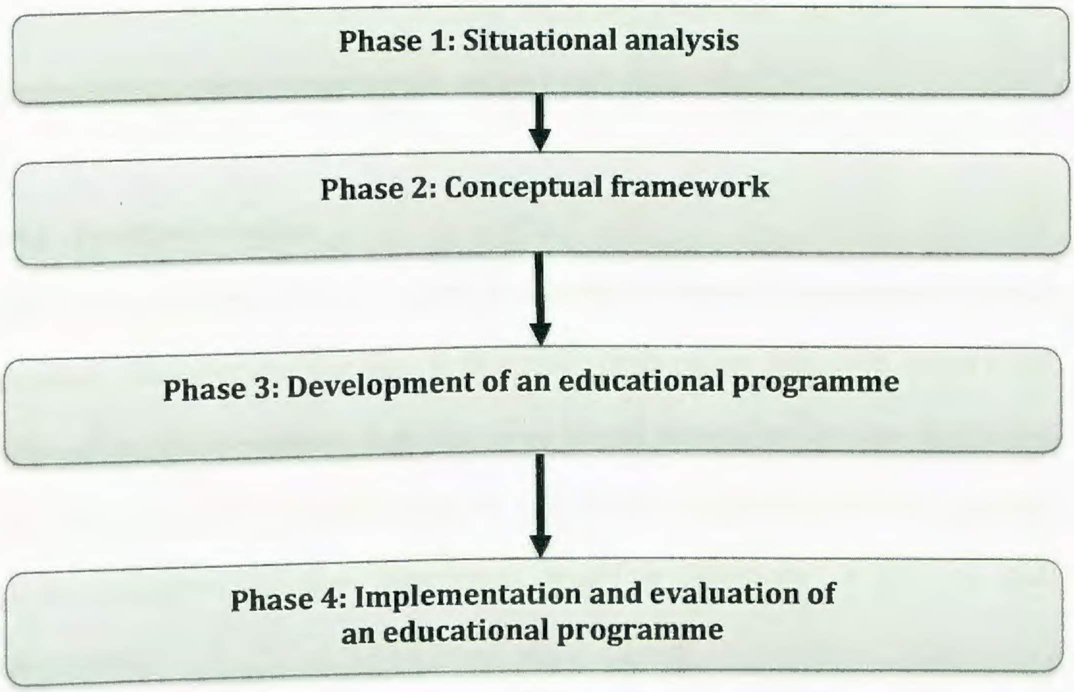


Figure 2.1: Phases of the study

2.4 SITUATIONAL ANALYSIS (PHASE 1)

This phase focused on situational analysis in which the experiences of caregivers of ALHIV on disclosure of the HIV status to the adolescents was explored and described through focus group discussions (FGDs). An exploratory, descriptive and contextual design was utilized.

2.4.1 Explorative design

An explorative design helps a researcher to gain new insights and experiences in a particular area or focus of research. Such a design in an experimental setting is strictly designed and tightly controlled and as the aim is to find out whether an intervention works under ideal or selected condition, and how and why it works (De Vos, 2011). In this study the researcher adopted an explorative design to gain new insight and experiences of the caregivers of ALHIV regarding disclosure, and then to help to develop an educational programme to support such caregivers.

2.4.2 Descriptive design

Generally a descriptive design enables a researcher to describe a particular research situation, phenomena or findings. In this study descriptions were used to get exact information and experiences from the caregivers of adolescents on how to disclose HIV status to ALHIV. The data, from the FGDs of the caregivers of ALHIV, assisted in the description of their experiences regarding disclosure of HIV to such adolescents.

A descriptive conceptual framework was also used as it guided the development of an educational programme to support the caregivers of ALHIV regarding disclosure (Groves, Burns & Gray, 2013).

2.4.3 Contextual design

A contextual design was used in this study to understand the experiences of caregivers of ALHIV regarding disclosure in Oshikoto region. Its usage helped the researcher to understand events against the background of the study and how the context conferred meaning to the experiences of caregivers regarding disclosure of HIV to ALHIV (Babbie & Mouton, 2009). It was used to understand the experiences of the caregivers of ALHIV regarding disclosure in a natural setting or context to ensure true, valid and accurate information without influences of external factors. It was conducted in three hospitals, namely, Intermediate Hospital Onandjokwe, Tsumeb and Omuthiya district hospitals in the Oshikoto region. The participants were drawn from the surrounding communities. They had interactions with the researcher through FGDs. The caregivers were given an opportunity to express their experiences as well as their challenges in the disclosure of HIV status to ALHIV.

2.4.4 Population

Population, according to Grove, Burns and Gray (2013), refers to all elements that meet certain inclusion criteria in a given universe. Population refers to individuals who possess specific characteristics (De Vos, 2011). However, due to the large size of populations, researchers often cannot test every individual in a study population because is too expensive and time consuming. In this study the population consisted of all caregivers of ALHIV. There were inclusion and exclusion criteria in this study.

2.4.4.1 Study sample, sampling techniques and inclusion and exclusion criteria

Sampling is a process of selecting a sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest (Brink, 2010). Groves, Burns and Gray (2013) state that sampling involves selecting a group of people, events, behaviors, or other elements, with which to conduct a study. In this study, non- probability, purposive sampling was used to select the participants. A sample was taken from the caregivers of ALHIV attending the Intermediate hospital Onandjokwe, and the district hospitals at Tsumeb and Omuthiya. In other words the caregivers of ALHIV at the selected hospitals were purposefully selected.

In purposive sampling a researcher chooses people that are regarded as typical of a group or those who represent diverse perspective on an issue. Respondents are chosen based on a researcher's judgment (Struwig & Stead, 2009). Caregivers of ALHIV were purposefully selected by the researcher to participate in this study.

In qualitative research a sample size is determined by data saturation. Saturation occurs when additional sampling provides no new information (Groves, Buns & Gray, 2013; Creswell; 2007). Put differently in this study saturation of data determined the sample size and not the number of caregivers of ALHIV. The cut-off for selection of participants in a qualitative study is when saturation of information is deemed adequate and has been achieved.

The characteristics essential for eligibility or membership in a target population are the inclusion criteria (Burns, Gray & Groves, 2009). Studies usually have inclusion and exclusion criteria and in this study they were as follows.

➢ **Inclusion criteria**

- Caregivers of adolescents living with HIV
- Caregivers had to be registered at any of the three selected hospitals in the Oshikoto region in this study

- Caregivers had to reside in the Oshikoto region
- The caregivers had to have the capacity to make sound decisions and had to be at least 18 years old
- The caregivers had to be willing to participate in the study and to give informed consent
- The caregivers had to speak and understand Oshiwambo as it is the common local language spoken in the Oshikoto region

➢ **Exclusion criteria**

- Caregivers who resided in other regions
- Caregivers who were not willing to participate in the study
- Caregivers with diminished competence and/or decision-making capacity

2.4.4.2 Pilot testing

A pilot study is defined as a small-scale study conducted prior to the main study on a limited number of subjects from the population (Brink, 2010). A pilot study was conducted with caregivers of ALHIV regarding disclosure in preparation for the main study. Its aim was to test the FGDs and to make changes if problems were encountered. Its format was that of the main study. Inclusion and exclusion were the same as the main study. The same setting and collection of data were used as well as analysis techniques.

De Vos (2011) explains the role of a using a pilot study. It is conducted for the following reasons.

- To determine whether a proposed study is feasible
- To identify problems with the design

- To develop or refine the data collection instrument
- To assess the validity and reliability of the research instrument
- To determine whether the sampling technique is effective

In this study the researcher purposively selected four caregivers of ALHIV regarding disclosure to participate in the pilot study. They had to be making use of HIV services at the Onayena Health Centre, which is under the Intermediate Hospital, Onandjokwe. This centre had similar patient characteristics as those in the three main study sites. The pilot study was done to determine possible problems or shortcomings in the methodological approach and instruments. The pilot study FGD was audio-recorded after the participants gave permission.

The discussions were undertaken in Oshiwambo and translated into the English language by the researcher. During the pilot study, some of the questions were not clear to the participants and were subsequently reviewed by the researcher.

The following questions were posed to the caregivers

1. Do you think it is necessary for the ALHIV to know their HIV status?

   This question seemed to be closed-ended in terms of the responses the participants provided. The researcher rephrased it for the main study as follows. What do you think about the adolescents in your care knowing her/his HIV status?

2. What challenges are you facing regarding disclosure? was changed to: What are your experiences in caring for adolescents living with HIV regarding disclosure?

3. How did you accept it that the adolescents in you care is living with HIV? was changed to: What was your reaction when you found out that the adolescent in your care is living with HIV?

During the pilot study the duration of the FGD, as well as the quality of audio-recording, were also checked. The researcher asked the participants for their opinion regarding the duration of the FGD and they indicated that they thought it was adequate. The researcher was also satisfied with the audio quality of the recordings on play back.

2.4.5 Preparation of the research field

Prior to carrying out the fieldwork to collect data for the study, the researcher contacted the management of the three hospitals and informed the nurse manager of each hospital that data collection would not impact on the daily routine services. The nurse in-charge of the ART clinic in each hospital was asked to assess whether the location would be conducive for data collection. The environment and the room where the study was conducted were prepared before the data collection. Preparation of the participants was done by the researcher and the nurse in-charge of the ART clinic where the study was conducted. Those who agreed to participate were then referred to the researcher. The researcher facilitated the FGDs.

2.4.6 Focus group discussions

The caregivers were recruited from two district hospitals, namely Tsumeb and Omuthiya, and the Intermediate hospital, Onandjokwe. Two FGDs were conducted per hospital and each group consisted of four to five participants. Tsumeb district hospital provided nine participants. They were divided in two groups: group 1(n=4) and group 2 (n=5). There were two groups for the nine participants from the

Omuthiya district hospital: n=5 and n=4. There were 10 participants at the Intermediate Hospital Onandjokwe. They were equally divided into two groups: n=5.

Before the commencement of each FGD the researcher welcomed the participants in the interview room and offered them seats. The researcher introduced herself and the participants were introduced to the research topic, and the aim and the objectives of the study. The entire data collection procedure was explained. Participants were informed that the proceedings of the meeting would be tape-recorded. Written consent was obtained from each participant prior to the start of each FGD. Participants were assured that they could freely withdraw their consent and participation at any time and that such withdrawal would not be held against them in any way. A tape recorder was used during each FGD to ensure accuracy of data collections and to check the transcriptions. A guide was used for the FGDs.

The main question was: What are your experiences in caring for adolescents living with HIV regarding disclosure? At the end of each FGD the researcher replayed the audio recording so that the participants could listen to the information they provided to confirm accuracy of the data collected. The researcher thanked the participants for their participation. The caregivers and the adolescents were provided with refreshments afterwards.

2.4.6.1 Communication techniques used during data collection

De Vos (2007) defines communication skills as being of paramount importance during a research process to enable participants to express themselves freely during data collection with the purpose of enriching data collected. The following communication skills were used in this study during data collection.

- Language use

The questionnaire was translated into Oshiwambo as it the vernacular language of the participants. All FGDs were conducted in Oshiwambo so that the caregivers could be comfortable expressing themselves in their vernacular language. The researcher, as the facilitator, used language that was understood by the participants.

- Probing

The probing was done in order to get more information from the participants. Probing assisted to identify and to explore their perceptions in such a way as to help them to engage more constructively in communication and to pursue their lines of thought (Polit & Beck, 2012). Probing such as 'explain more about it' and 'what do you mean' were used during the FGDs.

- Paraphrasing

Paraphrasing was used to keep the original meaning so that the facts remained intact without adding new ideas.

- Clarification

When the researcher was not sure about the participants' comments clarification was used. It helped the researcher to establish whether what was heard was correct.

- Minimal verbal responses

Minimal verbal responses from the researcher encouraged the participants to keep talking. Responses such as: I hear what you are saying or Ok' were used to indicate that the researcher was following what the participants were saying.

2.4.7 Field notes

Field notes are defined as notes made during and immediately following an observation (Groves, Burns & Gray, 2013). They are also defined as a record of observations in the field; taking field notes is considered an important component of field research. Observations are put into written words as records which a researcher undertakes while observing or immediately afterwards (Holloway & Wheeler, 2010). The researcher used field notes during the FGDs to supplement the recorded discussions.

2.4.8 Data analysis

According to Polit and Beck (2012) the purpose of data analysis is to organize, provide structure to, and elicit meaning from the data. Brink (2010) defined data analysis as categorizing, ordering, manipulating and summarizing the data and describing them in meaningful terms. Transcribed data from the tape recordings and field notes were the raw data, and they provided a descriptive record of the content of the FGDs. Making sense of the data by sifting and interpreting them to provide explanations of the phenomenon under consideration is what analysis entails (Pope & Mays, 2006). In this study data were collected to explore and describe the experiences of caregivers of ALHIV regarding disclosure. The analysis was done concurrently with data collection. Data were analysed through coding and theme formation using data driven or open coding. Grove, Burns and Gray (2013) define coding as a mean of designating or classifying words or phrases.

In this study the researcher followed Tesch's steps of data analysis to analyse the data. Table 2.1 shows Tesch's steps of data analysis and how the researcher applied it in this study.

Table 2.1 Tesch's steps of data analysis and its application

Tesch's steps of data analysis	**Application to the study**
1. The researcher reads the entire transcripts carefully and gets sense of the whole and jots down some ideas	The researcher read carefully and repeatedly the transcripts in details and got sense of each transcript
2. The researcher selects one case, goes through it and gets the meaning	The researcher read the transcripts of each focus group discussion with the aim to find underlying meaning in the information
3. A list is made of all the topics into column of major topics	The researcher made clusters together of similar topics in column as themes and sub-themes
4.Applies the list of topics to the data, writes next to the appropriate segment of the transcript if new codes will arise	The researcher arranged the topic into column and gave the code to the topic and wrote each code to the appropriate segment of the transcripts.
5. Finds the most descriptive wordings of the topic and turns them into themes	The researcher reduced the total list of categories by grouping topics that related to each other and a number of themes were generated
6. Makes a final decision on each category/theme	The researcher went through the transcripts and field notes and made final category and subcategories
7. Assembles the data which belong to each category in one place	The researcher reduced the data through coding with similar description and organised the data for the final conclusion
8. Re-codes existing data if necessary	The researcher re-coded the data after initial coding

In this study the recorded data were transcribed verbatim in the same language used by the participants. All of the participants opted to respond in their vernacular language: Oshiwambo. The transcribed text was then translated into English by the researcher. A colleague of the researcher, who is fluent in both languages, was requested by the researcher to listen to the tape recordings and review the transcribed text and the translated version. Any disparities were resolved by listening to the tape again and the correct information was agreed and recorded in the transcription and translation.

The transcribed texts and the field notes from the focus interview groups were studied by the researcher. This was done in order to list topics and similar cluster topics. Five themes and nine sub-themes were identified. They are presented in Chapter 3.

2.4.9 Measures to ensure trustworthiness

The respective strategies of Lincoln and Guba, as cited by Tappen (2011), and Polit and Beck (2012) were adopted to establish trustworthiness of the data. These strategies were credibility, transferability, conformability, and dependability.

2.4.9.1 Credibility: truth-value

In qualitative research, truth-value is usually obtained from the discovery of human experiences as they are lived and perceived by informants (De Vos, 2011). Qualitative research is then credible when it presents an accurate description or interpretation of human experience so that people who also share that experience would immediately recognise the description (Krefting, as cited by De Vos, 2011). Credibility was ensured by means of adoption of research methods through prolonged engagement, triangulation, member checking, and independent coders.

- Prolonged engagement

The researcher met with the participants before data collection and explained the study and its aim. The amount of time was considered in data collection until data saturation was reached.

- Triangulation

For this study the data were collected at three different hospitals in the Oshikoto region to give different views from different areas and FGDs were used.

- Member checking

After the FGDs the audio-tapes were played back for the participants to confirm whether the recorded discussion (findings) was an accurate reflection of what is said. This provided them with an opportunity to point out errors that had to be corrected or to provide more information.

- Independent coders

Independent coders may check the data and the report of the analysis.

2.4.9.2 Transferability: applicability

Research meets the criterion of transferability when the findings fit into other contexts outside a study situation in terms of the degree of similarity between the two or more contexts (Krefting as cited by De Vos, 2011). The descriptions of the procedure and findings in the study have been sufficiently detailed to allow for comparative studies and therefore satisfy the criterion of transferability. Transferability in this study was ensured through purposive sampling, generalisation from the sample to the target population, and a description of the study.

- Purposive sampling

The caregivers of ALHIV regarding disclosure who met the criteria for study were purposively selected. This involved the use of inclusion and exclusion criteria.

- Generalisation from the sample to the target population

The sample was purposively selected to represent the target population. The participants' views could be said to reflect that of the target population.

- Description of the study

Adequate and clear descriptions of the study methods were provided to allow for transferability.

2.4.9.3 Conformability

Conformability is defined as the degree to which a study's results are derived from the characteristics of participants and the study context and not from a researcher's biases (Polit & Beck, 2012). Conformability in this study was accomplished by ensuring that the data from the FGDs were solely used for analysis and in the report. Tape recorded data, field notes, summaries; coded data and the themes were reviewed by the researcher's academic supervisor.

- Audit conformability

For the purpose of potential auditing of the data, the tapes of the recorded FGDs and notes from them have been stored in a locked safe in line with the guidelines on research data.

- Peer group discussion

The findings from the study are available for peer review and will be made available to relevant stakeholders.

2.4.9.4 Dependability

Polit and Beck (2012) defined dependability as evidence that is consistent and stable. It is defined by Grove, Gray and Burns (2015) as documentation of steps taken and decisions made during analysis. Dependability in this study was maintained through a dense description of research methods, inquiry audit and code-coders (Babbie & Mouton, 2001).

- Dense description of research methods

Researcher methods such as research design, population sample, data collection and analysis of the data were clearly indicated

- Inquiry audit

Both the academic supervisor and co-supervisor guided the researcher. The collected data and relevant documents were sent to them for corrections.

- Code-recode procedure

The coding of the data was done by the researcher. This was repeated after two weeks in order for the same data to be recoded and the results were then evaluated.

2.5 DEVELOPMENT OF A CONCEPTUAL FRAMEWORK (PHASE 2)

Phase 2 of this study covered the conceptual framework. The conceptual framework was developed based on the results of the first phase one. The framework was underpinned by the survey list of Dickoff et al. (1968). The list included the context, agent, recipient, dynamics, procedure and terminus.

- Agent

The researcher was a Senior Health Programme Officer who received training in Nurse Initiated Management of Antiretroviral Therapy (NIMART) and was the facilitator of the programme

- Recipient

Caregivers of ALHIV

- The context

Public health facilities that provided services to ALHIV in the Oshikoto region

- Dynamics or motivating factors

Challenges experienced by the caregivers of ALHIV regarding disclosure

- Procedure

Intended an educational programme to support caregivers of ALHIV to address challenges identified during the situational analysis

- Terminus

Knowledgeable and supported caregivers of ALHIV regarding disclosure. The conceptual framework is explained in Chapter 4.

2.6. DEVELOPMENT OF AN EDUCATIONAL PROGRAMME (PHASE 3)

Phase 3 focused on the development of an educational programme to support the caregivers of ALHIV regarding disclosure. The problems identified during the situational analysis in Phase 1 were used as a basis to develop the programme. An educational programme deemed necessary to support the caregivers of ALHIV in the

Oshikoto region. The survey list of Dickoff et al. (1968) was adopted in the development and implementation of the educational programme in this study.

2.7 IMPLEMENTATION AND EVALUATION OF THE DEVELOPED EDUCATIONAL PROGRAMME (PHASE 4)

Phase 4 of this study covered implementation and evaluation of the educational programme. This was based on Kolb's experiential learning theory. The programme was implemented by conducting a one-day workshop for the caregivers of ALHIV regarding disclosure in Oshikoto region. The workshop venue was at the Intermediate Hospital Onandjokwe, which is the referral hospital in the region. Evaluation of the programme was done by administering pre and post-tests to the participants. Chapter 6 covers the implementation and evaluation of an educational programme in this study.

2.8 ETHICAL CONSIDERATION

A proposal of the study was be submitted to the Post-Graduate Studies Committee at the University of Namibia and to the Research Management Committee of the Ministry of Health and Social Services (MoHSS) for approval. In addition, approval to conduct the approved study in the selected region was obtained from the regional health director and the management of the three hospitals. Ethical principles were adhered to throughout the study in accordance with the Helsinki declaration (Brink, 2012). Each principle is discussed below.

2.8.1 Principle of beneficence and non-maleficence

The principle of beneficence and non-maleficence involves doing well and to do no harm. Harm can be physical, emotional, spiritual, economic, social or legal (Brink, 2012). It is the responsibility of a researcher to protect participants against discomfort and harm.

The FGDs were conducted in a non-threatening secure environment within the hospital premises and no physical harm was done to the research participants. The discussions were scheduled to take place on the day the participants usually brought the adolescents to the clinics. The FGDs did not last for more than one hour, which meant that there was not unnecessary economic harm to the participants. The researcher also avoided probing questions that could have embarrassed the participants.

The researcher made arrangements with the hospital social worker at each district in case any participant needed emotional and psychological support and participants were informed of this. The benefits of the study were made clear to the participants. The information about the study was explained to them so that they could use it to help others caregivers with similar experiences.

2.8.2 Principle of justice

Justice refers to fair treatment. The participants were selected based on the selection criteria in relation to the problem being studied to ensure fairness. In this study all potential participants who turned up at the clinic on the day of the data collection and met the inclusion criteria were informed about the study. Those who showed interest were treated equally and invited to participate in the FGDs. Participants were reassured that all the data collected would be confidentiality handled. They were told all information obtained would be coded and there was no chance that a participant's identity could be revealed. Access to collected data was limited to the researcher and academic supervisor and those involved in the research. A personal computer with a password was used to store the data and was only accessed by the researcher.

2.8.3 Principle of autonomy and respect for human dignity

The rights of the participants were taken into account. The participants with a capacity to act with autonomy were selected to participate in the study. Participants were all adults over the age of eighteen years. Participants were autonomous, meaning they had the right to self-determination that had to be respected. Right to self-determination includes participants` right to decide whether or not to take part in a study without the risk of penalty or prejudicial treatment (Brink, 2012). The researcher provided sufficient information to them in a language they understood. The aim, objectives and process of the study were fully explained to them so that they could make an informed decision and to give written consent. Participants were given a chance to ask questions before signing the consent form.

2.9 SUMMARY

In this chapter, the research design and methodology were discussed in-depth.

The method for each of the four phases of the research was covered: situational analysis, conceptual framework, development of an educational programme, implementation and evaluation of the developed educational programme were explained. Ethical consideration and measures to ensure trustworthiness of the research were described. The next chapter presents the results, identification of themes and sub-themes as well as literature control on the topic.

CHAPTER 3

DATA ANALYSIS AND LITERATURE CONTROL

3.1 INTRODUCTION

In the previous chapter the research design and methods used to conduct this study were presented. Phase 1 (situational analysis) explored and discussed the experiences of caregivers of ALHIV regarding disclosure in the Oshikoto region. In this chapter the following are covered. The findings generated from analysis of the data collected through focus group discussions are presented and discussed. The discussion refers to the literature on the subject.

3.2 BACKGROUND INFORMATION OF DATA COLLECTION AND ANALYSIS

Data were collected at the Intermediate Hospital Onandjokwe, Tsumeb and Omuthiya district hospitals. The former is the referral hospital for the Oshikoto region. Twenty-eight participants participated in this study. There were 28 participants who were caregivers taking care of ALHIV aged 10-19 years old. Ten participants were from Intermediate Hospital Onandjokwe, nine from Omuthiya and nine participants from Tsumeb districts. Sixteen (n=16/n=28) were biological parents: mothers= 14/fathers=2). The remainder (n=12) were non-biological female caregivers (grandmothers, aunts, and a stepmother). The data were collected from April to June 2017.

Tesch's method of data analysis was used. Five themes and nine sub-themes were identified on the experiences of caregivers of ALHIV regarding disclosure. Literature control was used after data analysis. Literature should not be reviewed before the data have been collected and analysed so that the literature does not interfere with a researcher's ability to suspend what is known and to approach the topic with openness (Munhall, 2012). Five identified themes and nine sub-themes, as shown in Table 3.1, formed the basis for the development of an educational programme to support the caregivers of ALHIV regarding disclosure in Oshikoto region.

Table 3.1: Themes and sub-themes

Themes	Sub-themes
3.2.1 Theme1: Caregivers experienced barriers to disclose HIV status to adolescents living with HIV	**3.2.1.1** Caregivers experienced stigma and discrimination **3.2.1.2** Caregivers lack of disclosure skills delays disclosure to adolescents **3.2.1.3** Caregivers own HIV positive status influence negatively on disclosure **3.2.1.4** ALHIV age and mental challenges Influence negatively HIV disclosure
3.2.2 Theme 2:Caregivers experienced emotional trauma related to the diagnosis	**3.2.2.1** Fear that the ALHIV would die **3.2.2.2** Sense of hopelessness among caregivers
3.2.3 Theme 3: Caregivers experienced mixed feelings when adolescents were diagnosed with HIV	**3.2.3.1** Initially caregivers were shocked when the adolescents were diagnosed with HIV, but then later accepted the diagnosis as the will of God

3.2.4 Theme 4: Non-biological parents are more at ease to care for ALHIV	**3.2.4.1** Less emotional attached to care for ALHIV
3.2.5 Theme 5: Caregivers experienced resistance from ALHIV to take the ART	**3.2.5.1** Poor adherence to ART

The themes and sub-themes are discussed below.

3.2.1 Theme 1: caregivers experienced barriers to disclose HIV status to adolescents living with HIV

One of the greatest psychosocial challenges that parents and caregivers of HIV infected children face is the disclosure of HIV status to their infected children, even though there are a myriad of benefits associated with disclosure (Gyamfi, Okyere, Acheampong & Appiah-Brempong, 2017). The World Health Organisation (WHO, 2011) recommends that as part of their long-term management, children of school age should be told their HIV status. The WHO further recommends that in order to prepare younger children of their HIV status that disclosure should be done incrementally to accommodate their cognitive skills and emotional maturity. The American Academy of Pediatrics (2009) recommends that children of school age and all adolescents should be told their diagnosis, and underscores the importance of adopting an individualised approach in the disclosure process.

In this study, participants indicated their barriers to disclose the HIV status to ALHIV. As shown in Figure 3.1 there were sub-themes for barriers to disclose HIV to ALHIV.

- Caregivers experienced stigma and discrimination
- Caregivers lack of disclosure skills delays disclosure to adolescent living with HIV
- Caregivers own HIV positive status influence negatively to disclose
- ALHIV age and mental challenges influence negatively HIV disclosure.

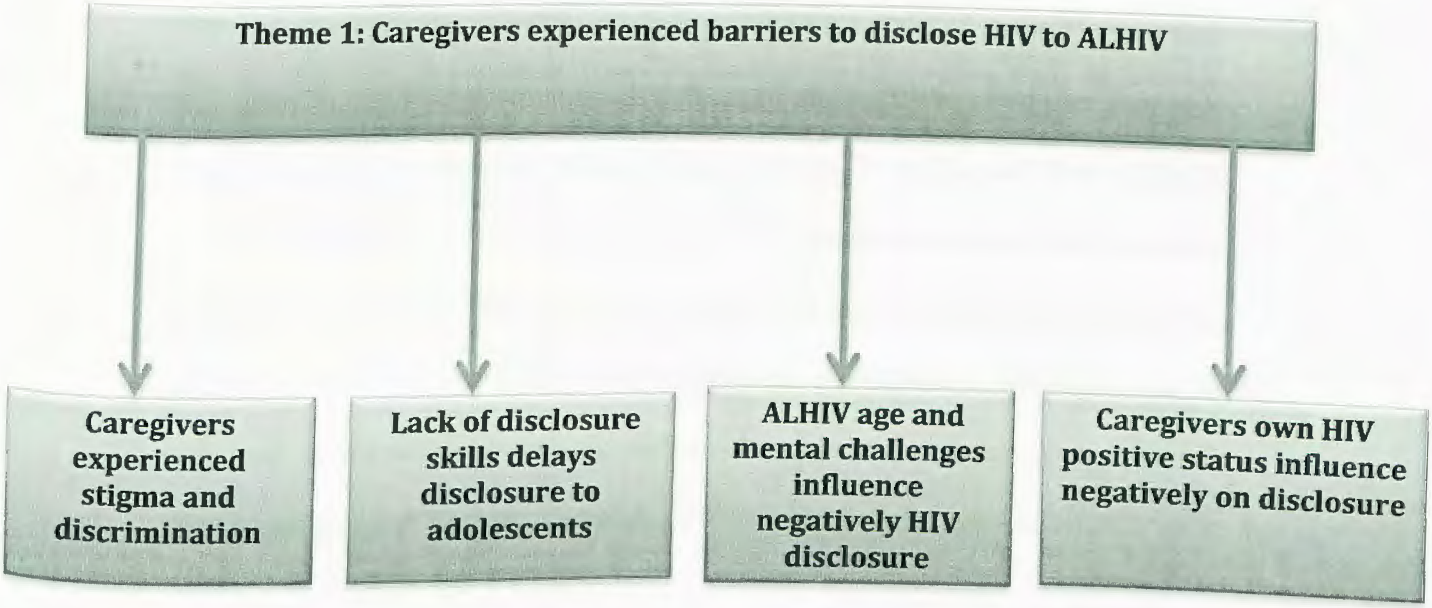


Figure 3.1 Barriers to disclose HIV to adolescents living with HIV.

3.2.1.1 Caregivers experienced stigma and discrimination

Stigma affects all aspects of caring for people living with HIV. People living with HIV are stigmatised and discriminated for many reasons. HIV is a slow, incurable disease that eventually results in illness and death, and many people believe that HIV is a death sentence. HIV disclosure to children is more complicated than to disclose to an adult. Children have little control over their emotions on how and when to be informed about their diagnosis. Many caregivers lack communication skills on HIV.

They also may lack skills on how to disclose HIV status to the ALHIV, and could fear having to answer questions related to how HIV is spread. They may also fear being blamed by ALHIV. Domek (2010) indicated that caregivers in developing countries often struggle with the issue of how to talk to the child, what should be said, and who should talk to the child who is infected by HIV.

The literature indicates that some caregivers could not tell the adolescents about their HIV positive status for fear of exposing them to stigma in the event that their peer came to know about their HIV status. Wiener, Mellins, Marhefka and Battles (2007), in a study conducted in South Africa, indicated that caregivers usually hold the power to decide what is in the best interest of the child and may be reluctant to disclose for various reasons. HIV and AIDS-related stigma and discrimination worldwide can be expressed in discriminatory actions such as abandonment, avoiding contact, verbal harassment, physical violence, verbal discreditable blaming and gossip.

Findings from this study are in keeping with UNAIDS (2010), namely, that even though HIV-related stigma often leads to discrimination, a person can feel stigma towards another but can decide not to act in a discriminatory or unfair way. Conversely, a person can discriminate against another without personally holding stigmatising beliefs.

Caregivers' fears of their infected child was that the child could experience being discriminated because of their HIV status, including losing friends or not being able to share food or sleep in the same room as other children.

Caregivers caring for a child with HIV experience HIV stigma and has a high levels of psychological distress compared to those who did not care for a child with HIV (Kalomo & Liao, 2018). The findings in this study indicate that some caregivers delayed disclosure of HIV status to ALHIV because of fears of rejections. This was evident from the verbatim statements (in italics) of participants.

"When your husband/partner gets to know you or your child is HIV positive there will be no peace anymore in the house, so is better to keep it as secret." - [Biological mother of 13 years old ALHIV].

"I was having problem to inform my husband that we were tested HIV positive, me and my daughter. It took me many days to inform him. I was worried that he will not accept it." - [Biological mother of 13-years-old ALHIV].

"You can no longer leave your child with anybody because she is on medications. They will find out and start calling you bad names and this will remind you about this terrible disease." - [Aunt of 10 years old ALHIV].

(Looking not happy) - *"Some family members, they do not know how to keep secret they will end up telling everyone even at the cuca shop and expose you that you, your husband and your child are living with HIV and this is not good at all."* - [Biological mother of 10 years old ALHIV].

(With low voice and with tears in her eyes)- *"I am living with my mother. Sometimes when she gets angry with me she will tell me 'Do you know that the sick child we have in this house you are the cause of his sickness?*

(paused)...... *These stress me too much."* - [Biological mother of 13 years old ALHIV].

"I was afraid to disclose the HIV status to the adolescent because she was the only one in the house living with HIV. I was thinking the other children in the house will refuse to play with her." - [Aunt of 10 years old ALHIV].

"My husband is not infected with HIV. My daughter and I we are living with HIV. So it's not easy to tell the relatives of my husband that we are living with HIV." - [Biological mother of 12 years old ALHIV].

(Crying and with low voice) – "*Sometimes when your neighbors see you and your child going to the hospital almost every month they already know or suspect that you are living with HIV even you did not inform them. They are already know* ...(paused) *what are the reasons to visit the hospital every month nowadays?"* (Still crying). -[Grandmother of 11 years old ALHIV].

"*Sometimes there is a need to inform the teachers at school where the child is schooling* (with low voice) *...but at the same time, you are also informing them that you are also HIV positive, they will accused you of infidelity..........you are the mother of the child."* - [Biological mother of 10 years old ALHIV].

The findings of a Kenyan study by Mchenry, Nyandiko, Scalon, Fischer, McAteer, Aluoch, Naanyu and Vreeman (2017) were that caregivers of ALHIV whether they are HIV infected or not often experience rejection and discrimination in the community. Caregivers also feared being discriminated against because of their HIV status including the child losing friends or not being able to share food or sleep in same room as other children.

De Silva, Penwill, Sabi, Gifford, Li, Fujie, Weiwei, Yongzhen, Hongyan, Xuemei, Barnoon, Gill and Bonawits (2007) reported that their study in China caregivers concerns about stigma towards children and families were associated with reluctance to disclose. Caregivers were also worried about risking the stigma and isolation for the entire family.

Washington and Oberdorfer (2013) reported that in their study done in Thailand many caregivers kept the adolescent's HIV infection a secret and they did not want to talk to anyone about their respective adolescent's HIV status. Their main reason being fear of stigma and discrimination. If caregivers hear that an adolescent has been rejected at school they usually meet with the teacher and see what can be done in the classroom to stop stigma (WHO, 2014).

A study conducted by Scalon, Mwangi, Turissini Ayaya and Tenge (2014), revealed that caregivers often have fears about the negative emotional effects of disclosure and HIV- related stigma and discrimination. Caregivers also fear their infected child being discriminated against because of their HIV status, including the child losing friends or not being able to share food or sleep in the same room as other children. Therefore, caregivers need to stand up and care for adolescents living with HIV even when they are discriminated against and stigmatised by others due to HIV.

3.2.1.2 Lack of disclosure skills delays disclosure to adolescents

Disclosing HIV status to adolescents is a challenging dilemma because they are usually asymptomatic in the early stage of HIV and yet they need close monitoring and daily medications. Caregivers are faced with challenges pertaining to disclosing HIV status to the adolescents including why, when, how and what is in the best interest of adolescents to know their HIV status. The findings of a study conducted in North West Ethiopia by Alemu, Berharnu and Emishaw (2013) were that caregivers delayed disclosure because they believed that they did not know how to tell or how to approach the disclosure of the HIV diagnosis to their children.

Disclosure of HIV status to ALHIV is believed to be beneficial and helps the children to gain a better understanding about the need to adhere to treatment and better self-care (Abebe & Teferra, 2012). However, caregiver's acknowledgement of their lack of disclosure skills is the reason for not informing adolescents of their HIV status. In addition, some caregivers may not disclose HIV status because they may lack adequate knowledge about the benefits of disclosure (Mweemba, Musheke, Michelo, Halwiindi, Mweemba & Zulu, 2015). Although disclosure is often delayed because of child related reasons, caregivers also delay disclosure because of their own lack of readiness to do so as may be characterised by anxiety and lack of skills and ability to disclose the HIV status to their child (Madiba, 2016). In this study this participants indicated that they lacked skills and knowledge to disclose HIV status to adolescents as revealed through the following verbatim quotes in italics.

(With low voice) - *"To tell the child at the beginning, was difficult* ……(paused)... *is true, it is always difficult. I was sad. I did not know how to inform her that she is living with HIV and I was not trained to do it."* - [Biological father of 11 years old ALHIV].

(Shaking her head) - *"No, no I was not trained. I just decide myself that this child is growing now. She was also keeping asking me why am I taking this medications every day?"* - [Grandmother of 15 years old ALHIV].

"It was so difficult to tell him that he is living with HIV. He used to complain that why he is always taking medications and when is he going to stop taking the medications. I am not trained. I took him to the hospital for the nurses to inform him." [Grandmother of 13 years old ALHIV].

"I did not have an experience on how to disclose HIV status to adolescents. Up to now I did not tell her that she is living with HIV. I just tell her that the medication will stop her cough. I am not trained." - [Biological mother of 12 years old ALHIV].

"My big fear why I did not tell her earlier was, I was afraid that she will feel bad." - [Aunt of 13 years old ALHIV].

"I was keeping delaying the HIV disclosure to my granddaughter, because she was the only one in the house infected with HIV and taking medication every day." - [Grandmother of 11 years old ALHIV].

> *"I was always thinking that if I disclose the HIV status to my grandchildren they may feel bad. For a long time I just keep on giving them medications without telling them why are they taking the medications. I was afraid to tell them that they are living with HIV. I did not know where to start."* - [Grandmother of 11 years old ALHIV and 14 year ALHIV].

The quotes above are a clear indication that caregivers acknowledged their lack of disclosure skills as the reason for not informing the adolescents of their HIV status. A study done by Madiba (2016) found that most caregivers felt that disclosure of HIV to ALHIV was complex and difficult; they thus were concerned that they did not have the necessary skills to disclose.

Madiba and Mokwena (2016) found that that although caregivers believed that they were primarily responsible for disclosure to children, they however reported lack of disclosure skills and as a result they required support from healthcare workers during the disclosure process. Furthermore, they (the caregivers) hoped that the healthcare workers would help them to answer some questions and deal with any negative emotional reactions regarding the disclosure. Kyaddondo, Wanyenze, Kinsman and Hardon (2013) found out that fear of difficult questions sometimes make parents or caregivers of adolescents to avoid disclosing to the infected child. Caregivers further acknowledged the presence of a counsellor eased the process of disclosing and facilitated communication between them.

Most of the studies conducted on HIV disclosure to infected children reported on the challenges experienced by the caregivers to disclose HIV status to their children (Madiba, 2012). In a South African study, by Madiba and Mokgatle (2015), it was revealed that the reasons why the caregivers delay telling the children that they have HIV included fear that the child would be angry, hate, blame, judge and reject them. For these reasons caregivers were not ready to disclose stating that it was not the right time to do so. Furthermore, caregivers lack of experience in disclosure hindered them in disclosing HIV status to their children living with HIV.

3.2.1.3 Caregivers own HIV status negatively influence disclosure to adolescents on their HIV status

When someone tests positive for HIV, it can be very difficult to decide whether to tell the children or not. Parents have feelings of guilt, blame and responsibility for their children's HIV infection and they fear that their children will be hurt or angry with them. Sometimes the adolescents want to know how their parents were exposed to HIV and this then puts the caregivers in a spot on how to answer the questions about how they got infected with HIV.

According to Heeren, Jemmott, Sidloyi, Ngwane and Tyler (2014), caregivers have fears of answering questions related to the source of HIV infection for fear of being judged and blamed by the adolescents. The literature further indicates that caregivers reported being reluctant to inform adolescents of their HIV status in order to protect their own reputations when the caregivers were also HIV positive. This was particularly the case in instances where the adolescents had acquired HIV through mother-to- child transmission (Madiba, 2016). This was also evident in this study based on comments from the participants.

> (With tears in eyes) – *"I cannot disown my child, where can I take her? I know that I am the one who infected her with HIV."* - [Biological mother of 10 years old ALHIV].

> (With low voice) - "*I know that I am the cause of her problem so when I speak with her I have to do it nicely.*" - [Biological mother of 12 years old ALHIV].

> *"Hmmmm... If you know that you are also HIV positive, you have to speak to her nicely. I cannot shout at her even she did something wrong. I have to control my anger.*" - [Biological mother of 13 years old ALHIV].

> (With low voice) - *"When my child was tested HIV positive, it is clear that I am the one who infected her with HIV ...... It is difficult to tell the child that I am the one who infected her with HIV. She may think that I was sleeping with many men. It is not easy at all.*" - [Biological mother of 12 years old ALHIV].

These findings correlate with a study done in Uganda by Kyaddondo et al. (2013) as they found that caregivers postponed disclosing to their children out of fear that the children would blame them for having multiple partners. According to Madiba (2012), biological mothers, as compared to non-biological caregivers, experienced disclosure as traumatic, and feared that they would be blamed for the HIV infection. Mweemba et al. (2015) reported that other caregivers expressed being reluctant to inform adolescents of their HIV status in order to protect their own reputation in instances where they (the caregivers) were also HIV positive. This was particularly the case in instances where the adolescents had acquired HIV through mother-to-child transmission. A study in sub-Saharan Africa found that some caregivers who did not share their own HIV status with their children had informed their children of their HIV status in moment of angers (Vaz et al., 2010). Therefore some caregivers found it difficult to inform their children that there are also living with HIV.

3.2.1.4 ALHIV age and mental challenges influence negatively HIV disclosure

Disclosure to children and young adolescents should depend on their stage of development. Young children need to have partial disclosure. They only to know that they are sick and they have to go to the hospital and that they need to take the medications to feel better. The older children and young adolescents need to have full disclosure. They need to know that they have HIV and should understand the disease and their medication and actively participate in their own care and treatment. Parents/caregivers are strongly encouraged to be mindful that disclosing HIV infection to school aged children and young children should be done incrementally to accommodate their cognitively skills and emotional maturity (WHO, 2011). Therefore caregivers should move from partial to full disclose gradually and should help adolescents to understand and cope with knowing their diagnosis.

At the beginning caregivers usually argue that their child is too young to know about their HIV diagnosis and thus delay disclosure (Kouyoumdjian, Meyers & Mtshizana, 2005). In that study, many caregivers that had not partially or fully disclosed HIV status to ALHIV feared and worried that their children were too young to be informed. The WHO (2015) recognised that lack of disclosure affects the wellbeing of the child including access to paediatric HIV treatment and care as well as adherence to treatment. In this study caregivers feared that the adolescents were not mature enough to understand the issue of HIV or ART as indicated by the comments of the participants.

> *"I am afraid if my child knows that she is HIV positive she may just start telling everybody that me and my mother we are HIV positive. I think she is too young to keep the secret."* - [Biological mother of 10 years old ALHIV].

> *"I try many times to inform my child that she is living with HIV but I think she is too young to understand."* - [Biological mother of 12 years old ALHIV].

> *"I am taking care of my sister's child, she looks like mentally retarded or somebody who is having disease of the brain. No matter you try to explain anything to her she does not understand what you trying to say.* " - [Aunt of 10 years old ALHIV].

> *"Up to now I did not tell my boy that he is living with HIV. I think he is too young to understand this HIV things...(*clearing her throat) -- *he is 13 years old now. I just tell him that you are going to take this medication without missing any dose."* - [Biological father of 13 years old ALHIV].

> *"At seven years I think the child is too young, is better to start at ten years to inform the child that is living with HIV. At seven years is too young. I think it will confuse the child."* - [Grandmother of 10 years old ALHIV].

> *"My daughter is mentally retarded. When you look at her she looks normal but she forget easily. I have tried many times to explain to her why she is taking medications but it did not help."* - [Biological mother of 11 years old ALHIV].
>
> *"She is twelve years old, she looks like mentally retarded. I just gave medications she does not remember anything. She does not know why she is taking the medication. I think that her brain is not well developed."* - [Grandmother of 12 years old ALHIV].

These comments showed that the caregivers were not disclosing the HIV status to adolescents because of their perceptions of their age and maturity. These findings are in keeping with those of Aderomilehin, Hanciles-Amur and Ozoya (2016). They indicated that thinking that a child is too young creates barriers to disclose HIV to adolescents by most parents and caregivers.

The most common barrier for caregivers to disclosure was that their child was too young to understand their illness (Gyamfi, Okyere, Appiah-Brempong, Adjei & Akohene, 2017). A Kenyan study on caregivers fear of adverse psychological consequences for a child indicated that caregivers believe their children were not develop mentally ready to understand the implications of the HIV diagnosis (McHenry et al., 2017).

3.2.2 Theme 2: caregivers experienced emotional trauma related to adolescent HIV diagnosis

Emotional trauma is a common but usually short lived response among the caregivers of ALHIV. Parents and caregivers of ALHIV are the centre of their respective child's life. Their care and dedication are essential to promote a healthy and happy life. Caregivers need reassurance and assistance to help to deal with emotional trauma related to ALHIV.

Emotional trauma is defined as the result of extraordinarily stressful events that shatter a person's sense of security, making one feel helpless in a world that is regarded as dangerous (WHO, 2013). Despite the availability of ART caring for ALHIV continues to be a burden and a challenge to caregivers. The burdens associate with high level of stress usually manifesting as anxiety or depression (Abbasiubong, Bassey, Ogunsemi & Udobang, 2011). The impact on caregiving for someone living with HIV could be enormous, leading to high levels of stress and manifesting as anxiety and/or depression (UNAIDS, 2010). Figure 3.2 shows the sub-themes that were identified under emotional trauma.

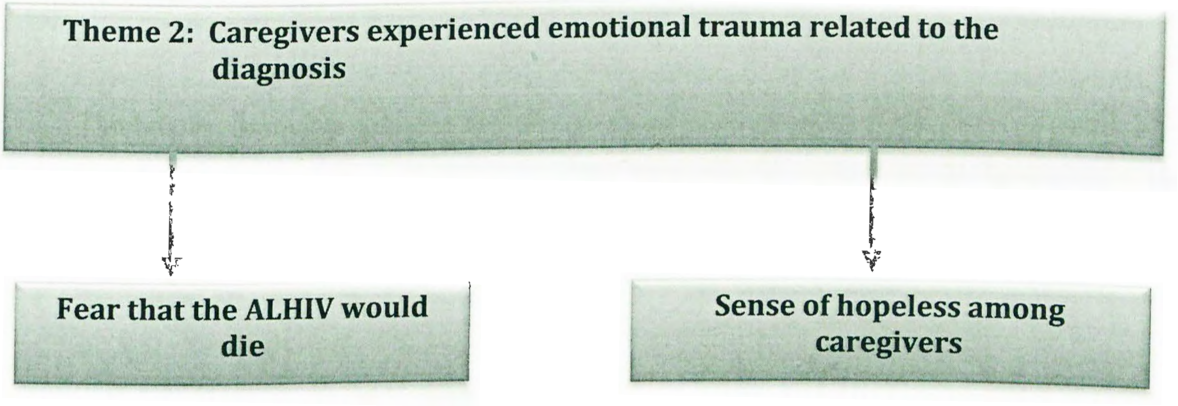


Figure 3.2: Emotional trauma related to adolescents diagnosis

3.2.2.1 Fear that adolescents living with HIV would die

In many parts of the world, HIV/AIDS is still viewed as a terminal illness: a disease from which there is no recovery. However, with the availability of ART, HIV is increasingly recognised as a chronic, rather than terminal, illness. The biggest fear of parents or caregivers when a child is diagnosed with this chronic condition is that the child will die. A study done in Uganda revealed that some people still believe that once a child is diagnosed with HIV, death is imminent (Kyaddondo, Wanyenze, Kinsman & Hardon, 2013).

A study by McHenry et al. (2016) revealed that although HIV treatment was generally believed by community members to improve the health and survival of those living with HIV, many people in the community still viewed it as a death sentence. In other words they believed this meant the end of life because when one is diagnosed with HIV there is no longer life. Some caregivers or parents worried that the moment their child was diagnosed with HIV that death was unavoidable. However, the WHO (2013) indicated that due to the success continuum of HIV care and ART a growing numbers of children are living into adolescents. Therefore the caregivers of ALHIV need to be reassured and register their children for HIV care at health facilities.

The below comments of the caregivers in this study highlighted that they had similar fears and were worried about death when their children were diagnosed with HIV.

> (With low voice) - *"When I received the HIV positive result of my child, I was just thinking that this is the end of my child's life ....she will die."* - [Biological mother of 11 years old ALHIV].

"Soon after my son was diagnosed with HIV, he was also diagnosed with TB it was very serious. He used to take medications for these two diseases and I thought he is going to die." - [Biological mother of 13-years-old ALHIV].

"I was afraid my heart was very heavy when my child was diagnosed with HIV. I was worried if the child will get medications or he will die." - [Biological mothers of 10 year old ALHIV].

3.2.2.2 Sense of hopelessness among caregivers

Hopelessness places an enormous burden on caregivers of ALHIV. It is a particularly heavy one for older persons who care for orphaned grandchildren living with HIV after the death of their parents. According to Tichauya (2013), the findings of a study conducted in Zimbabwe showed that caregivers of ALHIV feel helpless and have feelings of confusion.

Some caregivers in this study reported similar feelings of hopelessness as shown in their comments.

(With tears in her eyes) - "*My grandson is nineteen years old now. Sometimes you tell him to go and take his medications but he will not take it. I tried many times to ask him to take the medications and tell him that his life depends on thise medications. He hides the medications under his bed in his room. Now I do not want to take care of this boy anymore. I have tried many times now I am tired.*" - [Grandmother of 19 years old ALHIV].

"Keep reminding the child to take his medication is not easy at all, you are always shouting and calling them to come and take their medications." - [Aunt of 13 years old ALHIV].

"I don't feel good at all because he does not want to take his medications. His life depends on this medication. I am always feeling bad and angry with him. This medicine is his life.'' - [Aunt of 11 years old ALHIV].

(Shrugged her shoulder) - *"What can I do? The mother of this child died long time ago. I am the one who takes care of this child now but to make him to take his medications is always difficult. I will continue taking care of him. What can I do? I cannot do anything."* - [Aunt of 14 years old ALHIV].

"What have I done? I am HIV positive and so my child. This is clear that I am the one who infected the child with HIV." - [Biological mother of 10 years old ALHIV].

3.2.3 Theme 3: caregivers experienced mixed feelings when adolescents were diagnosed with HIV

This theme related to the caregivers experiencing mixed feelings when adolescents were diagnosed with HIV. They however accepted the diagnosis of the adolescents as the will of God as displayed in Figure 3.3.

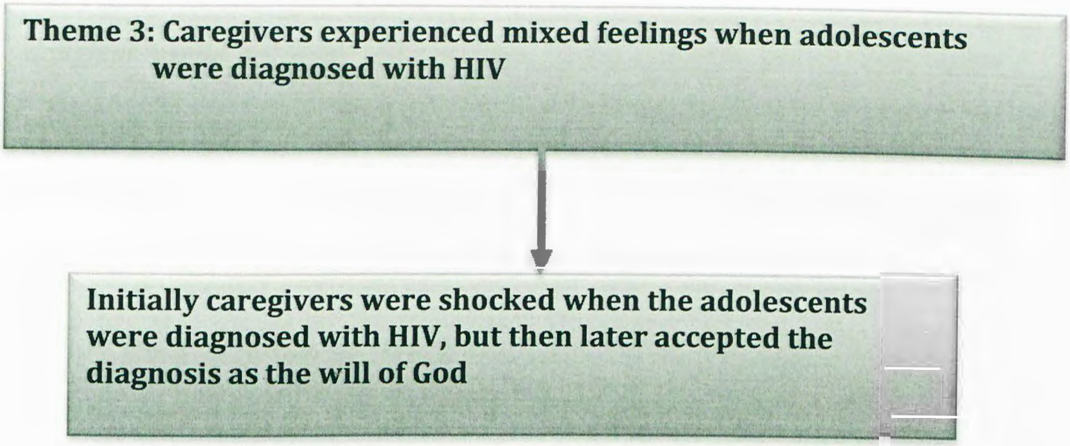


Figure 3.3: Mixed feelings when adolescent diagnosed with HIV

3.2.3.1 Initially caregivers were shocked when the adolescents were diagnosed with HIV but then accepted the diagnosis as the will of God

Being diagnosed with a chronic illness such as HIV can be a blow. When a child is diagnosed with a chronic medical condition it poses a challenge to parents as well as caregivers. It is normal to experience a range of emotions in the wake of such a diagnosis. Therefore a system of informal and formal counselling and support must be accessible to caregivers of ALHIV in order to assist them in coping with their child's illness (De Silva, Silva, Rodriques, Neto, da Silva & Sousa, 2017).

The participants in this study expressed the following regarding mixed feelings when their children were diagnosed with HIV.

> *"I know that I am living with HIV even before I go t pregnant. When I take my child for HIV test she was tested HIV positive. I was shocked when the counselor told me that my daughter is HIV positive. I did not expect that my*

daughter would be tested HIV positive. Later I accept it." - [Biological mother of 10 years old ALHIV].

"For me it was easy to accept it and was also difficult to accept it at the same time. I was confused a bit, but I accepted it because the child was sick and need to be started on treatment." - [Biological mother of 10 years old ALHIV].

"When they told me about my son's result that he is living with HIV I was shocked, I just accept it as I believe this is God's will. What can I do?" - [Biological mother of 12 year old ALHIV].

"I felt very bad about the child's diagnosed with HIV and I have accepted it. Only God knows why it happens like that." - [Grandmother of 10 years old ALHIV].

"I never suspected that my child could be infected with HIV and the worst part is that I infected the child. I just accepted as God's will. With available treatment my child is doing well, he was never admitted." - [Biological mother of 11 years old ALHIV].

"I was shocked to hear that my grand child is living with HIV. Her mother passed away without telling me anything. On the other hand, I was happy because the treatment for HIV is available now." - [Grandmother of 14 years old ALHIV].

"When I was told that my son is living with HIV I was relieved. I was worried about my son's sickness, he used to be admitted several times one week he is in the hospital; the other week he is at home. I was very happy about the diagnosis, now I know what is wrong with my child and he will get the correct medications." - [Biological mother of 14 years old ALHIV].

(With low voice) - *"I was happy about the child's diagnosis. The mother died and she did not want the child to be tested. Now I know what is wrong with the child."* - [Aunt of 12 years old ALHIV].

"When the child tested HIV positive I felt very bad, it worried me too much. When I look at him I feel pity for her then I say this child of God is too small to suffer like this. Sometimes when I think about it I just start crying even now, but I know that God will help her." (crying). - [Grandmother of 16 years old ALHIV].

These findings are in keeping with those of a South African study. Caregivers of ALHIV identified churches as their sources of support to cope with child illness and this promoted acceptance of their child diagnosis (Majumdar & Mazaleni, 2010). Human beings are fully in control of what happens in their lives (McDaniel, 2018).

3.2.4 Theme 4: non-biological parents are more at ease to care for ALHIV

The relationship between a caregiver and their child influences HIV disclosure to adolescents. Biological parents experience trauma and fear that their child would blame them for their HIV infection, whereas non-biological parents do not fear any blame. A study conducted in South Africa by Madiba (2012) found that non-biological caregivers often disclosed impulsively to children soon after the child was diagnosed with HIV or came under their care.

Non-biological participants in this study who were not mothers felt at ease to care for ALHIV as shown in Figure 3.4.

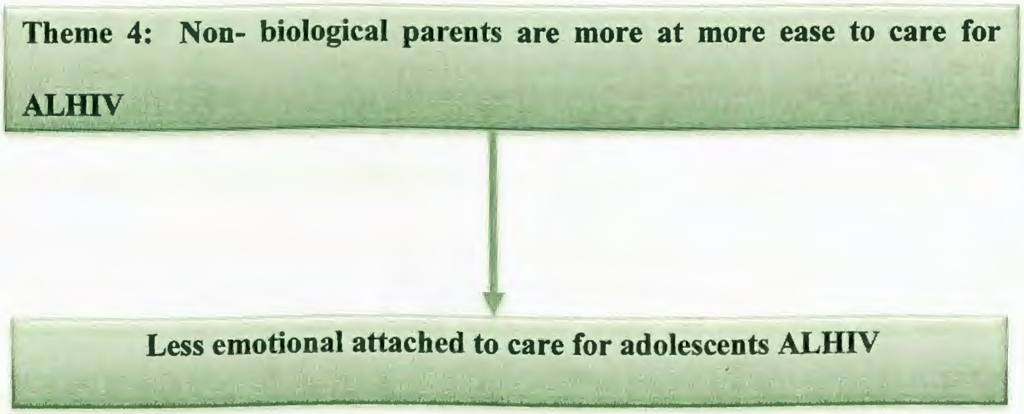


Figure 3.4: Non-biological parents are more at ease to care for adolescents living with HIV.

3.2.4.1 Less emotionally attached to care for ALHIV

When a once off or accidental disclosure occurs then usually caregivers do not expect a lot of questions from the adolescents. For caregivers who are not biological parents of the child it is easy, and they often disclose without planning. In reality some of the disclosure events were accidental, unplanned and impulsive (Madiba & Mokwena, 2012).

The below quotations from non-biological parents in this study indicated less emotional attachment to caring for ALHIV.

> *"I am living with my two grandsons. They wanted to know why are they taking the medication, I told them that they are suffering from the same disease which killed their mother and that disease is called HIV."* - [Grandmother of 11 years old twins living with HIV].

> *"I disclosed the HIV when he came to stay with us after his mother passed on. I read it in his health passport that the child is taking antiretroviral therapy."* - [Stepmother of 12 years old ALHIV].

> *"I told her one day that she is living with HIV when she refused to take her medications. She wanted to kill herself but I am not the one who infected her with HIV."* - [Grandmother of 17 years old ALHIV].

> *"The reason I decided to tell her was, she was is always crying when I call her to come and take the medications and she said she is tired of taking the medications every day."* - [Aunt of 10 years old ALHIV].

> *"When I was told that the child is living with HIV I just accepted very well, the child is an orphan, I am the one who takes care of him after both parents died."* - [Aunt of 12 years old ALHIV].

> *"I cannot do anything because she was born with HIV virus. The mother died soon after giving birth to her. I have to tell her that she is living with HIV."* - [Aunt of 13 year old ALHIV].

It is therefore shown from these comments that the non- biological caregivers in this study were able to disclose the HIV status to adolescents, through accidentally. According to the literature not every disclosure event was planned and prepared. Some of the caregivers disclosed during moments of frustration in response to their child's refusal to take ART (Vaz, Eng, Maman, Tshikandu & Behets, 2010).

3.2.5 Theme 5: caregivers experienced resistance from ALHIV to take the ART

Explaining to the adolescents that they are living with HIV fulfills their right to know about their own health. One of the main reasons to disclose HIV to adolescents is to improve adherence to their treatment regimen and for them to stay healthy. The literature indicates that another reason for informing the adolescents about their HIV status was poor adherence to treatment by some adolescents, where caregivers showed that some adolescents do not take the medications and sometimes threatened to stop taking medications (Mweemba, Musheke, Michelo, Halwiindi, Mweemba & Zulu, 2015). Figure 3.5 shows the identified sub-theme.

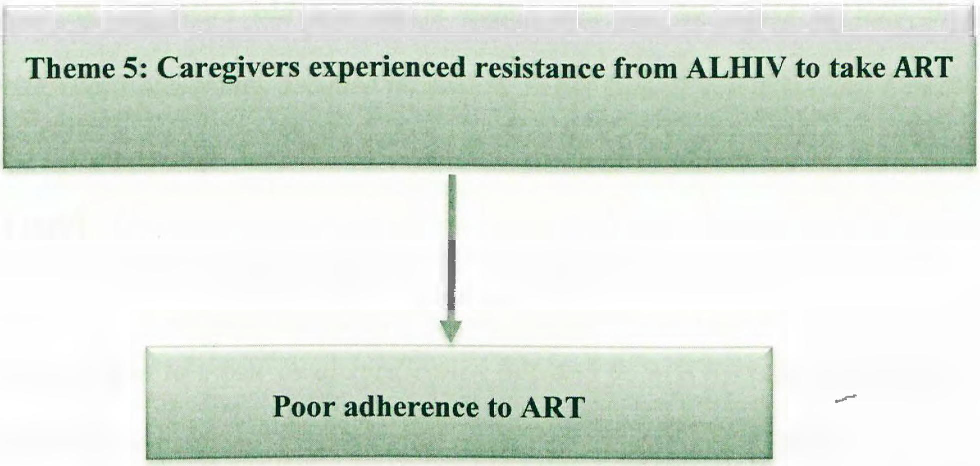


Figure 3.5: Resistance from adolescents living with HIV to take the antiretroviral therapy

3.2.5.1 Poor adherence to ART

Poor adherence to ART appears to be more prevalent in ALHIV. Disclosure of HIV status to infected children has become an essential part of their care to increase their access to ART. The benefits of adolescents knowing their HIV status include increased adherence to medications, treatment regimens, doctor visitation and hospitalisation. The World Health Organisation (2011) recognised that the lack of disclosure ultimately affects the wellbeing of the infected child, including access to paediatric HIV treatment and care and adherence to treatment.

When ALHIV takes their dose of ART medications they become asymptomatic and they do not understand the importance of visits to healthcare facilities for routine checkup and the continuous taking of medications. (Kallem, Renner, Bhebremichen & Paintsil, 2010). This claim is also evident to this study as indicated in what some of the participants said.

"My son, 18 years old now he is doing well but he refuse to take the medications sometimes because he said he is not sick. If you don't call him to take the medication he will not come." - [Biological mother of 18 years old ALHIV].

"My son used to throw away medication because he was not told why he is he taking the medication." - [Biological mother of 11 years old ALHIV].

"I thought my child is taking the medication, but one day I took her for follow up the viral load was high, this showing that she was not taking his medication very well." - [Biological father of 15 years old ALHIV].

"I have to make sure that she swallows the medications. Many time she spit out the medications." - [Biological mother of 12 years old ALHIV].

"Sometimes she refuses to take the medications, she just put the tablets in the mouth and later she spit the tablets out. I reported him to the nurses during our regular follow up, we were referred for adherence counseling." - [Grandmother of 12 years old ALHIV].

"He is doing fine but sometimes he refused to take the medications. But if I talk to him nicely he will take his medications." - [Aunt of 14 years old ALHIV].

"My boy likes to play a lot. If I do not call him he will not remember to come and take the medications." - [Biological mother of 13 years old ALHIV].

Some participants were of the opinion that when ALHIV refuse to take their medication then disclosure was not done properly. This is in keeping with the literature. Gyamfi, Okyere, Appiah-Brempong, Adjei and Akohene (2015) claimed that some caregivers wait until their child begins to refuse medication on the grounds that they do not feel sick and therefore do not see the need to take medication daily. Caregivers indicated that ALHIV who do not know their HIV status have poor adherence to ART.

3.3 SUMMARY

In this chapter the findings of Phase 1 of the study were covered. The findings of the experiences of caregivers of ALHIV regarding disclosure were presented and discussed. The discussion was based on five main themes: caregivers experienced barriers to disclose HIV status to adolescents living with HIV; caregivers experienced emotional trauma related to adolescents diagnosis; non-biological parents were more at ease to care for ALHIV; caregivers experienced mixed feeling when adolescents were diagnosed with HIV; and caregivers experienced resistance from ALHIV to take their ART. These themes and sub-themes formed the conceptual framework for the development of an educational programme. The conceptual framework is presented in the next chapter.

CHAPTER 4

A CONCEPTUAL FRAMEWORK

4.1 INTRODUCTION

In the previous chapter data analysis and results of the study for Phase 1 were described based on the experiences of caregivers of ALHIV regarding disclosure of HIV status to the adolescents. This chapter covers Phase 2 of the study: the conceptual framework. The conceptual framework was important in the development of an educational programme to support the caregivers of ALHIV regarding disclosure.

4.2 DEVELOPMENT OF A CONCEPTUAL FRAMEWORK AND RESEARCHER'S REASONING MAP

According to Burns and Grove (2013) a conceptual framework enables a researcher to link the findings of a study to the body of knowledge and to conceptualise these findings in practice. The survey list of the practice orientated theory, by Dickoff et al (1968), was used to develop a conceptual framework in this study. According to them a conceptual framework is defined as a structure, which guides the development of a programme. It enables a researcher to relate the results of a study to the existing body of knowledge. A survey list that related to six questions by Dickoff et al. (1968) was used in this study. The six elements included the following:

- Agent: this refers to who would perform the activity that facilitated the development of the educational programme
- Recipient: this refers to who would receive the activities
- Context: this refers to in what context would the activities be performed

- Dynamic: this refers to interaction, challenges, findings
- Procedure: this refers to the guiding procedure, technique or protocol of the activities
- Terminus: this refers to the outcomes of the activities

These elements were important for the researcher to develop an educational programme to be used by the caregivers of ALHIV regarding disclosure. The survey list of Dickoff et al. (1968) was adopted for the development of the researcher's 'reasoning map' and is discussed below. Figure 4.1 displays the reasoning map.

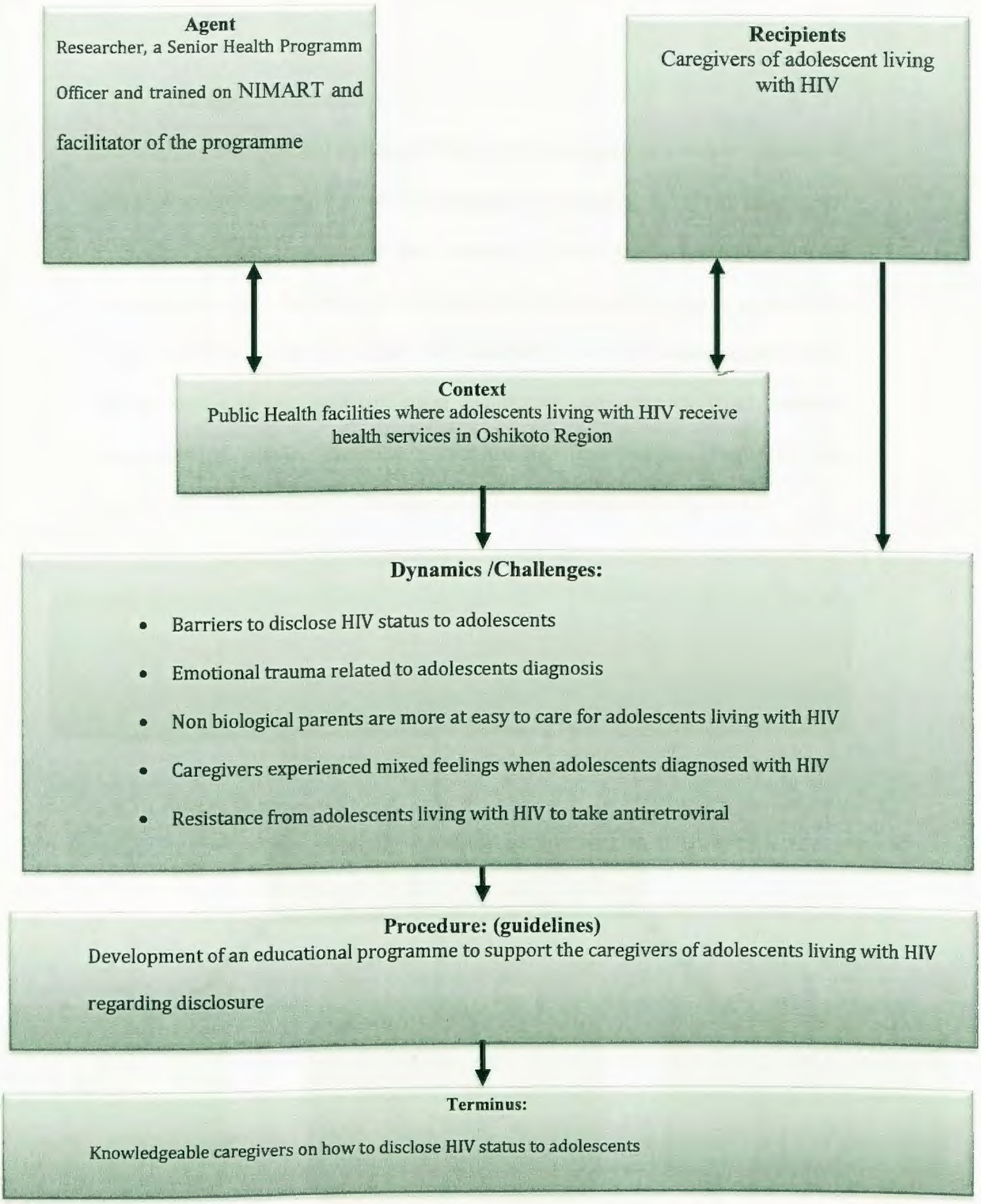


Figure 4.1: Reasoning map

4.2.1.1 Knowledge on programme designing and facilitation

The researcher is a senior registered nurse who is trained in NIMART and has the relevant knowledge, as well as scientific knowledge and research skills, to carry out the study. During the implementation of the developed educational programme the caregivers were supported to provide disclosure HIV status to ALHIV.

4.2.1.2 Communication skills

Hornby (2016) defines communication as the ability to transfer or share ideas and feelings effectively. Effective communication is a two-way process that requires effort and skill by both a sender and a receiver. Communication skills are those tools that can be used to remove barriers to effective communication. The agent in this study was responsible to facilitate the process of developing the communication skills of the caregivers. This required developing guidelines to support them based on the findings of the study. The agent use verbal and non-verbal communication for effective communication with the recipients.

Body language can influence a message being conveyed to recipients. In this study the agent was mindful of the importance of good eye contact, tone of voice, and hand gestures. Thus, throughout the training the agent maintained communication in a friendly tone and good eye contact. To communicate effectively requires certain skills; these include listening, questioning, paraphrasing, giving feedback, and summarising. These are explained below.

- **Listening**

An agent must be attentive and involved during an activity, which includes listening when someone is speaking. A good listener is one of the best ways to be a good communicator. Through active listening an agent better understands what the other person is trying to say (Doyle, 2016). In this study the agent listened attentively to the caregivers of ALHIV on which strategies they were using regarding disclosure of HIV status to the adolescents.

- **Questioning**

In order to implement the educational programme the agent in this study had to possess skills to ask questions during the facilitation process to test the knowledge of the participants and to probe for further insights. By constantly asking questions shows that an agent is interested in the discussion. The recipients in this study were asked questions to test their knowledge before, during, and after each topic.

- **Feedback**

Giving and receiving feedback is an important communication skill of an agent (Doyle, 2016). As stated above effective communication is a two-way process thus the agent in this study gave and received feedback from the recipients. Feedback was also given to the recipients during the implementation of the educational programme. In order to motivate them the agent used feedback to praise them where they did well.

- **Summarising**

In this study the agent was responsible for summarising the main points at the end of training. Summarising also assisted the (recipients) caregivers to reflect on what had been discussed, and to link a previous discussion to the next session. Summarising helped the agent to be on the same page as the caregivers during the FGDs as well as during the training on the educational programme.

4.2.1.3 Personal value

George (2014) defines value as the process of living cherished beliefs while adding to one's worldview. Personal values are one of the characteristics that an agent needs to possess to be able to transfer information to recipients. For this study personal values included respect, trust, empathy, and objectivity.

- **Respect**

According to Doyle (2016) people will be more comfortable and communicate more openly with an agent if their ideas and their opinions are respected. In this study the participants (recipients) were called by their preferred names. The agent maintained eye contact with them and actively listened to the opinions they put across regarding disclosure of HIV status to the adolescents.

- **Trust**

According to English Living Oxford dictionary (2016) trust is defined as the ability of someone to believe in the other or something. In this study there was open communication between the recipients and the agent. This helped to foster trust between the two parties.

- **Empathy**

The English Living Oxford dictionary (2016) defines empathy as the ability to understand and share the feelings of another. In this study the agent showed empathy by trying to understand the recipients' situation and by putting herself in their shoes without becoming emotionally involved. The researcher, as the agent in this study, described, developed and facilitated an educational programme to support the caregivers of adolescents living with HIV regarding disclosure in Oshikoto region, Namibia.

- **Objectivity**

The English Living Oxford dictionary (2016) defines objectivity as striving to reduce or eliminate biases. The agent in this study clearly explained the purpose and objectives of the study to the participants (recipients) in a transparent manner. During the implementation of the educational programme the agent remained neutral and was not influenced by the participants.

4.2.2 Recipient: caregivers of adolescents living with HIV

Recipients are defined as vulnerable and dependent patients who are characterised by personal attributes, problems and capabilities, including the ability to cope (George, 2014). According to the English Living Oxford dictionary (2016) a recipient is a person or thing that receives or is awarded something. Dickoff et al. (1968) refer to a recipient as persons who receive activities from the agent. In this study the recipients were the caregivers of ALHIV regarding disclosure in terms of the development of an educational programme

The findings of this study showed that the caregivers experienced the following. Barriers to disclose HIV status to ALHIV, emotional trauma related to diagnosis of HIV, non-biological parents being more at ease to care for ALHIV, caregivers experienced mixed feelings when ALHIV diagnosed with HIV and resistance from the ALHIV to take ART. The developed programme thus addressed providing caregivers with sufficient knowledge and skills regarding disclosure of HIV status to ALHIV. This in return supported them to cope with the situation and to accelerate the disclosure process. The caregivers needed to have certain characteristics in order for them to benefit from the developed programme as shown in Figure 4.3.

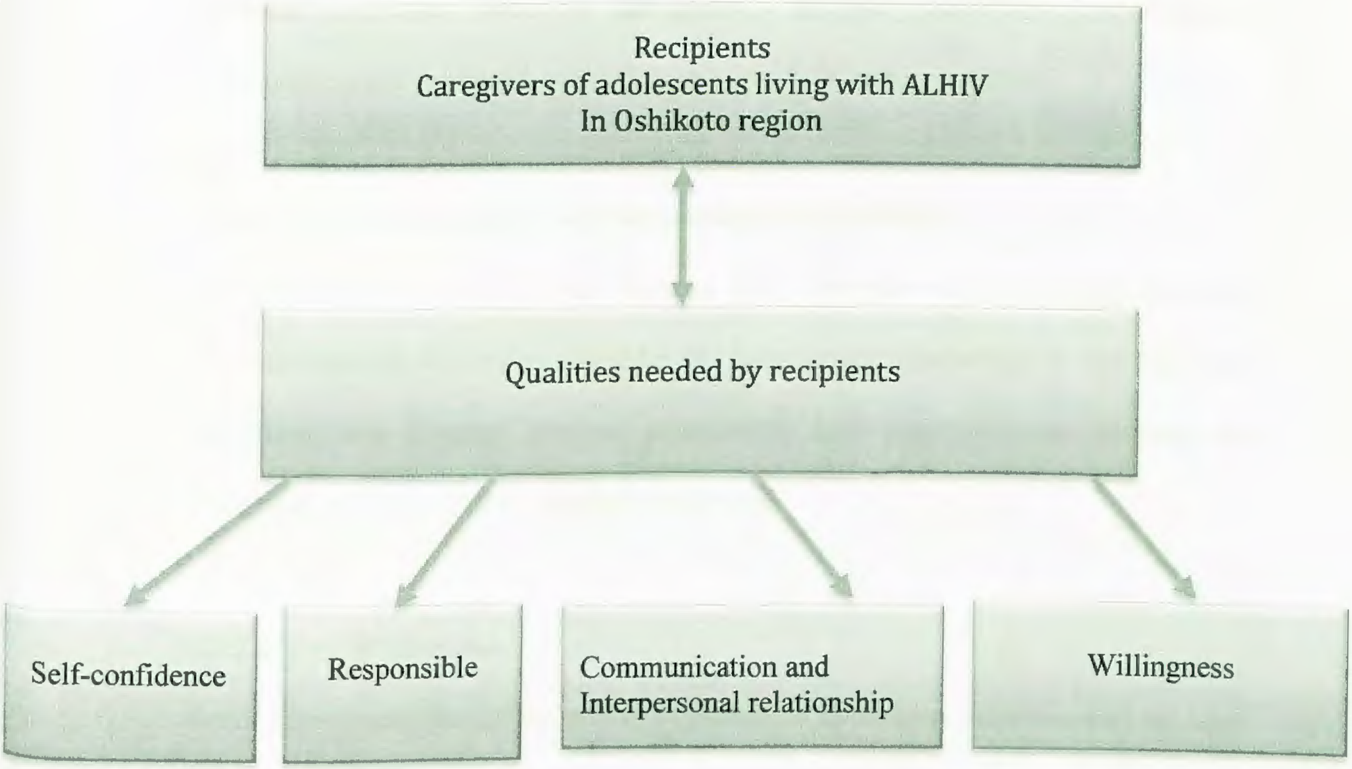


Figure 4.3: Qualities of recipients

The qualities shown in Figure 4.3 are discussed below.

4.2.2.1 Self-confidence

Self-confidence is an important characteristic of the recipients; it includes a combination of belief and trust. Having self-confidence meant the caregivers would be able to disclose HIV to ALHIV. FGDs require teamwork hence they were conducted during data collection so that caregivers could work together as a team.

4.2.2.2 Responsible

The English Living Oxford dictionary (2016) defines responsible as having control over or care for someone as part of one's role. Being a caregiver requires one to be responsible. In other words the caregivers in this study had to have knowledge, be accountable, and involved in disclosure of the HIV status to ALHIV.

4.2.2.3 Communication and interpersonal relationship

Communication is said to be the basis of every interpersonal relationship. Effective communication is the key to a healthy and long lasting relationship. It was important that there was a good personal relationship and communication between the caregivers and the ALHIV regarding disclosure.

4.2.2.4 Willingness

Willingness is defined as the power of people to make own decisions and act upon decisions (George, 2014). Willingness is the quality of being able to be prepared to take action and ready to do anything. The caregivers thus had to be ready and willing to commit themselves to learn new idea.

4.2.3 Context: Public Health Facilities where ALHIV receive health services in the Oshikoto region

Context refers to the situation in which activities take place (George, 2014). Context also is defined as a situation in which something happens and helps one to understand it (Hornby, 2015). The context in this study was the public health facilities where

ALHIV received health services, namely, the Intermediate Hospital Onandjokwe, Omuthiya, and Tsumeb District hospitals in the region. The programme in this study was presented in the Intermediate Hospital Onandjokwe which is the referral hospital in the region. There is a need to put the context into consideration; the context can influence the outcome of the programme activities. Resources and information can influence the outcome of the context activities. Figure 4.4 below indicates factors that could have influenced the context of the study.

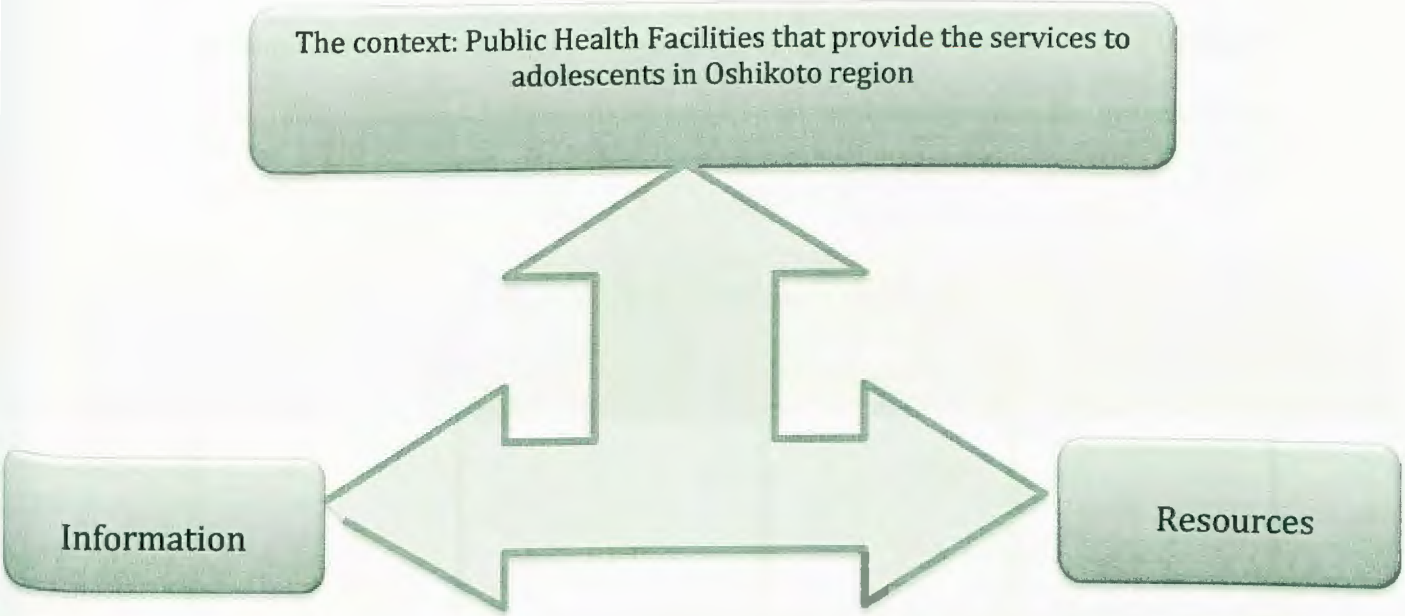


Figure 4.4: Factors influencing the context

4.2.3.1 Information

The researcher and the participants (recipients) communicated in the language they understood very well. The handouts for the training were prepared in English and translated into Oshiwambo. The participants were informed that they should communicate openly in the language comfortable to them.

4.2.3.2 Resources

An educational programme for this study was implemented in the form of a one-day workshop. The venue was the Onandjokwe Regional Health Training Centre hall in the Intermediate Hospital Onandjokwe. The selected venue was able to accommodate all of the workshop participants. It was well ventilated and equipped with chairs and tables. Resources such notes books, pens, marker pens, flip charts, laptop, and projector were prepared by the researcher.

4.2.4 Dynamics or motivating factors

Dynamic refers to the energy source or motivating factors behind the activity (Dickoff et al, 1968). Figure 4.5 shows the dynamics that were derived from the themes of the findings.

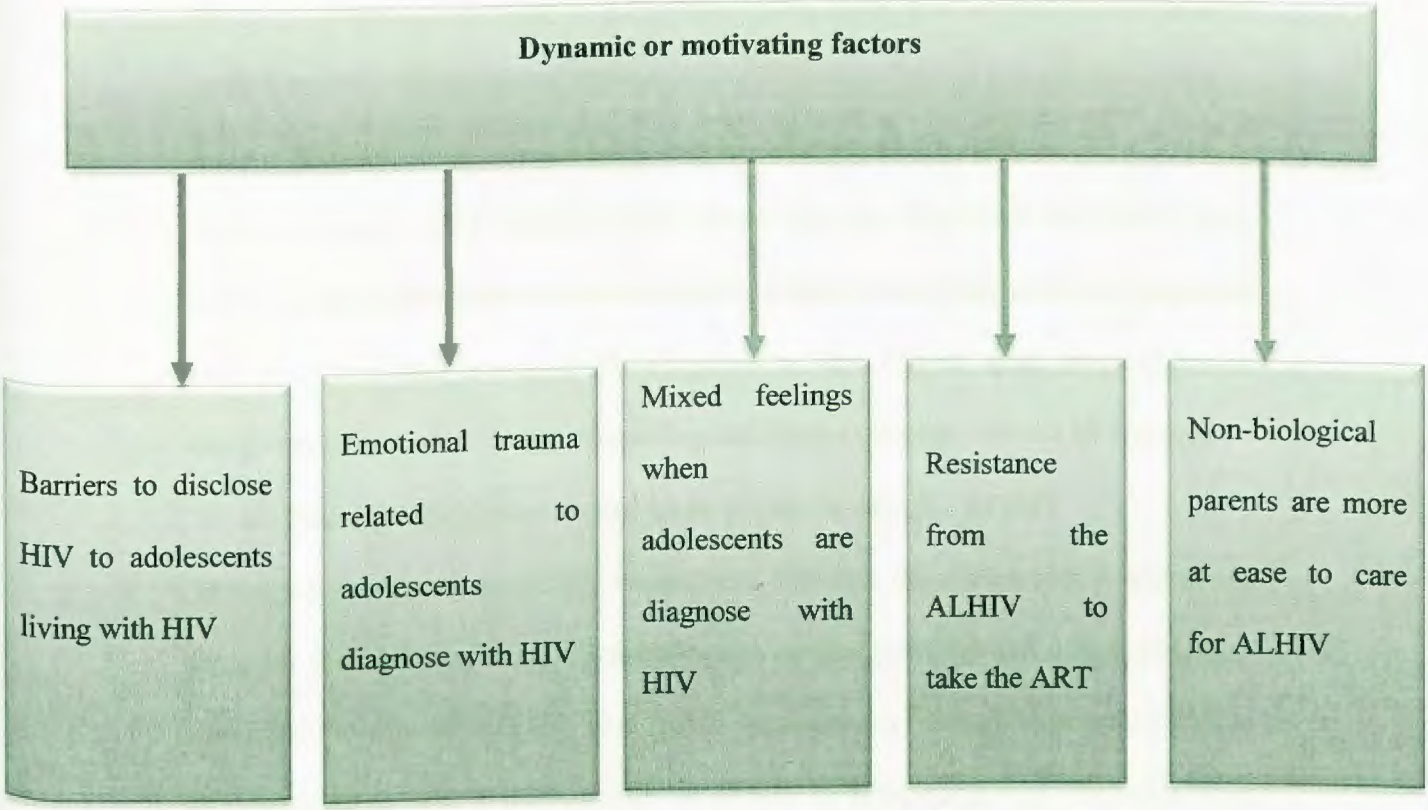


Figure 4. 5 Dynamics in this study

Barriers to disclose HIV to adolescents living with HIV

Caregivers experienced barriers to disclose HIV to ALHIV. These barriers included stigma and discrimination, lack of disclosure skills, caregivers' own HIV positive status influenced negatively on disclosure and ALHIV age and mental challenges influenced negatively HIV disclosure. Caregivers needed knowledge and skills on how and when to disclose HIV status to the ALHIV hence need to develop and implement the educational programme.

- **Emotional trauma related to adolescents diagnose with HIV**

Caregivers experienced emotional trauma related to adolescents diagnosed with HIV, which included fear that the adolescents would die soon after diagnosis. As a result the caregivers experienced a sense of hopelessness. Due to emotional trauma caregivers needed to be supported by empowering them with the correct information on how to deal with emotional trauma.

- **Mixed feelings when adolescents are diagnose with HIV**

Caregivers had mixed feelings when adolescents are diagnosed with HIV. They expressed being shocked when the respective adolescent in their care was diagnosed with HIV, but later accepted the diagnosis as the will of God. By implication caregivers thus needed formal counselling and support to cope with ALHIV illness.

- **Non-biological parents are more at ease to care for ALHIV**

Biological caregivers of ALHIV experienced fear that the adolescents would blame them for their HIV infection. Non-biological parents however had a less emotional attachment to care for ALHIV. Due to this dynamic, non-biological parent needed to be counselled on how to disclose HIV to ALHIV to avoid accidental disclosure since this could result in emotional trauma for the adolescent concerned.

- **Resistance from the adolescents living with HIV**

Caregivers experienced resistance from ALHIV to take ART as well as poor adherence to ART. Therefore, caregivers needed to be supported with the information regarding the following: the benefits of ART; the importance of adherence to medications; and regular follow-ups to hospital by the adolescent concerned.

4. 2. 5 Procedure

The English Living Oxford dictionary (2016) defines procedure as a fixed, step-by-step sequence of activities or course of action. Dickoff et al. (1968) refer to procedure as the way in which activities take place. The procedure in this study refers to activities of an educational programme to support the caregivers of ALHIV regarding disclosure. The implementation of the programme was based on Kolb`s experiential learning cycle. This procedure addressed the following barriers to disclose HIV status to ALHIV: mixed feelings when adolescents are diagnosed with HIV, non-biological parents at ease to care for ALHIV, and resistance from the adolescents to take ART. Figure 4.6 indicates the procedure that was carried out in the implementation of the educational programme of this study.

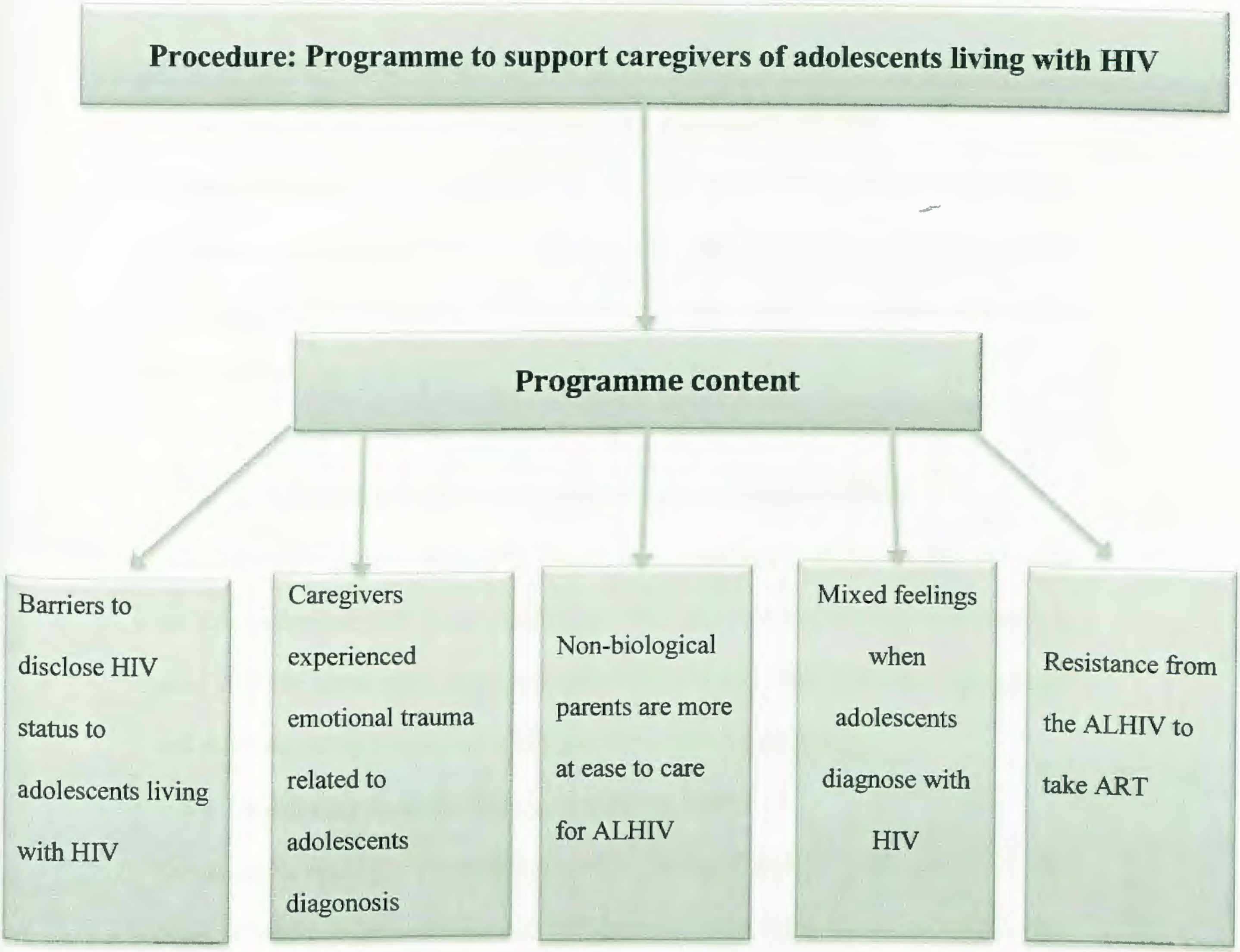


Figure 4. 6: Procedure for an educational programme

- **Barriers to disclose HIV status to adolescents living with HIV**

Caregivers needed to be equipped with knowledge and skills on how and when to disclose HIV to ALHIV. The World Health Organisation (2011) recommends, as part of their long-term management that caregivers of school age children who are living with HIV should make sure that these children are informed about their HIV status. The WHO (2011) further recommends that in preparation for full disclosure younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity.

- **Mixed feelings when adolescents are diagnosed with HIV**

Caregivers needed to be counselled and to accept ALHIV when diagnosed with HIV. It is also important that they be counselled on how to cope with ALHIV illness. Caregivers needed to be given information on how to identify churches as the sources of support to cope with ALHIV illness and promote acceptance ALHIV illness.

- **Non-biological parents are more at ease to care for ALHIV**

Non-biological parents of ALHIV needed to be equipped with knowledge and skills on how to disclose HIV status, including status disclosed impulsively to adolescents soon after the latter were diagnosed with HIV or came under their care. Knowledge and skills regarding disclosure would prevent accidental disclosure.

- **Resistance from the adolescents to take ART**

Caregivers needed to be supported on how to disclose the HIV status to ALHIV. By doing so would improve adolescents' adherence to their treatment and as a result their health would be improved. In addition, it is the fundamental right of ALHIV to know about their health status.

4.2.6 Terminus

Terminus refers to the end results from the activities (Dickoff et al., 1968). Terminus involves the accomplishment of the activity or the outcome of a programme. The terminus in this study was the educational programme to have knowledgeable caregivers of ALHIV regarding disclosure in a region in Namibia.

It was anticipated that after the implementation of the educational programme in a one-day workshop that the caregivers would then be able to discuss and disclose the HIV status to ALHIV. The programme covered the identified needs of the caregivers. They needed assistance to help adolescents to take their ART, to learn to cope when adolescents were diagnosed with HIV, and to be able to feel more at ease to care for ALHIV.

4.3 SUMMARY

The conceptual framework of this study was described to support the caregivers of ALHIV. The conceptual framework was structured according to the survey list of Dickoff et al. (1968).The researcher used their survey list, namely, agent, recipients, context, dynamic, procedure, and terminus, to develop a reasoning map. The development of an educational programme to support the caregivers of ALHIV regarding disclosure is covered in the next chapter.

CHAPTER 5

DEVELOPMENT OF AN EDUCATIONAL PROGRAMME TO SUPPORT THE CAREGIVERS OF ADOLESCENTS LIVING WITH HIV REGARDING DISCLOSURE

5. 1 INTRODUCTION

In the previous chapter the conceptual framework was described based on the survey list of Dickoff et al. (1968). The focus in this chapter is the development of an educational programme to support the caregivers of ALHIV in the Oshikoto region, Namibia. A programme is defined as a plan of activities designed to be implemented to achieve set goal and objectives (Hornby, 2015). In this study an educational programme was developed to support the caregivers of ALHIV regarding disclosure. The challenges identified during phase 1 (situational analysis) of the study were used to design the activities of an educational programme.

5.2 DEVELOPMENT OF AN EDUCATIONAL PROGRAMME

During data analysis in phase 1 (situational analysis) the following challenges were identified: caregivers experienced barrier to disclose HIV status to ALHIV; caregivers experienced emotional trauma related to the diagnosis; caregivers who are not biological parents are more at ease to care for ALHIV; family, community and friends support make it easy for caregivers to care for ALHIV; and caregivers experienced resistance from ALHIV to take ART.

After data analysis and development of conceptual framework, the researcher developed an educational programme to support the caregivers of ALHIV regarding disclosure. The developed programme, which consists of the purpose, the objectives and content, is explained in the following sections.

5.2.1 Title of the programme

The title of the programme: *An educational programme to support the caregivers of adolescents living with HIV regarding disclosure in Oshikoto region, Namibia.*

5.2.2 The purpose of the educational programme

The purpose of the educational programme was to support the caregivers of ALHIV regarding disclosure. Emanating from the situation analysis the following challenges were identified.

- Caregivers experienced barriers to disclose HIV status to ALHIV
- Caregivers experienced emotional trauma related to adolescents' diagnosis
- Caregivers experienced mixed feelings when adolescents were diagnosed with HIV
- Non-biological parents are more at ease to care for adolescents living with HIV
- Caregivers experienced resistance from adolescents living with HIV to take ART

Based on the identified challenges it was evident there was a need to address the challenges in order to support the caregivers to be able to disclosure the HIV status to ALHIV. The goal of this study was to have knowledgeable caregivers on how to disclose HIV status to ALHIV.

5.2.3 Target population

The programme was targeted at the caregivers of ALHIV regarding disclosure in the Intermediate Hospital Onandjokwe. This hospital was chosen because it is a referral hospital for the Oshikoto region.

5.2.4 Programme objectives

The developed programme had five main objectives. These are explained below.

5.2.4.1 To empower the caregivers with the knowledge and skills to address the barriers to disclose HIV status to ALHIV

This objective addressed the barriers of disclosure experienced by the caregivers including stigma and discrimination, lack of disclosure skills which delays disclosure to ALHIV, caregivers own HIV status negative influence on disclosure, adolescents living with HIV in terms of their age and mental challenges negatively influencing HIV disclosure.

5.2.4.2 To support the caregivers on how to deal with emotional trauma related to the diagnosis

This objective was intended to help the caregivers to deal with the fear that adolescents living with HIV will die and their sense of hopelessness.

5.2.4.3 To support the caregivers who are not biological parents of ALHIV with knowledge and skills regarding disclosure

This objective intended to help and support the caregivers not to disclose HIV accidentally to ALHIV as non-biological caregivers have less emotional attachment to care for ALHIV.

5.2.4.4 To strengthen support from the community, family and friends to support the caregivers to care for ALHIV

This objective intended to encourage community, family and friends to support the caregivers and build partnerships to make it easier for the caregivers to support the adolescents living with HIV.

5.2.4.5 To develop a structured programme of counselling adolescents living with HIV regarding adherence to the antiretroviral therapy

This objective intended to develop a structured programme of counselling ALHIV regarding taking and adhering to ART.

5.2.4 Programme structure

The developed programme in this study was implemented in the form of a one-day training workshop. The workshop was conducted at the Intermediate Hospital Onandjokwe in the Onandjokwe Health Training Centre. The programme structure is shown in Figure 5.1.

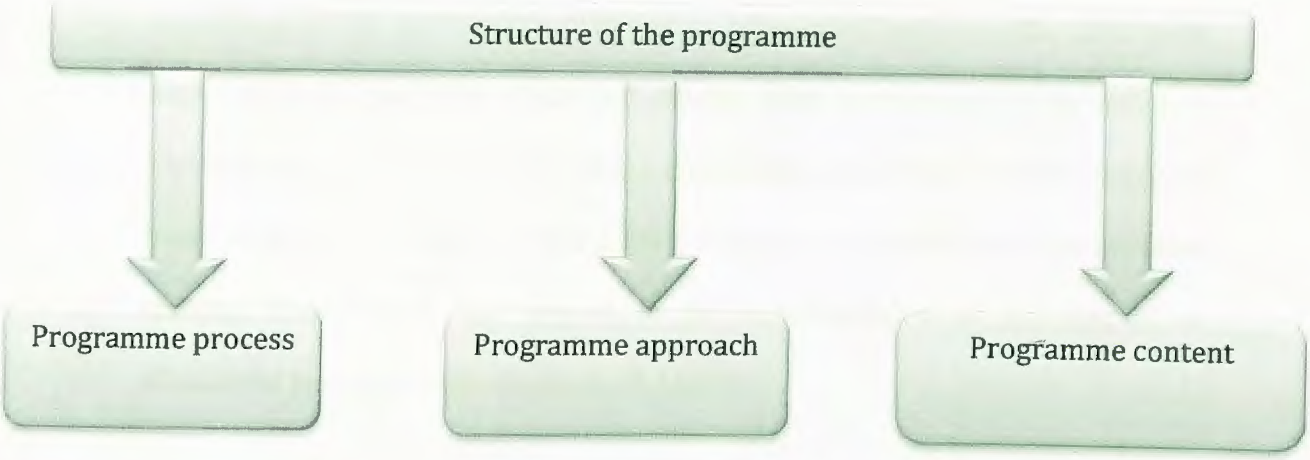


Figure 5.1: Programme structure.

5.2.4.1 Programme process

The developed educational programme comprised three phases: orientation phase, working phase, and termination phase. The orientation phase covered discussion of the purpose and objectives of the programme, as well as the date and venue for the workshop. The working phase covered the activities of different sessions and group work that would be done to support the caregivers of ALHIV regarding disclosure. In the termination phase there had to be evaluation of all the activities done during the workshop and to then reach consensus.

5.2.4.2 Programme approach

The educational approach was used in this programme. Kolb's experiential learning theory and Knowles' adult learning theory were used to develop the educational programme.

- **Kolb's experiential learning theory**

According to Kolb and Boyatzis (1999) in an experiential learning cycle, participants learn from their direct experiences and through active participation in the activities. The implementation of activities of the educational programme for this study was based on Kolb's experiential learning cycle. Figure 5.2 illustrates Kolb's experiential learning cycle, which was applied to the implementation of activities of an educational programme for caregivers of ALHIV.

Figure 5.2: Kolb`s experiential learning cycle (Macleod, 2013).

- **Concrete experience**

At this stage, participants explore a new experience of situation or a reinterpretation of existing experience (Macleod, 2013). In this study the participants acquired new experiences on how to disclosure HIV status to ALHIV or they tried to observe the existing experience.

- **Reflective observation**

During this stage learners reflect and observe the new experience (Kolb & Boyatzis, 1999). The participants reflect on their own previous experiences and they will try to understand the difference between past and new experiences.

- **Abstract conceptualisation**

At this stage, the participants give rise to a new idea or a modification of an existing abstract concept (Macleod, 2013). The participants try to have a more in-depth understanding of new experience and they start to modify their existing experiences.

- **Active experimentation**

At this stage the participants plan or act out what they have learned.

➢ **Knowles' model of andragogy**

Knowles (1984) listed five assumptions regarding adult learners as follows. There is a need to explain to an adult why specific things are taught, experience provides the basis for learning activities, adults are interested in learning subjects that are relevant to their personal life, and since adults are self-directed instruction should allow the learners to discover things and knowledge themselves (Pappas, 2013). In this study all the activities included in the programme need to be explained. To achieve the objectives the participants were required to evaluate their learning activities.

5.2.5 The content of the educational programme

The information from phase 1 (situational analysis) and the other information gained from the literature review were used to compile the content of the educational programme. The educational content included all the activities to support the caregivers of ALHIV regarding disclosure of the HIV status to the respective adolescents. Additionally the activities included challenges that were identified as affecting the caregivers of ALHIV to educate them on how to disclose the HIV status to adolescents. Tables 5.1 show the structure of the educational programme.

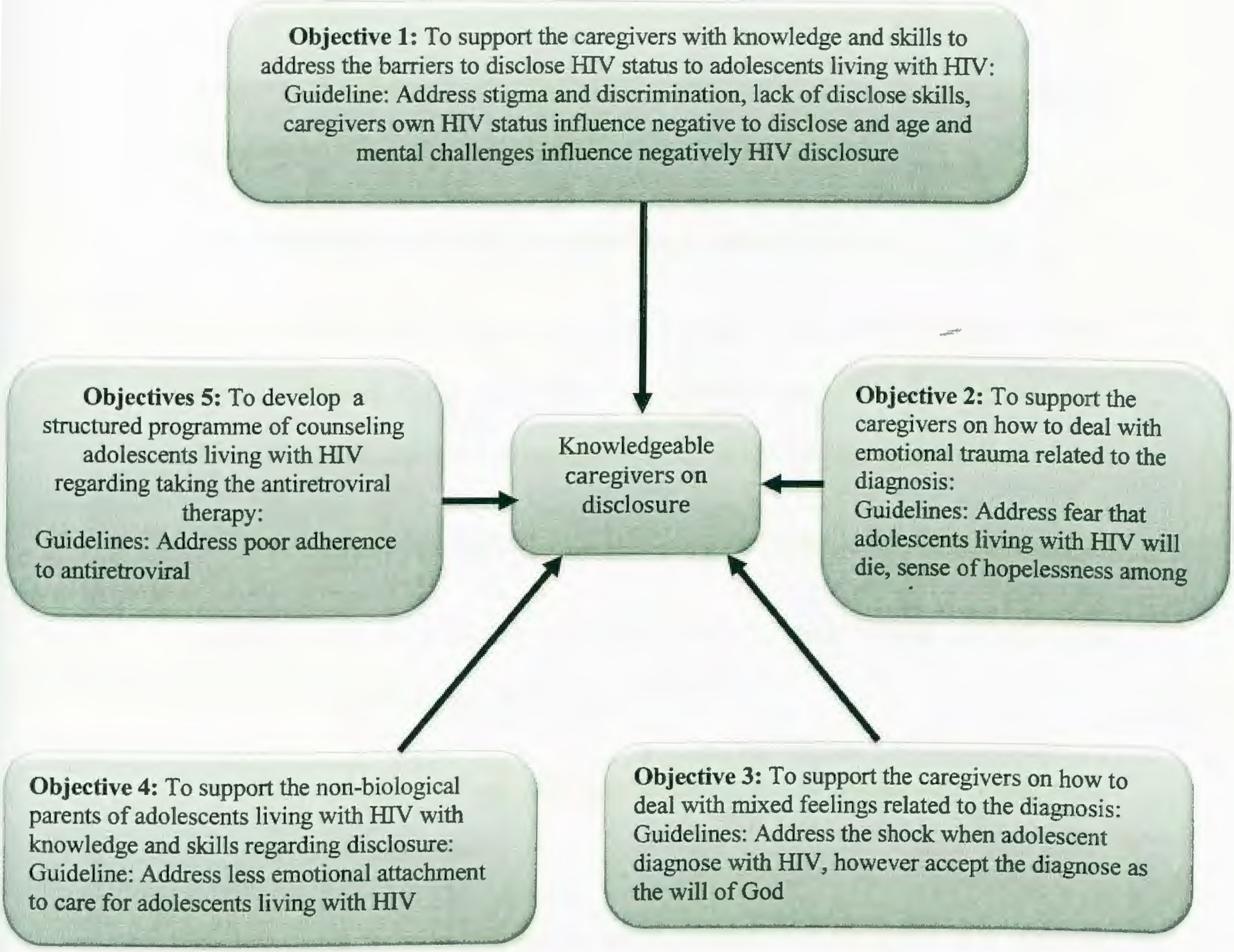
Table 5.1: Structure of the educational programme

Title *An educational programme to support the caregivers of adolescents living with HIV regarding disclosure in Oshikoto region, Namibia*	
Aims: To support the caregivers of adolescents living with HIV regarding disclosure	
Objectives of the programme	• To empower the caregivers with knowledge and skills to address the barriers to disclose HIV status to adolescents living with HIV • To support the caregivers on how to deal with emotional trauma related to the diagnosis • To support the caregivers who are not biological parents of adolescents living with HIV with knowledge and skills regarding disclosure • To strengthen support from family, friends and community to support the caregivers to care for adolescents living with HIV • To develop a structured program of counseling adolescents

	living with HIV regarding taking the antiretroviral therapy
Teaching methods	Lecture presentations, brainstorming, group discussions, role-play, debating and case scenario.
Target population	Caregivers of adolescents living with HIV regarding disclosure
Implementation phases of the programme	- Orientation phase - Working phase - Terminus phase
Evaluation	Pre-test and post-test, programme evaluation

5.2.6 Description of the content

The content of the developed programme was based on the objectives that were identified during data analysis. The guidelines to be followed to address the identified problems are shown in Figure 5.3.



Objective 1: To support the caregivers with knowledge and skills to address the barriers to disclose HIV status to adolescents living with HIV: Guideline: Address stigma and discrimination, lack of disclose skills, caregivers own HIV status influence negative to disclose and age and mental challenges influence negatively HIV disclosure

Knowledgeable caregivers on disclosure

Objective 2: To support the caregivers on how to deal with emotional trauma related to the diagnosis:
Guidelines: Address fear that adolescents living with HIV will die, sense of hopelessness among

Objective 3: To support the caregivers on how to deal with mixed feelings related to the diagnosis:
Guidelines: Address the shock when adolescent diagnose with HIV, however accept the diagnose as the will of God

Objective 4: To support the non-biological parents of adolescents living with HIV with knowledge and skills regarding disclosure:
Guideline: Address less emotional attachment to care for adolescents living with HIV

Objectives 5: To develop a structured programme of counseling adolescents living with HIV regarding taking the antiretroviral therapy:
Guidelines: Address poor adherence to antiretroviral

Figure 5.3: Guidelines for an educational programme.

5.2.7 Guidelines for the implementation of an education programme

- **Objective 1: To support the caregivers with the knowledge and skills to address the barriers to disclose HIV status to adolescents living with HIV**

In order to address barriers to disclose HIV status to ALHIV important relevant issues are underscored below.

- **Mitigation of stigma and discrimination**

Caregivers of adolescents living with HIV need to know how to cope with stigma and discrimination when adolescents are diagnosed with HIV.

- **Impartation of disclosure skills that promote disclosure**

Caregivers of ALHIV need to have skills on how to disclose HIV status to avoid delaying disclosure. Caregivers need also to be made aware of the benefits for ALHIV to know their HIV status as recommended by the World Health Organisation.

- **Prevention of caregivers' own HIV status negative influence to disclosure**

Caregivers need to understand that their own HIV status should not affect the disclosure of HIV status to ALHIV.

- **Harmonisation of age and mental challenges of adolescents living with HIV and disclosure**

Caregivers need to know the appropriate age when to disclose the HIV status to ALHIV.

➢ **Objective 2: To support the caregivers on how to deal with emotional trauma related to the diagnosis**

To overcome the emotional trauma related to adolescents diagnosed with HIV the following issues need to be taken into consideration through the following guidelines.

- **Mitigation of the fear that the adolescents living HIV will die**

Caregivers of ALHIV need to be reassured that if adolescents are diagnosed with HIV there is ART available to suppress the virus and prolong the life of ALHIV.

- **Transform hopelessness**

Caregivers need to be encouraged and made aware on how to overcome hopeless and continue to care for ALHIV. They need to have faith and belief on the effectiveness of existing treatment, care and support services to help the adolescents live a happy and fulfilled life.

- **Objective 3: To support the caregivers on how to deal with mixed feelings related to the adolescents' diagnosis**

This objective was geared to support and counsel the caregivers when adolescents are diagnosed with HIV.

- **Accept the adolescent's diagnosis as the will of God**

Caregivers of ALHIV need to be counselled and supported to accept the adolescents' diagnosis and register the adolescents for continuum of HIV care at the nearest health facility. Trusting God and accepting what cannot be changed and making use of available medical and support services will bring relief to the caregiver and quality of life for the ALHIV.

- **Objective 4: To support the non-biological parents of adolescents living with HIV with knowledge and skills regarding disclosure**

This objective aimed to help and support the non-biological parents of ALHIV. Caregivers need to be supported not to disclose HIV status to ALHIV accidentally due to their less emotional attachment to such adolescents. This needs to be done by following the below guideline.

- **Mitigate the non-biological parents less emotional attachment to disclosure**

Non-biological parents need to be provided with the knowledge and skills on how to disclose HIV status to ALHIV. Through empowerment of the caregiver on the negative psychological effects of accidental disclosure to the adolescent the caregiver should adopt a more structured and humane approach to disclosure.

- **Objective 5: To develop a structured program of counseling adolescents living with HIV regarding taking the antiretroviral therapy**

In order to promote adherence to ART by AL HIV, the following issues of resistance to take the required therapy need to be addressed. The aim is to support the caregivers on counselling and disclosure of HIV to ALHIV through the following guideline.

- **Prevention of poor adherence to antiretroviral therapy**

Caregivers need to be provided with information to support ALHIV to adhere to ART. The dangers of non-adherence to ART need to be fully explained in a simple and understandable way to the caregivers so that they can impart such knowledge to the adolescents.

5.3 SUMMARY

In this chapter the process of an educational programme development to support the caregivers of ALHIV regarding disclosure was described. An educational programme was developed based on the findings from the situational analysis and the literature review. The survey list of Dickoff et al. (1968) was used to guide the researcher according to the six survey components. The purpose and the objectives of the educational programme were also described. Application of Kolb's experiential learning theory was illustrated in the development of the educational programme for this study. The next chapter deals with the implementation and evaluation of the educational programme.

CHAPTER 6

IMPLEMENTATION AND EVALUATION OF THE PROGRAMME

6.1 INTRODUCTION

The development of an educational programme was described in the previous. This chapter deals with implementation and evaluation of an educational programme to support the caregivers of ALHIV regarding disclosure in Oshikoto region. There are two parts in this chapter: programme implementation, and programme evaluation.

6.2 PART 1: IMPLEMENTATION OF THE EDUCATIONAL PROGRAMME

In this section the programme content is discussed as well as the procedures, which were used to carry out the planned activities. Also discussed are the theories that were applied during the implementation of the educational programme. In preparation for the implementation of the programme, the researcher conducted a one-day workshop on 25 June 2018 to support the caregivers of ALHIV regarding disclosure of HIV. The workshop was conducted at the Intermediate Hospital Onandjokwe in the Onandjokwe Regional Health Training Hall in the Oshikoto region.

6.2.1 Population for implementation phase

The study population for this phase were caregivers of ALHIV in Intermediate Hospital Onandjokwe. Fifteen caregivers were invited to take part in implementation phase. Thirteen (13/15=86%) caregivers managed to attend; two (2/15=13%) did not show up.

6.2.1.1 Sampling method

From the sample of twenty-eight caregivers that were interviewed for the FGDs, fifteen caregivers of ALHIV were selected to attend the workshop using the non-probability purposive sampling method. The inclusion criteria used to select the caregivers are presented below.

- The caregivers who take care of ALHIV,
- The caregivers who were registered at any one of the three hospitals in the region: Intermediate Hospital Onandjokwe, Tsumeb and Omuthiya district hospitals,
- The caregivers who were residing in the Oshikoto region,
- The caregivers who had the capacity to make sound decision and who were 18 years old and more,
- The caregivers who were willing to participate in the study and gave informed consent,
- The caregivers who were able to read and write in Oshiwambo as it the common local language spoken in the Oshikoto region,

6.2.2 Advanced arrangements for the educational programme implementation

For the programme to run smoothly the following arrangements were made.

6.2.2.1 The venue

The Onandjokwe Regional Health Training Hall that is located within the premises of Intermediate Hospital Onandjokwe was used as a venue for the workshop. Permission to use the hall was granted by the medical superintendent of the hospital and the officer in-charge of Onandjokwe Regional Health Training Hall. The venue was well equipped with enough chairs and tables and was also well ventilated and big enough to accommodate the participants.

6.2.2.2 Programme schedule

The programme for the implementation was divided into five sessions to be covered over a period of one day and was run in the form of a workshop. The five sessions were divided into three phases: orientation, working, and termination. The workshop was from 08H00 to 17H30; with tea for 30 minutes (10H00-10H30) and lunch for one hour (13H00 -14h00). During the workshop, the facilitator and the participants adhered to the programme schedule. Flexibility was allowed to accommodate attendance to the immediate needs of the participants when very necessary (see attached programme annexure N).

6.2.2.3 Resources and training materials

The content of the programme was organised by the facilitator. This included all required learning material for the programme implementation and refreshments for the participants to help them to concentrate during the session. The learning material included a laptop, projector, pens, marker pens and flip charts. The training was conducted in Oshiwambo, the common local language. All the participants spoke and understood Oshiwambo very well.

6.2.2.4 Ground rules for the workshop

The participants agreed on the ground rules themselves. Cellphones on silent mode, fingering of one's chance, respect others' opinion and clear and speaking out loud to enable others to hear.

The participants were asked to introduce themselves by name, their village and their favorite food. They were assured that their privacy and confidentiality would be protected and that discussions during the workshop would only be shared with relevant stakeholders. Their names would not be included. The facilitator explained the purpose of the gathering to them. They were made to feel comfortable. They were also given a chance to come up with their expectations for the training. Their expectations were as follows.

- Get more information on how to disclose HIV status to ALHIV
- Know how to encourage adolescents who were living with HIV to take the medications very well and on time
- Know how to tell adolescents who were living with HIV not to infect others
- Gain more knowledge and skills on how to disclose HIV status to ALHIV

6.2.2.5 Facilitation techniques

Schwarz (n. d) explains that facilitation techniques are designed to involve all members of a group to participate actively to maximise individual commitment and engagement and build team spirit. For this study, the facilitator assisted the participants to discover their existing experiences and to develop their personal learning as stated by Knowles' model of andragogy (Knowles, 1984). The participants were adult learners; the facilitator assumed that they did have some experiences in disclosing HIV status to ALHIV. Selected techniques were used during the implementation of the educational programme of this current study and are described below.

6.2.2.5.1 Icebreakers

The English Living Oxford dictionary (2016), defines an icebreaker as a game or activity that is used to introduce people to each other so that they feel more relaxed together. In this study, icebreakers were implemented to encourage cooperation, and also for the participants to break out of their cliques (Knox, n.d). At the beginning of the training, the facilitator asked the participants to write their name in the air first with their right hand, then with their left hand. This exercise was to help them to get to know each other.

During the training, in between each session, the participants were requested to come up with icebreakers for them to laugh and enjoy themselves while learning, and this enhanced active participation.

6.2.2.5.2 Lecture method

A lecture is a talk or verbal presentation given by a trainer or speaker to audiences. A lecture method is still a backbone widely used in teaching and in training participants (Sajjad, n. d). Sajjad further explains that during a lecture method dramatic deliverance of the information should be used by using examples to make such information memorable.

During the lecture presented as part of the implementation of the educational programme, there was very limited or no active involvement by the participants (adult learners) even though they were given an opportunity to ask questions and give more information on the topic. Because a lecture method has limitation, other methods such role-play; brainstorming, group discussion and debating were used in this study to encourage active participation of the group.

6.2.2.5.3 Role-play

Role-play occurs when participants take on different roles in a simulated mode. These may be highly prescribed, including biographical details and even personality, attitudes and beliefs or loosely indicated by an outline of the function or task (Sajjad, n.d). This facilitation method needs two or more participants to act out a situation under the direction of facilitators.

To ensure that the participants understood what role-playing entails the facilitator briefed them, and created a scenario related to experiences of caregivers of ALHIV regarding disclosure. The scenario was either a real life or fictional situation. The participants were given time to prepare. During their role-play, the facilitator kept quiet listened and took notes.

6.2.2.5.4 Brainstorming

Brainstorming is a strategy used to generate a number of ideas to help solve a particular problem. The technique has been around for over 70 years and is still used today to engage students in solving a range of problems (Baumgartner, n.d). It is useful for problem solving, decision-making, creative thinking and team building (Sajjad, n.d). In this study every participant was given a chance to express his or her thoughts regarding the discussed topic. The researcher wrote down all the ideas without evaluation to generate the ideas and linkages.

6.2.2.5.5 Group discussion

A group discussion is a free verbal exchange of ideas between group members. For effective discussion, participants should have prior knowledge and information about the topic to be discussed (Doyle, n.d). In this study, the participants were divided in small groups so that they could feel comfortable to freely discuss the given topic. After their small group discussions that included important points being raised, they gave feedback in the plenary discussion followed by comments and questions from the whole group.

6.2.2.5.6 Debating

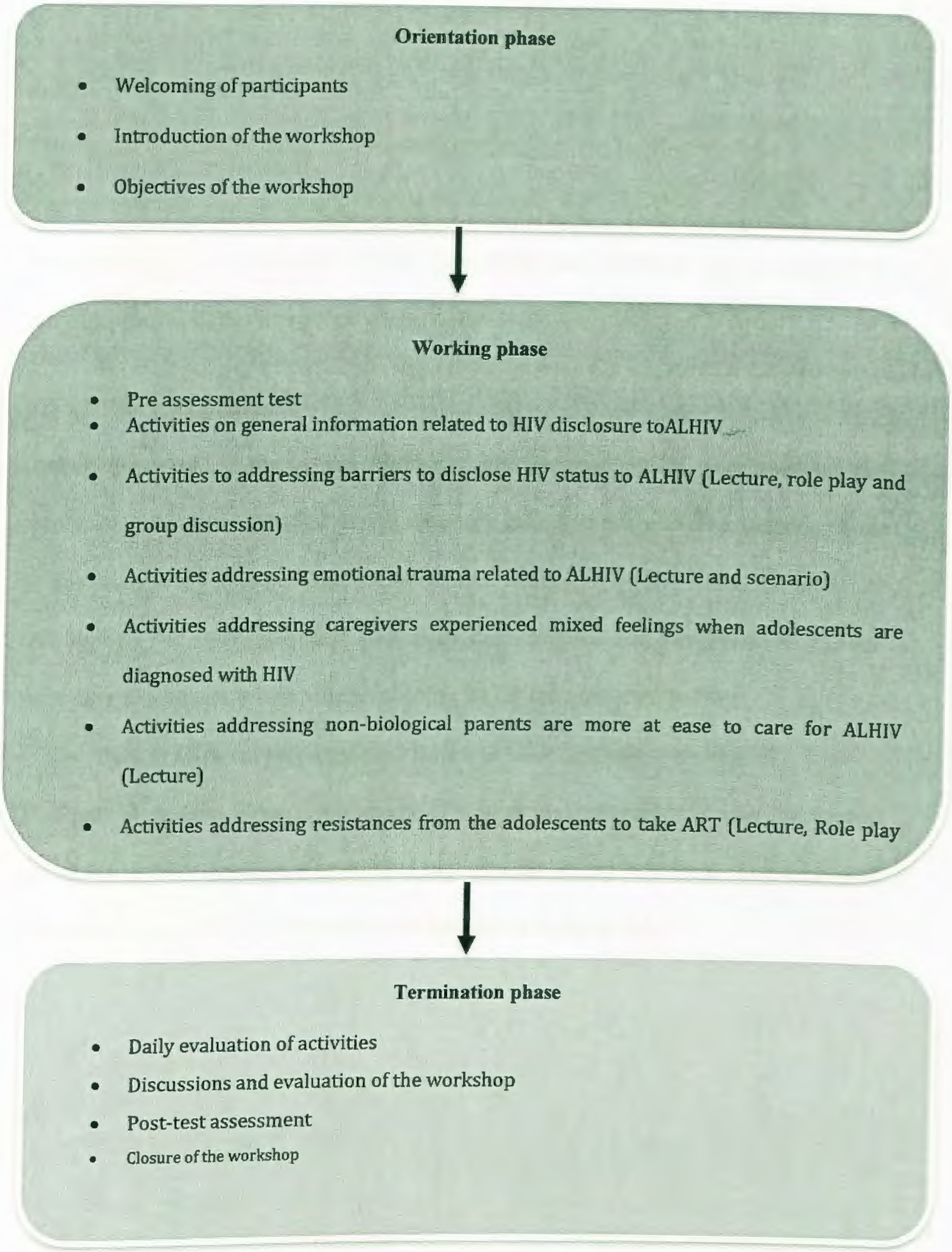
Debate refers to the process of considering multiple viewpoints and arriving at a judgment, and its application ranges from an individual using debate to make a decision in his or her own mind to an individual or group using debate to convince others to agree with them (Kennedy, 2007). Participants in this study were given an opportunity to debate issues regarding disclosure of HIV to ALHIV

6.3 PROCESS OF EDUCATIONAL PROGRAMME IMPLEMENTATION

In order to implement the educational programme a one-day workshop was conducted by facilitator, as the aim was to support the caregivers of ALHIV regarding disclosure.

6.3.1 Phases of an educational programme

The educational programme was implemented in three phases as shown in Figure 6.1.



Orientation phase

- Welcoming of participants
- Introduction of the workshop
- Objectives of the workshop

Working phase

- Pre assessment test
- Activities on general information related to HIV disclosure toALHIV
- Activities to addressing barriers to disclose HIV status to ALHIV (Lecture, role play and group discussion)
- Activities addressing emotional trauma related to ALHIV (Lecture and scenario)
- Activities addressing caregivers experienced mixed feelings when adolescents are diagnosed with HIV
- Activities addressing non-biological parents are more at ease to care for ALHIV (Lecture)
- Activities addressing resistances from the adolescents to take ART (Lecture, Role play

Termination phase

- Daily evaluation of activities
- Discussions and evaluation of the workshop
- Post-test assessment
- Closure of the workshop

Figure 6.1: Phases of programme implementation and evaluation.

6.3.1.1 Orientation phase

During the orientation phase, the researcher served as the facilitator of the workshop. The participants were orientated about the purpose, the objectives and other logistic arrangements of the workshop. Verbal consent for the workshop was obtained from the participants. Expectations and group norms were also discussed in detail.

6.3.1.2 Working phase

During the working phase, the facilitator and the participants addressed all the challenges that were identified during data collection and analysis. The working phase of this study was based on Kolb's experiential learning cycle and Knowles' model of andragogy. The working phase was aligned to support the caregivers of ALHIV regarding disclosure. It comprised six parts, which are presented below.

- **Part 1: General information related to HIV disclosure to ALHIV**
-

This part of general information aimed at helping the caregivers to gain knowledge and skills on HIV disclosure to adolescents who are living with HIV. The areas that were covered during general information are shows in Table 6.1.

Table 6.1: Approach used to cover general information on HIV disclosure

Content	**Teaching/learning strategies**	**Theories applied**
HIV Disclosure Definition of HIV disclosure When, how and who will disclose HIV status to adolescents Advantages and disadvantages of HIV disclosure	Lecture Group discussion	Kolb's experiential learning cycle and Knowles' model of andragogy
Partial, full disclosure and non-disclosure	Group discussion Brainstorming	Kolb's experiential learning cycle (concrete experience, reflective observation) Knowles' model of andragogy

- **Part 2: Addressing barriers to disclose HIV status to ALHIV**

This part dealt with barriers that prevent caregivers to disclose HIV status to ALHIV. The following topics were discussed under barriers.

- Stigma and discrimination
- Caregivers lack of disclosure skills that delays disclosure to adolescents
- Caregivers own status negatively influence disclosure for adolescents on their HIV status

Table 6.2 indicates the approach used to cover barriers to disclose HIV.

Table 6.2: The approach used to address barriers to disclose HIV

Content	Teaching / learning strategies	Adopted theories
Define barriers	Lecture (Power Point presentation) Group discussion and feedback	Kolb's experiential learning cycle (concrete experience, reflective observation and abstract conceptualisation)
Methods used to overcome barriers to disclose HIV status to adolescents living with HIV	Role-play Group work	Kolb's experiential learning cycle (concrete experience, reflective observation and abstract conceptualisation) Knowles' model of andragogy

Role-play scenario 1

Mother and her 13 year old daughter are both living with HIV and they are on antiretroviral therapy. "When my daughter is away, I would say I would tell her when she came home. When she arrives home, I become aware of how intelligent she is and can anticipate the questions she would ask. This thought put me off".

Two role-players needed: The mother and the daughter

The audiences observed and answered the following question: Why was the mother hesitating to disclose her own and her daughter HIV status?

Discuss the good way to disclose own HIV status to adolescent and how to disclose HIV of adolescent.

Scenario for debate

Paulus is a 14 years old boy on anti-retroviral for three years now. HIV disclosure was not done because his grandmother said that he is too young to know about his HIV status. One day the child asks his grandmother: "Why am I taking medications every day and I am not sick?

Two participants were pro the statement and two who were anti the statement enacted the scenario.

Two participants and a facilitator acted as judges.

- **Part 3: Addressing emotional trauma related to the diagnosis**

This part covered content related to emotional trauma experienced by the caregivers regarding adolescents' diagnoses, fear that the adolescents would die and a sense of hopeless among caregivers. Table 6.3 shows the process that was used to cover this part of the programme.

Table 6.3: The approach used to address emotional trauma

Content	**Teaching/learning strategy**	**Adopted theories**
How to overcome the fear that when an adolescent is diagnosed with HIV, he/she would die and sense of hopelessness among caregivers	Lecture Scenario	Kolb's experiential learning cycle (concrete experience, reflective observation and abstract conceptualisation) Knowles' model of andragogy

Debate scenario

Topic: A grandmother who is not able to overcome the fear that if the child knows about his HIV status the child would die.

Twelve participants were divided into two groups: six in each group. One group argued that it is true that if the grandmother discloses HIV status to the child, the child would die. The other group argued that it is not possible.

One participant and the facilitator acted as judges.

Each group was allowed to speak twice.

- **Part 4: Addressing mixed feelings about adolescents diagnosed with HIV**

This part covered the content related to shock that an adolescent is diagnosed with HIV, relief and acceptance of it as the will of God. The process that used to cover this part is shown in Table 6. 4.

Table 6.4: Approach used to address mixed feelings

Content	Teaching / learning strategy	Adopted theories
Mixed feeling about adolescents diagnosed with HIV: Shock that the adolescent is diagnosed with HIV, however accept the diagnosis for adolescents as the will of God	Lecture Role-play	Kolb's experiential learning cycle (concrete experience, reflective observation and abstract conceptualisation) Knowles' model of andragogy

Role-play

A single mother of one child aged 10, is on ARV for two years now. Her child has not been feeling well for sometimes with cough, fever and skin rashes all over the body. Admitted several times for the past three months: one week in the hospital, the other week is at home. The mother was very worried about the child sickness. The doctor requested the child be tested for HIV and the mother agrees for the test. The HIV test comes out positive.

Role-players: Mother, a child and the nurse

Audience listened, observed and answered the question. "What was the reaction of the mother after the child was diagnosed with HIV?"

- **Part 5: Addressing non-biological parents who are more at ease to care for adolescents living with HIV**

This part covered the content related to less emotional attachment to care for adolescents living with HIV. Table 6.5 shows the process that was used in this part of the training.

Table 6.5: Approach used to address non-biological parents

Content	**Teaching/ learning Strategy**	**Adopted theories**
The disadvantages of accidentally HIV disclosure to adolescents living with HIV	Lecture	Kolb's experiential learning cycle (concrete experience, reflective observation and abstract conceptualisation) Knowles' model of andragogy

- **Part 6: Addressing resistance to take antiretroviral therapy**

This part covered the content related to poor adherence to ART by the adolescent concerned. Table 6.6 shows the process that was used to cover this part of the training programme.

Table 6.6: Approach used to address resistance to antiretroviral therapy

Content	**Teaching / learning strategy**	**Adopted theories**
Definition of adherence counseling to antiretroviral therapy. Purpose of adherence counseling to antiretroviral therapy Side effects of antiretroviral therapy. How to overcome poor adherence to antiretroviral therapy.	Lecture Group discussion and feedback	Kolb's experiential learning cycle (concrete experience, reflective observation and abstract conceptualisation) Knowles' model of andragogy.

Group discussion and feedback

Topic: Aunty who needs to encourage her niece to adhere to her treatment

Participants were divided into two groups to discuss how to overcome poor adherence of adolescents who refuse to take her medications.

Each group gave feedback.

Two participants and the facilitator acted as judges

6.3.1.3. Application of Kolb's experiential learning cycle

Kolb's experiential learning cycle has four stages, which were applied in the implementation of the educational programme of this current study as discussed below.

- **Concrete experience**

The participants explored a new experience of situation or a reinterpretation of existing experience (Macleod, 2013). They were able to acquire new knowledge and skills gained through presentation and by taking part in the role-playing. Group discussions and feedback from other participants also provided more new ideas, and clarified questions about the topics discussed.

- **Reflective observation**

During this stage, the participants adapted new experiences by through reflecting on their own previous experiences; they tried to understand the difference between past and the new experiences. Group discussion and role-play helped them to reflect on their own experiences and to make a difference between new and old experiences. Therefore, they made a better choice to support them on how to disclose HIV status to ALHIV.

- **Abstract conceptualisation**

At this stage, the participants presented a new idea or a modification of an existing abstract concept. During the implementation of the educational programme of this study, the participants were assisted to deepen their understanding and they tried to modify their experiences regarding the disclosure of HIV to ALHIV.

- **Active experimentation:**

This stage involves taking action, so participants will apply what they have learned.

6.3.1.4 Application Knowles' model of andragogy

Knowles' model of andragogy has principles that were taken into consideration during the implementation of an educational programme of this study. Adult learners need to be involved in the planning and evaluation of their instruction. Adult experiences provided the basis for the learning.

6.3.1.5 Termination phase

The participants used the evaluation forms designed to help them identify areas that needed further explanations. They were requested to evaluate each and every session of the training including the lectures, role-play, group work and the brainstorming sessions. They were told that their evaluation would help the facilitator to determine the usefulness of the training workshop and programme.

6.4 PART 2: PROGRAMME EVALUATION

Programme evaluation was conducted after the implementation of the programme. An evaluation is defined by Bowling (2002) as the use of scientific methods, and the rigorous and systematic collection of research data to assess the effectiveness of organisations, services and programmes.

Different evaluation tools were designed to evaluate the programme in this study.

- The medical doctor who is HIV clinical mentor for Oshikoto, Oshana and Otjozodjupa evaluated the training manual and provided feedback on how to improve the manual and programme implementation.
- The participants were given an opportunity to evaluate the training. They wrote a test (post-test) at the end of the training to determine whether their knowledge as caregivers, in terms of disclosure for ALHIV, had improved.
- The participants' ideas were sought with respect to further programme implementation. They provided their inputs by using the evaluation forms designed for the training.

The evaluation tools were in English, but were translated into the Oshiwambo language, as all participants were comfortable with the language. Their responses were translated into English.

6.4.1 Participants' evaluation on programme implementation

After the training, the participants were requested to complete the evaluation tools at the end of the day. The evaluation tools consisted of open-ended questions to allow the participants to express themselves. Table 6.7 is an example of the training evaluation tool.

Table 6.7: Training evaluation form

Dear Participants **Please share your views regarding the implementation of this educational programme by answering the following questions**
1. What did you learn in today's training?

2. Which session(s) were most useful in today's training?
3. What did you not understand during today's training?
4. What other comments do you have about today's training?

6.4.1.1 Findings on evaluation of the training sessions

Participants gave comments on what they had learned, what they enjoyed most, what they did not understand, what needed to be changed, and general comments regarding the educational programme. Their comments for the evaluation questions .are presented in italics.

- **What did you learn in today's training?**

The participants responded as follows.

> *“I learned how to disclose HIV status to adolescents; this will help the child to take his medication well.”*
>
> *“I learned how to care for the child who is living with HIV.”*
>
> *“I learned many things today that I did not know before, especially at which age to disclose the HIV status to a child.”*
>
> *“I learned how to disclose HIV status to the child step by step.”*
>
> *“I learned how to tell the child that living with HIV is just like living with other disease like asthma or diabetic.”*
>
> *“I learned how to tell the child that it is not her mistake that she is living with HIV.”*

"I learned that if the child knows his HIV status he will take his medications very well."

"I learned that telling the child that he/she is living with HIV is my responsibility as a parent."

"I learned how to encourage the child who is living with HIV that if she takes her medications very well, she will grow well and become somebody in the community; she may become a teacher or a minister."

"I learned how to counsel the adolescents who refuse to take his ARV medications."

"I learned about the benefits of disclosure of HIV to infected child."

It is evident from the above quotations that they did learn from the programme the knowledge and skills to disclose the HIV status to ALHIV.

- **Which session(s) were most useful in today's training?**

The participants responded as follows.

"The session regarding advantages of HIV disclose to adolescents living with HIV

"To me all the sessions were useful."

"The session regarding factors that influence caregivers not to disclose HIV status to adolescents who are living with HIV."

"The session, which talks about the importance of training the caregivers of

adolescents living with HIV."

"The session regarding the disadvantages of not disclosing the HIV status to adolescents living with HIV."

"All sessions were useful because now I have confidence on how to disclose HIV status to adolescents who is living with HIV."

"All session were very useful especially the one about factors that influence caregivers not to disclose HIV status to adolescents living with HIV."

- **What did you not understand in today's sessions?**

The participants had this to say.

"I was very encouraged today regarding disclosure of HIV to adolescents, all sessions were clear."

"All sessions were clear and I was free to express myself."

"I understood everything, all the sessions were clear."

"All sessions were clear."

- **Any comments about today's training?**

The **participants** responded as follows.

"I have learned a lot in this training and I want this kind of training to be done every month to all the caregivers of adolescents living with HIV."

"This kind of training should continue. I have learned a lot in this training."

"I want to encourage you to continue training all the caregivers of adolescents

living with HIV during their follow up."

"This kind of training needs to be done in the community and in the church."

"This kind of training is for everybody in the community."

"Caregivers of adolescents living with HIV need to be motivated through this kind of training."

"Training can also be done though radio talk show to encourage caregivers on how to care for adolescents living with HIV, because through radio, a lot of people could be reached."

"This kind of training needs to be done at all the outreach points. Even if you do not have a child who is living with HIV today, you do not know what will happen tomorrow."

"I am happy that I attended this kind of training. I will go and gave feed back to my neighbour who is also having an adolescent living with HIV and did not get chance to attend the training."

It is evident from the above quotations that the participants felt happy that they were given an opportunity to attend the training; they felt well motivated and ready to give feedback to other caregivers of ALHIV who did not get the chance to attend the training. Some even suggested that this programme should be expanded to the community to create more awareness to support caregivers of ALIV regarding disclosure of their status. This would help the facilitator to determine the usefulness and effectiveness of the training.

6.4.2 Evaluation on the effectiveness of the programme

The participants also evaluated the effectiveness of the programme by completing a programme evaluation tool. Table 6.8 is an example of the evaluation tool together with comments by the researcher for questions 5 and 6. The participants' verbatim comments for question 7 are in italics.

Table 6.8: Programme evaluation tool

Dear Participant

Please complete the following questions regarding the effectiveness of this educational programme by encircling the number of your choice.

The 1st five questions encircle the number 0 = Poor, 1= Fair, 2= Good, 3= Very Good and 4 = Excellent

1. Do you think that this training is important?	**0 1 2 3 4 5**
2. Do you think that this training was helpful to you?	**0 1 2 3 4 5**
3. Do you think that this training has improved your knowledge regarding disclosure of HIV status to an adolescent living with HIV?	**0 1 2 3 4 5**
4. To what extent do you feel prepared to implement task regarding disclosure of HIV to adolescents living with HIV?	**0 1 2 3 4 5**

5. Which sessions do you think were most useful to you and why?

The following session were most useful according to the participants:

- Advantages / benefits of HIV disclosure to adolescents living with HIV.
- Factors that influence caregivers not to disclose HIV to adolescents living with HIV.
- Important of training the caregivers of adolescents living with HIV regarding disclosure.

6. Which sessions do you think was not useful to you and why?

The participants did not find any session that was not useful

7. What do you think need to be changed in this training programme?

The participants respond as follows:

"The programme should continue because I learned a lot of information".

"I think this training needs to be given every month to all the caregivers of adolescents living with HIV."

"I think this training covered everything that needs to be known by the caregivers".

"This kind of training needs to be given in the community or in the church so that a large number of people will be reached."

"I don't think there is anything that needs to be added or changed in this training programme everything is fine."

6.4.2.1 Findings regarding effectiveness of the programme

All participants who evaluated the programme indicated that the training was very informative and educative. They also indicated their readiness to share what they had learned with other caregivers regarding disclosure of HIV to ALHIV.

6.4.3 Evaluation on the impact of the training programme

The participants were assessed as to whether they had improved their knowledge regarding disclosure of HIV status to an adolescent living with HIV. This was done through a pre-test before the training workshop commenced and a post-test at the end of the training programme. There was a significant improvement from the pre-test results to the post-test ones. The outcome of pre-test range from 45% to 60% and post assessments ranged from 55% to 85% respectively. Hence this shows that the educational programme was successfully implemented.

Caregivers experienced barriers to disclose HIV status to ALHIV and had mixed feelings about adolescents diagnosed with HIV. Non-biological parents were more at ease to care for ALHIV. The participants indicated a resistance from ALHIV to take ART.

The training addressed all of these issues and the caregivers felt motivated and empowered. Caregivers of ALHIV were therefore supported through the education programme that was implemented as part of this research.

6.5 SUMMARY

In this chapter the implementation and evaluation of training programme to support the caregivers of ALHIV was discussed. Strategies that were used in the implementation of the programme were explained; the programme evaluation was also discussed. The outcome of evaluation programme shows that the programme was successfully implemented to support the caregivers of ALHIV regarding disclosure of HIV status to the adolescents concerned. The conclusion, limitations, and recommendations of the study, are presented in the next chapter.

CHAPTER 7

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

7.1 INTRODUCTION

The previous chapter dealt with the implementation and evaluation of the educational programme to support the caregivers of ALHIV regarding disclosure of their HIV status. The overarching aim of this chapter is to consider whether the purpose and the objectives of the study were achieved. The discussion focuses on the study outcomes, conclusions, and recommendations. The latter are based on the study findings. Limitations of the study are presented.

7.2 RATIONALE OF THE STUDY

The rationale for conducting this study was to develop, implement and evaluate an educational programme to support the caregivers of ALHIV in Oshikoto region in terms of them disclosing the HIV status to their adolescents. The study aimed to develop an educational programme to support these caregivers regarding disclosure of HIV status to the adolescents in the Oshikoto region.

Due to the success continuum of HIV care and ART, a growing number of HIV infected children are entering adolescence. Therefore the issue of informing them of their HIV status arises. As they grow older, their caregivers are faced with the difficult decision of when, and how to inform their child of his/her HIV status.

Most of the time disclosure is delayed because the caregivers lack disclosure skills (Madiba & Mokwena, 2009). In Oshikoto region not much has been done to assist and support the caregivers of ALHIV regarding disclosure. Consequently, some caregivers in Oshikoto region do not disclose the HIV status to the adolescents; they only provide them with ART. This scenario prompted the researcher to investigate the challenges experienced by the caregivers regarding disclosure of HIV status to the ALHIV in Oshikoto region. The collected data and findings underpinned the development of an educational programme to support these caregivers regarding HIV status disclosure to the adolescents.

7.3 CONCLUSIONS BASED ON STUDY FINDINGS

According to Werber (2017) a conclusion is a final decision or judgment, an opinion or decision that is formed after a period of thought or research. The conclusions from the findings of the current study are presented in relation to the objectives as outlined in the sections below.

7.3.1 Purpose and objectives of the study

Although consequences of non-disclosure are evident in Namibia, and elsewhere, little was known about what coping mechanisms were available to caregivers of ALHIV in Oshikoto rgion. The purpose of this study was to develop, implement, and evaluate, an educational programme to support the caregivers of ALHIV regarding disclosure in Oshikoto region. The conclusions derived from the study are discussed according to the objectives of the study as presented in chapter 1.

The researcher sought to understand what the experiences of the caregivers of ALHIV regarding disclosure were, in order, to develop an educational programme to support the caregivers of ALHIV regarding disclosure. Four objectives were formulated to achieve this general aim. A description of each objective is presented below as well as a discussion on its achievement.

Objective 1: Conduct a situation analysis through exploring and describing experiences of caregivers of adolescents living with HIV regarding disclosure

In order to achieve this objective, literature related to experiences of caregivers of ALHIV regarding disclosure was explored. Empirical qualitative data were also collected from the participants through FGDs about caregivers' experiences regarding disclosure of HIV status to ALHIV. The findings of the situational analysis revealed the challenges that are summarised under the following themes.

- Caregivers experienced barriers to disclose HIV status to ALHIV. The barriers included experiences of stigma and discriminations, and that lack of disclosure skills delays HIV disclosure to adolescents. Caregivers' own HIV status negatively influenced disclosure to adolescents of their HIV status. The age and mental challenges of adolescents concerned also negatively influenced HIV disclosure.
- Caregivers experienced emotional trauma related to their respective adolescent's diagnosis. Such trauma included fear that ALHIV would die, and a sense of hopelessness among caregivers.

- Caregivers experienced mixed feelings, which included shock that an adolescent was diagnosed with HIV. They did however accept the diagnosis for the adolescent as the will of God.
- Non-biological parents were more at ease to care for ALHIV; this could be seen as reflecting less emotional attachment to care for ALHIV.
- Caregivers experienced resistance from the ALHIV to take ART and this resulted in poor adherence.

7.3.2 Objective 2: Develop a conceptual framework, which forms the basis of an educational programme to support the caregivers of ALHIV regarding disclosure

The challenges identified during the situational analysis resulted in the development of a conceptual framework. Conceptualisation of the elements, on which the educational programme for supporting the caregivers of the ALHIV regarding disclosure was based, had to be done to develop the conceptual framework. Six elements of practice-oriented theory of Dickoff et al. (1968) were used. Agent, recipient, context, dynamics, procedure, and terminus were used to guide the conceptualisation process as discussed in chapter 4. The agent in this study was the researcher and a practicing nurse. The recipients were the caregivers of ALHIV. The context was the public health facilities where ALHIV receive healthcare. The dynamics were the challenges identified through data analysis. The procedure was the development of an educational programme and its activities to support the caregivers of ALHIV regarding disclosure. The terminus was the end result of knowledgeable caregivers on how to disclose HIV status to adolescents who live with HIV.

7.3.3 Objective 3: Develop an educational programme to support the caregivers of ALHIV regarding disclosure.

The development of an educational programme to support the caregivers of ALHIV regarding disclosure was achieved. This was done by using the results from the findings from situational analysis and literature from the six elements (agent, recipients, context, dynamic, procedure, and terminus) of the survey list of Dickoff et al. (1968).

After the data were analysed, the challenges experienced by the caregivers of adolescents living with HIV were illuminated, and an educational programme was developed to support the caregivers of ALHIV regarding disclosure. The format of the programme consisted of five sessions.

- Session 1: General information related to HIV disclosure to ALHIV.
- Session 2: Advantages / benefits of HIV disclosure to ALHIV.
- Session 3: Disadvantages of non-disclosure of HIV to adolescents.
- Session 4: Factors that influence the caregivers not to disclose HIV status to ALHIV.
- Session 5: Importance of training the caregivers of ALHIV regarding disclosure.

7.3.4 Objective 4: Implementation and evaluation of the educational programme to support the caregivers of ALHIV regarding disclosure

The developed programme was implemented by conducting a one-day training workshop for caregivers of ALHIV in the Oshikoto region. A test was conducted before commencing the workshop training to determine the caregivers' knowledge of how much they knew about HIV disclosure to ALHIV. The lowest score was 45%

and the highest was 60%. After the training they were tested again post-test was range from 55% - 85%. This showed that there were significant improvements among caregivers' knowledge regarding disclosure of HIV to ALHIV.

7.4 RECOMMENDATIONS

The English Living Oxford dictionary (2016) defines a recommendation as a suggestion or proposal as to the best course of action. From the findings of the study, the following recommendations are proposed.

7.4.1 Recommendations for practice

- Disclosure of HIV status to ALHIV should be part of routine health education sessions given at all health facilities, and there should be a public information campaign in the Oshikoto region to enhance the knowledge of caregivers of ALHIV.
- All healthcare workers, including doctors, nurses and health assistants, need to give necessary information and support to the caregivers of ALHIV regarding disclosure. The management of the three hospitals in the region and other health facilities should take urgent steps to ensure that healthcare workers are equipped with disclosure skills to counsel and empower caregivers on HIV status disclosure to ALHIV. Attending workshops and receiving training on HIV and care should give healthcare workers skills and increase their confidence in assisting the caregivers of AL HIV regarding disclosure (Rujumba, Mbasaalaki-Mwaka & Ndeezi, 2010).
- Joining available support groups in their respective communities would be of great help to the caregivers of ALHIV to help them cope with the effects of

HIV. Group support can help caregivers to cope with their emotional response to HIV based on accurate information and shared experienced (Raneri, Magongo & Kganakga, 2014). The regional directorate, together with the health facilities management and the ART outreach team, should identify appropriate support groups and counsel and support the caregivers in linking up with support groups in their communities.

7.4.2 Recommendations for education and training

The below recommendations were drawn from the conclusion of the study.

- The regional health training center, in conjunction with MOHSS Directorate of Special Programme in the region, should develop a training module to educate the caregivers of ALHIV regarding disclosure.
- PHC services should continually provide information, education and communication (IEC) material to caregivers of ALHIV regarding disclosure.
- The PHC services should develop a public educational programme for national and local radio stations to broadcast the information and educate the public in local languages regarding the importance of disclosure of HIV to ALHIV and how caregivers could go about the task.
- The Oshikoto regional management team of MoHSS, and stakeholders in the region, should organise and conduct training to ensure that caregivers of ALHIV have the necessary information regarding disclosure.

7.4.3 Recommendations for the policy-makers

The researcher recommends the following regarding policy on disclosure of HIV status to ALHIV.

- The Mo HSS should provide clear policy directives and guidance and clearly define the roles of caregivers of ALHIV regarding disclosure.
- The policy should promote and protect human rights and reduce stigma and discrimination related to HIV in line with international guidelines and recommendations.

7.4.4 Recommendations for future research

The following recommendations are made regarding future research.

- A similar study should be conducted in other regions of Namibia to investigate trends about the experiences of caregivers regarding disclosures of HIV status to ALHIV across the regions of Namibia.
- The knowledge, attitudes, and practice of caregivers of ALHIV regarding disclosure need to be investigated.
- A follow-up study should be done to evaluate the long-term effects (impacts) of the educational programme on the recipients at the three sites of this study in the Oshikoto region.
- A study to examine the effect of household characteristics on disclosure of HIV status to ALHIV should be done.

7.5 CONTRIBUTION OF THE STUDY

This study has contributed to the body of knowledge in the following ways.

- Caregivers experiences regarding disclosure to adolescents living with HIV were illuminated.
- The conceptual framework that was developed formed the foundation of an educational programme to support the caregivers of ALHIV regarding disclosure.
- The development, implementation and the evaluation of an educational programme was achieved.
- This study supported the caregivers of ALHIV in the Oshikoto region regarding disclosure. The participants evaluated the developed educational programme as being useful.
- A conceptual framework and the subsequent educational programme from the current study can be replicated to other regions of Namibia in support of caregivers regarding the disclosure of HIV status to ALHIV.

7.6 LIMITATIONS OF THE STUDY

Grove et al. (2013) define a limitation of a research as theoretical and methodological restrictions or weaknesses in a study that may decrease the generalisation of the findings. There were five limitations in this study.

- This was a qualitative and contextual study hence the results cannot be generalised to all regions in Namibia.
- The population and sample of the participants in this study were selected from a specific area: Intermediate Hospital Onandjokwe, Tsumeb and Omuthiya districts in the Oshikoto region. It would therefore be up to the interested

organisations to determine independently the transferability of the conclusions of the study and applicability of the subsequent educational programme to other regions or settings.

- The respondents may have given information, which they may have perceived as socially acceptable, rather than their genuine experiences that they might have believed would be negatively judged.
- The data were filtered through the perceptions of the interviewer and the co-coder, which could be seen as a limitation pertaining to the interpretation of the data.
- The implementation period, including the training and the evaluation of the educational programme, was carried out over one day. The period was rather short and may not have been enough to critically evaluate the effectiveness and impact of the programme.

7.7 SUMMARY

The aim and the objectives of the study were evaluated in this chapter. Conclusions were presented and recommendations were made to support the caregivers of ALHIV regarding disclosure. This study contributed to the existing knowledge of caregivers of ALHIV regarding disclosure of HIV status to concerned adolescents.

The experiences of caregivers of ALHIV regarding disclosure were illuminated. An educational programme to support caregivers regarding disclosure of HIV status to ALHIV was developed, implemented and evaluated; positive feedback was received from the direct beneficiaries.

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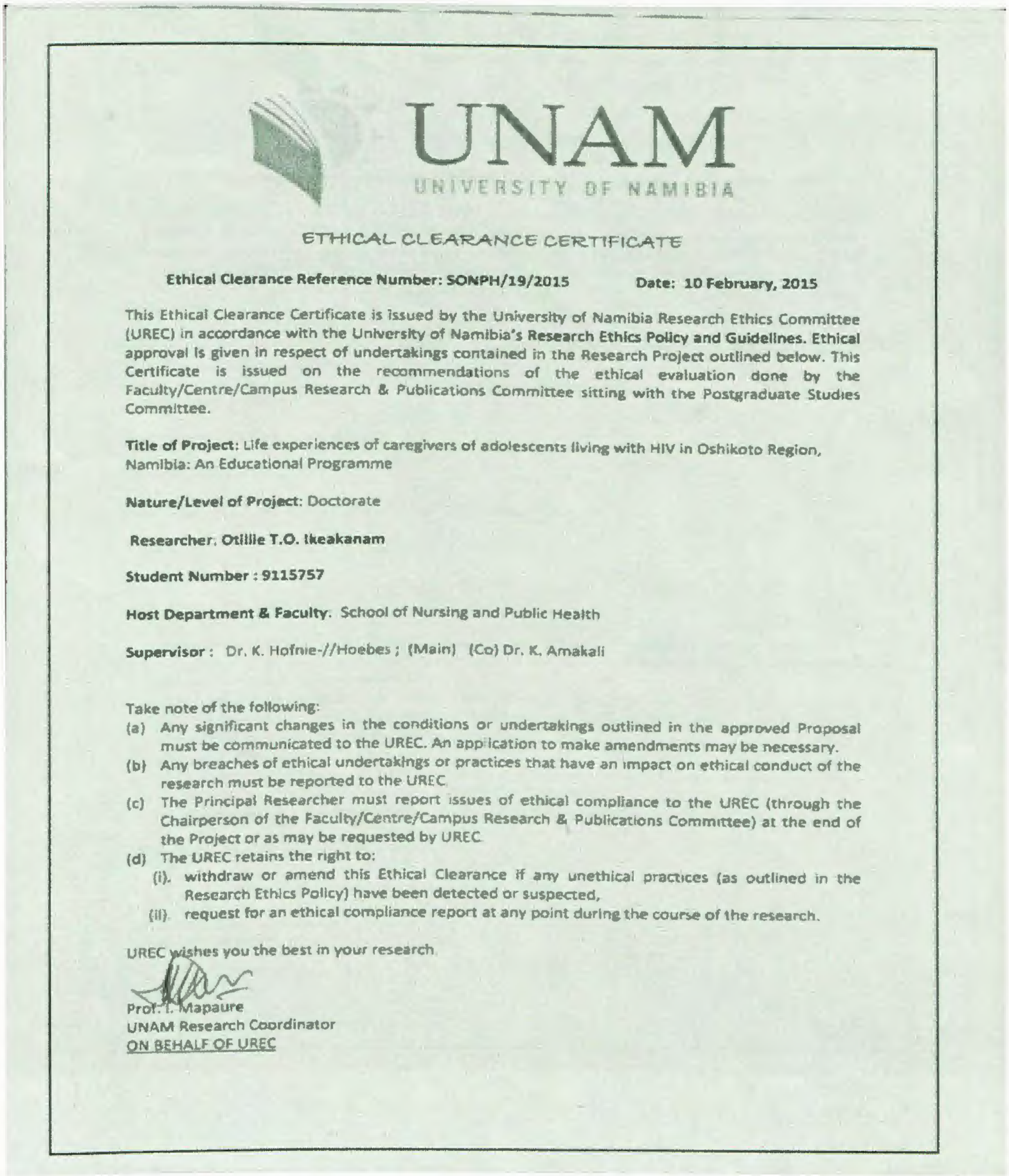
LIST OF ANNEXURES

ANNEX A: PERMISSION LETTER FROM UNAM POSTGRADUATE COMMITTEE



UNAM
UNIVERSITY OF NAMIBIA

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: SONPH/19/2015 **Date: 10 February, 2015**

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's **Research Ethics Policy and Guidelines. Ethical** approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: Life experiences of caregivers of adolescents living with HIV in Oshikoto Region, Namibia: An Educational Programme

Nature/Level of Project: Doctorate

Researcher: Otillie T.O. Ikeakanam

Student Number : 9115757

Host Department & Faculty: School of Nursing and Public Health

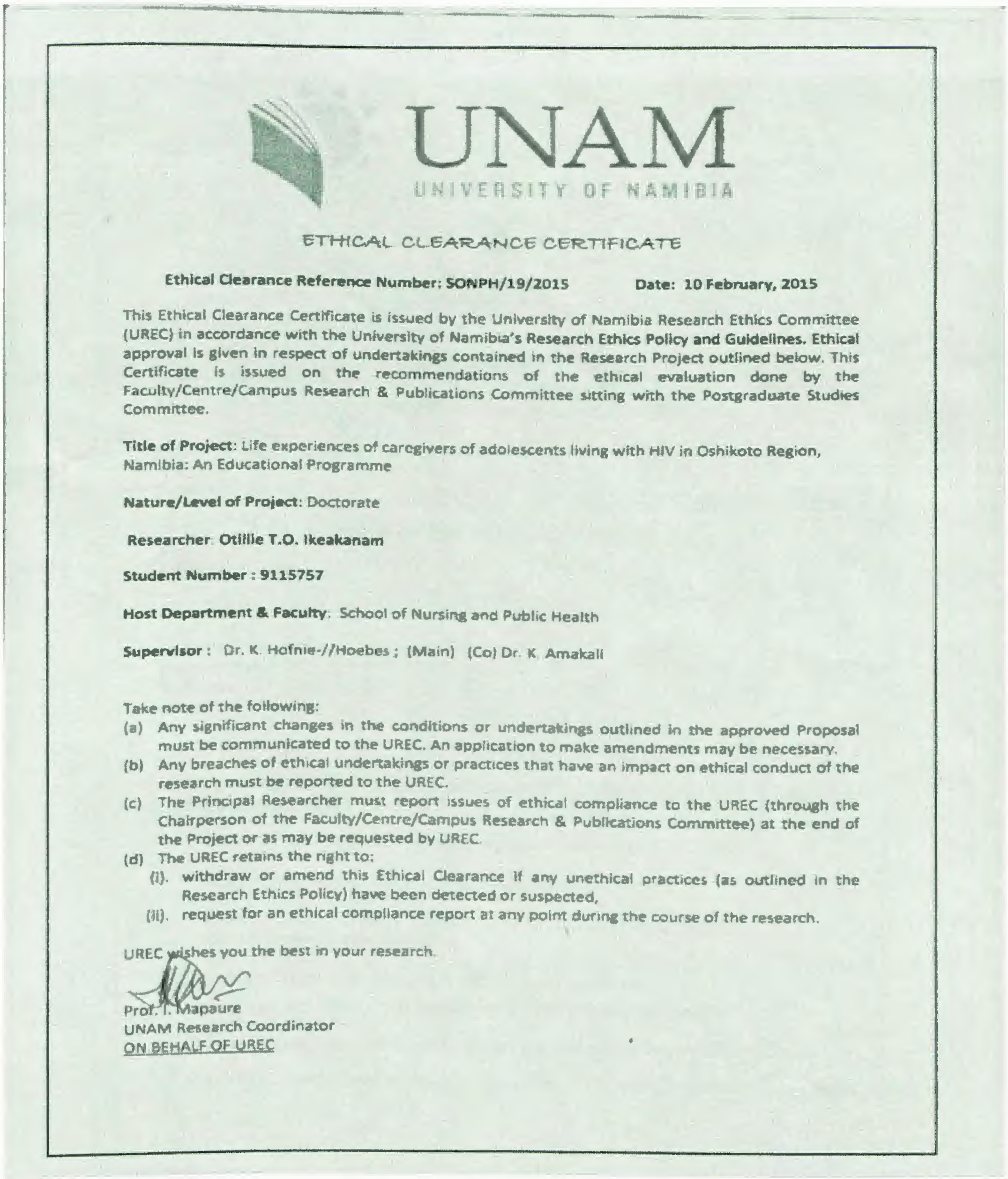
Supervisor : Dr. K. Hofnie-//Hoebes ; (Main) (Co) Dr. K. Amakali

Take note of the following:
(a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.
(b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.
(c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.
(d) The UREC retains the right to:
    (i). withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
    (ii). request for an ethical compliance report at any point during the course of the research.

UREC wishes you the best in your research.

Prof. I. Mapaure
UNAM Research Coordinator
ON BEHALF OF UREC

ANNEX B: ETHICAL CLEARANCE CERTIFICATE FROM UNAM



UNAM
UNIVERSITY OF NAMIBIA

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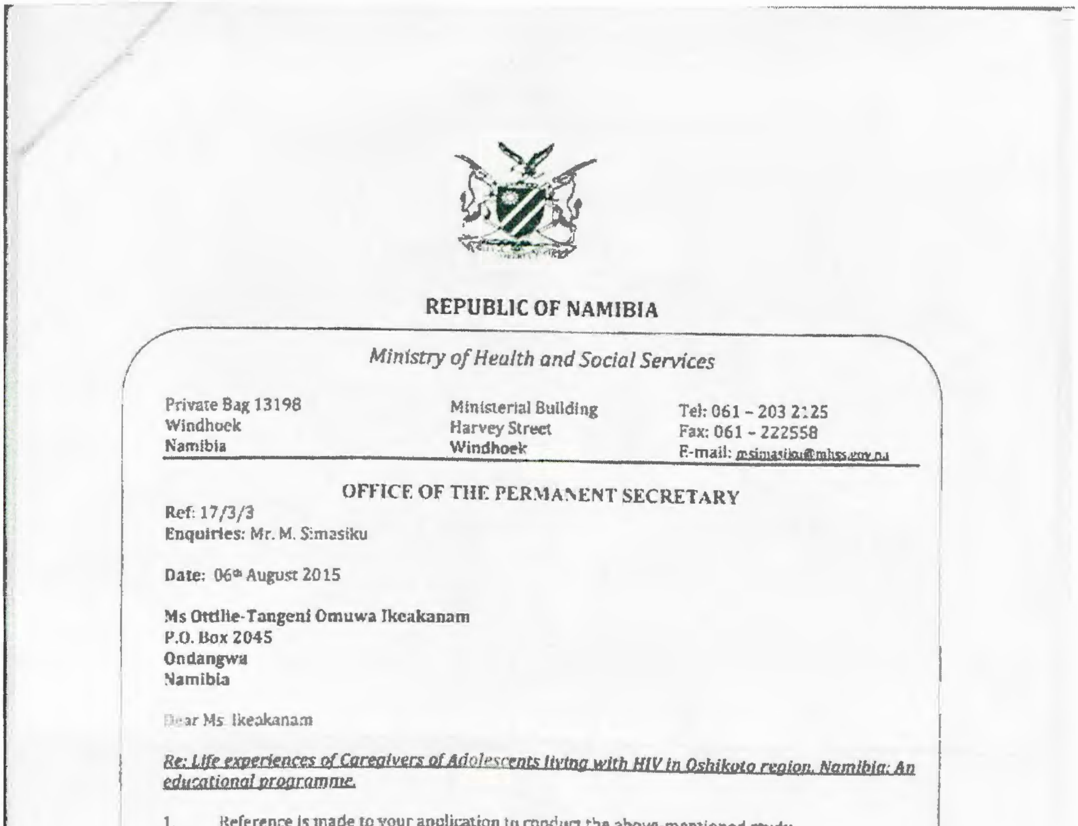
Prof. I. Mapaure
UNAM Research Coordinator
ON BEHALF OF UREC

ANNEX C: APPROVAL LETTER FROM THE MINISTRY OF HEALTH AND SOCIAL SERVICES



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 - 203 2125
Fax: 061 - 222558
E-mail: msimasiku@mhss.gov.na

OFFICE OF THE PERMANENT SECRETARY

Ref: 17/3/3
Enquiries: Mr. M. Simasiku

Date: 06th August 2015

Ms Ottilie-Tangeni Omuwa Ikeakanam
P.O. Box 2045
Ondangwa
Namibia

Dear Ms. Ikeakanam

Re: Life experiences of Caregivers of Adolescents living with HIV in Oshikoto region, Namibia: An educational programme.

1. Reference is made to your application to conduct the above-mentioned study.

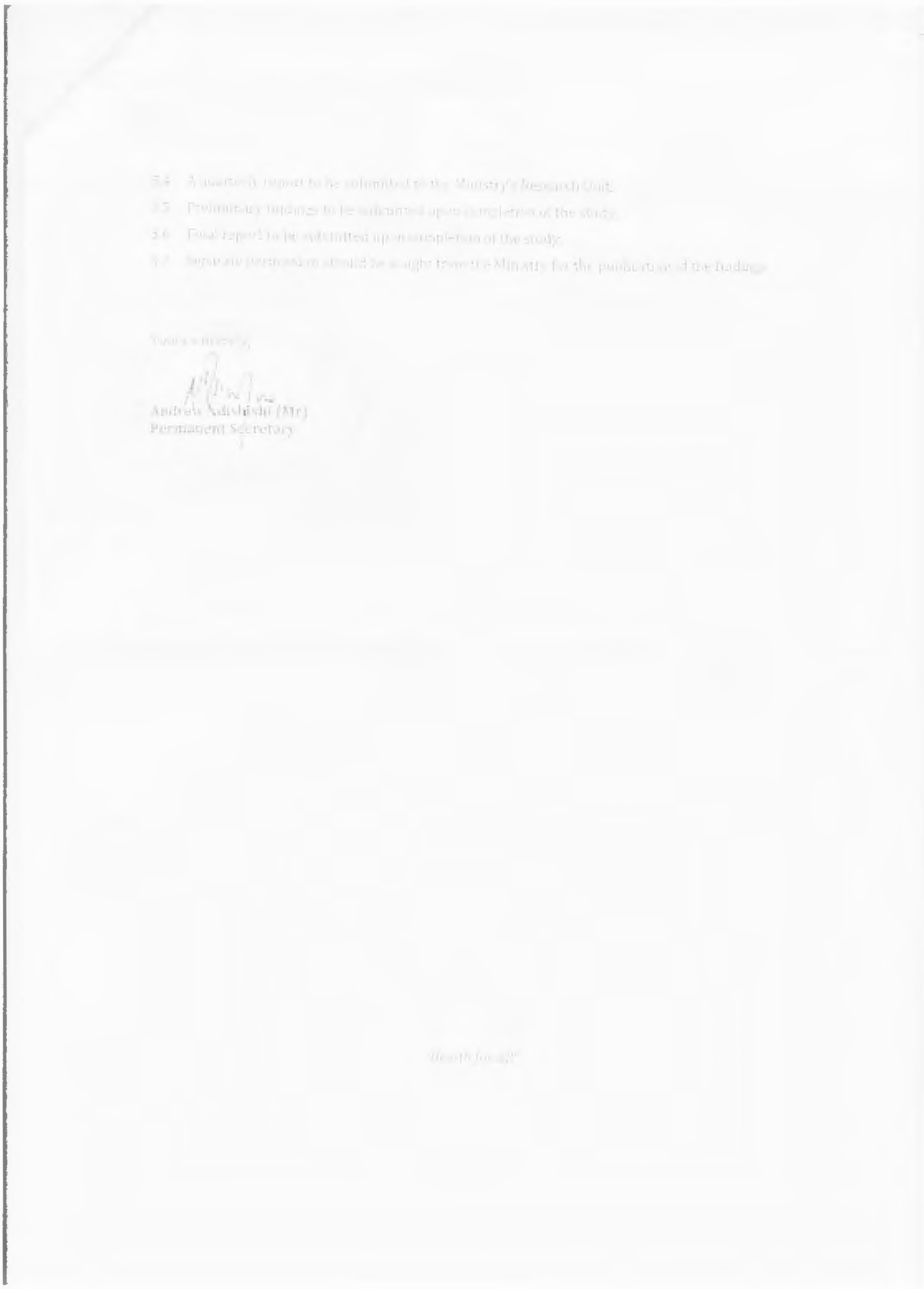
2. The proposal has been evaluated and found to have merit.

3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**

3.1 The data to be collected must only be used for academic purpose;

3.2 No other data should be collected other than the data stated in the proposal;

3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;



3.4 A quarterly report to be submitted to the Ministry's Research Unit.

3.5 Preliminary findings to be submitted upon completion of the study.

3.6 Final report to be submitted upon completion of the study.

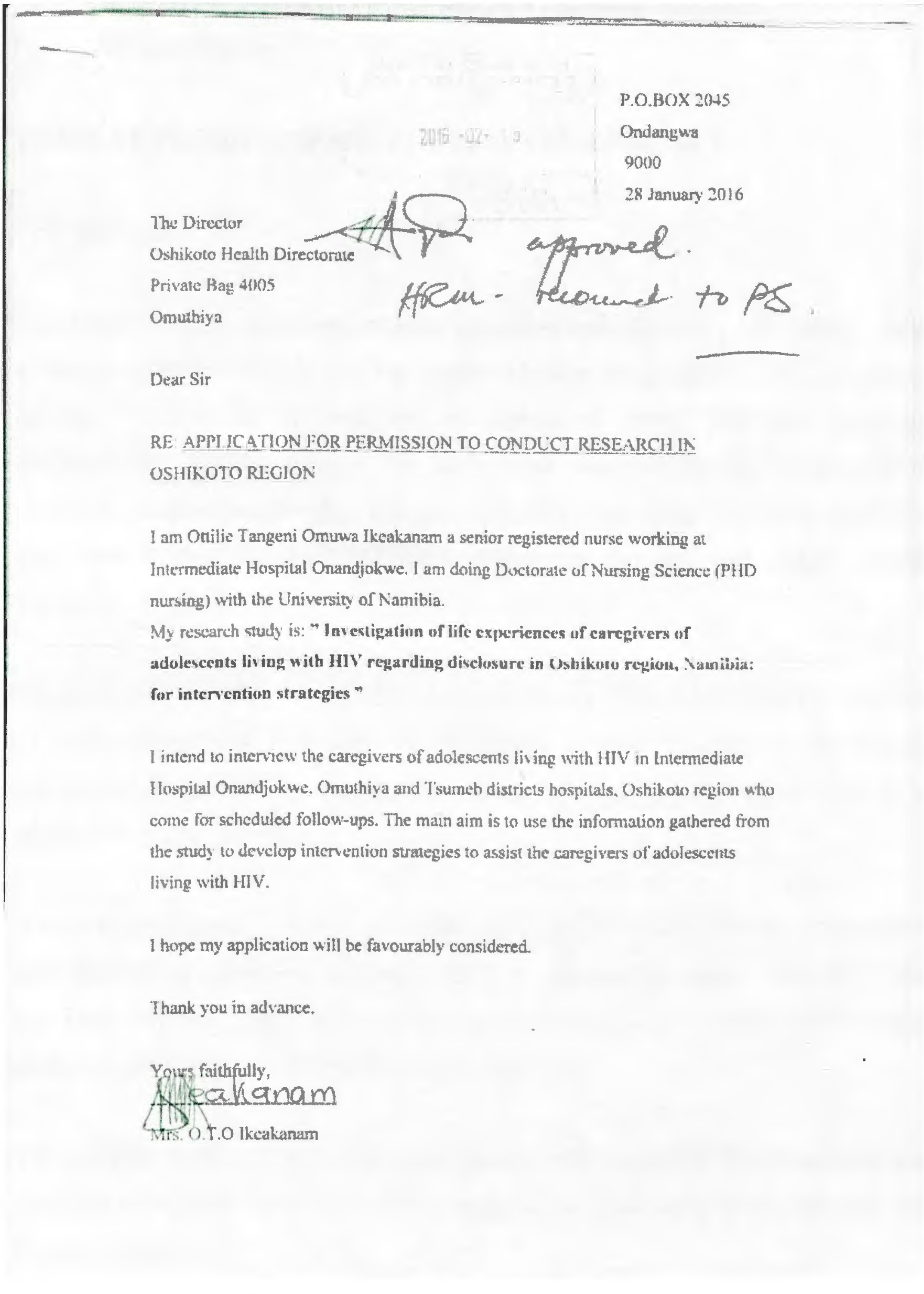
3.7 Separate permission should be sought from the Ministry for the publication of the findings.

Yours sincerely,

Andrew Ndishishi (Mr)
Permanent Secretary

"Health for All"

ANNEX D: REQUEST AND APPROVAL LETTER FROM THE DIRECTOR OF OSHIKOTO HEALTH REGIONAL DIRECTOR



2016 -02- 19

P.O.BOX 2045
Ondangwa
9000
28 January 2016

The Director
Oshikoto Health Directorate
Private Bag 4005
Omuthiya

approved.
HRM - recommend to PS.

Dear Sir

RE: APPLICATION FOR PERMISSION TO CONDUCT RESEARCH IN OSHIKOTO REGION

I am Ottilie Tangeni Omuwa Ikeakanam a senior registered nurse working at Intermediate Hospital Onandjokwe. I am doing Doctorate of Nursing Science (PHD nursing) with the University of Namibia.
My research study is: " **Investigation of life experiences of caregivers of adolescents living with HIV regarding disclosure in Oshikoto region, Namibia: for intervention strategies** "

I intend to interview the caregivers of adolescents living with HIV in Intermediate Hospital Onandjokwe, Omuthiya and Tsumeb districts hospitals, Oshikoto region who come for scheduled follow-ups. The main aim is to use the information gathered from the study to develop intervention strategies to assist the caregivers of adolescents living with HIV.

I hope my application will be favourably considered.

Thank you in advance.

Yours faithfully,
Ikeakanam
Mrs. O.T.O Ikeakanam

ANNEX E: CONSENT TO PARTICIPATE IN THE STUDY (English version)

To: Caregivers of adolescents living with HIV regarding disclosure
Oshikoto Region

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Dear Participant

I am Ottilie Tangeni Omuwa Ikeakanam registered with University of Namibia, doing a Doctor of Philosophy in nursing science. I wish to conduct a research project entitled: "Experiences of caregivers of adolescents living with HIV regarding disclosure in Oshikoto Region: An educational programme". The study will be conducted under the supervision and guidance of Dr. K. Hofnie, Tel:+26461206322O7 and Dr.K.Amakali,Tel:+264612063297 School of Nursing and Public Health, University of Namibia.

The purpose of the study is to explore and describe the lived experiences of caregivers of adolescents living with HIV on disclosure of HIV in order to develop an educational programme to support the caregivers regarding disclosure of HIV to adolescents living with HIV.

With your permission, you will participate in the interview whereby you will describe your experience regarding disclosure HIV to adolescents living with HIV. The interview will take about 35-45 minutes to complete. A voice record will be used during the interview session to ensure trustworthiness.

The recorded voice will be deleted after the study in completed. The researcher will share the transcribed materials with the supervisors. Your input in this research will be highly appreciated.

Anonymity and confidentiality will be maintained as no name or address will be required from you, so the information will not be linked to you. The interview will be conducted in a private room so that no one can hear the conversation except the researcher. You have the right to withdraw from the study anytime or discontinue participating without any penalty. You are under no obligation to participate in this research. Participation s voluntarily and there will be no reimbursement.

The study will provide a better understanding on the experiences caregivers regarding disclosure of HIV to adolescents living with. Findings from the study will be used as a basis for education programme of which you will be invited to attend if you are willing.

Should you agree to participate, please sign the consent provided. My contact number is 0811422559. If you have any questions that need clarification you are welcome to contact me or my supervisor

I...have understood the purpose and objectives of this study as it was fully explained to me and I have agreed to participate in this research project on my own will.

Signed at..

....	....
Participate Signature	Date

....

Research Signature

ANNEX F: CONSENT FOR PARTICIPATION IN THE STUDY

(Oshiwambo Version)

Consent for participation – Oshiwambo Version

Ku: **Omutekuli gwokanona taka lumbu nombuto yoHIV okuza poomvula 10-19 Oshikoto Region**

Edhina lyandje Ottilie Tangeni Omuwa Ikeakanam, ondili omwiilongi moshiputudhilo shopombanda (UNAM) tandi ilongele onkatu yuundohotola. Otandi ningi omapekapeko opo ndi gongele uuyelele wu na sha nokutseyithila omunona kutya ota lumbu nombuto yoHIV okuza poomvula omulongo sigo omulongo nomugoyi moshitopolwa shaShikoto. Elalakano lyomapekapeko oku e ta po opolohalama yoku gandja uuyelele nkene aatekuli taa tseyithile aanona kutya otaa lumbu nombuto yoHIV. Omapekapeko ngano otaga ningwa kohi yetonatelo lyomundohotola K.Hofnie, Ongodhi:+2646120632207 nosho wo omundohotola K.Amakali,Ongodhi: +264612063297,ayehe mbano ohaya longele oshiputudhilo shopombanda shaUNAM.

Otandi ku indile nesimaneko enene opo u kuthe ombinga momapekapeko ngaka, u kwathe ndje u lombwele ndje nkene wa tseyithile omunona ngoka to tekula kutya ota lumbu nombuto yoHIV. Omapulapulo otaga kwata uule wominute 35 – 45 lwaampoka. Otandi ku indile wo opo wu pitike ndje ndi longithe okakwatamawi ndi kwate oonkundathana dhetu, shino otashi ka kwathela ndje ndi vule oku ka shanga nawa uuyelele mbu to pendje. Ngele omapekapeko gapu uuyelele mbuno otandi ke u dhima mo mokakwatamawi. Uuyelele mbuno tandi gongele mpano itau ka pewa nande aantu yalwe yi ili, kakele aakuluntu yomapekapeko. Onda hala oku ku kwashilipaleka kutya edhina lyoye itali tumbulwa momapekapeko ngaka, nuuyelele mbu to gandja itau ka kopekwa kedhina lyoye, onkene kapu na ngoka ta vulu okumona kutya ongoye wa gandja uuyelele mbu. Omapulapulo otaga ningilwa mondunda tu li mo otse atuke, kapu na ngu ta vulu okuuva sho tatu kunathana

Ngele owu uvite kutya ino manguluka okukutha ombinga owu na uuthemba okutinda nenge oku kala ino yamukula omapulo nga inoo mangulukila.

Kapu na oshilanduli shasha ngele owa tindi. Kapu na sha tashi ka gandjwa kaakuthimbinga, ihe kehe gumwe oteshi ningi noku iyamba, ashike opolohalama ngele ya totwa, naamba ya kutha ombinga momapekapeko otaya ka hiywa opo ye ye ya mone uuyelele ngele otashi vulika.

Ngele owa zimine oku kutha ombinga , oto indilwa u shaine ombapila ndjika. Ngele owu na omapulo oto vulu okupula ndje ethimbo kehe. Ongodhi yandje 0811422559, nenge u ninge ekwatathano naakuluntu ya tumbulwa metetekelo koongodhi dhawo.

Ngame (edhina lyomukuthimbinga) .... ondi uvite ko nawa elalakano lyomapekapeko ngaka, nonda zimina oku kutha ombinga momapekapeko

Yashainwa (ehala).......................................

....

Eshaino lyomukuthimbinga Esiku

....

Eshaino lyomupekapeki

ANNEX G: INTERVIEW GUIDE (ENGLISH VERSION)

INTERVIEW GUIDE

TITLE: LIFE EXPERIENCES OF CAREGIVERS OF ADOLESCENTS LIVING WITH HIV REGARDING DISCLOSURE IN OSHIKOTO REGION, NAMIBIA: AN EDUCATIONAL PROGRAMME

Main question

As you have agreed to participate in the abovementioned study, please tell me your life experiences regarding disclosure of HIV to adolescents living with HIV?

Possible probing questions

What do you think about disclosure HIV to adolescents living with HIV?

-Do you think is necessary for the adolescent living with HIV to know his /her HIV status?

-What do you think can be done so that caregivers of adolescents living with disclosure the HIV properly?

-How did you find out that the adolescent you are caring is living with HIV?

-What challenges did you encounter regarding disclosure HIV to adolescents?

-What is your experience of disclosing HIV status to adolescents living with HIV and are trained to do so?

ANNEX H: INTERVIEW GUIDE –OSHIWAMBO VERSION

Interview guide – Oshiwambo version

Main question

"Kwatha ndje wu lombwele ndje kutya owuna ontseyo yithike peni mokutseyithila okanona kutya otaka lumbu nombuto yoHIV?

Possible probing questions?

-Oto dhiladhila ngiini kombinga yoku gandja oshizemo noku tseyithila okanona kutya otaka lumbu nombuto yoHIV?

-Owu wete kutya oshasimana opo okanona ka tseyithilwe kutya otaka lumbu nombuto yoHIV?

-Oshike mbela shina okuningwa po opo aatekuli yaanona mboka taa lumbu nombuto yoHIV ya tseyithile nawa aanona kutya otaa lumbu nombuto yoHIV?

-Oweshi tseya ngiini kutya okanona hoka to tekula otaka lumbu nombuto yoHIV?

-Omaupyakadhi geni wa tsakakaneke gena sha nokutseyithila okanona kutya otaka lumbu nombuto yoHIV?

-Owuna ontseyo yithike peni mokutseyithila okanona kutya otaka lumbu nombuto yoHIV na owalongwa po okushininga?

ANNEX I: TRANSCRIPTION OF INTERVIEW

Transcription 2 (English version translated from Oshiwambo)

R- As you have agreed to participate in this study, please tell me what are your experiences in caring for adolescents living with HIV regarding disclosure?

P – I think is good for the child to know that she is living with HIV, when he is small you cannot tell him that he is living with HIV, but from six,seven, nine to ten years the child need to be informed about his HIVstatus, because if I continue togive him the medications he may refuseor he will tell me that he is tired of taking the medications. So I have togive him the information that this medication is good for your health and your life depend on this medications. Sometimes he may total refuse to take

the medications or he may throw them away because he does not know why he taking medication every day. It is very important to inform thechild that you are taking these medications because you are living with HIV,so that child will also haveinformation.

P - It is necessary for the child to know why is she taking the medications, is because he is living with HIV. (With low voice) I tried many times to inform my child that she is living with HIV but I think she is too young to understand. As a caregiver I have to make sure that she is taking her medications every day. She is too young she is only eight years old now.

R- So, she does not know that she is living with HIV?

P- No, up to now she does not know that is living with HIV she is too young to undesratnd.she is nine years old now.

P- I was just gave the child the medications to drink and sometimes I have to beg her to drink the medications until one day he ask why am I taking the medications. Then, I explain to him that you are taking the medication because you are living with HIV.

R- Do you think it is necessary for the adolescents living with HIV to know their HIV status?

P- It is necessary for the child to know that he is living with HIV so that he will remember to take his medications on time, even when is playing with other children he will remember the time to take the medications. He can also remind the adult to give him his medications in case the adult forgets. It is not necessary to hide the HIV status to the child he needs to know where he standing when it come to HIV.

P- I think is good for the child to know that she is living with HIV and should be told from seven years, because at that time the child has grow up a bit to understand that he is living with HIV. Some children have started to take medications early at age three; they will not understand you if you try to tell her because they are too small. You wait the child to grow up a bit then you discus with child why, how and when to take the medications then the child will understand. At seven years the child will understand you very well and the reasons why is he taking medication everyday.

P- I think the child should be told as soon as they started the antiretroviral therapy. Some children forget easily. (With low voice) I am speaking on behalf of my daughter who is mental retarded when you look at her she looks normal but she forget easily.
I have tried many times to explain to her why she is taking medications but it did not help and this is a big problem to me.

P-May be at seven years old, but I think at seven years the child is too young to understand. I think is better to start at ten years to inform the child that is living with HIV and why is she taking the medications so that he will not forget to take his medications. Seven years is too young I think it will confuse the child.

P- No, I think the child need to be informed, because some of the child they don't want to take the medications at all even you try to explain the reasons why is he taking the medication. I explain to him that this is your life now.

R- What are your experiences of disclosing HIV status to adolescents living with HIV and are trained to do it?

P- I am the one who disclose the HIV status to the adolescents. I was trained to do so at Katonyala (Katonyala is a testing and counseling center based in Onandjokwe).
P- I do not have any experienced to disclose the HIV status to adolescent. I just told him that is living with HIV.

R- Why did you decide to tell him and you were not trained?

P – That day he refused to take the medication then I just decide to tell him the truth.

P- The child I am having is my sister child, she was always sick then I decided to take her for HIV test. It is when she was tested and I found out that she is living with HIV. Her mother is suffering from mental problem. I am the one who take care of the child; I am the one who also disclose the HIV status to the child and I was not trained I just heard it from Oshiwambo radio that people who are living with HIV need to be told that about their HIV status. I am also living with HIV (Low voice).

P- I disclose the HIV status to the child myself, but she is does not understand, she is twelve years old she is look like mental retarded. I just gave the medications she does not remember anything. She does not know why is she taking the medication, I think that her brain is not well developed.

P- I disclose the HIV status to my grandchild myself. She was tested when she was small. She was born with HIV. No, I was not trained nobody explained to me how to disclose HIV status to the child I just feel like its time for this boy to know the truth.

P- My child was born in 2003. After birth he started feeling sick. I brought her to hospital and asked for HIV test and was tested HIV positive. I also request to be tested and was tested HIV positive. We were referred to Katonyala for counseling. The child grows well and he started ARV treatment at seven years.

P-I disclose the HIV status to the child myself, and I told him the reason we are going to the hospital all the time is because we are living with HIV. I was not trained on how to disclose HIV status. I told him that we have to take our medication very well, is part of our life. I am living with my mother. My mother helps me to give the child medications, sometimes she refuse to take the medications she just put the tablets in the mouth and later she spit the tablets out I reported it to the counselors during our regular follow up, he was counseled again we were reminded the importance of taking the medications every day. Now he takes the medication very well.

P- I disclose the HIV status to my child myself, because he was born with HIV. She used to be sick most of the time when she was a baby. I decide to take her for HIV test, I was informed that she tested HIV positive. It take her along time to learn how to speak, she only speak well when he turn four years.I disclose the HIV to her when she was ten years old. I was not trained on how to disclose.

R-What challenges did you encounter regarding disclosure HIV to adolescents?

P- There are many challenges when you disclosure HIV to adolescents the challenge I noticed is I did not know where to start to tell the child that is living with HIV.I was not trained on how to do it.

P- Oh, after I disclosure the HIV status to the adolescents, as the caregivers you having a huge responsibilities especially at school you are afraid that the other children will call him bad names. Even at home you are just afraid that bad things will happen to her (with low voice). You do not know where to leave your child if you want to go to somewhere.

R – What bad things are you talking about?

P- We are in big trouble if you want to go somewhere you just forced to go out with you child. Oh, we are in really in big trouble (crying). Sometime you want to leave your child in the care of the neighbors but even that you don't trust them may they will find out that your child is living with HIV. Most of the time you are just force to go with your child wherever you are going and is not always possible. Oh, this are a big challenges to us who are having children living with HIV (still crying).

P- Another challenge I am encounter is about money for transport. If you decide to go to your friends to borrow money, they always ask you why are you going to the hospital every time? You do not want to tell them that you and your child are living with HIV, but they are always suspecting that you are living with HIV. You cannot hide this disease in your community. Truly speaking we are in trouble (crying).

P- I do not have challenges regarding money like the previuos speaker,because my child is on social grant. The money is the one I used for transport and to buy food. The challenges I was having was only how am I going to tell this child that is living with HIV? When he is away I encourage my self that I am going to tell him but when he return I don't where to start. I will just keep postpone it.

P- Another challenge is that when the child playing with others and found out that is living with HIV they laugh at her. When is time to take medications he refuse because other children are laughing at her because is having HIV.As a caregivers you have to explain to the child that those people laughing at you do not know anything. People all over the world are taking the medications so if you do not take your medication you will die. Sometimes you give the example of the person who died in your village although you do not mention the person name. You just tell the child that if you stop taking your medication you will die and people will not see you anymore. Just continue taking your medications do not worry about those people laughing at you.

R–How did you find out that the adolescent you are caring is living with HIV and what was your reaction?

P –My son has been sick for long time let me say from birth and we were refer for HIV test. When I was told that my child is living with HIV, it was relieve to me. I was worried about the child sickness, one week in the hospital the other week is at home. When I was told to take the child for HIV test I was happy, because I wanted to know what was wrong with my child. When they told me that the child is living with HIV I was happy. I was happy because I know that the child is going to get the correct treatment. I was also tired to come to the hospital every day and go back home without knowing what is wrong with the child. I accepted with the happy heart.

P- It is not easy to hear that new that your child is living with HIV at the beginning. When they told me that my son is living with HIV, I was shockedat the beginning but later I accept it and I believe that this is God's will. What can I do? What have I done I am HIV positive and so my child. This is clear that I am the one who infected the child with HIV. Although you yourself you did not know how it happen you just find yourself in that situation. It is difficult to tell the child that it is me who infected you with HIV. I am living with my mother, sometimes when she get angry with me she will tell me that 'Do you know that the sick child we are having in this house you are the cause of his sickness? Although you know that you did not infected your purposeful. These stress me too much (with low voice).

P- For me it was easy to accept it and was also difficult to accept it at the same time. I was confuse a bit, but I accepted it because the child was sick and need to be started on treatment My parents they are the one encourage us to go for HIV test. They told me that if we found out that we are HIV positive, I should just accepted it like other people. In the world people are taking their medication for ARV. We were test HIV positive. To inform my parents was not so difficult because they are the one who encourage me to go for HIV test. I was having problem to inform my husband that we were tested HIV positive. It took me many days to inform him. I was worried that he will not accept it.

P –When I was told that the child is living with HIV I just accepted very well, the child is an orphan, I am the one who take care of him both parents are dead.
He used to be sick most of the time and admitted in the hospital. I was advice to take him for HIV and was tested HIV positive. I follow the instruction from the councilors how to take the medications. He doing fine but sometimes he refused to take the medications but if talk to him nicely he will take his medications. That is only challenges I have with my child.

P- (With low voice) When the child tested HIV positive. I felt very bad, It worried me too much. When I look at him I feel pity for her then I say this child of God is too small to suffer like these. Sometimes when I think about it I just start crying even now, but I know that God will help him (crying). It is really difficult, for the adult you can say is better but for the child is very bad.

P- The child was not feeling well then I decide to take him to be tested for HIV. When I was told that the child is living with HIV I just accept it I think the child was born with the HIV virus. I can do anything I just has to accepted it like that.

R- What do you think can be done so that caregivers of adolescents living with disclosure the HIV properly?

P- (With low voice) We need training to help us to disclose HIV status to children who are living with HIV.

P- Is true what we needs is training. Like for I disclose the HIV status to the my child but Idont know if I did it correct.

P- Health educations needs to given at the community level even in the radio to educate all the caregivers of adolescents living with HIV.

P- Me I don't know where to start to disclose the HIV to the child, up to know I just gave him medications without telling him anything.

P- Caregivers and the community needs to educated on how to disclose HIV to the children who are living with HIV.This will help us to care for adolescents who are living with HIV.

P- I also think that is good for the family or caregivers to be educated about how to care the children who are living with HIV and how to disclosuse the HIV status to the children who are diagnosed with HIV. Nowadays almost in every family there is someone living HIV.

R-Is there anyone who wants to add anything?

P- I want also to support the ideas of giving information to each and everybody even there is child in the house who is having HIV you never know what will happen tomorrow.

R-Let me thank you for taking parts in this study.

ANNEX J: TRANSCRIPTION OF INTERVIEW (Oshiwambo version)

Transcription 2:

R-Ngaashi mwa zimine oku kutha ombinga momapekapeko ngano, onda hala mu kwathe ndje mu lombwele ndje kutya owuna ontseyo yi thike peni mokusila oshimpwiyu uunona mboka tawu lumbu nombuto yoHIV nonkene mwe wu tseyithile kutya otawu lumbu nombuto yoHIV.

P- Ondi wete ngaa kutya oshiwanawa opo okanona ka tseyithilwe kutya otaka lumbu nombuto oshoka pethimbo manga okashona ito vulu ngaa nee wuka lombwele ndele shaa ngaa ne kazi poomvula puhamano, heyali shuuka hwiya sigo omulogo, oka pumbwa ngaa okutseyithilwa shaashi ethimbo limwe shili shaa nda kala owala tandi kape omiti itaka kala ka hala, oto mono owala taka ti ngaye onda vulwa okunwa omiti. Onkee oto kape nee uuyelele nawa kutya tala omiti dhino odhina sha nuuwa-nawa woye dho odhina nomwenyo gwoye, shashi shaa inooka tseyithila ethimbo limwe ita kedhi hala nande –nande. Otashi vulika owala nokuli kedhi ekelehi shaashi kake shiwo kutya otake dhi ninwe molwashike. Osha pumbiwa nga nee omuntu wuka yelithile nawa nokuka lombwele kutya omiti ndhino oto dhi nu molwaa shono oto lumbu nombuto opo ngaa nee taka kala kena uuyelele.

P-Osha pumbiwa okaana opo ka kale keshi kutya eshi taka nu omiti omolwashi kena ombuto,(Newi li li pevi). Onda kedambala oikando iihapu okuka lombwele kutya okena ombuto yoHIV.Ondi wete kutya mbela okaana okashona natango okuudako. Ame ongo omudali ohandi fi ashike oshisho opo okaana ka kale kanwa omiti dako. Ondi wete kutya wange omushona natango okuna ashike eedula hetatu.

R-Omolwashike sigo opaife inoo ka lombwela okaana kutya otaka lumbu nombuto yoHIV?

P- Inandi ka lombwela natango shaashi omushona natango.

P- Ngame gwandje ohandi mu pe ngaa omiti anwe to mu heka heka ngaa ndele ethimbo limwe oto mono shi teku pula kutya omolwashike ano tandi nwine omiti, ngweye to fatulula nee kutya oto nu omiti shaashi ouli ngaha oto lumbu nombuto yoHIV.

R- Otamu dhiladhila kutya oshasimana opo okanano hono taka lumbu nombuto yoHIV ka tseyithilwe oshizemo shako?

P- Oshasimana opo okaana ka tseye kutya otaka lumbu nombuto yoHIV opo kale haka dhimbulukwa okunwa omiti dhako pethimbo. Nenge ando otaka dhana nuukwawo shaa ethimbo lyaadha lyokunwa omiti okeshishi kutya otaka kanwa omiti. Nuuna ka kala inaa ka nwa nena okena okupula ngu eli nako kutya inandi nwa omiti dhandje. Inashi pumbiwa okaana ka holekwe, oshizemo shako. Opo ka kale keshi kutya okathikama peni uuna tashiya kombuto yo HIV.

P- Ondi wete kutya oshiwanawa opo okaana ka lombwelwe kutya otaka lumbu nombuto yoHIV. Ando okutameke ngaa poomvula dhili heyali shaashi mpono okaana ondi wete kutya okafa ngaa ka koka kashona no kuuva ko kutya otaka lumbu nombuto. Ngaashi uunona wumwe owa tameka nale okunwa omiti manga wuna oomvula ndatu ito vulu okukala inoo ka lombwela iinima mbyo. Oto etha ngaa manga eta ka humu komeho eto kundathana nako to hokolola ehokololo kutya omolwashike taka nwine omiti naasho taka kala taka nu uuvite kutya otaka nwine shike omiti kehe esiku.

P- Osha pumbiwa lela okulombwela okanona mbala sho ka tameke omiti dhoARV. Uunona wumwe ohau dhimbwa mbala (Newi lili pevi).Ngame otandi popi peha lyokaana kandje ngaye ondina okanona koshilema momadhiladhilo maar sha we mu mono ou wete ngaa afa a kotoka. Oha dhimbwa mbala. Onda kambadhala iikando oyindji okumu tseyithila ndele inashi kwatha sha nashika uupyakadhi unene kungame.

P-Ngiika poomvula heyali ngaa lwaampo, ndele osho ngaa pamwe uunona wumwe, pomvula heyali ondi wete kutya ooshona ando opoomvula ngaa okuza pomulongo. Ando opo ngaaka ta lombwelwa nawa kutya omiti ndhino ohodhi nwine shike, opo ngaa kaa kale ta dhimbwa okunwa omiti. Oomvula heyali ondi wete ooshona pamwe otashi kemu ninga nayi momadhiladhilo.

P-Aaye, okaana oka pumbwa okutseyithilwa shaashi uunona wumwe inau hala ashike nande nande okunwa omiti. Oto kambadhaala ngaa okuka lombwele etompelo kutya tala eshi hayi ku lombwele kutya nwa omiti osheshi ouli monkalamwenyo yatya ngaha.

R- Ouna ontseyo yithike peni mokutseyithila okanona hono to tekula kutya otaka lumbu nombuto yoHIV?

P-Ngame, ongaye lela ndeka tseyithila shaashi ondali nda longwa po pethimbo ndjoka otwa li hatu yi kuKatonyala (Katonyala ehala lehugomwenyo lili mOnandjokwe)

P-Ngame kandina ontseyo yokutseyithila okanona oshizemo shako. Ondeka lombwele owali kutya owuna ombuto yoHIV poomvula omulongo nandatu lwaampo.

R-- Omolwashike wa tseyithile okaana kutya otaka lumbu nombuto yoHIV ngweye inoo longwa po?

P- Esiku ndyoka ndemu lombwela okwa li a tindi okunwa omiti opo owala nda tokola ndi mutseyithile oshili.

P-Okaana oko handi tekula okadalwa kumwaameme, ko oka kala nee okanghudi handi ka konaakonifa nee, oka konaakonwa miikonga yinya hayi ende monikunda opo nee ka monikila opo kutya okena ombuto. Meme wako oshilema shopomadilaadilo. Okaana aame handi ka tekula, ame naame ondi ikonakonifa kwaame mwene handi monika kutya ondina ombuto. Paife okaana oko aame nee handi tekula, aame handi ka eta koshipangelo aame ndeka shivifila ame mwene kutya otaka lumbu nombuto yoHIV (Ta hala okulila).

P- Onde ka shivifila ndee ka kena eendunge natango, okena eedula omulongo nambali kakena eendunge nawa. Ohandi kape ashike omiti.ndele ihaka dimbulukwa sha nande. Kakeshi kutya omolwashike haka nwine omiti natango shaashi ouluvi nawo mbela inawu kula natango.

P- Ngaye, ongaye mwene ndeka tseyithile okatekulu kandje kutya otaka lumbu nombuto yoHIV, shaashi ondi wete kutya okwa valwa nombuto yoHIV. Inandi longwa po nande mokutseyithila okanona kutya otaka lumbu nombuto. Onda mono owali kutya okanona hano oka koka oka pumbwa okutseyithilwa kutya otaka lumbu nombuto.

P- Ngaye okaana hono ondeka vala mo 2003, sho nee ndeka mono ngawo, oka tameke taka ehama, ngaye otandi yikoshipangelo tandi kongo nee omakonaakono, okaana kandje taka konaakonwa nangaye mwene atuhe otwa monika ombuto, tatu yi nee kuKatonyala tatu mono ehugomwenyo. Opo nee okaana ngaye tii ka tseyithile ne kutya oshiima nee hashi tu fala koshipangelo hwiya tuka tale omiti otuna ombuto ndjono yoHIV, otuna okunwa omiti dhetu odho owala onkalamwenyo yetu kutya oyoye kutya oyandje, ashike kandali nda longwa po okugandja iizemo. Ngame ondili megumbo lya meme gwandje oha kala nee ethimbo limwe inaa hala okunwa omiti. Ohaka taamba owali omiti ye otedhi tula mokana ye konima yokathimbo otedhi hiya mo. Oshinima shino ondeshi lombwele aahungimweyo sho hatu yi komaakonaakono. Otwa tumwa kehungomwenyo etatu lombwelwa esimano lyokunwa omiti. Paife okwa tameka okunwa omiti dhe nawa.

P-Ngame ongame mwene nda tseyithile okaana kandje, shaashi okaana kandje okavalwa nombuto, oka kala ngaa haka ehama ehama, ngaye tandi ka konaakonitha. Onda lombwelwa kutya okaana kandje okamonika ombuto sho nee ka ningi oomvula dhili omulongo shaashi oka kala kaashi kupopya nawa,sigo otaka yi poomvula ne. Ondeka tseyithile kutya otaka lumbu nombuto poomvula dhili omulongo. Onda li nda longwa po nkene tandi tseyithile okaana kutya otaka lumbu nombuto

R- Omashongo geni wuna mokutseyithila okanona kutya otaka lumbu nombuto yoHIV?

P-Omashongo opo ge li lela ogendji mokugandja oshizemo kokanona. Ethimbolimwe oto kala owali kuuwete mpoka to tameke opo wutsteyithile okanona kutyaotaka lumbu nombuto yoHIV. Ngame mwene inandi longwa po nkene ndinaokutseyithila okanona kutya otaka lumbu nombuto yoHIV.

P-Oh, shampa tuu wa tseyithile okaana kutya otaka lumbu nombuto yoHIV nenangoye ongo omutekuli owuna oshinakugwanithwa oshinene noonkondo unene tuungaashi kosikola owa tila owala kutya pamwe otaka ulwa omadhina omawinayi.nokuningilwa iinima iiwinayi. Omuntu kushi owali naampa to thigi okaana koyengele owa hala okuza po.

R- Iinima iiwinayi ongaashi naana shike ho kala watila?

P- Otu li muudhigu nande owuna mpa toyi owa thiminikwa wuye nokaana(newi lili pevi) Ethimbo limwe oho kala ngaa wahala wuka thigile aantu nenge oyo pushiinda natango kushi nokutya aatu oye li monkalo yatya ngiini. Aantu otaa mono ishewe nani kutya okaana okena ombuto yoHIV. Ethimbo alihe owa thiminikwa owala wuye nokaana koye shaampoka toyi sho itashi vulika nee. Oh mbuno uupyakadhi uunene kutse mba tuna uunona tawu lumbu nombuto (Ta lili).

P-Eshongo limwe ndi nda taalela ongaashi kombinga yoshimaliwashotransport.Ngele owayi pu kuume koye wuka indile po oshimaliwa nena otii pula kutya ohaa ka tala shike ano koshipangelo kehe omwedhi, ngweye ino hala wuya lombwele kutya omuna ombuto yoHIV.Ndele nando inoya lombwele otaa fekele nae kutya omuna ombuto.Ito vulu okuholeka omukithi nguka moshigwana.Okupopya oshili otuli muudhigu (Ta lili).

P-Aaye fye katuna nande Omashongo gasha niimaliwa yotrasport nenge yokulanda iikulya shaashi okaana ohaka kwata opezela okuza nale sho kena oomvula hamano. Yo iimaliwa mbyono oyo hatu longitha motransport nokuya koshipangelo. Uupyakadhi mbu ndina okuka lombwele kutya otaka lumbu nombuto shaa tuu kee po,ondina omukumo okumu lombwele ndele shampa eya ohandi kwatwa kuumbanda ngame otandi shi undulile komeho.

P-Omashongo omahapu ngaa nando omuudhano navakwawo ndee yakwawo taa uvu kutya okuna ombuto yoHIV ohaka yolwa, taka yolwa lela ndee eshi toya wukape omiti otaka ti itaka nu omiti shaashi ohandi kala tandi yolwa kuvakwetu, shaashi vati ondina ombuto ove to ningi ngoo to ka kumaida ngoo kutya ovo tave kuyolo, kave udi te ko. Ovanhu aveshe mounyuni otava nu omiti ndee ngenge owa kala itoo nu omiti, nena oto fi to yeleke ngoo nande eenghali dali pomukunda, toti ashike owa mona ngandi owo ali opo, okwa fya hano naave ngenge ito nu omiti edi, ohatu kala ashikeitaatu ku mono vali ngaashi nhumba owu afya omo, twikila ashike nokunwa omiti ino tila okuyolwa.

R- Oweshi tseye ngiini kutya okanona hoka to tekula otaka lumbu nombuto yoHIV na owa li weshi taamba ko ngiini?

P-Okanona kandje okatameke taka ehama ethimbo ele nadi tye okuza kevalo notwa li twa tumwa tuka konaakonwe ombuto. Onda li nda lombwelwa kutya ngame nokaana kandje otuna ombuto yoHIV. Onda li nduuvite nawa mokushi lombwelwa, onda li handi kala nda limbiliwa kuuvu wokaana oshiwike shimwe okeli moshipangelo oshikwawo okeli kegumbo. Sho ndali nda lombwelwa kutya nandi fale okaana ka konaakonwe onda li ndeshi pandula noonkondo naasho nda lombwelwa kutya okaana okena ombuto yoHIV, onda li ndeshi pandula noonkondo shaashi ondi wete kutya okaana paife otaka mono epango lyuukilila. Onda li ndeshi pandula lela shaashi olundji ohandi fala okaana koshipangelo kehe esiku ndele ihandi lomwelwa nandekutya okaana otaka ehama shike. Onda li ndeshi taamba ko nomutimaa gwayela.

P-Kungame kashal li oshipu petameko okutaamba ko kutya okaana koye otaka lumbu nombuto yoHIV. Sho nda li nda lombwelwa kutya okaana kandje otaka lumbunombuto yoHIV osha li sha halutha dje noonkondo. Ndele oneshi taamba ko owali kutya ndika ehalo lyaKalunga kandina nkene ndin okuninga. Ondi ipula kutya onda ningi ngiini ngeyi,ngame ondina ombuto ndele nokaana kandje okena ombuto. Shino osha yela kutya ongame nda pe okaana kandje omukithi nguka gwoHIV. Nando nangame mwene hasho ndali nda hala nangame ondi iyadha owali ndili monkalo yatya ngeyi. Ohashi kala nee oshidhigu okutseyithila okanona kutya ongame ndeku pe omukithi. Onda kala na meme gwandje ethimbo limwe ngele okwa geye nena ohashi vulika a nyenyete tati nandi kale ndi shishi kutya ongame osheetithi shokaana hoka keli megumbo taka ehama. Nonando okaana ino ka pa omukithi ngoka owina osha ningwa owali pamupya.(newi lili pevi).

P- Kungame ondali ndeshi taamba ko nuupu nosha li wo oshidhigu kombinga yimwe. Oshali sha piyaganeka ndje kashona ndele ondeshi taamba ko ngaa shaashi okaana okali taka ehama noka pumbwa okutameka epango.Aakuluntu yandje oyo ya tsu ndje omukumo opo ndi fale okaana ka konaakonwe. Oya lombwele dje kutya Ngele okaana oka monika omukithi nadi shi taamba ko owala ashike aantu ayehe muuyuni otaanu omiti dhawo. Oshali oshipu okutseyithila aakuluntu yandje. Onda li owali ndina uudhigu okutseyithila omusamane gwandje kutya tse nokaana otatu lumbu nombuto. Osha kutha dje omasiku ogendji okumu tseyithila, ashike okwe shi taamba ko ngaa hewa.

P- Sho ndali nda lombwelwa kutya okaana otaka lumbu nombuto ondeshi taamba ko owali nawa. Okaana okathigwa ,ngame ongame handi ka tekula shaashi aakuluntu yako oya mana nale oondjenda. Okaana okakala haka ehama olundji nokutaambwa mombete. Onda li nda lombwelwa opo ndi fale okaana ka konaakonwe, okali kamonika kutya okena ombuto yoHIV. Onda li nda landula omalombwelo okuza koshipangeklo. Paife okeli nawa ashike ohaka tindi okunwa omiti ethimbo limwe ndele shampa nda popi nako ohaka tameke ngaa okunwa omiti dhako nawa. Okunwa omiti oko owali uupyakadhi ndina nokaana.

P- (Newi lya gwa pevi) Okaana sho kamonika kutya otaka lumbu nombuto yoHIV, onda li nduuvu nayi noonkondo noshali sha yemateka ndje nayi. Shampa tuu ndeka tala ohandi ka etele ohenda noonkondo teti okaana kaKalunga taka mono iihuna yithike mpa. Ethimbo limwe ohashi lilitha nande nopaife shaa ndeshi dhiladhila ohandi tameke owala te lili ndele ondishi kutya Kalunga oteka kwatha (crying).

P- Okaana okatameke taka ehama etandi tokola ndi ka fale kaka konaakonwe okwa li ndeshi tamba ko owala shaashi oshima ondiwete kutya ombuto okwa valwa nayo kuna nkene wuna okuninga ngehelipi onde shi taamba ko ashike nawa.

R- Oshike shina okuningwa po opo aatekuli yaanona mboka taa lumbu nombuto yoHIV ya gandja oshizemo shokanona nawa?

P- (Newi lya gwa pevi) Otwa pumbwa owala okulongwa po tse pamwe naakwanezimo lyetu ayehe nkene tatu tseyithile okanona kutya otaka lumbu nombuto yoHIV.

P-Osho shili lela kutya otwa pubwa okulongwa. Ngaasshi ngame ongaye nda tseyithile okaana kutya otaka lumbu nombuto,ndele kandishi ngele ondeshi ninga ngaa nawa.

P- Ootundi dhuyelele odha pumbiwa moshigwana ngaashi nando okupitila opo aatekuli yaanona ya longwe po nkene taa gandja oshizemo kokanona hoka taka lumbu nombuto yoHIV.

P-Ngaashi ngame ona nyegwa owali kuty otandi shi tameke peni okuka tseyithila kutya otaka lumbu nombutosigo onena otandi ka pe owal omiti ndele inandi ka lombwela sha.

P- Aantu mboka taa tekula aanona mboka taalumbu nombuto pamwenaakwashigwana oya pumbwa lele oku endithwapo nkene taa tseyithile okaana, shino otashi tu kwatha okusila oshimpwiyu aanona mboka taa lumbu nombuto yoHIV moshigwana shetu.

P.Ngame otandi dhiladhila owali kutya aakwanezimo ayehe naya longwe po owala nkene taa gandja oshize mo kokaana hoka taka lumbu nombutoyoHIV.Mongashingeyi ambala kehe megumbo omuna omuntu ena omukithi nguka gwoHIV.

R- Opuna gumwe ta gwedha po sha ishewe tati ngiini?

P-Onda hala oku yambidhidha omadhiladhilo gaapopi mba yatetekele kutya uuyelele nawu gadjwe owali ando kukehe gumwe nonando megumbo kamuna okanona taka lumbu nombuto yoHIV.

R- Eewa nandi mu pandule amuhe shomwa li mwakutha ombinga momapekapeko ngaka.

ANNEX K: REQUEST FOR PERMISSION TO A HALL AS A VENUE FOR CONDUCTING TRAINING

P.O.Box 2045

Ondangwa

E-mail: ngopewa@gmail.com

Cell: 0811422559

23 August 2018

Medical Superintendent

Intermediate Hospital Onandjokwe

Oshikoto Region

Dear Sir

<u>Re: Request for permission to use a hall at Onandjokwe Regional Health Training Centre to conduct training for caregivers of adolescents living with HIV at Intermediate Hospital Onandjokwe in Oshikoto region.</u>

I am Ottilie Tangeni Omuwa Ikeakanam doing a Doctor of Philosophy in Nusing science at University of Namibia under the supervision of Dr. K.Hofnie and Dr.K.Amakali. I hereby wish to request for permission to use Onandjokwe Regional Health Training Centre as a venue to conduct training for caregivers of adolescents living with HIV regarding disclosure. I have conducted a study which was approved by Permanent secretary, MoHSS and by the health director of Oshikoto. The study was titled: **"Experiences of caregivers of adolescents living with HIV regarding disclosure in Oshikoto region: An educational programme".** The purpose of the study was to support the caregivers of adolescents living with HIV regarding disclosure in Oshikoto region and for the development of an educational programme.

The study was conducted into **4 phases**:

Phase 1: Explored and described the lived experiences of caregivers of adolescents living with HIV regarding disclosure.

Phase 2: Developed a conceptual framework which formed the basis of an educational programme to support the caregivers of adolescents living with HIV regarding disclosure.

Phase 3: Developed an educational programme to support the caregivers of adolescents living with HIV regarding disclosure.

Phase 4: Implement and evaluate an educational programme.

The study has identified the following challenges: caregivers experienced barrier to disclose HIV status to Adolescents Living with HIV (ALHIV), caregivers experienced emotional trauma related to the diagnosis, resistances from the ALHIV to take the Antiretroviral (ARV), caregivers who are not biological are at easy to disclose (accidentally) HIV status to ALHIV and community.

The researcher developed a training manual, which will be used to train the caregivers of adolescents living with HIV.

I intend to conduct such training on the 25 June 2018 and I only need to utilize the hall from 8H00 -17H30. Attached find permission letters to conduct the study.

Thank you for your response.

Sincerely Yours

OTO. Ikeakanam

ANNEX L: INVITATION LETTER TO THE PARTICIPANTS TO ATTEND TRAINING (English version

P.O.BOX 2045
Ondangwa

Enquiry: Ms. OT. Ikeakanam
Cell: 0811422559

To: Ms./Mr. ______________________

Subject: Invitation to the training of caregivers of adolescents living with HIV regarding disclosure

Dear Madam/Sir

You are cordially invited to the training of caregivers of adolescents living with HIV regarding disclosure which will take place as follow:

Date: **25 June 2018**
Venue : **Onandjokwe Regional Health Training Centre Hall**
Time: **08h00**

Your presence will be highly appreciated.

Thank you

Yours sincerely

....

Ottilie T. Ikeakanam
Nurse at Omuthiya Regional Office /Student in PHD Nursing Science (UNAM)

ANNEX M: INVITATION LETTER TO THE PARTICIPANTS TO ATTEND TRAINING (Oshiwambo version)

PO.BOX 2045
Ondangwa

Omapulo: Ms. OT.Ikeakanam
Cell: 0811422559

Ku: Meme/Tate ______________________

Oshinima: Ehiyo komadheulopukululo gaatekuli yaanona mboka taa lumbu nombuto yoHIV mokuya tseyithila nkene taa lumbu nombuto yoHIV.

Omusimanekwa

Oto hiywa nesimaneko enene komadheulopukululo gaatekuli yaanona okuza

poomvula 10-19 mboka taa lumbu nombuto yoHIV. Omadheulopukululo ogena sha nokutseyithila okanona kutya ota lumbu nombuto yoHIV.

Esiku: 25 June 2018
Ehala: Osikola yaapangi mOnandjokwe
Ethimbo: 08H00

Eholoke po lyoye otali simanekwa unene.

Tangi unene

Gweni

Ottilie T. Ikeakanam
Omupangi koombelewa dhopashitopolwa Omuthiya / nomunasikola mOshiputudhilo shopombanda (UNAM)

ANNEX N: SCHEDULE FOR PROGRAMME IMPLEMENTATION AND EVALUATION OF AN EDUCATIONAL PROGRAMME

An education programme to support the caregivers of adolescents living with HIV regarding disclosure in Oshikoto region (Implementation and Evaluation)

Date: 25 June 2018
Venue: Onandjokwe Regional Health Training Centre

Programme Schedule

Monday: 25 June 2018

Time	**Activity**
08h00 – 08h20:	Registration
08h20 – 08h45:	Introduction of participants
08h45 – 09h15 :	Training introduction, expectations and objectives
09h15 – 09h30:	Ground rules
09h30 – 10h00:	Pre assessment test
10h00 – 10h15:	Tea
10h15 -11h00	General information related to HIV disclosure to adolescents living with HIV Tea Break
11h00-11h15:	Dicussions
11h15 – 11h45:	Barriers to disclose HIV status to adolescents living with HIV
11h45 – 12h00:	Discussions
12h00 – 12h30:	Emotional trauma related to adolescents diagnosis with HIV

12h30 – 12h40:	Discussions
12h40 – 13h0:	Experienced mixed feeling when adolescents diagnose with HIV
13h00-14h00:	Lunch
14h00-14h15:	Discussions
14h15-14h45	Non- biological parents are at easy to care for adolescents living with HIV
14h45-14h50:	Discussions
14h45-15h15:	Resistances from the adolescents to take the Antiretroviral Therapy
15h15-15h30:	Discussions
15h30-16h00:	Daily evaluation
16h00-16h15:	Programme evaluation
16h15- 17h00:	Post assessment
17h00 -17h30:	Closure

ANNEX O: PRE AND POST TEST –ENGLISH VERSION

Pre and post test assessment test

Answer the entire question in this paper. Tick the correct answer and write the information required in the space provided.

1. According to Namibian National Guidelines of adolescents living with HIV (2012) fully disclosure should be done at the following ages:

A. 2 years

B. 8 years

C. 5 years

D. 10 years

2. All the adolescents living with HIV have the right to be informed about their condition.

A. True

B. False

3. All the adolescents living with HIV have the right to go to school

A. True

B. False

4. If the adolescents living with HIV is taking her/his medications very well there is no need to disclosure the HIV status

A.True

B. false

5. The person who to disclose the HIV status to adolescents living with HIV needs to be trained on how to disclose.

A.True

B. false

6. Who should disclose HIV status to adolescents living with HIV?

A. Biological parents / caregivers/ health care workers

B. Teachers

C. Neighbours

7. Mention any four (4) advantages of disclosing the HIV status to adolescents living with HIV.

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8. Mention any four (4) advantages of disclosing the HIV status to adolescents living with HIV.

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9. Mention any four (4) disadvantages of disclosing the HIV status to adolescents living with HIV.

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10. Mention factors which can prevent the caregivers not disclose the HIV status to the Adolescents living with HIV

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ANNEX P: PRE AND POST TEST- OSHIWAMBO VERSION

OKAKONAAKONO KAHUGUNINA

Yamukula omapulo agehe, Tula okangombe peyamukulo ndjoka wu wete kutya olyo li li mondjila, nyola mpoka sha pumbiwa.

1. Omulandu gwaNamibia guna sha naanona mboka taa lumbu nombuto yoHIV (2012) otagu ti omunona ta lumbu nombuto yoHIV na tseyithilwe kutya ota lumbu nombutoyoHIV okuza poomvula ngapi?

A. Opoomvula mbali

B. Opoomvula hetatu

C. Opoomvula ntano

D. Opoomvula omulongo

2. Aanona mboka taa lumbu nombuto yoHIV oyena uuthemba oku tseyithilwa kutya otaa lumbu nombuto yoHIV.

A. Osho

B. Hasho

3. Aanona mboka taa lumbu nombuto yoHIV oyena uuthemba okuya kosikola?

A. Osho

B. Hasho

4. Omunona ngoka ta lumbu nombuto yoHIV ngele otanu nawa omiti dhoARV ina pumbwa atseyithilew kutya ota lumbu nombuto yoHIV

A. Osho

B. Hasho

5. Omuntu ngoka ta tseyithile omunona kutya ota lumbu nombuto yoHIV okwa punbwa okudheulwa po nkene ena okushininga

A. Osho

B. Hasho

6. Olye ena uuthemba oku tseyithila okanona kutya ota lumbu nombuto yoHIV?

A. Aavali yokaana / aatekuli yokaana / aagandji yundjolowele

B. Aalongisikola

C. Aaashiinda

7. Tumbula omauwanawa kutya omolwashike sha simana opo okanona ka kale ka tseyithilwa kutya otaka lumbu nombuto yoHIV

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8. Oshapumbiwa ngaa opo omutekuli gwokanona hoka taka lumbu nombuto yoHIV a kale a longwa po nkene ena okutseyithila okanona kutya otaka lumbu nombuto yoHIV?

8.1 Ngele eeno, omolwashike

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8.2 Ngele aawe, omolwashike

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9. Tumbula iinima mbyoka hayi imbi opo omuvali/Omutekuli gwokanona hoka taka lumbu nombuto yoHIV kee katseyithile kutya otaka lumbu nombuto yoHIV.

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ANNEX Q: APPLICATION FOR PERMISSION TO CONDUCT RESEARCH IN OSHIKOTO REGION

P.O.BOX 2045
Ondangwa
9000
APRIL 4, 2015

The Permanent Secretary
Ministry Of Health and Social Services
Private Bag 13198
Windhoek
Namibia

Dear Sir,

RE: APPLICATION FOR PERMISSION TO CONDUC RESEARCH IN OSHIKOTO REGION

I am Ottilie Tangeni Omuwa Ikeakanam a senior registered nurse working in Onandjokwe Lutheran hospital. I am doing my Doctorate of Nursing Science (PHD nursing) with the University of Namibia.
My research study is: **" Experiences of Caregivers of Adolescents living with HIV in Oshikoto region, Namibia: An educational program"**
I intend to interview the caregivers of adolescents living with HIV in Oshikoto region, who come for scheduled follow-ups. The main aim is to use the information gathered from the study to develop an educational program to assist the caregivers of adolescents living with HIV.

I hope my application will be favourablyconsidered.

Thank you.

Yours faithfully,

Mrs. O.T.O Ikeakanam