

**PERCEPTIONS OF FACTORS CONTRIBUTING TO PSYCHOLOGICAL
DISTRESS IN HIV POSITIVE CHILDREN ON ANTIRETROVIRAL THERAPY
IN MOCHUDI, BOTSWANA: A FAMILY CAREGIVER AND HEALTH CARE
WORKER ANALYSIS.**

by

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UNIVERSITY *of the*
WESTERN CAPE

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KEY WORDS

- Orphan and vulnerable children (OVC)
- Human Immunodeficiency Virus (HIV)
- Acquired Immunodeficiency Syndrome (AIDS)
- Psychological distress
- Behaviour problems
- Family caregivers
- Nurses
- Social workers
- Kgatleng district
- Botswana



ABSTRACT

Background: The repercussions of being HIV positive coupled by the complications of antiretroviral therapy are likely to cause distress, emotional and psychological problems particularly among children infected by the virus. The limited support services for children experiencing distress intensify the urgency to address this challenge. Despite the availability of social workers and nurses' interventions currently in place, the number of children in need of psychological care continues to increase. This is particularly true at Deborah Retief Memorial (DRM) hospital, one of the main antiretroviral therapy facilities in Kgatleng district, Botswana.

Method: The purpose of this study was to explore and describe the perceptions of social workers, nurses and caregivers on key factors contributing to psychological distress of HIV positive children. A descriptive, exploratory qualitative study design that employed the use of in-depth interviews was used to conduct this study. Participants included four caregivers of HIV positive children who seek antiretroviral therapy at DRM hospital Infectious Diseases Control Clinic, together with five nurses and two social workers who worked in the same clinic. Conventional content analysis was used to analyse the in-depth interview transcripts.

Results: Perceived psychological stressors for HIV positive children included disclosure of HIV status, orphanhood, social problems, lifelong treatment, stigma, poor caregiver-child relationship and lack of caregiver's love, care and support. However the caregivers did not fully understand the psychological distress the HIV positive children were experiencing, hence were unable to recognize it in these children. The study highlighted that major challenges faced by the health-workers included lack of qualified personnel,

lack of adequate knowledge and skills, and a non-conducive working environment required to effectively assist children with psychological distress. The findings also indicated the need for education and support of caregivers and HIV positive children by the educators, family and health-worker systems.

Conclusion: The profile of key stressors of psychological distress, the challenges and support needs suggested by the participants in this study can provide a framework for improving the existing services for HIV positive children with psychosocial problems. This information is important for use in training nurses and social workers involved with children with psychological behaviours.



DECLARATION

I declare that *Perceptions of Factors Contributing to Psychological Distress in HIV Positive Children on Antiretroviral Therapy in Mochudi, Botswana: A Family Caregiver and Health Care Worker Analysis* is my own work, that it has not been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANecca	African Network for the Care of Children Affected by HIV/AIDS
ART	Antiretroviral Therapy
ARV	Antiretroviral
BSI	Brief Symptom Inventory
CBCL	Child Behaviour Checklist
DRM	Deborah Retief Memorial Hospital
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency virus
IDCC	Infectious Diseases Control Clinic
NLE	Negative Life Events
SADC	Southern African Development Community
USAID	United States Agency for International Development

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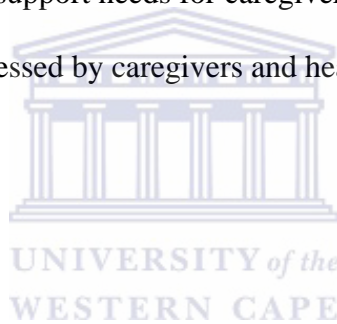
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CHAPTER ONE

INTRODUCTION

This chapter provides a background to the study, the problem statement and the rationale of the study. It concludes by providing an outline of the rest of the research report.

1.1. BACKGROUND

The Human Immunodeficiency Virus (HIV) infection and longevity of life resulting from antiretroviral therapy (ART) poses considerable psychological distress and behavioural problems among the many children whom nurses and social workers encounter in ART clinics daily (Rao *et al.*, 2007). The national prevalence rate of HIV infection is 17.6 % and an estimated 25 000 (7.8 % of the total infections) children under the age of 15 years had been infected by the virus in Botswana by the end of 2008 (Ministry of Health, 2009). The high HIV sero-prevalence rate of pregnant women which stood at 32.4 % in 2008 and vertical (mother to child) transmission are responsible for the large burden of paediatric AIDS in the country (Ministry of Health, 2009).

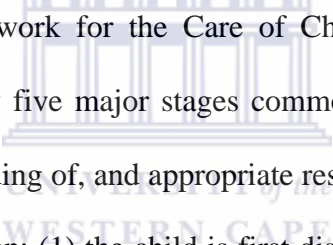
The availability of ART and its success has meant that more people living with HIV, including children, have begun to survive longer, posing unique challenges not only on the health system, but within broader society (Brown & Lourie, 2000). As a result of ART HIV/AIDS has since transformed from a short term terminal illness to a long term chronic condition (Microft *et al.*, 2003; Stuart, 2008). This has, however come with certain challenges such as psychological and mental distresses as individuals cope with

the illness and treatment. Often HIV positive people, both adults and children directly or indirectly experience emotional pain and complex feelings of loneliness, guilt, anger, confusion, depression and fear as a result of their condition (Domeck, 2006). As treatment coverage increases more children survive their infant years to become adolescents (Microft *et al.*, 2003). As they grow up, HIV positive children are increasingly having to deal with the HIV associated emotional issues and often psychological distress is more pronounced compared to their counterparts (Steele, Nelson & Cole, 2007; Smith *et al.*, 2006).

The psychological distress among children is largely associated with disease progression of HIV (Greeson *et al.*, 2008). Therefore the government had to come up with interventions to alleviate the HIV/AIDS disease. In year 2000, Botswana embarked on a national ART program for all eligible citizens in order to curb the devastating impact of HIV/AIDS on both adults and children (UNDP, 2008). The ART program has since expanded such that by the end of year 2009 it covered over 90 % of people in need of treatment (UNAIDS 2010). Without this intervention, the estimated death rate was estimated to reach 130 000 per annum by 2016 (UNAIDS, 2010).

There are many conditions apart from the HIV status of a child that can influence psychological well-being of the child (Domeck, 2006). Emotional/ behavioural disorders, including anxiety, depression and general behaviour problems have been detected in varying proportions of HIV positive children worldwide (Grover, Pensi & Banerjee, 2007; New, Lee & Elliot, 2007; Steele, Nelson & Cole, 2007). The children have special

psychological and material needs such as the support they require for coming to terms with being HIV positive, the prospect of being on lifelong treatment, and protection from dealing with stigma or discrimination from family or peers and teachers at school (Brown & Lourie, 2000; Domeck, 2006). Many of these children live in deeply impoverished households with HIV often aggravating the vicious cycle of poverty and compounding emotional and psychological well-being (Domeck, 2006). As such providing care for them is a challenge to both the professional (health-workers) and family member caregivers (Steel, Nelson & Cole, 2007; Brown & Lourie, 2000; Hansell *et al.*, 1999). The latter will be referred to as caregivers throughout the rest of the text.



According to the African Network for the Care of Children Affected by HIV/AIDS (ANECCA) there are generally five major stages common in the lives of HIV positive children in which an understanding of, and appropriate responses to their emotional needs are most crucial. These are when: (1) the child is first disclosed to his or her HIV status, (2) the child starts ART and has to deal with issues of medication adherence, (3) dealing with HIV/AIDS related stigma and discrimination, (4) dealing with trauma when a parent dies and (5) dealing with end of life issues should treatment fails (ANECCA, 2006). There is a belief that health and well-being of these children may be significantly related to medical and social issues that are not directly related to the virus (Remafedi, 1998 in Brown & Lourie, 2000; ANECCA, 2006; Mellins *et al.*, 2003). Thus from these five aforementioned stages, most of the HIV positive children are likely to report behaviour and emotional problems rather than physical ones. Since children with psychological distress require nursing intervention through identification of the stressors or unmet needs

(Ridner, 2004), there is a continuous need for understanding and responding to their mental or psychological health needs by the health-workers and caregivers as the children grow up.

1.2. PROBLEM STATEMENT

In recent years there has been a general increase in the number of HIV positive children on ART that have been referred to the nurses and social workers for psychological care and counseling in Botswana (personal communication, ART clinic Head Nurse, February 2009). The increased number of referrals for counseling of the HIV positive children has implied that there is an increase in the workload, time and resources needed by the nurses and social workers in dealing with HIV positive children. Considering the large number (25 000) of HIV positive children in Botswana (Ministry of Health, 2009), it may follow that there are a lot of them with unmet needs and therefore require psychological care and counseling. Besides these challenges the nurses and social workers continue to support and assist the children often with limited expert capacity and wherewithal. There is therefore real urgency for the public services to meet the knowledge and skills demands required to support these children to tackle the emotional challenges they are facing.

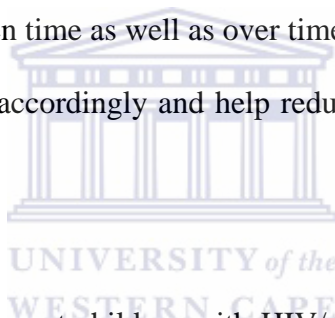
1.3. RATIONALE

To meet the increased demand of psychological care of the HIV positive children, the nurses and social workers therefore require knowledge, skills and possibly training in dealing with the various factors that cause psychological distress in HIV positive children. Unfortunately, in Botswana like in most African countries, paediatric medicine

is not yet an established discipline, health facilities do not have specific mechanisms to address the special needs of children, and the health-workers have not been adequately trained to effectively communicate and manage the children well (Eley *et al.*, 2006). Current trainings largely focus on medication adherence without emphasis on the psychological aspects of HIV infection and ART in children. A study conducted in Rwanda by van Griensven *et al.* (2008) discovered that sufficient numbers and training of nurses with particular emphasis on psychosocial needs of children and their caregivers were the key elements for the successful scaling-up of use of antiretroviral (ARVs) drugs at a nurse-based care system of ART. Health-workers in studies conducted in the developed countries have also expressed concern on the lack of adequate information and skills required in dealing with issues of psychological health of HIV positive children.

This inadequate capacity to identify, manage and support psychologically traumatised children prompted ANECCA to call upon governments, health leaders and non-governmental organisations to “prioritise and promote child focused HIV/AIDS care through capacity building at all levels of the healthcare system in the form of pre- and in-service training” of health-workers in paediatric HIV care and treatment, psychosocial care and counseling (Eley *et al.*, 2006: 685). By identifying HIV positive children with psychological distress and implementing coping mechanisms it is hoped that intervention would improve their quality of life by reducing and or managing stressors associated with HIV and or ART (Brown & Lourie, 2000).

Caregivers play a crucial role in providing psychosocial needs of HIV positive children. They often form the first line of psychosocial support to these children (Xu *et al.*, 2009). An understanding of the caregivers' perspectives of psychological distress of the HIV positive children is of central importance in understanding this problem as well as informing appropriate interventions based on the realities of the HIV positive children and their caregivers. As part of the solution to help reduce psychological distress in HIV positive children, the caregivers too, like the nurses and social workers, must be aware and sensitive to the needs and concerns of HIV positive children. Caregivers themselves have been reported to find it beneficial to be informed in advance about what to expect of their "special" child at any given time as well as over time (Grotberg, 2004: 5). This, it is hoped, enables them to adjust accordingly and help reduce the psychological distress of their HIV positive child.



Before the advent of the ART most children with HIV/AIDS did not survive past early childhood. As a result many of the studies performed on HIV positive children had an inclination on providing comfort in death and dying (Domek, 2006). Living with a chronic disease has been shown to cause several psychosocial problems (Evans, 2004). Unfortunately not much research has been done on the psychosocial problems of children infected with HIV/AIDS. In Botswana, there are no published studies that have specifically focused on issues of psychological distress experienced by HIV positive children. Rather, available research focuses mainly on orphans (Anarb & Serumaga-Zake, 2006; Avert, 2009a). Although most orphans in Botswana are HIV/AIDS orphans (Ministry of Health, 2009) it has not yet been established whether the psychological

distress they undergo is similar to that of HIV positive children. Thus the lack of information concerning the psychological distress experienced by HIV positive children in Botswana (who are not necessarily HIV/AIDS orphans) makes it difficult to plan and provide appropriate responses to their psychosocial and material needs. For these reasons the purpose of this study was not to focus on the HIV orphaned children but to focus on the social and emotional functioning of HIV positive children regardless of orphan status.

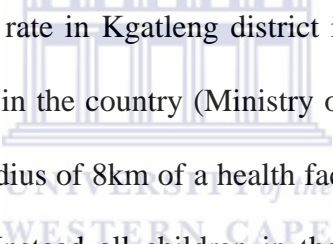
This study therefore was designed to partly address the gaps mentioned above and address the following research questions: What do the social workers, nurses and caregivers perceive to be the key psychological stressors for HIV positive children? What support and training do nurses, social workers and caregivers need to effectively deal with psychological distress of HIV positive children? This information was sought from individual face to face interviews with nurses, caregivers and social workers. Such information is crucial in developing training materials for nurses, social workers, other health professionals (such as doctors and lay counselors¹), as well as caregivers to better prepare and equip them with the skills and knowledge required to deal with the possible factors that may cause psychological distress in HIV positive children.

1.4. STUDY SETTING

This study was carried out in Mochudi, the main village of Kgatleng district which is 40km away from Gaborone, the capital city of Botswana. The district has a total

¹ Lay counselors are high school graduates trained for 4 to 6 weeks and originally employed to perform pre- and post-test counseling, supportive counseling for the prevention of mother to child transmission (PMTCT) program. Their role has since expanded to involve counseling and HIV rapid testing for the national antiretroviral therapy program.

population of 73, 507 and is generally representative of most districts in the country in terms of infrastructure and sociopolitical organisation (Central Statistical Office, 2001). The main economic activities in the district are subsistence farming and animal husbandry (Kgatleng District Council, 2003). The district is served by a single district hospital, 12 public sector clinics and 15 health posts, three private clinics, two private pharmacies and a single private dental clinic. The district hospital, Deborah Retief Memorial hospital (DRM), has a special unit, the Infectious Diseases Control Clinic (IDCC) which offers highly active antiretroviral therapy (HAART) to about 3 300 adults and 290 children (DRM, 2009).



The estimated HIV prevalence rate in Kgatleng district is 15.8 % making it one of the highest HIV burdened districts in the country (Ministry of Health, 2009). About 80% of the population lives within a radius of 8km of a health facility, most of which offer ART to adults but not to children. Instead all children in the district access ART from the district hospital's IDCC unit in Mochudi, which is approximately 50 km from the furthest health post. The hospital Social Work Department provides counseling and psychosocial services to these children during the paediatric clinic once a week. On this day a Social Worker is based full time in the department in order to attend to all the cases that will be referred by the nurses and doctors.

1.5. OUTLINE OF THIS REPORT

This study consists of six chapters. The first chapter puts the study into context. In the second chapter a review of the literature related to psychological distress and its causes in

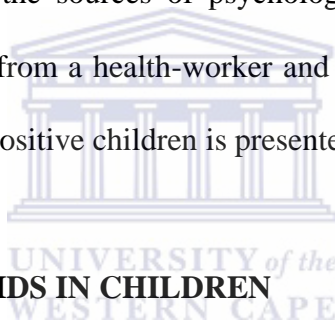
HIV positive children is presented. The third chapter describes the methodology that was used to carry out this study. The fourth chapter presents the results of the study and the fifth chapter presents an analysis, discussion, and interpretation of the results. The sixth and final chapter presents the conclusion and recommendations drawn from the study.



CHAPTER TWO

LITERATURE REVIEW

This chapter reviews key literature on psychological distress in HIV positive children in order to place this research topic in a wider context. It will firstly give a brief statistical overview of HIV/AIDS in children. Secondly a clarification of the concept of psychological distress follows. Thirdly a discussion of the theoretical approaches to the study of psychological distress will be presented. Fourthly a review of literature regarding the prevalence and the sources of psychological problems in HIV positive children, as well as the issues from a health-worker and caregiver perspective regarding psychological distress in HIV positive children is presented.



2.1. OVERVIEW OF HIV/AIDS IN CHILDREN

According to the 2010 UNAIDS global report on the AIDS epidemic, of the 33.3 million people globally living with HIV in 2009, about 1.9 million were children under the age of 15 years (UNAIDS, 2010). Sub-Saharan Africa carries the highest of HIV prevalence burden in the world. It accounts for 91% of new HIV infections among children under the age of 15 years worldwide (UNAIDS, 2010). In fact HIV/AIDS is a major cause of infant and childhood mortality and morbidity in Sub-Saharan Africa. In Botswana, an estimated 320 000 people (17.6 %) of the population are living with HIV and AIDS of which 25 000 (7.8 %) are children under the age of 15 (Ministry of Health, 2009).

2.2. THE CONCEPT OF PSYCHOLOGICAL DISTRESS

Psychological distress is referenced frequently in nursing, medical, social science literature, but it is rarely defined as a distinct concept (Ridner, 2004). Most of the definitions tend to include the aspects of: unpleasant subjective states of depression and anxiety that manifest both emotionally and physiologically (Mirowsky & Ross, 2003); markedly unusual behaviour that impairs everyday function (Nicholas *et al.*, 2003); personal or collective suffering covering a range of negative feelings and physical sensations that are as a result of adverse external circumstances (Murray, 2006); and a relationship between the human being and his environment that is appraised as potentially endangering to one's well-being coupled with loss of ability to cope or resulting in harm (Lazarus & Folkman, 1984; Ridner, 2004). All these states of the human tend to be communicated through behaviours that include feelings of anger, sadness, frustration, depression, hopelessness, anxiety, loneliness and isolation and a number of other negative mood states or physical signs such as stomachaches and dizziness (Mirowsky & Ross, 2003; Nicholas *et al.*, 2003).

Taking into account the above mentioned aspects an operational definition of psychological distress for this study was defined as: *any deviation by a child from a normal state of behaviour and mental health as reported by their caregiver, which the IDCC nurses and doctors perceive will warrant the evaluation of the child by a social worker. The manifestations of such deviation from the norm will include a child's signs of depression (feeling sad, demoralized, lonely, hopeless or worthless, wishing one were*

dead, feeling everything is an effort ,crying, having trouble sleeping) or signs of anxiety (being tense, restlessness, being worried, irritable and afraid).

2.3. THEORETICAL APPROACHES TO PSYCHOLOGICAL DISTRESS

Attempting to assess psychological distress tends to employ one or a combination of any of three approaches: the universal lens, transcultural psychiatry lens and cultural relativist lens (Murray, 2006). The universal lens model views psychological distress as a neurobiological problem that is thought to manifest as psychiatric disorders that are assumed to remain constant across different cultures. The model employs a standardised international set of symptoms, usually in the form of a questionnaire based instrument such as the BSI (Bachanas *et al.*, 2001; Mendoza *et al.*, 2007) to diagnose psychological distress (Murray, 2006). In these standardised instruments if a clinically trained worker identifies a certain number of criteria, a diagnosis of psychological distress is made (Murray, 2006).

The transcultural model asserts that psychological distress is expressed differently across different cultures hence it questions the validity of the universal diagnostic instruments in non-Western cultures for which they were originally designed. The model recommends the tailor-making of the Western diagnostic instruments by translating and validating the instruments before using them in non-Western population (Murray, 2006). This study adopted the cultural relativistic model approach which uses open discussions to unearth the ways in which the caregivers, social workers and nurses constructed their lived experiences and perceptions of psychological distress of HIV positive children.

2.3.1. Cultural relativism lens model

The social context of many HIV positive children involves poverty, lack of resources and many family deaths, factors which can impact on medication adherence, family relationships, disclosure of illness and psychological distress (Brown & Lourie, 2000; Domeck, 2006). In addition cultural lens or viewpoints and subsequent beliefs may also pose a significant impact on the ability to cope with illness in these children (Murray, 2006). The cultural relativism lens model, like the transcultural model, argues that different cultures have different perceptions of psychological phenomena. It however disregards the transcultural lens in the fact that the latter fails to pick the different meanings people attach to their experiences and responses. The culturally relativistic approach instead, puts emphasis in the way local people understand and perceive psychological distress through the use of qualitative research methodologies (Murray, 2006) such as face to face interviews and focus group discussions in order to understand the peoples lived experiences (Cluver & Gardner, 2007; Nyamukapa *et al.*, 2010).

In this model responses are informed by the socio-cultural context rather than a set of “proforma” questions from a standardised questionnaire (Murray, 2006: 34). Through face to face individual interviews the nurses, social workers and caregivers participating can recount the experience of taking care of psychologically distressed children and how this affects their everyday life. It is for these reasons that the culturally relativistic approach was felt appropriate for this study in that it attempts to look at things from the “insider’s point of view” (that of the caregivers, social workers and nurses attending HIV

positive children) in order to understand the subjective ways in which people perceive and respond to psychological distress in HIV positive children (Murray, 2006: 35). Unlike the universal and transcultural approaches which usually take the view of the outsider the cultural relativism lens provides a powerful tool to interpret more descriptive sources of data such as interviews. In addition, the information on psychological distress in HIV positive children comes from the developed world (Steele, Nelson & Cole, 2007), thus using a cultural relativism framework generates data that will be specific to the local population. Consequently interventions that designed can be more suited to the specific local cultural context.

2.4. PREVALENCE OF PSYCHOLOGICAL PROBLEMS IN HIV POSITIVE CHILDREN

A large proportion of available data on HIV positive children is based on the Western and developed world using largely quantitative diagnostic methods (Steel, Nelson & Cole, 2007). Quantitative methods however may fail to pick different meanings and ways people attach to and respond to their experiences which probably make the universal diagnosis of psychological problems a rather difficult task (Murray, 2006). The range of psychological effects of HIV in an individual changes quite considerably over time (Kalichman in Basta, Reece & Shacham, 2008). Immediately after diagnosis there is a major increase in psychological distress symptoms such as anxiety and depression. With time these symptoms decline as an individual psychologically adjusts to the disease. Later on, as physical effects of the disease such as weight loss and lymphadenopathy set in the individual, psychological symptoms become more pronounced and there is a higher

like hood of depression and anxiety (Reece *et al.*, 2007; Basta, Reece & Shacham, 2008). Ridner (2004) proposes that the emergence of harm, which often appears in the form of pain, change in vital signs (blood, pressure, weight and body temperature) suicide gestures and desire to leave against medical advice (such as non-adherence to medication) occur as a sign of psychological distress state in an individual.

Emotional or behavioural disorders, including anxiety, depression and general behaviour problems have been detected in varying proportions of HIV positive children worldwide. In a study of 140 HIV positive children and 301 age matched controls between 6 and 11 years in India, 80.7 % of HIV positive children compared to only 18.3% in controls were found to have behavioural problems (Grover, Pensi & Banerjee, 2007). A Haitian baseline data analysis of a pilot psychosocial youth program reported high levels of anxiety that were characterized by constant fidgeting, restlessness and too much worrying in respectively 86%, 83% and 56% of the 492 HIV positive adolescents that participated in this study (Smith *et al.*, 2010).

In the Dominican Republic, a study performed among 43 HIV positive children aged 2 to 8 years to determine caregivers perceptions of behavioural problems using the child behaviour checklist (CBCL) found that high proportions of internalizing problems of 40% and 46% were present in both younger (less than 5 years) and older children (over 5 years) respectively. A high proportion of older children (46 %) also exhibited high levels of externalizing problems such as aggression and rule breaking (Mendoza *et al.*, 2007). In a cross-sectional study conducted in Uganda, Musisi & Kinyanda (2009) found

that about half (51.2 %) of the 82 HIV positive children enrolled for this study had significant psychological distress and 17.1 % had attempted suicide in the 12months prior to the study. The study also found high anxiety (45.6%) and depression (40.8%) levels in this study population.

In contrast, some research studies failed to demonstrate the link between HIV infection and increased levels of behaviour problems (Gadow *et al.* 2010; Mellins *et al.*, 2003). Rather they claim that the poor behavioural outcomes found in perinatally infected HIV positive children are as a result of other biological and environmental factors (Mellins *et al.*, 2003). They argue against the conclusion linking HIV as the cause of poor behavioural outcomes in these children to be the fact that many of the studies did not have adequate control groups which made it difficult to investigate a lot other factors that place HIV positive children at risk of behavioural problems. Such factors include among others poverty, trauma, family disruptions and bereavement and stigma (Mellins *et al.*, 2003, Rao *et al.*, 2007). These factors are reviewed in the next sub-section.

2.5. SOURCES OF PSYCHOLOGICAL DISTRESS IN HIV POSITIVE CHILDREN

The factors which tend to elicit some adjustment reactions and emotional strain which may culminate into psychological distress in HIV positive children can be classified as biological, psychological and social factors (Rao *et al.*, 2007).

2.5.1. Biological factors

Biological causes of psychological distress include physical pain and discomfort that is usually associated with living with a chronic illness and the common conditions associated with HIV infection (Rao *et al.*, 2007). Neuropsychological impairments such as HIV associated progressive encephalopathy, a condition which affects about 30 to 60 % of the children and adolescents at any time in their lifetime forms a major part of biological related causes of psychological distress (Millana-Cuwevas, Portellano & Martinez-Arias, 2007). HIV associated progressive encephalopathy may cause neurological deficits that negatively affect the children's normal development, academic performance and cognitive function (Brackis-Cott *et al.*, 2009; Puthanakit *et al.*, 2010). Changes in number and functionality in killer lymphocytes are also believed to mediate the relationship between higher levels of psychological distress (defined by perceived stress, anxiety and depressive symptoms) and greater HIV disease severity as defined by HIV-1 viral load and T-helper CD4 cell count (Greeson *et al.*, 2008).

2.5.2. Psychological factors

Psychological factors often include fear of death, anxiety, loss of self esteem and confidence, stigma, and disclosure of HIV infection (Brown & Lourie, 2000; Abadia-Barero & Castro, 2006; Grover, Pensi & Banerjee, 2007; Rao *et al.*, 2007). In one study of 34 HIV positive children in Thailand, the children expressed deep fears and worries of dying (Punpanich *et al.*, 2008). These worries were believed to be caused by the fact that caregivers tried to justify the need for the children to continuously take medication by telling the children that should they refuse to take the medication they will die. For those

to whom their HIV status had been disclosed, there was always a psychological threat that any kind of illness reminded them of their impending death (Punpanich *et al.*, 2008).

Disclosure of HIV infection has been found to be an important determinant of psychological distress in HIV positive children. Literature shows that disclosure of HIV status to the HIV positive children has many positive outcomes that include: open communication with the children regarding their disease which leads to improved caregiver-child or healthcare institution-child relationships; better psychological adjustment; less behavioural problems and providing the opportunity for children to be able to participate in social support networks that can help reduce psychological distress (Abadia-Barero & Larusso, 2006; Klitzman *et al.*, 2008; Rwemisisi *et al.*, 2008; Steel, Nelson & Cole, 2007; Vaz *et al.*, 2010). The lack of openness between caregivers and the HIV positive children is believed to result in children not getting convincing answers to their questions regarding their illness and such unconvincing responses further plunges them into more anxiety and psychological distress (Abadia-Barero & Larusso, 2006).

Despite these benefits of disclosure and its potential in reducing psychological distress, the disclosure rates are quite low in many parts of the world. In a study carried out in Thailand reported only about one third (30.1%) of 103 caregivers had told their children that they had HIV/AIDS (Oberdorfer *et al.*, 2006). Another study in Uganda found that about 50% had disclosed the status to the children by the median age of 9 years (Rwemisisi *et al.*, 2008). Reasons for non-disclosure were sighted as fear of imposing emotional distress to the child, perception of the child being too young, and lack of

benefits in the children from knowing HIV status (Oberdorfer *et al.*, 2006; Rwemisisi *et al.*, 2008). Another reason is the stigma associated with the fear of the question, “What if they ask how I got it?” (Rwemisisi *et al.*, 2008: 36). In contrast, a USA study that investigated the impact of disclosure on paediatric quality of life did not find any statistical differences between paediatric quality of life before and after disclosure (Butler *et al.*, 2009). It then concluded that disclosure can be done at any age but at an appropriate time depending on the child’s understanding of what is going on.

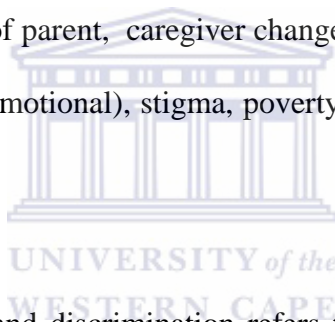
As children on ART survive longer into school going age, absenteeism in order to meet the doctor’s appointments, stigmatisation from classmates and teachers have been noted as the most common potential causes of psychological distress in school going HIV positive children (Domeck, 2006; Vijayarasa, 2010). In a study among 55 HIV positive children aged 8-17 years school life related events were the most common and they predicted child-reported depressive symptoms (Elliot-DeSorbo, Martin & Wolters, 2009).

2.5.3. Social factors

Lack of social support has been shown to worsen the effect of life stressors on psychological distress, adherence and treatment outcomes (Cohen, 2007). Orphanhood, stigma, poverty, negative life events, and cultural factors are the major social factors that have been found to cause psychological distress in HIV positive children.

Orphanhood: HIV positive children usually have to cope with their own mortality as well as that of their parents with HIV/AIDS (Domeck, 2006). This is because most of the HIV

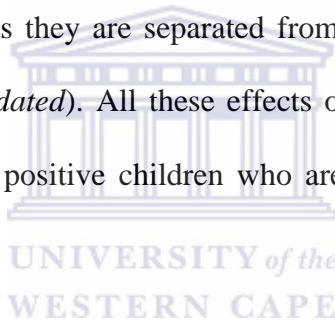
infections in children are perinatally acquired and it is likely that a HIV positive child will experience loss of one or both of parents at some point in their life and they become AIDS orphans. Consequently HIV positive children will tend to be at risk of psychological distress which is experienced by other (non-infected) HIV/AIDS orphans. AIDS orphans in Sub-Saharan countries such as Uganda, Zimbabwe and South Africa suffer higher levels of psychological problems than both orphans from non-AIDS causes and non-orphaned children (Atwine *et al.*, 2010, Cluver, Gardner & Operarrio, 2007). A study among 60 AIDS orphans, 42 caregivers and 20 social workers in Cape Town, South Africa, found that the major causes of psychological distress in AIDS orphaned children were bereavement from death of parent, caregiver change after death of parent, caregiver illness, abuse (sexual, verbal, emotional), stigma, poverty and lack medical care (Cluver, Gardner & Operarrio, 2007).



Stigma: AIDS related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV/AIDS (Avert, 2009b). Stigma can result in HIV positive people including children being shunned by family, peers and the wider community (Abadia-Barero & Castro, 2006). It can result in poor treatment in healthcare and education settings, psychological damage and it can negatively affect the success of treatment (Avert, 2009b). A Brazilian study among 50 HIV positive children found that AIDS related stigma formed part of the HIV positive children's lived experience as it is almost always present in the their family, school and neighbourhood (Abadia-Barero & Castro, 2006). In Botswana, in a study that aimed to describe the perceptions of HIV positive adolescents towards stigmatisation due to HIV/AIDS,

Tshweneyagae (2010) found that the major ways used by the adolescents to combat the high levels of stigma towards HIV/AIDS were: strict adherence to medication, getting early treatment for common ailments and keeping their HIV status a secret. This study confirmed the presence of HIV-related stigma experienced by the HIV positive adolescents in the country.

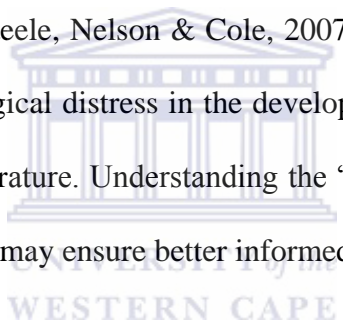
Poverty: HIV positive children living in very poor households are at risk of deterioration of health through infection, under-nutrition and poor health care. They lose their livelihoods through the illness and death of parents and breadwinners and also lose their families and social networks as they are separated from siblings after death of parents (van Gelder & Kraakman, *Undated*). All these effects of poverty aggravate the risk of psychological distress in HIV positive children who are already battling with medical effects of HIV infection.



Negative life events (NLE) such as change in homes or serious illness of a family member pose a risk to the health-related quality of life and psychological distress in children and youth living with HIV/AIDS. A study among 1 018 children and youth aged between 5 and 21 years discovered that children with one or more NLEs exhibited markedly low health perception, more symptom distress and more behaviour problems than children with no reported NLEs (Howland *et al.*, 2007).

Cultural factors: People exposed to similar stressors respond differently at a physical, psychological and societal level (Mechanic, 1986). This is probably because different

cultures have different “recognizable languages of distress” which may be verbal, non-verbal, physical or psychological, with which people express their suffering (Murray, 2006:32). For example, cultural beliefs and attitudes may have an effect on people’s behaviour, reactions to death and on how individuals cope with illness (Brown & Lourie, 2000). A cross-cultural comparison of psychological distress among 234 individuals living with HIV in the USA and 284 individuals in Kenya found marked differences in the expression of psychological distress in these individuals who had self-enrolled into HIV-related mental health care within the two different care settings (Shacham *et al.*, 2010). Since most of the information on psychological distress in HIV positive children comes from the developed world (Steele, Nelson & Cole, 2007), it remains uncertain whether the characteristics of psychological distress in the developing countries like Botswana is similar to that in published literature. Understanding the “language of distress” (Murray, 2006:32) in Botswana children may ensure better informed interventions.



2.6. CHALLENGES OF PROVIDING PSYCHOLOGICAL CARE TO HIV POSITIVE CHILDREN

Literature indicates that both health-workers and caregivers have their own unique challenges in caring for psychologically distressed children.

2.6.1. Health care worker related challenges

Health care workers of HIV positive children encounter challenges and stressors of dying patients, families in conflict, an always changing science and often insufficient treatment resources (Brown & Lourie, 2000). There is a dearth of literature regarding challenges and

perspectives of health-workers on psychological distress in HIV positive children in Sub-Saharan Africa. ANECCA regards the major challenges faced by health-workers in addressing the psychosocial needs of HIV positive children as lack of knowledge and skills for effective communication with the children, insufficient time to develop a relationship that gains trust from the children to make them open up, lack of information appropriate for a child's developmental stage, and not having or unaware of referral options in cases of children who need further specialized psychosocial evaluation (ANECCA, 2006). This is compounded by sheer shortage of staff, often resulting in staff being stretched beyond their capabilities. A study in Uganda by Rujumba, Mbasalaki-Mwaaka & Ndedzi (2010) concur with ANECCA as their findings indicated that the main challenges faced by health-workers were lack of counseling skills, failure to cope with the knowledge demand, difficulty to facilitate HIV status disclosure, caregiver regarding HIV positive child as burden, children not expressing themselves easily thus requiring more time for counseling, heavy work load and lack of other support services.

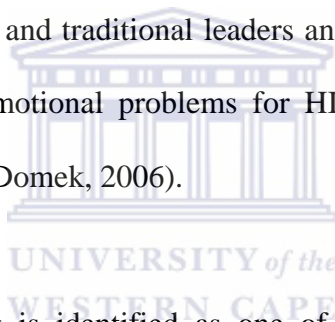
In a study which sought to investigate the common challenges that were faced by American nurses and social workers in HIV services provision, Olivier & Dykman (2003) argued that nurses and social workers share a lot professional values and challenges and are inevitable partners in responding to challenges associated with HIV service provision. The study found that both these groups experience challenges/feelings of: lack of up to date information, feelings of helplessness, grief due to loss of clients, and lack of adequate referral services for mental and emotional health needs of HIV positive patients (Olivier & Dykman, 2003). In most ART clinics in Botswana, nurses and social workers closely to provide psychosocial care to HIV positive children. Gaining

knowledge of the similar challenges they face can greatly assist draw up interventions that can simultaneously address both cadres.

2.6.2. Caregiver related challenges

Providing care for a HIV positive child is a challenging task that affects the caregiver and the entire family. The presence of an HIV positive child in a family usually implies that there is an adult who is also living with HIV within the same family which is often the mother (Hejoaka, 2009). In Botswana, mothers like most other caregivers are economically disadvantaged, are socially isolated, endure stigma and psychological distress, and lack basic care-giving education (Ama & Seloilwe, 2010). In a study among 20 mothers of HIV positive children aged between 8 and 18 years of age in Burkina Faso, it was found that the mothers perceived formal psychosocial support addressing child related issues as inadequate and they had feelings of isolation in caring for their children (Hejoaka, 2009). The study also indicated that mothers were always in constant fear that their children will somehow discover their own status and always had to devise strategies of concealing from the children the real reason why the children were taking medication. The study suggested that these perceptions of mothers were as a result of HIV/AIDS related stigma which caused secrecy around the disease hence hampering the openness that is required in providing care and receiving psychosocial support. As a result many children not told of their HIV status will probably get into depression which often goes unnoticed and untreated.

According to Foster (2004) the relatives, neighbours and school personnel are probably the immediate source of psychosocial support (after the caregivers) for the HIV positive children as opposed to professionals such as social workers, psychologists or nurses that work in a set up that provides professional mental health care. However, stigma associated with HIV/AIDS often makes it difficult for caregivers to reveal their child's HIV status to relatives, neighbours and school authorities (Abadia-Barrero & Castro, 2006; Punpanich *et al.*, 2010). Since implementation of coping mechanisms through a mental health program for a HIV/AIDS is not usually a viable task in resource-poor settings such as Botswana, community based systems that empower members of the community, teachers, religious and traditional leaders and health-workers with the skills to recognize and deal with emotional problems for HIV positive children have been recommended as more viable (Domek, 2006).



Caregiver's mental well-being is identified as one of the major factors determining emotional and behavioural functioning, treatment outcomes and psychological distress of the HIV positive child (Mellins *et al.*, 2006; Marhefka *et al.*, 2006). The quality of the HIV child-caregiver relationship is found to be significantly associated with caregiver depression, caregiver burden and the HIV positive child depression (Miller *et al.*, 2007). Caregivers who report more psychological distress tend to also reported more internalizing and more externalizing behaviour problems in their children, regardless of the child's illness status (Bachanas *et al.*, 2001). Therefore it is important to look at the perspective of the caregiver of every HIV positive child who may be psychologically distressed.

2.7. CONCLUSION

This review sought to highlight the major causes of psychological distress in HIV positive children and the major challenges that have been faced by caregivers and health-workers in dealing with these children. A significant proportion of the information on psychological distress in the HIV positive children is generated from the Western world, largely using quantitative methods. Since the inception of the Botswana national ART program in year 2001 there are a number of issues concerning psychological issues of HIV positive children that have not yet been established. The main ones, which are the focus of this study are: (1) knowledge of a profile of unique factors that cause psychological distress of HIV positive children irrespective of orphan status is not yet established and (2) knowledge of challenges and perceptions of caregivers and health-workers in dealing with psychological distress in HIV positive children is not yet established in Botswana. The next chapter looks at the methodology that was employed in order to find answers to some of the knowledge gaps stated above.

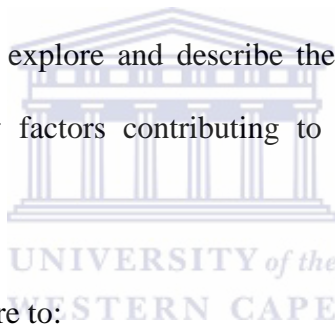
CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

This chapter presents the methodology used to carry out this study. It will first outline the aim and the objectives of the study. It will then give details of the study design, the population and sampling techniques, methods of data collection and analysis, rigor and ethical issues relating to the study.

3.1 AIM AND OBJECTIVES

This qualitative study aims to explore and describe the perceptions of social workers, nurses and caregivers on key factors contributing to psychological distress of HIV positive children.

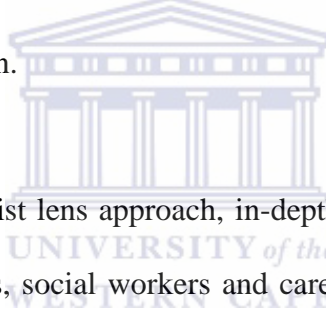


The objectives of this study were to:

- Explore the social workers and nurses' perceptions of psychological stressors for HIV positive children attending the DRM Hospital IDCC clinic in Mochudi.
- Explore the caregivers' perceptions about psychological stressors for HIV positive children in Mochudi.
- Identify the support and training needs the nurses, social workers and caregivers believe they need to effectively deal with psychological distress of HIV positive children.

3.2 STUDY DESIGN

This was a descriptive, exploratory qualitative study. A qualitative study design is well-suited for this study in that its goals are to understand a phenomenon from the perspective of the research participants as well as understanding their interpretations of their realities and experiences (Mack *et al.*, 2005). According to Marshall and Roseman (1995), in order to understand human behaviour, one has to understand the framework within which participants interpret their thoughts, feelings and actions. Thus, using a qualitative – as opposed to a quantitative research approach - will enable the researcher to explore in greater depth the experiences, perceptions and feelings of the caregivers, social workers and nurses and note what they believe to be some of the key causes of psychological distress in HIV positive children.



In line with the cultural relativist lens approach, in-depth interviewing was employed to obtain information from nurses, social workers and caregivers of HIV positive children by using a semi-structured interview schedule. The choice of in-depth interviews is appropriate when the researcher requires detailed information about a person's thoughts and behaviours (Boyce & Neale, 2006:3). In-depth interviews are useful for learning about perspectives of individuals as opposed to for instance, group norms which are best collected by focus groups (Mack *et al.*, 2005; Liamphuttong & Ezzy, 2005). In in-depth interviews participants are less influenced by direct presence of their peers when responding to questions posed to sensitive subjects such as HIV/AIDS (Mack *et al.*, 2005). These face to face interviews offer an opportunity to modify one's enquiry and following up interesting responses in a way that a questionnaire may not be able to follow. In this sense the in-depth interview technique was chosen for this study because it

yields information rich information from the participant's perspective on the research topic (Mack *et al.*, 2005).

The limitations of using in-depth interviews however are that they are time intensive and often yields huge amounts of data (Boyce & Neale, 2006). Due to the interpretivist nature of qualitative methods the data is shaped and interpreted according to the researcher's impressions of the meanings related by the caregivers, nurses and social workers. Thus the researcher's personal biases may influence the investigation. This implies that subjective interpretations are constructed by the researcher and the participants (Liamphuttong & Ezzy, 2005). It is therefore important that the researcher sets clear his assumptions regarding psychological distress in HIV positive children.

3.3 RESEARCHER ASSUMPTIONS

The researcher takes for granted that caregivers, nurses and social workers have experiences they would like to share concerning the HIV positive children they take care of. The researcher believes that psychological distress of HIV positive children is a marginalized aspect of children health, which caregivers and health-workers have not always had a platform to voice their experiences and opinions. The researcher also assumes that some of the HIV positive children and their caregivers' experiences and making meaning of reality are different from HIV orphaned children whose experiences have been documented in the country (Ministry of Health, 2009).

3.4 STUDY POPULATION AND SAMPLING PROCESS

Study Population: The study population included 11 nurses and three social workers currently working in the DRM hospital IDCC, together with the caregivers of HIV positive children who attend the DRM hospital IDCC.

Sampling Process: Purposive sampling was used to recruit participants. This is because in order to elicit a deeper understanding about a phenomenon, a researcher needs to identify an appropriate informant, that is one who has knowledge and experience the research is looking for, has ability to reflect and has time to be interviewed (Morse, 1994). In this study a caregiver informant was one whose child had been identified by the IDCC nurses, through reported observable behaviour, of having psychological distress and was referred to the social workers for evaluation. For this purpose the researcher met with the IDCC Social worker who helped to review the social work IDCC patients' records in order to identify the children whose caregivers could be included in this study. From these Social Work Department records, selection of eligible primary caregivers to be interviewed included the following criteria: (1) the caregiver should have been taking care of a HIV positive child (who is on ART) between the ages of 10 and 14 years, (2) the caregiver must have stayed with the child for at least six months prior to the interview date and should be one who spends a lot of time with the child (3) the caregiver being 18 years or older and (4) caregiver possessing the ability to provide informed consent. These criteria were established based on the researcher's assumption that 10 to 14 year olds respond with behaviour which can be noted by their caregiver, and over a period of six

months the caregiver would have had sufficient experience of the child's feelings and behaviour.

Selection of the nurse and social worker participants was based on the following criteria:

(1) having worked in the DRM IDCC for at least 6 months prior to the interview date and
(2) the nurse provides counseling to IDCC patients in need of such care. By six months the researcher assumes that the nurse or social worker is likely to have come across the majority of the children who attend the clinic and have had sufficient experience and an understanding of the key factors that they believe cause psychological distress in the HIV positive children attending the clinic.

Study Sample: Applying the above mentioned criteria, the study sample consisted of four caregivers of HIV positive children that seek ART at DRM IDCC clinic, together with five nurses and two social workers that worked in the same clinic.

3.5 METHOD AND PROCESS FOR DATA COLLECTION

3.5.1 Individual interviews process

After identifying a participant, the participant and the researcher mutually determined the time and place where the interview would be held. One to two days before the interview the researcher availed to the participant, an information sheet which was available in the language of the participant's choice, either English or *Setswana* (Appendix 1). This participant information sheet contained an explanation of the study, the benefits and

possible risks of participating in the study, as well as the contact phone numbers of the supervisors and the representative of the local ethics review committee.

On the interview date and agreed time and place, the researcher greeted the interviewee in a friendly manner, introduced the note taker and went on to explain the purpose of the interview using the information sheet as a guideline. This process was crucial to establish rapport and put the participant at ease. After describing the topic the researcher turned attention to the consent form (appendix 2), a copy of which he handed to the participant. The consent form which was also available in either English or *Setswana*, contained a declaration to be signed by the participants that the study had been described to them and they freely and voluntarily agreed to participate after all their questions about the study had been answered. The researcher went through the consent form together with the participant, reading it loudly. After going through the consent form and all participants concerns clarified, the researcher and the participant signed both copies. The researcher kept one and participant kept the other copy of the consent form.

The researcher then turned on the digital recorder and as the first point of the interview recording, he started by briefly summarising the purpose of the research and confirming the participant's consent to be interviewed verbally. The researcher then guided the participant through the conversation until all the issues on the appropriate interview guide were explored (appendix 3 or appendix 4). For *Setswana* speaking participants, a bilingual translator who also acted as a rapporteur was engaged to assist in translating the questions to the caregiver and relaying their responses to the researcher as well as taking

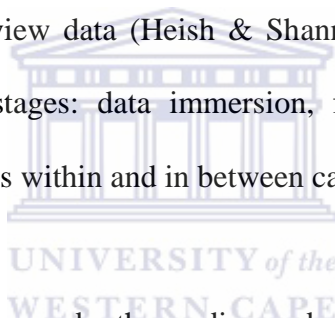
notes during the interview. In total two translators were engaged and each participated in two interviews. The translators both worked in the IDCC, one was a nurse and the other was a health care auxiliary. Both of them had been working in the clinic since its inception and were well known to most of the clients who attended the clinic. It was hoped that this would make it easier to establish rapport and result in more fruitful discussions with the caregiver participants. Challenges with translations involve disruption in the flow of the discussions and some questions may be posed differently to different participants.

In all interview sessions, though the researcher used an interview schedule to conduct the interview, he allowed the interview to flow naturally depending on the information provided by the participant. As a result the researcher did not necessarily insist on a specific order of the questions and at times would omit the inapplicable questions (Mack *et al.*, 2005; Boyce & Neale, 2006). The interviews lasted about 45-60 minutes. All of the interviews were conducted between December 2010 and February 2011.

3.6 DATA ANALYSIS PROCESS

Data cannot speak for itself in its raw form of interview transcripts. An exploratory descriptive study typically yields a large amount of qualitative data, which in its raw state, it is suitable for an archive, but not for presentation in a thesis of a limited number of words (Ryan, 2006). Therefore data analysis produces evidence, makes the “familiar strange” and ultimately sheds more light on research questions (Ryan, 2006: 95).

Data analysis was run concurrently with data collection so that emerging themes could be followed up in order to verify them. This was achieved through the researcher and the rapporteur meeting immediately after an interview in order to summarise and note down the main issues that came up in the interview. These main points were followed up in a subsequent interview. Before the final data analysis, all health-worker interviews were transcribed verbatim by the interviewer. All the *Setswana* interviews were transcribed and translated into English by a researcher's colleague. The accuracy of the translations was checked against the tape by the rapporteurs who were paid by the researcher for this as well as for having taken notes during the interviews. A conventional content analysis was used to analyse the interview data (Heish & Shannon, 2005; Powell, 2003). This process involved five main stages: data immersion, focusing analysis, categorising information, identifying patterns within and in between categories and interpretation.



Data immersion: This process began by the reading and re-reading each transcript and re-listening to the tape recordings in order for the researcher to familiarise with the data, writing any impressions as he moved from transcript to transcript.

Focus analysis: The researcher decided to start analysis by trying to answer a few preset questions that directly address the objectives of the study such as: what do the participants view as causes of psychological distress in HIV positive children? What are the challenges? What are the training needs that are being mentioned by participants? The researcher read again each transcript carefully, looking at how all individuals or the groups of nurses, social workers or caregivers responded to each of these topics,

specifically looking for sections of the data which seemed to be distinct incidents, anecdotes, or stated opinions about discrete topics such as the aforementioned questions (Seidel, 1998). This was achieved by highlighting text and noting in the margin of the text a key word or phrase that appear to summarise the key factor causing psychological distress, the challenge or training need. This formed a code. Texts that fell in the same code were highlighted with the same colour for easy identification later during categorisation. This process helped to derive initial codes.

Categorise information: As the researcher worked through the first 3 to 4 transcripts, descriptive labels for codes came up that were reflective of the key thoughts of the participants. These labels were in the form of abbreviations of a few letters describing what is included in the code. For instance the code “Trng” described as text that referred training needs. The researcher then coded the remaining transcripts using these codes, and adding new ones in the event that he came across data that did not fit in the initial codes. After all the transcripts had been coded, the researcher created folders in a Windows Microsoft Office Word application and named these folders as the initial categories that emerged during the coding process. All the texts that belonged to a specific code were cut and pasted into the respective folders. The colour codes made earlier on made identification of codes easier. The researcher re-read the specific texts in the respective folders again so as to test, revise, and refine the initial gross categorisation.

Identifying patterns within and in between categories: The researcher then examined all the data within a particular category/folder, looking for key ideas within it, similarities and

differences in the way the participants responded to similar questions. He also looked for meaningful relationships between the various codes and combining them or even splitting the larger codes into smaller ones. For instance, a category which is described as “what the participant needed to reduce psychological distress in children” could be split into subcategories such as more training (Mtrg), resources (Rsc), etc. The researcher continued to read and re-read the text to ensure all data were correctly categorised. This process stopped when no more new categories could be identified.

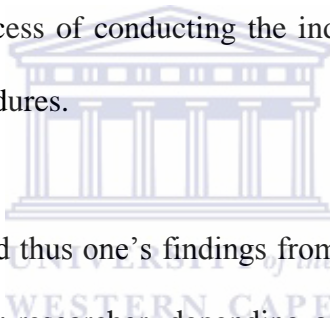
Interpretation: This stage aimed to make sense out of the various categories, codes and the connections or relationships between them, as well as general discoveries about perceptions of psychological distress of HIV positive children. Related codes were regarded as those that appeared consistently together in the data sets or somehow suggest cause and effect relationships. In reporting the findings, examples from each code were identified from the data and used as they were spoken by the participant.

3.7 RIGOR

Rigor, defined as the trustworthiness of qualitative research is said to exist when findings of a qualitative study represent validity (Holloway & Wheeler, 1996; Krefting, 1991). Durrheim (1999) suggests that research can attain validity if the design of the study is coherent in terms of the purpose of the research, its theoretical paradigm which informs the research, the context within which the research is carried out and the techniques of data collection and analysis. According to Durrheim (1999), if these dimensions of the

design have all been incorporated and they fit together with precision and logic, then it is said that the design is valid.

To achieve rigor the researcher provided a detailed description of the study setting (in the introduction), the study participants (in the results section) and the themes identified within the data in order to allow the audience to judge for themselves this study's applicability or transferability to other settings or similar contexts. Holloway and Wheeler (1996) believe that a decision trail provides a way of establishing rigor in qualitative research and auditing the entire study. In this regard, the researcher gives a detailed description of the process of conducting the individual interviews and the data analysis code and recode procedures.



The procedures for analysis and thus one's findings from a particular set of data may be different from those of another researcher, depending on the theoretical sensitivity and the particular interests of that researcher. Therefore it is necessary to clearly outline the processes by which data was analysed so that readers and other researchers can judge how one did it, agree or disagree on the findings, and possibly suggest other ways the data might be analysed (Ryan, 2006). The researcher has, in the methodology section of this report, again endeavored to make clear the process of data analysis by giving a detailed description of the process of conventional content analysis used to analyse the data. The researcher also kept comprehensive notes in a field diary of the decisions made through data analysis, the reasons for the focus taken, the category labels created, the revisions on the categories that were made and any other observations made concerning

data as he worked through it. This was designed to allow personal monitoring and allow the supervisors to understand how the researcher came to the conclusions hence increase credibility of the findings (Marshall & Rossman, 1995). A sample of the transcripts and the stages of the coding process were also provided to the supervisor for review.

To address concerns that the natural subjectivity of the researcher can mould the research (Marshall & Rossman, 1995), the researcher explains his assumptions regarding psychological distress in HIV-infected children and gives worldview and theory behind the study. In addition, member checking (Sandelowski, 1993) was performed by restating, summarising and clarifying the main points raised by the caregivers, the nurses or the social workers at regular intervals during the course of each individual interview. In this way participants were given the opportunity to correct errors and challenge what are perceived as wrong interpretations hence improve accuracy of the data collected.

Triangulation in the form of different groups of participants (nurses, social workers and caregivers) is used in this research to look for patterns of convergence to develop or corroborate an overall interpretation of the perspectives of psychological distress in HIV positive children (Mays & Pope, 2005).

3.8 ETHICAL ISSUES

The three fundamental principles of human research ethics: autonomy, beneficence and justice were followed throughout the course of this study (Polit & Hungler, 1993; Orb, Eisenhauer & Wynaden, 2000). To ensure the participants' autonomy, participation in

this study was on a voluntary basis and before commencing an interview, a written informed consent from a participant was obtained (Appendix 4). Before signing the consent form, participants were given an explanation of the benefits and possible risks of participating in the study (Appendix 3). They were informed that, should they feel so, they will be free to leave the study at any time without any harm and would continue to receive the service anyway. Participants were also given assurance that whatever they say in the interview would be kept confidential and every effort would be made to ensure that their identities did not form part of research or could not be easily deduced by the readers of the research outcomes. The researcher emphasised, explained and reminded and the importance of confidentiality of the interview content to the rapporteur/ translator. This rapporteur therefore had full understanding of the importance of confidentiality. The consent form (Appendix 4) also had a second signatory line for participants to sign if they agreed to have the interview recorded. The interview was not going to be digitally recorded if a participant did not agree to be recorded. Recording of the interview session was stopped if requested by a participant at any point during the interview.

To uphold the principle of beneficence, that is, doing good to others and preventing harm participants were informed that discussing HIV/AIDS issues affecting the children they take care of can be emotionally sensitive. Therefore a professional counselor was always going to be available at no monetary cost, for them to talk to should they have felt the need for one to talk to after the interview. In order to adhere to the principle of justice the researcher made sure that the participant and information sheet were both translated into

the local language, *Setswana*, in order to ensure that participants clearly understood the research before agreeing to participate (Orb, Eisenhauer & Wynaden, 2000). Lastly Ethical clearance was obtained from the University of Western Cape Higher Degrees Committee (Appendix 5) as well as from the Botswana Human Research and Development Committee (Appendix 6). Permission² to carry out the research at the hospital was also sought and granted from the DRM Hospital Superintendent (Ref no. DRM 14/3/11).



² Permission was first granted verbally in December, 2010. The official permission letter was written after data collections had finished.

CHAPTER FOUR

RESULTS

The purpose of this chapter is to present the major research findings. Firstly a biographical profile of the research participants is given and secondly a presentation of the themes and sub-themes that emerged from the process of data analysis.

4.1 PROFILE OF THE RESEARCH PARTICIPANTS

A total of 11 participants, seven of which were health-workers (five nurses and two social workers) and four primary caregivers participated in this study. Of the seven health-workers only two were males (one nurse and one social worker). All the caregiver participants were females with mean age of 36 years (range of 22 to 49 years). They were all unemployed and lived in and around Mochudi.

Nurse participants described their roles in the IDCC clinic to include counseling, health education, checking vital signs, blood collection, prescribing ARVs and translating to doctors during consultation. Social workers described their duties as offering psychosocial support and attending social problems of HIV positive children. One common role provided by both nurses and social workers was counseling of HIV positive clients including children. Tables 1 and 2 below show the profile of the health-worker and caregiver participants respectively.

Table 1: Biographical Profile of Health-Worker Participants

Participant Code	Gender	Time working In IDCC	Total years of experience
Nurse 1	Female	1 year 8 months	8 years
Nurse 2	Female	4 years	7 years
Nurse 3	Female	3 years	7 years
Nurse 4	Male	2 years 8 months	5 years
Nurse 5	Female	2 years	7 years
Social Worker 1	Female	2 years	2 years
Social Worker 2	Male	1 year 6 months	9 years

Table 2: Biographical Profile of Caregiver Participants

Participant Code	Gender	Age	Relation To child	Highest level of education	Employment status
Caregiver 1	Female	42	Auntie	Standard 4	Unemployed
Caregiver 2	Female	49	Auntie	Standard 6	Unemployed
Caregiver 3	Female	48	Mother	Standard 6	Unemployed
Caregiver 4	Female	22	Eldest sister	Form 5	Unemployed

4.1.1 Description of caregiver participants

Caregiver 1 is a 42 year old primary caregiver of her 11 year old HIV positive nephew who is on ART. She referred her nephew to the Social Worker on the basis that he was being discriminated by his other aunt. The nephew was first seen by a Social Worker in February 2010. According to the Social Worker the child presented with a lot of issues such as failure to honor appointments and there was evidence that he could have been undergoing delayed grief. The Social Worker also suspected that there was neglect by the caregiver. Counseling was conducted firstly with the child (nephew), later on involving the primary caregiver (caregiver 1). The focus was on how to support the child, as well as making the caregiver aware of legal consequences of neglecting the child as stipulated in the Children's Act. The Social Worker sessions were still ongoing at the time of data collection.

Caregiver 2 is a 49 year old woman, a primary caregiver to her 9 year old niece who is currently on HAART. The niece was abandoned by her mother and she started being cared for by different relatives. The mother had been arrested on several occasions for neglecting children but to no avail. This case was first registered in the DRM Social Work Department in February 2010 after being referred from the IDCC nurses due to a history of poor adherence to medication. Caregiver 2 and her niece were both seen by the Social Worker over a number of sessions, to address the issue of poor adherence as well as to assess how the issue of the mother had affected the child. The sessions were terminated after the Social Worker observed that there was an improvement on adherence as well as with the child accepting her situation.

Caregiver 3 is a mother of an 11 year old daughter. They are both on HAART. The child was referred to the Social Worker by the IDCC nurses with a history of being bullied by the neighbours' children and at school. After extensive assessment she was assisted for emotional abuse and self concept, as they were identified as the underlying issues. Counseling was done to enhance the child's coping skills. The case had since been terminated as all issues were addressed.

Caregiver 4 is a 22 year old lady who is the eldest sister to a 10 year old girl who is currently on HAART. Caregiver 4 became the primary caregiver after the death of both parents due to HIV/AIDS. The child was identified as undergoing emotional problems by one of the nurse counselors during consultation in June 2010. She also had a history of non-adherence to antiretroviral medication. Counseling was done to both the child and the caregiver on several occasions. The child continues to be evaluated for emotional issues in all forthcoming visits.

4.2 THEMES AND SUB-THEMES

Three main themes emerged from the in-depth interviews.

- Factors contributing to psychological distress
- Health-worker related challenges and support needs
- Caregiver related challenges and support needs

Before embarking on the presentation of the perceptions of caregivers, nurses and social workers on psychological distress of HIV positive children it may be necessary to articulate the participants' understanding of the concept of psychological distress. Most of the participants found it difficult to give a straightforward definition of psychological distress in children. In attempting to define the concept of psychological distress, the nurses mentioned that they tended to suspect psychological distress when the child shows most of the following features; poor medication adherence, missing appointments, looking depressed, being arrogant, reports of unusual behaviour, and being withdrawn as reflected in the following quotes:

When you ask some questions they just keep quiet...they just keep quiet. Or they become angry to their parents. Even if you are there when you ask, how do you get treatment, they just don't answer nicely, and, the caretaker, actually the way they talk to each other you can see that there is a problem? (Nurse 2)

Others they don't turn up for check ups so when you start to ask them why didn't you come for a check up...? You then end up seeing that there are some problems at home...that is making them not coming this side (Nurse 3)

...to define this term it means that children who are diagnosed HIV positive...well they can be not mentally fit... they can not relate well with the disease especially those who understand what is happening...Some of them they are still young and they don't understand anything, but those that understand, when you are disclosing to them the condition, what is happening, they don't take it well, they're not mentally fit...don't understand what is wrong... (Nurse 5)

The social workers however had more straightforward definitions as illustrated in the following quote:

It's a situation where a child displays some emotions that show that they are overwhelmed by a particular situation. These emotions can even translate to behaviours as a result of the emotion that they are going through, for example a child may be reserved because they have been saddened by the situation, and a child may start to behave differently than they are used to... (Social Worker 2)

Some of such behaviours being referred to by Social Worker 2 include that "the child has been throwing the medication away... poor performance at school ...withdrawal from friends and family" (Social Worker 2).

With regards to caregivers, it seemed they did not understand what psychological distress is at all. When asked some just said "I really don't understand what you mean by psychological distress, **psychological distress!**" (Caregiver 4), or they would describe some unusual behaviour (such as a child being too quiet or reserved). Rather they view it as normal, that is, they think "maybe it is because of the way [the child] is" (Caregiver 1).

I don't really understand. I was never depressed because I took this like any other disease or ailment... Her [child] only problem is when she is offended and she never fights back with others.

I don't know if that qualifies as psychological distress? (Caregiver 3)

If at all they picked something unusual they did not really think or know whether certain behaviour was due to psychological distress or not.

4.2.1 FACTORS CONTRIBUTING TO PSYCHOLOGICAL DISTRESS

The theme dealt with what the participants believed to be the key factors that cause psychological distress in HIV positive children. This theme was divided into the following sub-themes which are summarised in Table 3:

Table 3: Causes of psychological distress based on caregivers, nurses and social workers' perceptions

THEME 1: Factors Contributing to Psychological Distress
<ul style="list-style-type: none">• Knowing what the “bad guy” is<ul style="list-style-type: none">▪ <i>Anger towards/ blaming parents</i>▪ <i>The process of disclosing of HIV status to child</i>▪ <i>“So am not like other kids”</i>• Orphanhood/ Death of Parent• Social problems<ul style="list-style-type: none">▪ <i>Rape, abuse and poverty</i>▪ <i>Teenage hood</i>• Caregiver induced problems<ul style="list-style-type: none">▪ <i>Caregiver distress</i>▪ <i>Caregiver-child relationship</i>▪ <i>Type of caregiver</i>▪ <i>Lack of love care and support</i>• Lifelong treatment• Stigma• Compounding of issues

The next seven sub-sections reveal what nurses, social workers and caregivers believed to be the key factors contributing to psychological distress of HIV positive children.

4.2.1.1 Knowing what the “bad guy” is

4.2.1.1.1 Anger towards/ blaming parents

Initially when the HIV positive children are growing up they are told by the caregivers that they have a “bad guy” in their bodies (meaning the HIV) which will always make them sick. Most of the health-workers mentioned that psychological distress is triggered when the children begin to know what this “bad guy” is, that is when they begin to know that they are HIV positive. Psychological distress is believed to begin when they begin to comprehend that they “have to live with the situation that they did not bring on themselves and even come to terms and understand what it means for them and the path of life that they will have to take” (Social Worker 2). This comprehension of their own reality is believed to trigger feelings of anger towards their parents in that they will want to know, “which one of you [parents] brought this?” (Nurse 1) or they will just say “I’m not the one who got the disease, it’s my mum who brought the disease to me...” (Nurse 5). This anger towards parents and blaming them for having given birth to them with the HIV infection is reflected in the following quotes:

...there is a lot that happens with these kids psychologically especially when it comes to knowing what the bad guy is, knowing that they have HIV, knowing that the HIV they didn’t get it themselves, they got it from somebody else...Oh my God, what did she bring in my life? What did he bring in my life? So it’s a lot of stress with them” (Nurse 1)

...for a kid only to learn that he is HIV positive...knowing that the HIV transmits through different things, like sexual intercourse, blood transfusion, when she, him or her knows has never been involved in all these things, that’s where the stress comes from...

The knowledge of their HIV status can be so overwhelming such that some of the HIV positive children can even wish “if only” they had never been born at all, as noted:

At times they are thinking behind their minds...If “only” I had lived without this thing. If “only” they had not brought me into this life, I would not have been living with this thing?” (Nurse 1)

This latter comment shows the difficulty faced by children in learning to accept their situation as it is and that it will never change.

4.2.1.1.2 The process of disclosing of HIV status to child

Disclosure of the HIV status to the child is believed to be a potential source of psychological distress. If done inappropriately or too early it can have adverse effects especially when the child has not mentally developed enough to understand what will be happening in their lives. One nurse noted “...when you are disclosing to them the condition, what is happening they don’t take it well, they’re not mentally fit...don’t understand what is wrong...” (Nurse 5). If disclosure of the HIV status to the child is delayed until they have grown up to teen age, it can have adverse effects on the psychological well-being of the child – for it will be like “a bomb to the child”.

Most of the families choose to say hey the child is not old enough to understand about the issues of disclosure or about their illness you see... so they will wait for the child to turn around 16 years or 15 you know, and ... it will just be a bomb to the child. And then they will start struggling you know...the issues of change the child will start to...maybe [get] in the state of denial...” (Social worker 1)

This finding shows the absence of early disclosure of the HIV status to the children.

4.2.1.1.3 “So am not like other kids”

The health-workers believed that another cause of psychological distress in the HIV positive children was that it is in the nature of children that when they are growing up “they share experiences, they compare themselves to other children and that is when if

they have not been exposed to any situation they will get to know that that the life they are leading is different from what the others are leading” (Social Worker 1). Such discoveries can psychologically impact on them in that they always ask themselves why it had to be them and not others, as reflected in the following quote:

Sometimes when you disclose to a child about his or her status... after some time, they ask some things like...How, why me? How come I get this condition...especially those who are doing Form 1 to Form 5. (Nurse 5)

This often leads them to compare themselves to their siblings.

...you see that you are born two in a family the elder and the younger and then you find that my elder brother is not taking but myself I am always taking the tablets...they are forcing me to take the tablets ... at the end of the day you see these people [children] are not coping. (Nurse 3)

In the end the children will then “start to isolate themselves from others” (Nurse 2) which may further deep them into psychological distress. This finding points to the lack of empowerment of the HIV positive children with the appropriate knowledge regarding their situation early enough so that as they grow up they already know why they are different from other children in the family.

4.2.1.2 Orphanhood/ death of parent

Most of the times when a parent dies children are moved to go and stay with the relatives. This “change of living environment can also contribute” to psychological distress. A child who used to be a center of attention in his/her own parents home will upon death of parents soon realize that the situation is now different as the new parents will not paying that particular attention the child is used to, as one social worker noted:

...when the mother dies or the parent passes away they are being moved to be cared for by the parents in a remote area where they are not used to staying there you see...so that change of environment can also cause a lot of psychological distress... (Social worker 1)

Furthermore the love of most caregivers is believed to be not as good as that of biological parents hence the child always wishes his/her parents were alive as reflected:

... if at home they are not taken care of very well...then they tend to blame someone [that] maybe if my mum was around, maybe if my parents were still living...especially those who don't have biological parents, those who are being taken care of by the grandmothers...they do have problems, social lifestyle at home. (Nurse 5)

Some of these kids their mothers or fathers have passed away so the caretakers, you find that [they are] the grannies and the aunts...they [kids] don't get that love as from their parents...so most of them you find [that] they [caregivers] don't treat them as nicely as their own kids... (Nurse 2)

Sometimes relatives may not be willing to stay with the orphaned HIV positive child and the child may be moving from household to another between relatives which can become a source of psychological distress. This concern is illustrated in the following quote:

...we had one case where a child was always being tossed from one area to the other, from Mahalapye to this place, termed delinquent and all that...from this place she moved, she kept moving from one family member to another to the extent that the last I checked she was being taken to a boarding school because she had exhausted all the relatives and nobody wanted to take care of this particular child (Social Worker 2)

This sub-theme suggests the importance of evaluating guardianship of an HIV positive child in the event of death of parent(s).

4.2.1.3 Social problems

4.2.1.3.1 Rape, abuse and poverty

Some participants also perceived that social problems like rape, sexual and physical abuse as well as economic problems can also contribute to psychological distress in the HIV positive children, as noted in the following quotes:

You find that some of them they are being abused by elder man outside there, you see. So that's a problem truly, you don't know really how to tackle that one... (Nurse 1).

...this child explained everything [that] I am not well taken care of at home...I am leaving with this woman here, the aunt to my mum...she is mistreating me...sometimes instead of coming to school with her car...only her children are the ones who are taken care of at home...sometimes when there is that...relish meat, I am not taking meat. I am taking sour milk or porridge at night. I walk a long distance from home to school everyday and I always find her children already in class...so this child kept on crying, crying, and well we understood there is a problem (Nurse 5)

The latter quote illustrates a case of physical and emotional abuse or ill-treatment of an HIV positive child by a caregiver as narrated by one nurse participant. This issue reflects the need to always have screening questions during visits to detect forms of abuse of any kind in HIV positive children under foster care.

4.2.1.3.2 Teenage hood

The HIV positive children who are getting into teenage hood feel limited when it comes to having intimate relationships which most teenagers explore at this stage of life, and this is believed to have a great psychological impact on their lives, as “sometimes they blame themselves about their condition, how can I get involved with this person... (Nurse 5), as noted in the following quote:

...intimate relationships...they are having issues on how to disclose to partners about their HIV status, so that alone you find that even a child can go to an extent of committing suicide because they don't want to disclose their status to the partner..." (Social worker 1)

This finding suggests the need for proper counseling and support for HIV positive teens who are now exploring sexual relationships

4.2.1.4 Caregiver induced causes

This sub-theme involved issues of caregiver distress affecting the child, caregiver-child relationship, and the type of caregiver and lack of love, care and support.

4.2.1.4.1 Caregiver distress

The participants revealed that caregivers may also be undergoing psychological distress which may also spill on to the HIV positive child they take care of

So you find that they become distressed more than the patient and the patient becomes distressed too and end up not taking treatment well. (Nurse 1)

They [caregivers] too may also be subjected to abuse of this child, coz the child may also abuse them, may even subject them to emotional distress. (Social Worker 2)

The pattern of abuse is often not sided, both the caregiver and the child are likely to abuse the other, hence the need for evaluating both the caregiver and the child needs during clinic visits.

4.2.1.4.2 Caregiver-child relationship

The lack of openness in the relationship between the caregiver and the HIV positive child is believed to result in children bottling up their problems in themselves and aggravate psychological distress:

...they can't even be friends with the parents. And they can't open up with the parents or the caregiver and they can be stressed with this thing that is always troubling them. And they end up doing other things which they are not supposed to do. (Nurse 1)

...if my mum was around...she will be taking care of me nicely...or I could [ask her]...some questions I could ask her or him some of the things that I can't ask to my grandmother or uncle...(Nurse 5)

If caregiver attitude towards the child is bad it can contribute to psychological distress in the child. As one nurse noted sometimes the aunties and grandmothers who are now old feel as if it is a “workload” to them because most of them have long finished rearing children. Such bad attitude can also be expressed in the way the caregiver talks to the child, giving the impression that taking care of the HIV positive is a burden:

...the way they talk...Yah how they talk to them like the bad words that they will be saying to them! Usually they say *mugare wa gago*, like this is your HIV, *wantapisa* [you make me tired], you have to take your treatment and they [HIV positive children] become distressed. (Nurse 1)

This finding shows some disadvantages and effect of care-giving by old-aged grandparents.

4.2.1.4.3 Type of caregiver and lack of “love care and support”

Non-biological parents as caregivers tend to neglect the children. Their “lack of love, care and support” is believed to be another contributing factor to psychological distress:

You find that there is an element of negligence, like I was saying the lack of care, love and support can stress the child. So I think it's an element of neglecting the child and not fulfilling the expected duties of a guardian, of being a guardian to the child. (Social Worker 1)

...the lack of care by the people that they are staying with, the guardian, the relatives, the grandparents, the aunties and all those, in most cases they will feel that they are not treated the same as the children of that elderly person. (Social worker 2)

This finding suggests that providing “love, care and support” from the caregiver is of paramount importance in maintaining the psychological well-being of the HIV positive children.

4.2.1.5 Lifelong treatment

All participants mentioned the burden of taking medication for life as a cause of psychological distress in the HIV positive children. The participants believed that the issue of having to take medication sometimes becomes a “hassle” and uncertainty of “how long they would take the medication” was a major issue for the children and caused some anxiety. It was also mentioned that the idea of taking tablets everyday in itself is tiring and can be a source of psychological distress to the children:

...sometimes to them it becomes difficult, they will feel I am not like this child who is not taking treatment every day, some of them just feel its tiring for them to take those tablets every day. They have what we call pill fatigue... (Nurse 5)

For those children who have not yet understood why they are taking medication every day the reasons given to them seem unconvincing. They feel they are not being told the truth, as reflected in the following quote:

You see the problem is when they are giving this child medication most of them they are telling them that this is for your head [ache], this is for something... they are not telling them the truth so the child will now be wondering that “why am I taking these pills for headache while my head is not aching?”... (Nurse 3)

Being on ART for life automatically translates to frequent clinic visits for CD4 and viral load monitoring. These visits and the regular blood checking for life are believed to be another source of psychological distress to these children:

ARV is one thing that need monitoring almost every after some months, monitoring after two weeks, coming here after almost two weeks, meeting long queues here...sometimes it can cause that stress...and this pricking that happens here after blood collection... Imagine you are going to be pricked for the rest of your life...how someone can feel about that...it can be traumatising to... [the children]. (Nurse 4)

For most children the veins are not always visible and as one nurse noted, “...at times when you collect blood, failing to find veins and puncturing them several times” can be traumatising to the children.

This sub-theme stresses the multi-dimensional effect of the prospect of lifelong medication on the psychological well-being of HIV positive children on ART.

4.2.1.6 Stigma

It was mentioned that there is a lot of stigma associated with the school environment. The HIV positive children are believed to be in constant fear that other students may know that they are HIV positive.

They [HIV positive children] are subjected to medication, they may have these opportunistic infections and kids being kids they are playful they can tease each other and all that and our communities if they get to know that the child is living with HIV/AIDS I think it may be a challenge that they can stigmatise them (Social Worker 1)

As a result it makes it difficult for the children to take medication at school in the presence of other students, as noted.

We have one boy who was in senior secondary school, he once told us that he is...right now he has defaulted...he once told us that he is having a problem of taking medication because other students at school it's like they laughing at him. (Nurse 3)

Uhm there is stigma because we once had those who said, when you ask them they tell you [that] some kids they don't want to play with them or they are discriminating against them... (Nurse 5)

To curb the need to take medication at school the caregivers resort to the children waking up very early to take medication before they leave for school which further impact on the children emotionally:

...they can't take their medication in front of peers at school, so usually you find that the arrangement is such that the child will wake up at around 5, so that by 6 o'clock they've already taken the medication before they leave for school... having that fear [that] peers at school will find out that they are taking medication and it's an issue... (Social Worker 1)

Sometimes parents or caregivers, even after they have disclosed the HIV status to the child they encourage the child to keep it as a secret. This may send wrong signals to the child that probably being "HIV [positive] is bad" or associated with being anything negative in life. This causes the child to live with these self stigmatising perceptions and maybe psychologically affected. At times the HIV positive child may just be paranoid,

always thinking that other students are laughing at him/her because of the HIV status, as noted in the following quotes:

...they [caregivers] usually encourage to keep it...so they are adding an element of stigma to that child, the child starts believing that you know what...being HIV is bad... so you find that they [the HIV positive children], most of the time they are stigmatising themselves even when the colleagues are not even aware of their status... So at times when they are not aware, you know kids they will think that ah this comment is just being made, maybe the teacher knows, maybe they are just passing remarks to me... (Social Worker 1)

One suggestion made in order to try and solve this problem was that there is need to “de-stigmatise HIV/AIDS and ARV” to allow people to perceive them as issues concerning chronic diseases such as the way diabetes and hypertension treatments where one “can inject [oneself] in front of other students, people...” with no negative perceptions (Nurse 4). This finding on stigma demonstrates the need to educate the community concerning HIV/AIDS with the ultimate goal that once the community understands what the disease really is, they will not stigmatise those who suffer from it.

4.2.1.7 Compounding of issues

The combination of many factors in addition to being HIV positive is also believed to be a contributory factor to psychological distress of HIV positive children. The factors include HIV associated illnesses, orphanhood, poverty, lack of love care and support, abuse, and many household chores all on a single child, as noted in the following quote:

But if you have to deal with HIV/AIDS you have to deal with poverty, you have to deal with lack of shelter, lack of food, lack of clothing, lack of care, lack of love, if you have to deal with being abused, being overburdened with responsibilities, household chores and all that you really wonder what, you really wonder if life is worth living. (Social worker 2)

This finding stresses the need for interventions that will address the many problems affecting the psychological well-being of HIV positive children and not just attending to one problem at a time.

4.2.2 HEALTH-WORKER CHALLENGES AND SUPPORT NEEDS

This theme was subdivided into the following 2 major sub-themes: Health-worker related challenges and Health-worker support needs as shown in Table 4 below.

Table 4: *Challenges and support needs for health-workers of HIV positive children as expressed by caregivers and health-workers*

HEALTH-WORKER RELATED CHALLENGES AND SUPPORT NEEDS
Challenges
<ul style="list-style-type: none"> • Not enough manpower • Inadequate or lack of training • Lack of co-operation from the HIV positive children needing psychosocial intervention • No public sector driven peer support groups for children • Compassion fatigue • Working environment not child friendly • Lack of support from hospital administration and staff • Communication barriers with deaf or blind HIV positive children
Support needs
<ul style="list-style-type: none"> • Need for more and qualified personnel • Need for more and adequate training • Need for more Teen Clubs • Need for a supportive hospital management and staff

In presenting this theme, where available some of the challenges are presented with a corresponding support need(s) as was perceived by the participants in the study. As such some of the following subheadings will be in the format: “challenge...need”.

4.2.2.1 Not enough manpower... need of more and qualified personnel

Both social workers and nurses felt that the social workers in the hospital were understaffed. They also felt that there was a lack of qualified personnel such as psychologists to attend to the psychologically distressed children in the facility as reflected in the following quotes:

We have issues of manpower, we are not enough we need to reinforce on the issue of medication adherence. So if it was possible we would review each and every child who is assisted on each and every visit. But then you find that we get to someone who is being referred because when the nurse or pharmacist was doing a pill count they realized that ah they are defaulting treatment...so you find that manpower is not enough...we lack human resources. (Social Worker 1)

... they [Social Workers] deal with different issues they are not many, they are understaffed...they have to be dealing with patients at the ward, clinics, they are not, not enough. (Nurse 5)

... we don't have a lot of psychologists in the country. That's why you find them in referral facilities and a few at district hospitals. I believe in time maybe we will have psychologists in, in all health facilities (Social Worker 2)

The health-workers argued that assessing psychological distress in children requires more time with children for them to open up. However due to high workload and lack of manpower this may not always be possible, as noted by one nurse:

Another thing is we have a shortage of doctors, so when the child gets into the doctor's consultation room we just rush to finish so that we can attend others waiting outside, so if we had many doctors, the doctor will give the child a chance to talk to him and say everything that he wants to tell the doctor. But we are always rushing. (Nurse 3)

Caregivers also felt the impact of this shortage of manpower in that they have to wait for long queues before they can be assisted.

By the time they go for their lunch which is their right to take, the line would still be long and therefore we have to be attended in the afternoon. Maybe we should mobilize the government to extend working hours or generally improve the number of personnel. (Caregiver 3)

The shortage of manpower was also believed to be a reason of insufficient access to psychosocial services in the district. The health-workers felt that the caregivers and the HIV positive children did not have sufficient access to psychosocial services in the district due to the fact that service providers themselves were not sufficient. The perception of insufficient psychosocial services in the district is reflected in the following comments:

.... they are not sufficient, if they have a problem those people usually see a social worker, there are no psychologists...yah its only the social workers who are assisting with counseling both at the local clinics and at the local government and those whom we have here. (Nurse 4)

On the contrary one caregiver felt the psychosocial services were quite available for them and could be accessed with relative ease:

The social worker is always available and sometimes even comes to see us in the line to encourage us to come and see her if there is a need. (Caregiver 4)

Thus the availability of psychosocial services in this latter comment seems to be viewed only in terms of availability of social workers. This finding suggests the need to improve

awareness among caregivers on the various forms of psychosocial services that may be utilized by their children and themselves as well.

As a recommendation to the issue of lack of manpower both nurses and social workers also felt they needed to have properly qualified personnel sent into the district to attend to the children because these “these people they are well trained, they know how to handle kids...” (Nurse 5).

I think we need people [professionals] who are qualified to talk to people [children]. I think there are not enough social workers; we should have more social workers. Ideally each session, I mean every time a child comes here, after seeing the doctor there they should see a social worker. (Nurse 3)

... [We need] more social workers brought into the district and even a psychologist, an access to a psychologist, yah at least one for this district because it doesn't have a psychologist... (Nurse 4)

Lack of manpower as a finding demonstrates the limitation of high workload on the quality of service that will be offered to HIV positive children.

4.2.2.2 Inadequate training....Need for more and adequate training

4.2.2.2.1 Health-worker related training challenges

The interviews revealed that lack of adequate training and skills of dealing with psychologically distressed children attending the clinic was a major challenge. Almost all of the nurses and social workers said that they did not really emphasise on the aspects of psychological distress during their pre-qualification trainings, as one nurse reflected, “...well in my time there was nothing like that I don't know this time around, I finished long back in 02 [2002]...” (Nurse 1). The feeling that the health-workers were not well

trained for tackling the problem of psychological distress in HIV positive children is expressed in the following quotes:

...us nurses who are working this side we haven't done paediatric Kitso [A short training course tailor made for nurses who monitor antiretroviral therapy in children], so we're just using information that we are also using for dealing with adults ... When we first came this side we were oriented by these other old nurses this side who were just helping us with how they work this side [IDCC clinic], and when [name of nurse2] was doing adherence counseling we would then hear what she will be saying [to clients]... Yah, we ended up doing a form, we created a form which is guiding us [checklist]. (Nurse 3)

...if you never went for the counseling session or training you won't counsel like someone[who has gone for training] you know... even if they can watch you, listen to you counseling, the way I am going to do it is different from *wena* [you] who went for training. If it can be done by those who went for training it could be better...than just go and get oriented by this nurse then tomorrow you do the counseling. (Nurse 2)

In addition to just the simple orientation by fellow nurses mentioned by nurse 2 above, the current trainings in place are only short courses which are mainly concerned with the medical aspect of ART. The nurses felt that these courses were designed “only for the medication adherence not psychological” and that “...no one went for psychological [courses] or anything related...” (Nurse 2). These short courses are presumed inadequate because they are not dealing specifically with issues of psychological distress in the children:

Usually we go for short courses dealing with medication adherence and counseling, what we call paediatric Kitso, we are trained on ARV concerning children...there is a bit of counseling again in there...I wouldn't say I am fully equipped, maybe I need some, a lot of training. (Nurse 4)

The health-workers felt that this lack of adequate skills and knowledge negatively affected them on the services they render to the HIV positive children and their parents, as reflected in the following quote:

...you know from my experience what I have realized is that it's quite a challenge to work with children...somebody needs a lot of experience in working with children. So the kind of services that we, that we offer I feel they are not really up to standard to the extent that we don't always meet the needs of the children. At times we don't even make an impact because we offer a general service, we don't specialize (Social Worker 2)

You see at times we try to do these things, you see that a child doesn't understand, so most of the time we refer them to the best, to the people who understand, but at times these people will not be there, like the social worker... You see most of the time we are referring these people to the social worker but they don't seem to be understanding what we are talking about. (Nurse 3)

It seems that the current measures used to help children with psychological problems are not really being effective hence need to consider alternative solutions.

4.2.2.2.2 Health-worker training needs

To help avert the problem of inadequate skills the health-workers recommended that they needed more and better training courses on counseling for nurses and social workers who attend to psychologically traumatised children. They recommended that someone has to be sent for training such as “paediatric Kitso...before they can start helping the psychologically distressed child”. They felt the courses should comprise adequate training not just short courses but can be long term ones and where there is need for one to specialize after that training, for example “child psychologists or a social worker trained to specifically to deal and work with children”.

Well if, if there is an opportunity for somebody to be adequately trained so that they can best address the needs of children...a lot of us would opt for that and feel very comfortable to help and assist children because we will know that we can best meet their needs since we will be equipped with the skills. Not just a short term thing...Yah...and then when you come from there you specialize, you work only with children. (Social Worker 2)

The courses should not be just a once off thing but should be followed up with refresher trainings on a regular basis so as to keep the health-workers up to date with the issues affecting the children psychologically. These training needs are reflected in the following quote:

I believe I need better training...in counseling skills...in order for me to deliver this...more training and counseling ...there has to be refreshers courses, not actually to have been trained two years back and they leave you like that, you need to go for refreshers courses because this world is changing...the information that you got two years back may no longer be [valid]... (Nurse 4)

This finding of lack of adequate training and the need for qualified personnel suggests that there is need to revamp the training and skills support of nurses and social workers who are deployed in the antiretroviral clinic to attend to HIV positive children who may have psychological problems.

4.2.2.3 Lack of co-operation from the HIV positive children needing psychosocial intervention

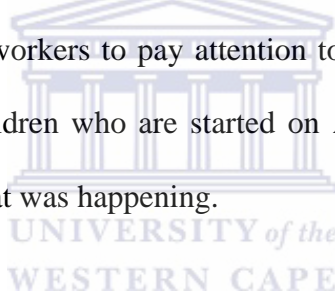
Most of the children are usually put on medication when they are young. As they grow they begin to “reject” assistance from health-workers and are difficult to deal with. Sometimes some children may decide not to co-operate in the counseling sessions. The

perception of the lack of co-operation from psychologically distressed children is reflected in the following quotes:

I think the other challenges we face is maybe they have been put on medication when they are still very young, by the time they start to understand the medication they start to reject and you find there are issues of poor adherence, of defaulting treatment and so that most of the challenges that we encounter in dealing with especially teenagers who are on medication... (Social Worker 1)

You ask her, she won't say anything, she will be quiet throughout the counseling. Everything is fine with her. You ask her, what's wrong? Nothing [she would respond], I'm ok. Are they abusing you? No I am fine. What is wrong then? Nothing. But then she is not taking her treatment. And then at times you find...Uhuh... how am I going to help this one? It's a little bit difficult (Nurse 1)

Thus there is need for health-workers to pay attention to the age specific psychological needs of the HIV positive children who are started on ART when they are young and were not yet fully aware of what was happening.

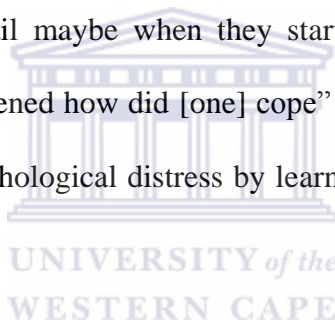


4.2.2.4 No public sector driven peer support groups for children

Most participants expressed concern that there was no government owned initiative in the form of support groups for HIV positive children in the study setting. They were not happy that the only such initiative, called the Teen Club was privately owned, as noted in the following quotes:

...you know with our hospitals with our clinics around the country. We don't have where we get to see kids coming together as a social club and having to discuss such things as like support groups. We don't have such. Yah it's only with private sectors [non-governmental organisations]. They have a few and they are not very known...Yah but if we can do that you know and the kids get to support each other, support each other that will be great." (Nurse 1)

Healthworkers recommended that the government should introduce similar Teen Clubs in public hospitals and not leave it entirely to private sector, indicating that these clubs would be beneficial to the children. One caregiver participant (Caregiver 1) shared the same sentiments too when she said that “ It is my desire that this child can stay with others in his condition, that way he can be able to learn a lot from them”. Such support groups are believed to have activities that help the child realise they are not alone, but that many other children are faced with similar circumstances of being HIV positive as well. One such activity as narrated by one nurse participant (Nurse 2) is called “journey of life” whereby children are asked to narrate whatever they “...recall from young [childhood] up to the age until maybe when they started to realize [that] I am HIV positive, from there what happened how did [one] cope” . Such activities are believed to help reduce the impact of psychological distress by learning how others are coping with the situation.



4.2.2.5 Compassion fatigue

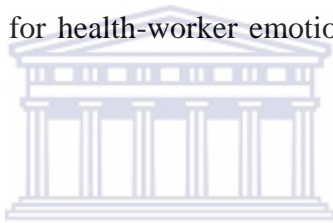
The nurses working with the HIV positive children on ART mentioned that they are overwhelmed by the emotions of feeling sorry for the children each time they attend to them, and try to explore their problems. Furthermore for the multiple pricks they may have to inflict on the children during blood collection from the children, seeing the children cry each time this happens can be emotionally traumatising to the nurses.

Hey...you know its very painful dealing with these people, when you see a young child, or a small baby with HIV, you just feel for her. So it's very emotionally painful dealing with them...at times when you collect blood, failing to find veins and puncturing them several times you know...it's not nice...[Nurse 3]

Since they felt that “...it’s stressful to deal with patients who are like this almost every day” (Nurse 4), the nurses expressed that there is need for a psychologist for them to see should they become emotionally overburdened by the sad stories they always get when trying to help the children and families undergoing psychological distress.

So sometimes when you...especially for kids when you ask them, you will just feel sorry for them. Ehee for us I think if we just have a psychologist who can help us to deal with these things...sometimes even us we need some support like ongoing counseling for us workers, coz we see a lot of things but sometimes when you think about them...uhm [signals index finger in a circular motion pointing to her ear, a sign which means you can get distressed] (Nurse 5)

This finding suggests the need for health-worker emotional support to help them avoid compassion fatigue.



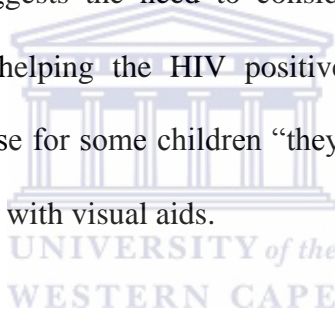
4.2.2.6 Working environment not child friendly

The social workers described the offices which they use for their counseling sessions with psychologically distressed children as not conducive environments for working with children. They felt that the office set up which is currently in place may make the children uncomfortable hence they will not be able to talk freely about any problems they may be having, as noted in the following quote:

...the child may not open to you, you may find it difficult to establish a relationship with child, even the atmosphere itself imagine having a child in this environment, coz a child needs a child friendly atmosphere and environment where you can even manipulate and use other resources like toys, play therapy, playing kits and all that so that you can be part of the child’s life and communicate with the child better, in a language they can best understand...but our setting is tailor made for adults where they can express themselves freely, they can know, even if they are

not express themselves it's ok, the assumption is they can take care of themselves so that is all that I can say about them. (Social Worker 1)

The social workers and nurses recommended that the hospital should “put in place some centers where, or a center or an office where, that is conducive, that is child friendly...where anyone working with children would use that facility or that room to interview” the children. The social workers felt that these centers should be designed to ensure the children “can be comfortable, they can feel free, they can be relaxed and hence we can pull something out of them, as opposed to being attended to in a room...what we're having right now” (Social Worker 2). In addition to advocating for a child friendly center the latter comment suggests the need to consider use of tangible educational materials such as videos in helping the HIV positive children understand what is happening in their lives, because for some children “they believe in seeing...”(Nurse 5), meaning they understand better with visual aids.



4.2.2.7 Lack of support from hospital administration and staff...Need for a supportive hospital management and staff

The hospital administration was also blamed for not being supportive of the Teen Club and associated initiatives, as noted in the following quote:

...at first the hospital didn't recognize these...because I remember for this Teen Club to start, I had gone to attend one of the paediatric Kitso, that's when I learnt at Baylor [paediatric AIDS initiative] [that] they have this [support group called] Teen Club, then I tried to sell this idea to my bosses then they said it can't work because there is no money...where are we going to get the resources, things like that. (Nurse 2)

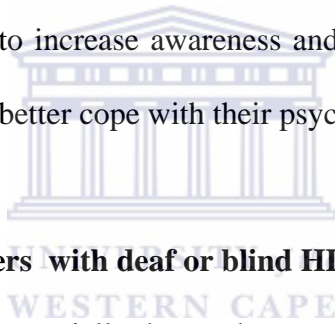
One nurse participant alluded that other staff members were not willing to volunteer their services to the Teen Club, the only peer support group in the district for HIV positive children.

...you find that other nurses it's like they don't want to participate in this Teen Club... so it's like... [isn't it] it's voluntary... so you are not being paid to do it...(Nurse2)

The nurses felt that the hospital management could come in and support their efforts by providing them with transport, as noted:

...if we can get some home visits, if we can visit them, especially those who are not working, I think it will help us. But we are having a challenge of transport, there is no transport for doing home visits. Sometimes if the patient has defaulted it is very difficult to trace him... (Nurse 5)

This finding stresses the need to increase awareness and encourage staff to take part in activities that help the children better cope with their psychosocial problems.



4.2.2.8 Communication barriers with deaf or blind HIV positive children

Dealing with disabled children especially those who cannot see, hear properly or are deaf was mentioned as another challenge the health-workers are facing. Sometimes these children come alone to hospital so communication is done only by “writing on paper” since all the nurses and social workers in the IDCC clinic do not know sign language as reflected in the following quotes:

...hey its, it becomes a barrier especially those who can't speak well, those who can't hear it becomes a barrier. We once had a small boy around 14 years old who can't speak and hear properly so we keep on writing on a paper. (Nurse 5)

...the other thing you have kids those who are disabled those who can't see, those who can't hear properly. It's a challenge too. (Nurse 1)

This sub-theme of difficulties in dealing with deaf children stresses the importance of considering the needs of disabled HIV positive children in the design and provision of services in the paediatric HIV program.

4.2.3 CAREGIVER RELATED CHALLENGES AND SUPPORT NEEDS

This theme was subdivided into the following 2 major sub-themes: (1) Caregiver related challenges and (2) Caregiver support needs as shown in Table 5 below.

Table 5: *Challenges and support needs for caregivers of HIV positive children as expressed by caregivers and health-workers*

CAREGIVERS CHALLENGES AND SUPPORT NEEDS	
Challenges	support needs
<ul style="list-style-type: none"> • Lack of caregiver commitment/co-operation • Caregiver not ready to disclose • Inability to recognize psychological distress • Financial constraints 	<ul style="list-style-type: none"> • Education as a support system • Family as a support system • Caregiver peer support groups • Health-workers as a support system

4.2.3.1 Caregiver related challenges

4.2.3.1.1 Lack of caregiver commitment/ co-operation

At times the caregivers feel as if it is a burden to take care of the children and may send the child alone for follow up visits to the clinic. In this case it may not be possible to help the child if there is a problem, as noted by one nurse:

And it's a problem there is one who is always comes here [alone], we want the parent to come with them and the parent doesn't come. We always try to tell them please come with the child to the clinic and they don't come, and it's always a problem (Nurse 1)

Sometimes the caregivers may change their contact details and will not update the clinic:

...you may find that maybe the contact number that they have given is not the correct one. You try to follow through the lines the phone number is not available. May be that number they gave you is not, it's a wrong number...But again, you find that they just tell you that I stay in Makakatlela, but Makakatlela where? [that is] the physical address is not traceable. (Nurse 2)

In some cases the caregiver is “only concerned with the benefits of having an [HIV positive] orphaned child in their house”. These benefits include food baskets provided by the government. This creates problems in that “usually you find that the family will be fighting to get that benefit, and the person who is going to win custody of that child is not the right person for the love, care and support of that child”(Social Worker 2).

Sometimes there may be lack of co-operation from a caregiver who feels “challenged” may not turn up for the next appointment as noted by one social worker.

The expectation is that when you work with a child and you have started in a particular program you should complete it so...if a parent or guardian feels that they are not impressed or they are being challenged, then they may not bring the child to another session...if you are to have subsequent sessions... They don't want to be showed that you can do much better than what you are doing...(Social Worker 1)

The caregivers at times do not “expose the problem that they have at home about the kids” because “they think that if they expose the information to us maybe we [health-workers] are going to end up blaming them for the behaviour of the kids...so they are trying to protect their name...” (Nurse 4).

Some caregivers may not be supporting the children's peer support such as Teen Club:

I don't know whether they are reluctant to allow their kids to go there...because you find their kids attend this month, next month they don't. The next month he comes when you ask why? He says my mother said I should stay in the homestead with the kids. (Nurse 2)

At times a caregiver or child who has been identified as undergoing psychological distress may not be willing to see a social worker for help as recommended by the nurses.

Yes you find that you meet many... kids who are [what do you call it] psychological disturbed [distressed], not only the kids maybe the [aunties], or the elderly people, who may be not opt to go to the Social Worker...(Nurse2)

Sometimes children having emotional problems only prefer to be attended to by specific nurses whom they trust and not any other nurses or social workers, as narrated below:

... these kids...it goes with trust... ..if they know [Nurse 2's surname] or [Nurse 2's forename] when I talk to her she can listen to me...because I mingle with them at the Teen Club, they know me...[such that] if there is something they come straight to me. So if there is something they can't go to someone other than me. So they say *ke kopa gobona* [may I see]... [Nurse 2's forename]...if I'm not there they don't say anything? Even if with this Teen Club, if I'm not there, if there is something they want to share they can't go to any other nurse...so it's like I'm the only one here they know who [can assist them]. (Nurse 2)

In summary it is evident that the finding on lack of caregiver commitment is multi-factorial which poses many challenges to the health-worker attempting to assist the HIV positive children with psychological distress.

4.2.3.1.2 Caregiver not ready to disclose

Other caregivers may not be ready to disclose the child's HIV status to child. In such cases it may be difficult for the health-workers to deal with non-disclosed children, as noted in the following quote:

...you find that maybe the caretaker don't want to disclose the [HIV] status to the child...if it's like that you can't tell the child that you are HIV positive... when the mother says my child is still young... [even if you can see] its worth [that] the kid knows [that] I am HIV positive...that's when they can help them to adhere...(Nurse 2)

The caregivers may feel the child “is still young to understand” the fact they are living with HIV hence they postpone and plan to tell them later on in life, for example when they are now “ doing standard 7” (Caregiver 2).

The only challenge is the sick child as she is too young to comprehend. She sometimes wants to know why she is taking medication. My plan is to explain now so that she gets to know and grow with the understanding to avoid giving her a shock later in life... I have talked to her about it giving her examples that could make her understand. But I am not sure about her comprehension...I am not in a position to say [disclose] because she is too young to understand some things. Maybe when she is 13 and understands more about HIV and its implications than we might see some changes in her. For now all is well especially since she is not a sickly child. (Caregiver 3)

This finding demonstrates the need for ART clinics to pay particular attention to helping caregivers on issues of appropriateness and timing of disclosure of HIV status to the children.

4.2.3.1.3 Inability to recognize psychological distress

The other challenge is that the caregivers may be unable to recognize psychological distress in the children they take care of. This was attributed to cultural beliefs. They refuse to believe there is a genuine problem with the child which may need help from other people. Rather they view psychological distress and its manifestations as something

as such as bad behaviour in children or “it’s just that he [the child] is stubborn”, as noted in the following quotes:

I don’t think they [caregivers] are able to recognize that [psychological distress] because they feel, well you see with our parents they believe that’s how an African child is supposed to be brought up, right, the difficult way. I don’t think they recognize because they feel you are spoiling these kids. (Nurse 1)

...when it comes to medication... [the caregiver says] I obviously ask her to take the medication, this kid is stubborn this kid don’t listen to me. They never say that maybe that why he is lonely because of one, two, three... no. They jus say they never listen to them. Just that they are stubborn...they don’t listen, they don’t listen (Nurse 2)

These health-workers perceptions regarding caregiver inability to recognize psychological distress corroborated with some caregiver sentiments. The caregivers themselves try to convince themselves that “there is no problem, I can’t abandon him because he is my sister’s child, and there is no problem” (Caregiver 2). In one instance the caregiver appeared to believe that the main issue the child seemed not well was because the mother had abandoned the child and did not suspect any possible psychological distress, as noted in the following quote:

Sometimes the child would just be needing parent’s love, and he is not given that parental love...
Sometimes he will be lonely just needing their mother... They [HIV positive child and siblings] will be calling out their mother when she is not there... (Caregiver 2)

The health-workers believe this inability to recognize psychological distress in the children is probably because the caregivers “have never been trained on the basic skills of dealing with somebody who is psychologically stressed” hence cannot be able “to pick the point [that] this person there is a problem here maybe that is why this kid is not doing

this and this, and it's because of this and this and this..." (Nurse 4). Another reason is that those caregivers that recognize psychological distress may be negligent in that they recognize the problem but wait till next visit.

...we've realized as well that someone is trying to update you and telling you that I have now realized that, that's why I have decided to accompany this child today so that I can inform you about something that I noticed 3 months, 3 weeks back ... (Social Worker 1)

In this latter comment the social worker tried to imply that the caregivers lacked love and care to bring the child for professional help early enough but chose to wait till the next visit while the child continued to suffer.

4.2.3.1.4 Financial constraints

Another challenge facing caregivers is financial constraints. All the caregivers in this study were unemployed and appeared to come from a socio-economically disadvantaged background. Financial constraints were a recurring theme in the caregiver interviews. As one stated that "I am not working I don't have money, so if he[HIV positive child] needs something I have to ask for money from people or sometimes other people outside can assist" (Caregiver 1). Financial constraints as a sub-theme are reflected in the following quotes:

The waiting period at the hospital is a main concern too. She gets hungry and very weak while waiting. Well she can't get a snack or fruits which are readily available...so it's a challenge for me as I don't have money for milk and other things (Caregiver 3)

I would appreciate it if he could be able to eat nutritious food that he is supposed to eat in his condition. It is proving difficult at home since there are other children in the household and they will start to complain if the fruits are reserved for the infected child alone. (Caregiver 1)

For those caregivers who are working it may be difficult to manage to meet all the clinic appointments with the child because they may fail to get time off from work. Rather they opt to go for work and miss the clinic appointment with the child. This concern is raised by one nurse:

...the problem might be either the parent is to...maybe *o filwe* [has been given] 3 appointments, maybe 2 appointments in a month of which you find that its difficult [that he/she be] absent from work on the 1st of November, on the 22nd of November for, for blood collection and December for... [Interview interrupted by knock on door]. (Nurse 2)

This latter comment suggests the need to consider alternative support for primary caregivers who are working and hence may not always be able to be present at each and every clinic visit with the HIV positive children they take care of.

4.2.3.2 Caregiver related support needs

Having presented the major problems that were associated with the caregivers the following support needs for caregivers were raised by the participants.

4.2.3.2.1 Education as a support system

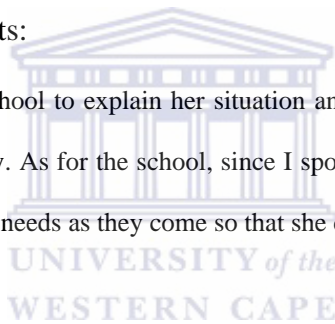
The health-workers felt there is a real need to continuously educate the caregivers and the HIV positive children concerning psychological distress in the children, what it is and how to deal with it:

If the parents as well at home try to understand the way, or what the child is going through...they will understand them better rather than put blame on them. You find that maybe the way we talk to the kids, it's not like the way we may talk to an adult, maybe we can change the way we address the kids [that is] put them to their age that's when they can understand that one. (Nurse 2)

In essence this quote suggests the need to ensure that the caregivers are made aware of the existence and potential of psychological distress in the HIV positive children they take care of.

The health-workers felt the caregivers needed to be encouraged to disclose the HIV status of their children to school authorities because it is generally believed that “the teacher during school hours is the parent of the kid. So they will be responsible to know that [the child] has taken treatment” without the other students knowing (Nurse 1). Alerting the teachers about the HIV status of the child has been seen to be working in some cases, as noted in the following comments:

I did go to meet with the school to explain her situation and suggest how better to deal with her and her emotional sensitivity. As for the school, since I spoke to them, she never came back with complaints. I try to meet her needs as they come so that she can see I care. (Caregiver 3)



My auntie had to share with them [Teachers] since she takes her medication at 0700hrs which will affect her times to come [report] to school and that they should understand if she comes late. She shared that she is living with the virus and currently takes ARV's (Caregiver 4)

If we can work hand in hand with teachers at, especially at junior schools coz that's where they start to have relationships...the teachers I understand that there are some counseling subjects, counseling teachers subjects there...ehe if we can work hand in hand, sometimes go there give lecturing to the whole [group of] teenagers who are there I think it will help. We are still lagging behind on that one. (Nurse 5)

This finding suggests that school authorities have a big role to play concerning the psychosocial well-being of HIV positive children. Informing school authorities is believed to result in more positive outcomes than negative ones.

4.2.3.2.2 Family as support system

Another recommendation made by health-workers was for caregivers to disclose the child's HIV status "especially to the immediate family members for reasons of support" because "then you find that even when the parent passes away, the family members already know how to live with that child..." (Social Worker 1). Support from the extended family seemed to be strong from the caregiver participants' perspectives. In all the caregiver interviews all family members inclusive of children seemed to know about the HIV positive child's status and the family is reported to have remained as a strong supportive fiber as reflected in the following quotes:

I made a decision that if my symptoms appear I will accept. So I called my immediate family my husband and kids, my mother and my siblings. So even when I wanted to come out I told my family first. The whole family therefore was the first to know about both of us. My family is very supportive. (Caregiver 3)

...they [family] have been very supportive. They helped her [the child] be initiated into HAART...They actually encourage her to take her pills when its time...Everybody is supportive (Caregiver 4)

On the contrary in one of the families there was lack of such support as narrated by the caregiver:

Even the times for the checkups the others [family members] will refuse to take him saying that they have to look for jobs since the mother is alive. I will plead with them asking them to at least fetch the ones that she will be using in the meantime...my wish is that you talk to the police so that they look for the mother, because now I have to go to the fields. And this is very dangerous because I am the one who usually force the others to take the child to the hospital, so if I am not there (am not sure what will happen)... (Caregiver 2)

The latter quote suggests how lack of support can be detrimental to the HIV positive child, not only in terms of psychological support but the medical aspect suffers as well. The child may not even be taken to hospital for regular check up visits.

4.2.3.2.3 Peer support groups

The health-workers also felt there was need to form caregiver support groups to help caregivers “to come together, share experiences of what, how it is, what others are doing so they can learn from others, coz even the aspect of parenting itself is quite a challenge (Social Worker 2). Thus the need for peer groups seemed not only necessary for the HIV positive children, but their caregivers equally needed them as well. Peer support was reported to be an ideal support mechanism because among any people “others have weaknesses and strengths so by coming together to know what other people are doing dealing with a child who is HIV positive and what they have to go through coz it also affect them in a way”, a lot can be achieved. (Social Worker 2)

4.2.3.2.4 Health-workers as a support system

Ongoing counseling “by professionals like psychologists” for both caregivers and HIV positive children was deemed as helpful and, essential, as noted in the following quote:

So if there was an initiative to say all the children be assessed for their coping to HIV/AIDS infection...not just a once off thing coz maybe a child at a particular age may not show signs of being affected or of emotional distress or being affected by their HIV/AIDS condition only for them to later show...so frequent assessments for children[are needed] so that even when they develop from whatever level to another level they are also reassessed so that if there are any signs that there is any need for intervention it will be put in place. (Social Worker 2)

As another recommendation to ensure ongoing counseling one nurse recommended there be a full time social worker based in IDCC to attend to the children that need help.

Yah at least somebody who is based here, a social worker or psychologist full time based here to deal with...here there is a lot counseling that is needed almost every day, both adult and paed there is a lot of counseling that needs to be done in order for them to adhere to medication well...a lot of teaching has to be done, teaching, teaching...teaching here it's a continuous process, it's not something that can be taken [lightly]... (Nurse 4)

This finding suggests the need for continuous psychosocial evaluation of HIV positive children at an individual level at regular intervals as they grow up.

4.3. SUMMARY OF RESULTS

Theme 1 presented what the caregivers, social workers and nurse participants believed to be the key psychological stressors of HIV positive children on ART. Theme 2 outlined the major challenges faced by health-workers and caregivers, while Theme 3 outlined the support they require in order to effectively deal with the problem of psychological distress of HIV positive children.

CHAPTER FIVE

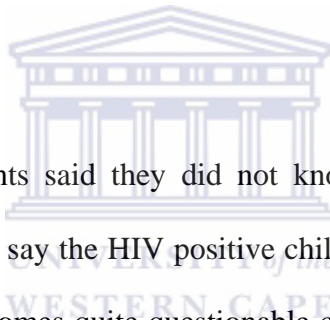
DISCUSSION

The purpose of this chapter is to discuss the significance of the findings. In presenting this chapter the researcher first discusses how the findings relate to earlier research by discussing the themes and sub-themes at the hand of relevant literature. Secondly a consideration of the limitations of the study follows and thirdly the recommendations are outlined. This study set out to find what the social workers, nurses and caregivers believed to be the key psychological stressors for HIV positive children, and what support and training needs that the nurses, social workers and caregivers needed to effectively deal with psychological distress of HIV positive children. The study findings indicate a broad spectrum of mainly psychological and social factors which the caregivers and health-workers (nurses and social workers) perceived to be contributing to psychological distress of HIV positive children. The study also identified a range of unresolved challenges faced by the caregivers, nurses and social workers in their quest to deal with psychological distress in HIV positive children.

5.1 UNDERSTANDING OF THE CONCEPT OF PSYCHOLOGICAL DISTRESS

It appeared most of the nurse participants could not come up with a clear cut definition for psychological distress while social workers had clearer definitions of the concept of psychological distress than those held by nurses. The lack of understanding of the concept of psychological distress is believed to create “confusion for nurses attempting to

manage the care of people experiencing psychological distress” because the concept itself is “seldom defined as a distinct concept and is often embedded in the context of strain, stress and distress” (Ridner 2004: 536). Since the concept is often confusing, it is important that nurses are given the opportunity to understand and to be able to recognize psychological distress so that they can be able to develop appropriate interventions to ameliorate it in their patients (Ridner, 2004). The difference of such understanding of the concepts of distress may be assumed to be because the line of work of social workers is more inclined with social problems of which psychological distress appears as one of the major manifestations unlike ART clinic nurses who, for most of the time are looking at the medical aspect of disease.



All of the caregiver participants said they did not know what psychological distress meant but then they went on to say the HIV positive children they take care of were fine and had no problems. That becomes quite questionable considering that all of them took care of the children who had earlier been referred to social workers for various problems which had negative psychological impacts on the children. This anomaly might have been the reason why the caregivers could not clearly identify the causes of psychological distress and probably confirms the health-workers’ perception that caregivers are generally unable to recognize psychological distress in the HIV positive children they will be taking care of because they view it as normal behaviour. The caregivers’ inability to recognize psychological distress may be explained by the certain local cultural factors which do not allow a caregiver to concede the existence of a problem of psychological distress in a child. For example, what can actually be a major problem is somehow

brushed away as something minor. In such instances a caregiver would not like other people to think that the child they are taking care of has psychological problems for fear that society may perceive this as a failure to look after the child of a relative. In this study, the caregivers, all coming from a black African origin do not culturally have an explanation to psychological distress or depression. Those people suffering from distress are regarded by society as being failures, weak and unable to cope with life challenges (Ridner, 2004: 536).

This lack of understanding of the concept and the embedded cultural beliefs has implications for interventions for psychological distress. The question to address will be: How can we reduce psychological distress in these HIV positive children when their caregivers cannot, to begin with describe it? It therefore means there is need to address the caregivers' inability to recognize psychological distress in their children first and then other interventions may follow suit.

5.2 PSYCHOLOGICAL STRESSORS FOR HIV POSITIVE CHILDREN

5.2.1 Disclosure

The nurses and social workers felt that there was a need to disclose HIV status to the child early on in the child's life while caregivers felt that they were not ready to tell the child about the disease status. This may be because the caregivers felt they did not have enough support to face their perceived fears about how the child will take it. Health-workers encouraged initiating partial and then full disclosure as the child grows up. Similar sentiments were shared by health-workers working in a paediatric HIV clinic in

Cape Town, South Africa in which they felt the ideal age to start general discussions about HIV with an HIV positive child is around 6 years and then specific disclosure should be postponed to an average age of 10 years old (Myer et al., 2006). In the current study only one caregiver shared similar concerns of early disclosure. The others felt the children were still too young to comprehend. Similar perceptions existed in a Thai study among caregivers in which “almost all agreed that they should tell the children their diagnosis in the future...” due to the “... fear that disclosure might have negative psychological or emotional consequences for the child” (Oberdorfer et al., 2006: 285).

Contrasting results of perceived emotional immaturity of the child by the caregiver were also discovered in a Zimbabwean study in which more than 73% of the caregivers perceived that HIV positive children should be told something about their status from the age of 5 onwards (De Baets *et al.*, 2008). The study however did a survey, as opposed to this qualitative study in which the goal was not to generalize findings but to get a deeper understanding, hence it may not be accurate to say there is a difference in caregiver perceptions between caregivers in this study and the Zimbabwean study.

The differences in opinions between the health-workers and caregiver participants regarding appropriateness and timing of HIV status disclosure to a child in this study may suggest the need for health-workers and caregivers to work together to encourage appropriate disclosure practices. These should occur not as a single event but as a gradual process that allows the child to adjust accordingly (Abadia-Barero & Larusso, 2006; De Baets *et al.*, 2008). Age is however not the only factor that determines whether the child should be told about their own status, the developmental stage of the child also comes

into consideration. Thus it has been suggested that disclosure can be done at any age but at an appropriate time depending on the child's understanding of what is going on (Butler *et al.*, 2009).

5.2.2 Lifelong treatment

The fact that ART has to be taken for lifetime being a major source of psychological distress in the HIV positive children was a recurring theme in all the interviews. Children who have not yet been made aware of their HIV status usually find it difficult to appreciate why they have to monotonously take medication for the rest of their lives (Punpanich *et al.*, 2008). This is compounded by the fact that caregivers' explanations as to why the children should be taking medication regularly are neither convincing enough nor are they encouraging to these children. This theme demonstrates the importance of early consideration of disclosure for those children who have been started on ART, and tactics used to encourage the children to take their medication.

5.2.3 Stigma

The findings of this study also suggested the presence of high levels of stigma which is facing the HIV positive children in the home, community and school environments. Similar situations have been reported in several parts of the world. In West Africa it is reported that lack of HIV/AIDS awareness in schools resulting in some HIV positive children refusing to attend, or facing difficulties in concentrating, not performing well and dropping out of school (Alidri *et al.*, 2002). Children in Kenya have also been reported to face subtle forms of discriminations resulting in many of them not willing to

disclose their HIV status to teachers and fellow students or secretly taking ARV (Vijayarasa, 2010). In Brazil, Abadia-Barero & Castro (2006: 1219) found that “structural violence in the form of poverty, racism, and inequalities of social status, gender, and age fuels children’s experiences of stigma”. The existence of such stigma in various settings prompted the East African Community to call for specific legislature addressing children’s needs on HIV as one method of protecting HIV positive children from HIV associated stigma (Vijayarasa, 2010). Such a model law exists here in the Southern African Development Community (SADC) and was adopted in December 2008 (SADC Parliamentary Forum, 2008).

The health-worker participants in this study perceived that caregivers were telling their children to keep the diagnosis of HIV to themselves as a result of the fear of stigma associated with being HIV positive. Similarly, a study conducted in Thailand reported that caregivers were guarded and reticent in managing the stigma of HIV and “keeping the diagnosis” of their children HIV positive as a secret (Punpanich *et al.*, 2008: S81).

5.2.4 Orphanhood and Social problems

The health-worker participants in this study believed that HIV positive children who have lost parents are psychologically affected by circumstances they find themselves in as a result of death of parents. Similar effects are noticed in east African children where a large number of the children orphaned by HIV/AIDS who in addition to being HIV positive themselves, needed to deal with social issues such as abuse, exploitation, stigma and sexual harassment by non- biological caregivers (Alidri *et al.*, 2002).

Issues of sexual abuse, exploitation and ill-treatment by caregiver were also mentioned by the participants as other contributory factors to psychological distress of HIV positive children in this study. Foster (2004) claims that similar cases of ill-treatment of fostered children exist in South Africa, particularly the female children who are taken in by relatives because of their economic value in terms of doing household chores. Foster (2004) further claims that though several studies have demonstrated that orphans are disadvantaged compared to non-orphans in other families, few studies have demonstrated significant differences in the ways relatives treat their own biological children compared to fostered children. This study however did not seek to demonstrate whether there are differences in the treatment between male and female children under foster care of the extended family. This remains to be investigated in Botswana.

5.2.5 Caregiver influences on psychological distress of HIV positive children

The study findings suggested that caregivers' characteristics which tend to aggravate psychological distress of HIV positive children included poor relationships with the child, caregiver psychological health as well as financial constraints. This confirms earlier findings of a study carried out in Botswana which found that most caregivers of orphans and vulnerable children are economically disadvantaged (Ama & Seloilwe, 2010). Caregivers who have reported more psychological distress have also reported more internalizing and more externalizing behaviour problems in their children, regardless of the child's illness status (Bachanas *et al.*, 2001). The quality of the HIV patient-caregiver relationship has been shown to be significantly associated with caregiver depression and burden as well as HIV patient depression, physical functioning and HIV medication adherence (Miller, Bishop, Herman, & Stein, 2007; Mellins *et al.*, 2006). Similar lack of

direct caregiver-child communication was also realised in a Ugandan study of HIV positive children in which the children expressed absence of direct and open communication with the caregivers which left them with a feeling that they had no one to talk to (Alidri *et al.*, 2002).

Foster (2004) asserts that children need more than good physical care, but they need to have affection, attention, security and social connections that families and communities can provide. If these are not available there can be a significant increase in psychological distress in a child. This is consistent with the fact of lack of love, care and support by mainly non-biological caregivers being responsible for psychological distress in the HIV positive children was a recurring theme in most of the interviews in this study.



5.3 ADDRESSING CHALLENGES ASSOCIATED WITH PSYCHOLOGICAL DISTRESS OF HIV POSITIVE

5.3.1 Provision of skilled manpower

The lack of manpower and qualified personnel such as psychologists to attend to psychologically distressed children in the IDCC clinic were mentioned as some the major challenges. Addressing this problem is a key to the success of the ART program, and the well-being of the HIV positive children in the district. It was mentioned that due to shortage of doctors the consultation of children during clinic visits is always done in a rush leaving no opportunity to assess any psychosocial problems that may be affecting the child. This problem is not unique to the study setting but it has been found that there

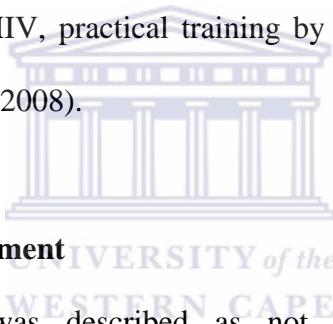
shortage of physicians in many African countries (van Griensven *et al.*, 2008). This calls for more strategic use of their skills, without compromising quality of care.

A Ugandan study of a nurse-based ART clinic which is similar to this study setting, discovered that one most critical factor in the success of the program was the increase in number of nurses or there was need to avoid overloading these nurses with many non-nursing duties so that they concentrate on identifying psychosocial problems in the children (van Griensven *et al.*, 2008). Rather most of the tasks traditionally performed by nurses in Uganda were taken over by new or reinforced cadres in the health centers: receptionists for administrative work and data collection/monitoring; counselors and community support groups for counseling; and lab-staff for blood collection.

Caregivers were concerned that service delivery was slow at the clinic and they usually take the whole day at the clinic which has also been described as child un-friendly environment as well by the nurses. This was mentioned as a potential source of distress for the children as well. Literature has shown that, nurses at times overlooked the negative effects of long waiting times and frequent hospital visits (Campbell *et al.*, 2010).

The lack of adequate training and need for proper training tailor made for dealing with children having psychosocial problems was a sentiment shared by all the nurses and social workers who participated in the study. This is a matter of major concern because it is argued that those workers who are either overwhelmed by workload or do not feel they have complete mastery over their duties are at an increased risk of burnout which may

result in them avoiding to help patients (Demmer, Undated). In drafting a handbook on Paediatric AIDS, ANECCA (2006) also acknowledged the deficiency in knowledge and skills to effectively communicate with children. The importance of adequate training as suggested by the health-worker participants in this study was demonstrated in a Uganda study which sought to review the success elements of a nurse-based ART clinic. The study showed the value of emphasising on comprehensive care that involves health-worker, family and child-centered approaches that include methods to address the psychosocial issues of HIV. This health-worker centered component of the approach included implementing the following: discussion groups for health care staff, training on psychosocial implications of HIV, practical training by psychosocial team, supervision and mentoring (van Griensven, 2008).



5.3.2 Child friendly environment

The working environment was described as not conducive for working with psychologically distressed children and hindered the social workers to effectively communicate with the children. Effective communication means trying to understand the child's thoughts and feelings and attempting to respond to a child in a manner that is helpful to the child (ANECCA, 2006). Similar perceptions of the need for a child friendly environment were also seen in a Ugandan study whereby social workers working in an ART clinic recommended integrating play in child targeted counseling sessions (Alidri *et al.*, 2002). Creating an environment that allows effective communication can ensure that the children can be able express themselves, raise their questions and worries and develop a positive attitude towards life with HIV (van Griensven *et al.*, 2008).

Support structures and support systems

The availability of antiretroviral drugs means that HIV positive children now survive longer into school going ages and beyond (Mocroft, 2003). Basing on the high levels of HIV-related stigma that has been reported in school environments in various settings, there is need for increased attention to education and appropriate disclosure practices as children grow up ((Abadia-Barero & Castro, 2006; Domeck, 2006). The findings of this study suggest that school authorities play a significant role in dealing with psychological distress of these children. However they need to work alongside strong family and community support systems.

The first line of support for vulnerable children including HIV positive children is usually their family, including the extended family and distant relatives. According to Foster (2004) this extended family safety net remains the most effective protection mechanism assisting HIV positive children socially, economically, psychologically and emotionally throughout Sub-Saharan. In the absence of formal psychosocial support services addressing child related issues as suggested by the study findings, the caregivers only have their families to turn to. The importance of family as a support system in the face of lack of formal psychosocial support is illustrated in a study of in Burkina Faso whereby:

As mothers live in fear of disclosure, they have to develop concealment strategies around children's treatment and the nature of the disease. Conversely, some mothers may share their secret with kin members, close relatives or their children to gain social support. As HIV/AIDS care is shaped by secrecy, these findings shed light on mothers' isolation in child care within a context of changing patterns of family bonds and lack of formal psychosocial support (Hejoaka, 2009: 869).

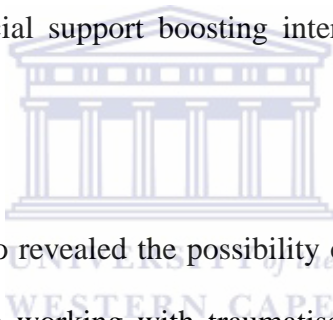
This sub-theme of family as a support system demonstrates the need for caregivers to be encouraged to disclose the HIV status of the children they take care of for reasons of support as re-iterated above quote.

Community support appeared to be present in this study as was similarly found in one South African study in which one of the participants narrated that their neighbours were quite supportive in taking care of each other's HIV positive patients such that "neighbours really became part of [her] family, not only helping [her] to help [her] child, but loving [the child] for who she [was] (Smit, 2007: 173).

Peer support groups for HIV positive children and their caregivers as well as health-workers themselves were another major support need raised by the participants in this study. Despite the feeling that more Teen Clubs were needed and that they had to be government driven as opposed to the current situation whereby they are run by private organisations or individuals, the general perception was the Teen Club were highly effective in helping reduce psychological distress in the children. A study in Uganda again demonstrated the suitability of such peer groups in which the groups, which comprised about 15 children from ages 7 and above were organised in such a way that the children themselves would gather, raise issues affecting them and discuss their innermost feelings regarding these issues (Van Grienson *et al.*, 2008).

In the endeavor to alleviate or prevent psychosocial problems in HIV positive the caregivers' needs are often forgotten. The caregivers themselves even forget about their

psychological well-being too. It has been found that due to the complexity of providing care for a child in the family set up, these caregivers usually sought for their own needs quite late in the process, that is if at all they seek such help (Linsk & Mason, 2004). As a result the caregivers are at risk of also developing psychological distress, which may in turn spill onto the child as they fail to execute their care-giving duties effectively. Caregiver support group discussions have the potential to empower caregivers on the possible ways of averting psychological problems in their children before they occur through learning from colleagues who will have already met similar challenges and overcome those (van Griensven *et al.*, 2008; Hansell *et al.*, 1999). This sub-theme demonstrated the need for social support boosting intervention for caregivers of HIV positive children.



The interviews with nurses also revealed the possibility of compassion fatigue, which is the emotional exhaustion from working with traumatised patients (Adams, Boscarino, Figley, 2006) as well as probable health-worker burnout in the study setting. This is what may have prompted some of the nurses to mention the need for personal support in the form of a psychologist for nurses who may be traumatised by the duties of counseling and helping HIV positive children with psychological distress. However the most common strategy for managing burnout among health care workers in HIV/AIDS care that has been implemented across various settings and with different occupational groups (nurses, social workers, physicians) is to provide support groups for the health-workers (Demmer, *undated* ; Scarnera *et al.*, 2008). Unfortunately, there have been few studies that

systematically evaluated the effectiveness of support groups for health care workers caring for patients with HIV/AIDS in terms of coping (Demmer, *undated*).

It is important that nurses and social workers working with HIV positive children are equipped with skills for self care and burnout prevention techniques such as ability to assess one's own emotional responses to patients, fellow workers and the environment as well. This will enable the workers to meet the emotional needs of their clients within a stressful environment without experiencing compassion fatigue (Adams, Boscarino, Figley, 2006). One nurse participant felt that health-workers needed to take a leading role in health promotion activities such as de-stigmatisation of HIV/AIDS such that society can regard it as any other chronic disease such as diabetes and hypertension. This view is supported by Mahomva *et al.*, (2006) in De Baets *et al.*, (2008) where health-workers are urged to spearhead de-stigmatisation of HIV/AIDS and other efforts in line with behaviour change in the community. It is also important that health-workers working with HIV positive children take caregiver and child-centered approaches which involve educating the caregivers on what psychological distress is, how it affects the children, its manifestations and how it can be averted. Such education can therefore be expected to deal with the problem of caregivers being unable to recognize psychological distress in the kids.

The sub-theme of difficulties in dealing with deaf children stresses the importance of considering the needs of disabled HIV positive children in the design and provision of services in the paediatric HIV program. The theme on financial constraints suggests

availing ART alone is not sufficient to ensure the well-being of HIV positive children. Hence other alternative interventions of improving financial security of caregivers can indirectly help reduce psychological distress of HIV positive children.

5.4 SIGNIFICANCE OF FINDINGS

This qualitative study focused on the perceptions of risk and protective factors for psychological well-being of HIV positive children (regardless of orphan status) in Botswana. Like findings from other literature on orphans and vulnerable children this study indicated presence of potential risk and protective factors for psychological distress in a range of dimensions, including bereavement, family functioning, social support, poverty, access to education and perceived stigma (Cluver & Gardner, 2007; Zhao, 2007; Punpanich *et al.*, 2008; Arnab & Serumaga-Zake; 2006). However, this study also identified factors which may be unique to this group, notably school environment related stigma, and lifelong antiretroviral treatment.

The study findings generally agree with other studies on psychological distress among HIV positive children. For instance, stigmatisation, dropping out of school, change in living environment, increased workload, discrimination and social isolation of orphans including HIV positive orphans all increase the stress and trauma of parental death. The caregivers, nurses and social workers managed to cite most of the psychological effects of HIV infection in children that have been mentioned in various literatures. Such effects include depression, anger, guilt and fear, anxiety, desire to live against medical advice, loneliness, isolation, problematic interpersonal relationships, feeling hopeless, and being

emotional among other many examples (Foster, 2004; Mirowsky & Ross, 1989; Murray, 2006; Nicholas *et al.*, 2003; Ridner, 2004).

Nurses and social workers in this study appeared to be facing common challenges such as lack of manpower and lack of adequate knowledge and skills to deal with psychological distress of HIV positive children. According to Olivia & Dykman, (2003), this commonality makes nurses and social workers make them natural allies in responding to the many challenges associated with HIV service provision. Study findings support collaboration in the areas of service delivery, policy development, advocacy and professional development. As proposed by Brazarsh (2004) there is need to integrate mental health needs into the primary health care system by training health-workers, particularly nurses to recognize childhood psychological problems so as to make mental health services more accessible to children living with or affected by HIV/AIDS

The findings of this study contribute to the growing body of research on psychological distress of HIV positive children and provide an opportunity in which affected families and health-workers provide input into intervention designs. The study also bring to light the need to look beyond providing simple ART to HIV positive and children, and put in place systems and mechanisms to support the children. The challenges and support needs raised by the groups of participants in this study can aid policy makers draw sound intervention mechanisms that will curb the occurrence of psychological distress in the HIV positive children.

Even though this study was carried out in Mochudi only, the researcher is of the opinion that the findings of the study may be relevant in understanding the phenomenon of psychological distress in other settings in Botswana, and perhaps in other parts of Africa facing similar challenges.

5.5 LIMITATIONS OF THE STUDY

The study limitations included the sampling of only one Kgatleng ethnic group which is the black *Bakgatla* community. Although this is the majority group most affected by HIV/AIDS in the community, the findings therefore may not necessarily apply to other ethnic or racial groups, but they do point out salient themes about psychosocial distress among HIV positive children. Furthermore the research did not gather information on the HIV positive children who are not yet on ART as they will not be attending the clinic. It also did not capture information on the HIV positive children from a different social class than those attending the ART clinic at DRM hospital, such as children from high income families who often use the private sector.

The use of a translator during the caregiver interviews, which were all in *Setswana* hampered free flow of discussions. The researcher felt it was not always easy to probe some aspects further, for there are some words in *Setswana* that cannot be translated to English with exactly the same impact in meaning. When using a translator in a semi-structured interview with no particular order of questions it is possible that questions could be interpreted and posed differently to different participants. However the major aspects of local causes of psychological distress of HIV positive children on ART and the

challenges/training needs which the study aimed to look for could be picked up from these interviews. The researcher thus acknowledges that language and a cultural barrier with the caregiver participants was significant. However the researcher had hoped that good rapport with the caregiver participants could be easily achieved because the two translators were well known and probably trusted by the caregivers as they were some of the pioneers of the IDCC clinic.

There may however be a problem with conducting qualitative research in an area in which the researcher works or is already known as this raises several issues and ethical considerations. Though the researcher and translators being clinicians and might have been likely better positioned to get better results because of knowing the situation and having the trust of participants, Orb, Eisenhauer & Wynaden, (2000) argue that the known researcher may get less information. This is because it is possible that caregivers and staff (nurses and social workers) in the clinic as potential participants may feel coerced to participate and this may limit the information they give. According to Field and Morse (1992) in Orb Eisenhauer & Wynaden, (2000) conducting research in one's work area creates problems related to the validity, reliability, and meaningfulness of the data. The solution then may be to conduct the research where one is unknown as recommended by Orb *et al.* (2000: 96)

Conducting research in another setting may mean that researchers have to spend more time and effort establishing rapport and learning the new setting. But, this change may result in more objective observations. Negotiation of the researcher's role on a clinical unit is important. If the role of the researcher is clearly identified by the group and the purposes of the study are discussed,

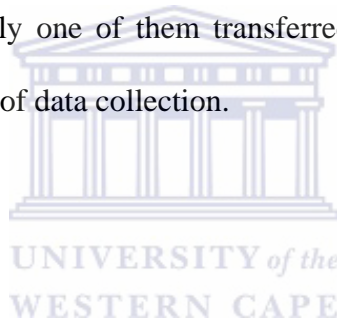
the researcher will be regarded as such and not as someone who is doing something dubious. It also will reduce the group's false expectations.

Conventional content analysis was the sole method used to analyse the data. According to Heish & Shannon (2005: 1280) the method fails to “develop a complete understanding of the context, thus failing to identify key categories. This can result in findings that do not accurately represent the data”. At its best the result of conventional content analysis is said to be concept development or model building (Lindkvist, 1981 in Heish & Shannon, 2005). Unlike other data analysis methods such as grounded theory methodology conventional content analysis does not go beyond content analysis to develop theory or a nuanced understanding of the lived experience (Heish & Shannon, 2005). In light of the aforementioned the study was influenced both by the time limiting nature of a mini-thesis which may not have allowed use of grounded theory and as well as the fact that the study was being conducted by a novice researcher and possibly shaping the findings “naively realistic” (Henning, Van Rensburg & Smit, 2004: 102).

Although the in-depth interviews appeared to have been successful in drawing the factors that contribute to psychological distress of HIV positive children, the children's perceptions were not known and were not assessed in this study. This information could potentially be important in understanding and ascertaining the sources of distress, challenges and support needs raised by the caregivers and health-workers in this study, hence making sure that future psychosocial interventions to help this group of children are relevant.

It is possible that the inclusion of other data such as effect of sex differences in the population may have made a difference in answering more fully the question of potential sources of psychological distress of HIV positive children and its associated challenges and support needs. The study did not gather whether there may be sex differences with regards to the causes of psychological distress in male and female children. The study did not also explore whether there are differences between male and female caregivers with regards to their challenges and support needs.

The researcher had initially targeted to interview all the three social workers that worked at DRM hospital. Unfortunately one of them transferred to another district before the researcher finished the process of data collection.

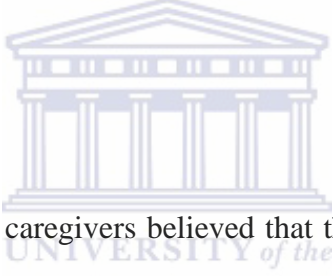


CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

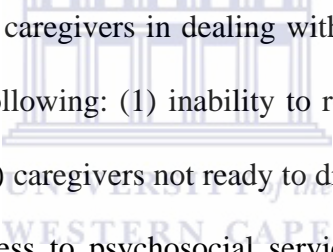
The purpose of this chapter is to bring this study to a close. Within this chapter the conclusions are provided first and then recommendations follow. This research study set to provide the answers to the following research questions. What do the social workers, nurses and caregivers perceive to be the key psychological stressors for HIV positive children? What support and training do nurses, social workers and caregivers need to effectively deal with psychological distress of HIV positive children?

6.1 CONCLUSIONS



The nurses, social workers and caregivers believed that the major factors that contribute to psychological distress of HIV positive children were: (1) the discovery of their HIV status and comprehension of the implications of their HIV status, (2) orphanhood and or loss of parent in addition to comprehending the HIV positive disease status, (3) social problems-rape abuse, poverty and teenage hood experiences of sexual life choices limited by HIV positive status, (4) caregiver distress, which is also believed to spill on to the child, (5) poor caregiver-child relationship resulting lack of openness between caregiver and child, (6) both community and school related stigma, (7) lack of love, care and support from the caregiver, (8) Lifelong treatment and (9) compounding of many factors to deal with in addition to being HIV positive

The major challenges faced by nurses and social workers in dealing with psychological distress of HIV positive children include the following: (1) lack of manpower to effectively deal with all the children with psychosocial problems, (2) lack of knowledge and skills to assist HIV children with psychological distress, (3) communication barrier with deaf HIV positive children, (4) compassion fatigue from dealing with psychologically traumatised children, (5) lack of support from the hospital administration and staff, (6) working environment is not child friendly hence difficult to allow children to open up during counseling sessions and, (7) lack of co-operation and commitment from caregivers of children put on a program to avert psychological distress.



The major challenges faced by caregivers in dealing with psychological distress of HIV positive children include the following: (1) inability to recognize psychological distress in the HIV positive children, (2) caregivers not ready to disclose HIV status to child early on in life, (3) insufficient access to psychosocial services to caregivers and the HIV positive children they take care of, and (4) financial constraints.

The support needs of the nurses, social workers and caregivers of HIV positive children included; (1) more qualified personnel (2) more and adequate training for nurses and social workers, (3) formation of more peer support groups, (4) a child friendly environment, (5) need for caregiver and HIV positive child education and support from the educators, family and health-workers.

In summary the causes of psychological distress, the challenges and support needs suggested by the participants in this study can provide a framework for improving the existing services for HIV positive children with psychosocial problems. These suggestions have been incorporated in the recommendations made from these findings and are outlined in the next section.

6.2 RECOMMENDATIONS

Based on these conclusions, the following recommendations are made. The recommendations are by no means exhaustive but the aim was to propose sound strategies that could lead to improved support of HIV positive children and their caregivers in Botswana, as their numbers continued to rise due to successes in ART.

6.2.1 Child-centered recommendations

- **Establishment of child support groups- more Teen Clubs in public hospitals:** As was recommended by the participants in this study Teen Clubs for children may be formed in all the public health institutions right across the country. At the current moment these are almost non-existent. The few that are available are being run by the private sector, for instance Stepping Stones in Mochudi and The Teen Club run by Baylor Paediatric Institute in Gaborone. In places where the Teen Clubs are existent the aim should be to increase their numbers. One suggestion would to identify some of the children in these groups who could be trained in counseling skills and support. These children will likely be more effective as they are likely to be able to get through to fellow HIV positive children than counselors in general.

- **Establish child- friendly environments and centers:** From the findings it was evident that the social workers, nurses and other professionals who will offer professional psychosocial support services to HIV positive children in the clinics will need child friendly environments in which to undertake counseling sessions with children. Ideally each and every clinic offering paediatric HIV ART must have a child center where children with psychosocial problems can walk in any time and get help.
- **Educator and school community support:** As indicated in the findings, issues of absenteeism in order to go for hospital appointments will always be a problem if the teachers are not aware of the child's HIV status. HIV positive learners can find it more beneficial to have school authorities know about their status. In this respect it would be of importance that school teachers are also trained on skills to offer psychosocial and emotional support to HIV positive children in their classes. It will also be of utmost importance if there could be school based support teams and educational psychologists based at schools to assist these HIV positive children who may be having psychosocial problems. The children will also need to be well informed of the existence and functions of the school based support systems so that they could be effectively used.

6.2.2 Caregiver-centered recommendations

- **Establishment of support groups for caregivers:** It will be of cardinal importance if all health centers or the community around health centers that offer ART to HIV positive children could organise discussion or support groups for caregivers of HIV positive children. These support groups will enable caregivers to develop coping

mechanisms or know how to deal with psychosocial problems in their children before they occur or as they are happening.

- **Family support:** It was once again evident from the findings that family support is crucial in helping caregivers and children with psychological distress to better cope with the problems they face. It is therefore important that caregivers of HIV positive children are encouraged to disclose their child's HIV status to family members for reasons of support.
- **Caregiver education, awareness and prevention campaigns:** There is need for educating the caregivers on what psychological distress is, what it means for them and the children they take care of. The community needs to be sensitized as well on the presence and effects of psychological distress in HIV positive children. Community campaigns to sensitize the members on the needs of the HIV positive children could also help.
- **Addressing economic challenges:** In addition to the psychosocial support they provide it is essential that caregivers and families of HIV positive children are provided with the economic means to enable them to provide material support to their children. One suggestion would be introducing income generating projects that may be conducted within caregiver support groups.

6.2.3 Health-worker-centered recommendations

- **Health-worker training:** It was evident from the findings that there is need to provide training on psychosocial implications of HIV in children. All health-workers need to be conversant with psychosocial aspects of the paediatric ART program. Such

training should be practical training that will involve supervision and mentoring by qualified tutors. Schools of nursing and social work should consider introducing professional courses tailor made for dealing with psychological issues in HIV positive children. Hospitals should consider forming a psychosocial team of professionals whose responsibilities will be to ensure that all health-workers are trained before they start attending to HIV positive with psychological problems.

- **Manpower:** There is need to increase the number of nurses and social workers in paediatric ART clinics in order to allow all HIV positive children to be continuously evaluated for psychological problems during each visit to the clinic. There is a definite need to provide the ART clinics with qualified staff trained to deal with psychological problems, for example cadres such as psychologist and psychiatrists.
- **Family-centered approach:** There is a need to emphasise a family based approach that will see nurses and social workers working in paediatric ART clinics working as a team with caregivers to identify children with possible risk of psychological distress. There needs to be standardised ways of helping caregivers to disclose HIV status of the child to both the child and the family.
- **Discussion groups for health care staff:** Discussion groups of health staff offering care to HIV positive children can help health-workers to share their challenges and successes, a move which can help prevent burnout. It is also important that health-workers can go for refresher camps or treats to help them take their minds off their stressful environment and relax. There is need for health-workers to be trained on how to deal with compassion fatigue.

- **Hospital administration support:** It was also evident from the findings that there is need for more support from the hospital administration in order for all the initiatives of psychosocial care of children in the paediatric ART clinic to be successful. Support can be provided in the form of availing transport for support visits in the villages as well as allocation of more staff to the IDCC clinics.

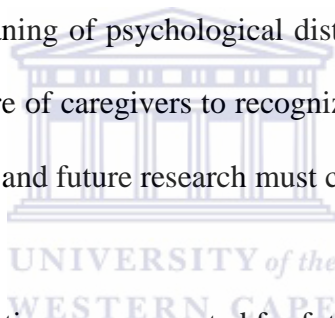
6.2.4 Recommendations for future research

In determining factors affecting child well-being, it is important to consider a range of sources of evidence, including those of service providers, caregivers and children themselves (Noble *et al.*, 2006). This study did not get the views of children directly, therefore it will be important that future research also considers designs that include identification of needs by the HIV positive children themselves. Whilst this qualitative approach allowed for participant driven identification of challenges and support needs and produced relatively high levels of corroboration between participants on a number of factors, there is a need to test the identified factors in both qualitative and quantitative research methodologies. Quantitative researches would allow for determining the extent of the identified concepts on a larger scale. The use of positivistic, experimental methods to complement descriptive phenomenological methods allows for increased validation of findings (Valle *et al.*, 1989 in Cluver & Gardner, 2007).

Whilst this study indicates participant-perceived stressors and protective factors, we also need to explore the effects of factors on prevalence of psychological problems such as depression. We need to distinguish which factors are specific to HIV/AIDS positive

regardless of orphanhood. Further study is needed to determine to what extent the mental health needs of children and their caregivers are being met. It will also be important that future research also test whether there are differences in the identified factors with sex of child or caregivers.

The study did not focus on disabled children. Given the magnitude of distress experienced by HIV positive children, the researcher assumes conditions may be much worse for disabled children. Based on inability to look at disabled children who are also HIV positive in this study, researcher recommends that future studies examine this group. The conceptualization and meaning of psychological distress seemed to be an important finding in this study. The failure of caregivers to recognize psychological distress among children is a cause for concern, and future research must consider this discrepancy.



In summary the following questions are suggested for future research:

- What is the magnitude of psychological distress in HIV positive children in the country?
- Are there any gender differences in risk and challenges of psychological distress between male and female children or male and female caregivers?
- To what extent are the mental health needs of HIV positive children being met in the country?
- What are the support needs of HIV positive children with disabilities?
- What support programmes for the HIV positive children and caregivers of HIV positive children can be developed?

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APPENDIX 1

INFORMATION SHEET

Project Title: Perceptions of factors contributing to psychological distress in HIV positive children on Antiretroviral Therapy in Mochudi, Botswana: A family caregiver and health care worker analysis.

What is this study about?

This is a research project being conducted **Anafi Mataka**, a student at the SOPH, University of Western Cape, in partial fulfillment of the Masters in Public Health Degree. I will be focusing on the nurses, social workers and family member caregivers' perspectives of psychological distress in HIV positive children. You are invited to participate in this research project because you as a family member caregiver/social worker/nurse of this clinic possess valuable knowledge and experiences about psychological distress in HIV positive children. The purpose of this research project is to explore the local context of perceptions of family member caregivers, social workers and nurses on key factors contributing to psychological distress in HIV positive children.

What will I be asked to do if I agree to participate?

You will be asked to respond to a number of questions from an interview guide. In order to gain a better understanding of what you, as a family member caregiver/social care worker/nurse perceive to be the key cause of psychological distress in HIV positive children, this interview will take at least one hour to an hour and a half. I will, with your permission, be recording the interview because I do not want to miss any of your comments. Even though I, as well as the rapporteur will be taking some notes during the session, we cannot possibly write fast enough to get everything down. Since we will be on tape, please be sure to speak up so that we do not miss your comments. The interview will not be digitally recorded if you do not agree to be recorded. Recording of the interview session can be stopped at your request at any point during the interview. Please find attached a summary of questions that will be asked (*appropriate interview guide, i.e. appendix 1 or appendix 2*).

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, I will at all times, keep you, the source of the information confidential and refer to you and your words by a participant number. I shall keep any other records of your participation locked away at all times, and destroy them after the data has been collected. If I write a report or article about this research project, your identity will be protected to the maximum extent possible. In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authorities information that comes to my attention concerning child abuse or neglect or potential harm to you or others.

What are the risks of this research?

There may be some risks from participating in this research study. Talking about the experiences of caring for HIV positive children may cause some unpleasant emotional feelings. A social worker will always be available, at no monetary cost, for you to talk to should you feel the need for one.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about your perceptions and lived experiences concerning the problem of psychological distress in the HIV positive children. We hope that, in the future, other people might benefit from this study through improved understanding of yours and that of other participants' perceptions, experiences, challenges and coping strategies to psychological distress in HIV positive children. Such an understanding will help come up with recommendations to alleviate the effects of this problem.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. Voluntary" means you can choose not to take part at all. The interview may touch on issues which concern people close to you. If there is anything that would not prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer either not to answer a question, or withdraw from the interview process should you feel the need to do so. I would really appreciate your guidance should I ask anything which you see as intrusive. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

As a student at the School of Public Health, University of the Western Cape, South Africa, I am accountable to Dr Busisiwe Nkosi who is contactable at number +2721959 9390 or c/o SOPH Fax +27 959 2872 or by email at bnkosi@uwc.ac.za If you have any questions about the research study itself, please contact Busisiwe or myself at phone number +26771772588 or by email at 2816303@uwc.ac.za. This research has been approved by the University of the Western Cape's Senate Research Committee and

Ethics Committee and the Botswana Health Research Unit. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department, Dean of the Faculty of Community and Health Sciences:
University of the Western Cape. Private Bag X17, Bellville 7535.South Africa
Or Mr P. Khulumani Botswana Health Research Unit. Gaborone. Botswana, Tel:
3914467





UNIVERSITY OF THE WESTERN CAPE



School of Public Health

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APPENDIX 1

PAMPIRI YA TSHEDIMOSETSO

Project Title: Perceptions of factors contributing to psychological distress in HIV positive children on Antiretroviral Therapy in Mochudi, Botswana: A family caregiver and health care worker analysis.

Tshekatsheko ke ka ga eng?

E, ke patlisisoe ee samaisiwang ke Rre Anafi Mataka, moithuti ko School of Public Health, University ya ko Western Cape. E ke nngwe ya tse di tlhokafalang gore feleetse dithuto tse di kgolwane tsa Masters in Public Health. Ke tlaabo ke itebagantse le baoki, bomma boipelego le batlhokamedi ba balwetsi ko lwapeng gore b akanya gore ke eng se se bakang kgatelelo ya maikutlo mo baneng ba ba tshelang ka mogare wa HIV. O lalediwa go tsaya karolo ka lebaka la gore o le mooki/mma boipelego kana ole motlokamedi wa ngwana o nne le kitso e e tshwanetseng le maitemogelo ka bana ba ba tshelang ka mogare. Maikaelelo a patlisiso tse, ke go sekaseka maikutlo a ba ba mo gae eleng baoki, bomma boipelego le bao ba ba tlhokometseng bana ba ba kwa gae.

Ke tla bodiwa eng fa ke dumela go tsaya karolo?

O tla kopiwa go araba dipotso tse di mmalwa. Gore o tlhaloganye sentle maikutlo le mathata a ngwana yoo tshelang ka mogare wa HIV, patlisiso maikutlo e e tla tsaya oura go ya ko go oura le sephato. Ka tetla ya gago ke tlaabo ke dirisa sekapa mantswe mo dipuisanyong tsa rona ka lebaka la gore fa re kwala ke ka nna ka seka ka kgona go tshwara dintlha tse dingwe tsa botlhokwa, ka jalo ke tlaabo ke kwala ke ntse ke dirisa le sekapa mantswe. Fa o sa battle re dirisa sekapa mantswe ke tlaa kwala fela sone ke sa se dirise. Fa o batla gore re emise go dirisa sekapa mantswe kana re emise dipuisano tsa rona, ke tlaa dira jalo. Ke kopa gore o lebalebe dipotso tse di tlaa bong di botswa mo appendix 1 kana appendix 2.

A go tsaya karolo game mo tshekatsheko e tse go tla nna sephiri?

Go tla diriwa ka bojotle gore go seka ga senolwa gore motsaya karolo ke mang. Ka dinako tsotle ke tla diragatsa gore se re se buisanang e nne sephiri sarena fela. Go diragatsa se, motsaya karolo mongwe le mongwe o tla neelwa nomoro e e tlaabong e

dirisiwa mo boemong jwa maina a gagwe. Dibukana tsotlhe tse di dirisiwang mo dipuisanong tsa rona di tlaa bewa sentle di lotleletswe go sireletsa matsaya karolo. Morago ka tshekatsheko e, di tlaa senngwa kana go latlhiwa. Go tsamaisana le diemo tsa semolao, batho ba ba mo taolang ya diputlisiso tse, ke bone fela ba bat la itseng ka dipuisano tsa rona. Ke tla itsise botlhe ba ba tshwanetseng le bagolwane fa ke ka lemoga kana ka itsesiwe ka kgokgontsho ya bana e e ka tswang e diragala.

A tshekatsheko e e diphatsa?

Go tsenela tshekatsheko e go ka na diphatsa. Go bua ka maitemogelo a go nna le ngwana o o tshelang ka mogare go ka gogomosa maikutlo. Ka jalo o ka ya go bona mmaboipelogo yo o nang le rona mo tshekatshekong e, mme a go thuse a sa go duedise.

Ke eng se o ka se akolang mo tshekatshekong e?

Tshekatsheko e e rulaganyeditswe go thusa wena. Mme maduo a ka thusa mmatlisisi go ithutha go le gontsi ka maitemogelo a gago mabapi le mathata a a aperetseng bana ba ba tselang ka mogare. Re solofela gore mo isagong batho ba tla akola mo tshekatshekong ka go tlhaloganya botoka ga gago le batsaya karolo ba bangwe, maitemogelo dikgwetlho le go anywa botshipa ba go thusa bana ba ba tshelang ka mogare se se ka thusa go fokotsa ditlamorago tsa mathata a.

A ke tshwanetse go tsaya karolo mo tshekatshekong tse kana ke ka emisa go tsaya karolo ge nngwe le nngwe?

Go tsaya karolo gago mo tshekatshekong ke go ithaopa. Go ithaopa go raya gore ka itlhopela go sa tseye karolo gotlhelele. Potsalotso e ka fithela dikgang tse di amang batho ba o gaufi le bone. Fa gona le sengwe se o sa batleng go bua ka sone, o gololesegile go ka bua jalo. Ke ka se kgopisege fa o ka ikogela morago mo puisanyong e e bile ga gona go nna le ditlamorago tse di sa siamang fa o ka dira jalo. Ke ka lebogela dikgakololo fa ke ka re mo potsolotsong e ka botsa sengwe se o kareng ke itshunya nko mo dikgangnyeng tse di sa nkameng. O ka se latlhegelwe ke go akola sepe kgotsa go otlhaiwa, fa o tlhopha go ikogela morago mo go tseyeng karolo mo ditshhekatshekong nako nngwe le nngwe.

Fa ke na le dipotso?

Jaaka moithui ko sekolong sa University ya Western Cape, South Africa ke okametswe ke Dr Busisiwe Nkosi yo o tshwaregang mo nomorong ya +27219599390 kgotsa ko c/o SOPH Fax: +27 959 2872 kgotsa mo email ya bnkosi@uwc.ca.za. Fa o na le dipotso ka patlisisoe e, ikgolaganye le Busisiwe kgotsa le nna mo nomorong ya +267 71772588 kana mo email ya 2816303@uwc.ac.za. Patlisiso e, e dumeletswe ke ba University ya Western Cape, Ethics committee, le ba Botswana health unit. Fa o na le dipotso mabapi le patlisiso e, le ditshwanelo tsa gago o le motsaya karolo, kgotsa o nale mathata mabapi le yone o bata go re a lemotsha, ikgolaganye le rona ko:

Head of Department, Dean of the Faculty of Community and Health Sciences:
University of the Western Cape. Private Bag X17, Bellville 7535.South Africa
Or Mr P. Khulumani Botswana Health Research Unit. Gaborone. Botswana, Tel:
3914467



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APPENDIX 2

CONSENT FORM

Project Title: Perceptions of factors contributing to psychological distress in HIV positive children on Antiretroviral Therapy in Mochudi, Botswana: A family caregiver and health care worker analysis.

The study has been described to me and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed, I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's study number.....

Participant's signature.....Audiotape: (*Sign/initial here if you agree*)

Interviewer's Signature.....Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator: Anafi Mataka
DRM Hospital
P O BOX 24
Mochudi
Telephone: 5777333 EXT 250
Cell: + 267 71772588
Email: 2816303@uwc.ac.za or anafim10@gmail.com



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APPENDIX 2

TUMALANO YA POTSOLOTSO

Project Title: Perceptions of factors contributing to psychological distress in HIV positive children on Antiretroviral Therapy in Mochudi, Botswana: A family caregiver and health care worker analysis.

Ke ne ka tthalosediswa ka patlisiso e ka jalo ke ithaopa ka kgololesego go nna le seabe. Dipotso tsame ka patlisiso e di arabilwe. Ke tthaloganya gore se tla nna khupamarama e bile ga gona ope yo o tlaa itseng gore tshedimosetso e e ntshitswe ke nna. Ke ka ikgogela morago nako nngwe le nngwe e bile ga ke patlelesege go ntsha mabaka a go dira jalo e bile se ga se na go nkama ka gope ka tsela e e sa siamang.

Nomoro ya ditshekatsheko ya motsayakarolo.....

Monwana wa motsayakarolo..... Sekapamantswe:.....(*Monwana fa o dumelana le tiriso ya sekapamantswe*)

Monwana wa mmotsolotsi..... Letsatsi:.....

Fa o na le dipotso mabapi le patlisiso e kgotsa o batla go bua ka mathata a o kopaneng nao mo patlisisong e leletsa morulaganyi wa patlisiso:

Leina la mmatlisisi: Anafi Mataka

DRM Hospital

P O BOX 24

Mochudi

Telephone: 5777333 EXT 250

Cell: + 267 71772588

Email: 2816303@uwc.ac.za or anafim10@gmail.com



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APPENDIX 3: Guide to conducting interview with IDCC Clinic nurses and Social workers

Archival No...

Site:

Interviewer:

Translator:

Date:

Start:

1. For how long have you been working in this clinic?
2. What is your definition of psychological distress in HIV positive children?
3. From your experiences, what are the major causes of psychological distress in HIV positive children? EXPLORE. How can these be mitigated?
4. Talk about challenges you have encountered in dealing with psychologically distressed HIV positive children. EXPLORE for support and training needs.
5. Discuss if you believe family member caregivers are able to recognize psychological distress and its causes in the HIV positive children they take care of.
6. Suggest possible solutions to the problem of psychological distress in HIV positive children. What recommendations do you have for future efforts?
7. What would you like to see put in place in order to help you better cope with caring for HIV positive children that are psychologically distressed?



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APPENDIX 4: Guide to conducting interview with caregiver

Date:

Archival No:

Interviewer:

Start:

Site:

Translator:

End:

1. CAREGIVER RELATION TO CHILD

- What is your relationship with the infected child?
- Establish family composition.
- Can you talk about how you became the primary caregiver of this child?

2. PSYCHOLOGICAL DISTRESS

- What does psychological distress mean to you? EXPLORE
- What do you think are the prevalent sources/causes of psychological distress/stress in your child? EXPLORE, (how can these be mitigated???)
- What role do other family members (living in the same household) play?
- What role does the extended family play in dealing with psychological distress in the HIV positive child?
- How much access to psychosocial services do you think the HIV positive children have? Reasons
- What challenges/barriers do you face with dealing with psychological distress in the child?
- How do you overcome these? What are the strategies do you as a family caregiver use to reduce psychological distress in the infected children?
- What would you like to see put in place to help you better able to cope with caring for your child?



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APPENDIX 4: Guide to conducting interview with caregiver

Date:

Archival No:

Interviewer:

Start:

Site:

Translator:

End:

1. O AMANA / SIKANA LE NGWANA (CAREGIVER RELATION TO CHILD)

- O sikana jang le ngwana ya o lwalang?
- Tlhalosa ka botlalo gore ba lelwapa ba kae le gore ba tshwere maemo afe mo lwapeng.
- Bolela gore go tlile jang gore o nne motlhokomedi mogolo wa ngwana.

2. KGATELELO YA MAIKUTLO (PSYCHOLOGICAL DISTRESS)

- O tlhaloganya jang kgatelelo ya maikutlo? Tlhalosa ka botlalo.
- Tlhalosa ka botlalo gore ke mabaka afe a ka tswang a baka kgatelelo ya maikutlo mo ngwaneng wa gago. A ka fedisiwa jang?
- Ba bangwe mo lelapeng ba ba nnang le ngwana ba mo thusa jang go fedisa kgatelelo ya maikutlo mo ngwaneng.
- Ba losika ba thusa ngwana yo o nang le mogare jang go lwantsha kgatelelo maikutlo mo go ene?
- Ngwana yo o nang le mogare o golosegile go le kae go akola dithuso tsa bogakolodi ja maikutlo le tsa selegae, ntsha mabaka ka botlalo.
- Bolela dikgoreletsi tse o kopanang le tsone mo maitekong a gago a go fedisa kgatelelo mo ngwaneng.
- O dira eng go hema kgotsa go fedisa dikgoreletsi tse o buileng ka tsone? Ba lwapa la lona ba dirisa methhale efe go thusa?
- O batla go ka diriwa eng go go thusa go tlhokomela ngwana yo o nang le mogare botoka?

APPENDIX 5: University of the Western Cape ethical clearance

**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH
DEVELOPMENT**

Private Bag X17, Bellville 7535
South Africa
Telegraph: UNIBELL
Telephone: +27 21 959-2948/2949
Fax: +27 21 959-3170
Website: www.uwc.ac.za


1 November 2010

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and the ethics of the following research project by: Mr. A Mataka (School of Public Health)

Research Project: Perceptions of factors contributing to psychological distress of HIV positive children on Antiretroviral Therapy in Mochudi, Botswana: A family caregiver and health care worker analysis

Registration no: 10/8/23


Peter Syster
Manager: Research Development Office
University of the Western Cape



**UNIVERSITY of the
WESTERN CAPE**

A place of quality, a place to grow, from hope to action through knowledge

APPENDIX 6: Botswana Human Research and Development Committee clearance

Telephone: (267) 363200
FAX (267) 353100
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

REPUBLIC OF BOTSWANA

REFERENCE NO: PPME 13/18/1 PS V (145)

29 November 2010

Health Research and Development Division

Notification of IRB Review: New application

Mr Anafi Mataka
DRM Hospital
P.O. Box 24
Mochudi

Protocol Title:

PERCEPTIONS OF FACTORS CONTRIBUTING
TO PSYCHOLOGICAL DISTRESS OF HIV
POSITIVE CHILDREN ON ANTIRETROVIRAL
THERAPY IN MOCHUDI, BOTSWANA: A
FAMILY CAREGIVER AND HEALTH CARE
WORKER ANALYSIS, 2010

HRU Protocol Number:

HRU 00663

Sponsor:

N/A

HRU Review Date:

26 November 2010

HRU Expiration Date:

25 November 2011

HRU Review Type:

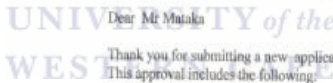
HRU reviewed

HRU Review Determination:

Approved

Risk Determination:

Minimal risk



Dear Mr Mataka

Thank you for submitting a new application for the above referenced protocol.
This approval includes the following:

1. Application form
2. Proposal
3. Consent Form
4. Data collection tool





This permit does not however give you authority to collect data from the selected site without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at pkhulumani@gov.bw, Tel: +267-3914467 or Mary Kasule at mkasule@gov.bw or marykasule@gmail.com Tel: +267-3632466

Continuing Review

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomoiso Motlhanka, e-mail address: kgmmotlhanka@gov.bw. As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomoiso Motlhanka, e-mail address: kgmmotlhanka@gov.bw. In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting

Other events which must be reported promptly in writing to the HRDC include:

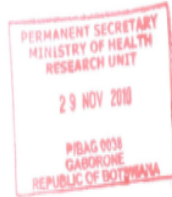
- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects



Do not hesitate to contact us if you have any questions. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely

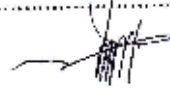

P. Khuhmani
For Permanent Secretary



APPENDIX 7: Permission to conduct research at DRM hospital

HOSPITAL SUPERINTENDENT

Dr. C. O. Mnyah



Yours faithfully

I wish you good luck in your study.

Manager.

You are however advised to get written consent from the people you intend to interview before the study. At the end of the study, you are expected to submit at least one hard copy and electronic copy of the report to the Hospital

Permission is hereby given for you to assess nurses and social workers at IDCC to assist you in your research to investigate the psychological distress in HIV positive children as perceived by professionals and family caregivers in Mochudi.

RE- PERMISSION TO USE IDCC NURSES AND SOCIAL WORKERS AS PART OF A RESEARCH SAMPLE FOR A MINI-THESIS - YOURSELF

WESTERN CAPE

Dear Sir

Mochudi

P O Box 24

Deborah Rerief Memorial Hospital Laboratory
Mr Aneth Mataka

REFERENCE: DRM

14 March 2011

REPUBLIC OF BOTSWANA

DRM HOSPITAL,
P.O. BOX 24,
MOCHUDI



TELEPHONE: 577333
FAX: 577336