

**Experiences of caregivers working with  
children living with HIV/AIDS**

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**Running head: EXPERIENCES OF CAREGIVERS**

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### **ABSTRACT**

The present study aims to explore the experiences of caregivers working with children living with HIV/AIDS in the context of a children's home. While there has been research conducted on family members as well as community based caregivers of people living with HIV/AIDS, there has been a paucity of research on caregivers of children living with HIV/AIDS in Children's homes. There is a strong need to address this area of deficit in order to identify and tackle areas of difficulty as well as rewarding aspects to enhance the caregiving experience

This pilot study adopted the interpretive research paradigm, is qualitative in nature and utilized in depth interviews as a means of data collection. Four women working as caregivers at the children's home were interviewed and the data obtained was analysed using thematic content analysis. The present study highlights the positive as well as the negative aspects of caregiving from the perspective of the caregivers. While caregivers identify the difficulties that they face as a result of caregiving, they also acknowledge the rewards that they attain from their line of work. Furthermore the present study emphasises the coping strategies employed by the caregivers on a personal and an organisational level as well as the resources that aid coping and the constraints against utilising the coping resources. In addition issues of attachment and detachment associated with caring for children, that are particularly pertinent to these non –familial caregivers have been explored.



**An Investigation of the experiences of caregivers working with children  
living with HIV/AIDS**

**CHAPTER ONE**

**INTRODUCTION**

Caring for people with HIV/AIDS is an enormous task. The fact that there is no cure for the disease adds an additional burden to caregivers when they see the numbers of those infected increase everyday. Armstrong (2000) believes that caregivers are a precious resource that needs to be protected against stress and burnout. She further argues that the quality of care they provide and their ability to do so over a sustained period of time depends on their own well - being and morale. The ability to sustain this morale and well being is, however, bound to be tested even further when those that are infected happen to be children. It is this very fact that propelled the researcher of the current study to look at this special population of caregivers in order to ascertain what kind of experiences they go through when they provide this essential care.

As the AIDS epidemic impacts on communities, children are often the most affected, particularly orphans and abandoned children who have to deal with a myriad of circumstances. Not only do they have to deal with the loss of parents and caregivers but they may also have to face being ostracized and denied social, economic, emotional and educational support due to the fear and discrimination associated with the disease (Interagency Coalition on AIDS and Development, 2002).

Children who are orphaned as a result of one or more of their parent dying of AIDS may be accommodated in different settings. In sub Saharan Africa where HIV/AIDS is the predominant cause of children becoming orphans, over 90% of the orphans live with relatives (United Nations International Children's Emergency Fund, 2004). AIDS orphans may also be supported by and integrated into families within their communities or at times even fend for themselves.

Unfortunately, for children who are orphaned and most importantly HIV positive themselves, the situation becomes critical as the above options become limited. Children with HIV may be abandoned by friends or families who find themselves unable to cope with the stigma associated with the disease or adequate resources required to care for a sick child. Some of these family members may also be too ill themselves to care for the orphaned sick child. In the absence of such alternatives, children with HIV/AIDS who are orphaned and abandoned may be accommodated in children's homes (ICAD, 2002).

An important point to remember is that initially these children's homes were not specifically set up to accommodate children who are HIV positive, but existed to provide accommodation for children who were abandoned or orphaned for a number of other reasons that were not necessarily related to HIV/AIDS. However, because of the increase in the number of children orphaned and abandoned because of HIV, an increasing number of children found in these homes are infected and affected by the disease. This suggests that care-giving or the demands of providing care for children in Homes has also changed, with care-givers having to sometimes provide palliative care.

Caring for people with a terminal disease is a physically, emotionally and sometimes, spiritually challenging undertaking, which places a great deal of pressure on the coping resources of the caregiver. As mentioned earlier, caregiving becomes an even more challenging undertaking when the people being cared for are children with HIV/ AIDS. However, because the main route of transmission of HIV for children is mother to child transmission as opposed to the sexual nature of the mode of transmission among adolescents and adults, there exists an element of blamelessness for these children. They may thus be regarded as innocent victims who contracted HIV through no fault of their own. The difficulty lies in having to contend with the loss of life of a young person whose full potential is yet to be fulfilled. In the context of caregiving at Children's homes, there exists the potential for the development of a close bond between child and caregiver, particularly since the caregiver represents the only viable and available nurturing adult figure in the child's life. These are some of the factors that impact on the experiences that caregivers have in their interaction with children living with HIV/AIDS as opposed to their interaction with adults who are also living with the disease.

While there have been studies on stress and burnout conducted on populations of healthcare professionals, the experiences of caregivers in Children's Homes have been inadequately researched and addressed. This can be attributed to the previously alluded to precarious position of Children's homes and care providers, who, because of the HIV/AIDS pandemic, found their roles changing from being just "house mothers" to including health care provision, among their many roles. Unfortunately this change in

their roles has not necessarily attracted interest of researchers and resources, as it has been the case with organisations that are known to specifically work in the area of HIV/AIDS. It is anticipated that this study will add a deeper understanding of the experiences of caregivers and address the gap found in research literature in this area.

The aim of this study is to investigate the experiences of caregivers working with children living with HIV/AIDS, using a sample of caregivers from a children's home in the Durban area. The experiences of caregivers would be used as a basis for recommendations for effective coping methods to enhance effectiveness in caregiving as well as identifying and enhancing rewards that may be attained through the process of caregiving.

### **1.1. Aim**

The aim of the study is to investigate the experiences of caregivers working with children with HIV/AIDS.

### **1.2. Objectives**

The objectives of this study are to investigate the stressors experienced by caregivers on a personal and organisational level, the way that caregivers cope with challenges associated with working with children living with HIV/AIDS and the rewarding aspects of caregiving.

### **1.3. Definition of terms**

#### **1.3.1 Caregiver**

According to the dictionary of psychology, the term caregiver refers to anyone involved in any of the phases of healthcare such as identification, prevention or treatment of illness or rehabilitation (Reber, 1985). However, for the purpose of this study Armstrong's (2000) definition of a caregiver will be adopted. In this case, the term caregiver refers to non-medically qualified people, falling outside of the formal health services, which have been recruited, trained and supervised by the organisation within which they are employed. They may be trained in basic nursing care, terminal care, pain management, psychosocial counselling and bereavement counselling skills.

#### **1.3.2 Orphan**

The term orphan is defined as a child under the age of 15 years who has lost a mother or both parents (ICAD, 2002).

#### **1.3.3 Coping**

Lazarus & Folkman (1984) define coping as the constantly changing cognitive and behavioural efforts that an individual makes to deal with internal and external demands that he/she perceives as exceeding the resources that he/she possesses.

### **1.3.4 Coping Resources**

The term coping resources is used to refer to factors that serve to reduce the demands of stress upon an individual (Lazarus & Folkman, 1984).

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1. Research on caregiving**

Because of the paucity of research literature that focuses specifically on caregivers of children living with HIV/AIDS in Children's homes, much of the literature employed in this review was adapted from research on healthcare workers in palliative care settings. These are people who provide care for patients suffering from chronic and terminal illnesses other than HIV/AIDS.

Also included is information obtained from research with AIDS emotional support volunteers as well as community based caregivers of people living with HIV/AIDS. Most of the literature reviewed indicated that caregivers usually deal with issues relating to personal identification with the disease and with the patient, family problems, negative community perceptions, fear of infection and burnout. (Armstrong, 2000; Cho & Cassidy, 2001). Of importance was the revelation that there are also rewards obtained from working in such an environment, which helps people remain in such a line of work. Although the populations under consideration in the literature may differ from those in the research sample, many of the experiences of caregiving were found to be similar.

## **2.2. Problems faced by caregivers**

### **2.2.1. Stress**

A number of researchers have attested to increased stress levels in caregivers who deal with patients living with HIV/AIDS (Armstrong, 2000; Cho & Cassidy, 2001). This may be attributed to the demanding and complex nature of their work. According to the abovementioned authors, increased stress levels are said to manifest in different ways. Some of the signs of stress among caregivers in the field of HIV/AIDS are manifested as psychological, behavioural and somatic complaints.

#### **2.2.1.1. Manifestations of stress**

Psychological manifestations of stress include feelings of inadequacy, helplessness, guilt, loss of confidence and lowered self-esteem. Behavioural manifestations of stress include irritability, tearfulness, depression and difficulty in getting along with people. Somatic manifestations of stress include loss of concentration, sleeplessness, excess fatigue and bowel disturbances (Armstrong, 2000). Furthermore the aforementioned author made reference to Pierre Brouard, who provides counselling for other counsellors in South Africa who asserts that chronic stress, which is the result of caring for people with HIV/AIDS, can manifest as either over-involvement or under-involvement on the part of the caregiver. Over-involvement is when the caregiver is so emotionally connected that



they lose all perspective and burn out quickly. Under-involvement is a withdrawn, unemotional and disconnected way of working with people.

### **2.2.2. Social stigma**

Caregivers find themselves having to contend with the social stigma and taboo associated with the disease, as well as the assumptions that they work with people with HIV/AIDS because they are themselves infected by the disease. This is known as “secondary stigma” (Armstrong, 2000). Secondary stigma has an adverse effect on the relationships that the caregivers have with their family, friends and the community at large. This may be dangerous as these are the very people they might need for support.

### **2.2.3. Personal Identification with children under their care**

According to Armstrong (2000) caregivers who are themselves HIV positive face the risk of personal identification with the client and his/her illness. In addition she indicates that HIV positive caregivers find it difficult to watch as their clients waste and wane due to the ravages of the disease. This makes it impossible for them not to be reminded of their own impending death. In 2002, Makhaba and Memela compiled a report which provided a detailed account of planned and executed intervention processes for caregivers at Durban Children’s Home. This followed observations made by management of numerous problems in coping that were experienced by caregivers following the deaths of children who were under their care. The report indicated that one of the confounding factors was that caregivers found themselves also having to deal with family members

and relatives who were HIV positive or had died from AIDS related diseases. This further increases their personal involvement with the disease.

#### **2.2.4. Negative perceptions of family and community**

Makhaba and Memela (2002) also reported that as a result of caregiving, caregivers often experienced problems in their own families. These problems included dealing with spouses or partners who often fear that they (caregivers) might be infected with HIV. In addition it was reported that caregivers had to deal with negative perceptions from their communities as it was often believed that they worked as caregivers for children with HIV because they were also infected with HIV. Thus, caregivers often experienced secondary stigmatisation as a result of the nature of their jobs.

#### **2.2.5. Fear of infection**

Makhaba and Memela's report also asserted that even though caregivers had received AIDS training they often doubted the information they had been given and reported feeling uncertain about their safety from possible infection. This was in line with the results from other surveys, which revealed that healthcare workers caring for people with AIDS, despite having a generally good knowledge base with regards to AIDS, often expressed negative attitudes towards patients with AIDS (Bellani, Furlani, Gneccchi, Pezzotta, Trotti & Bellotti, 1996).

### **2.2.6. Burnout**

In Guinan, McCallum, Painter, Dykes & Gold's (1991) exploratory study of stressors and rewards experienced by volunteers working as AIDS emotional support volunteers, it was asserted that in the context of caregiving associated with AIDS, the contact between caregivers and patients tends to be particularly sensitive as the chronic and terminal nature of AIDS tends to engender feelings of hopelessness, isolation and fear in both the caregiver and the patient. The abovementioned researchers have suggested that the persistence of such feelings lead to burnout, which is a syndrome characterised by chronic emotional exhaustion, depersonalisation and feelings of diminished personal accomplishment in the caregiver. Burnout in caregivers is a threat to effective care and may be a factor in determining whether or not a particular caregiver remains in the job.

### **2.3. Grief and bereavement**

When working with terminally ill patients, it is inevitable that one ruminates about issues related to death and dying. Since there is still no cure for HIV/AIDS, caregivers find themselves having to contend with issues related to death and dying. One of the areas that have been extensively researched with terminally ill patients, especially those with cancer, is grief and bereavement. Cho & Cassidy (2001) have focused on the examination of chronic bereavement resulting from working with HIV infected and affected clients. Their research provided different types of grieving processes that can be identified in people who work with such patients. These include, but are not limited to, multiple loss syndrome, anticipatory grief, chronic grief, disenfranchised grief and complicated grief.

However since the current study aims to investigate the broad experiences of caregivers working with children living with HIV/AIDS, and not specifically with how they deal with death it is unnecessary to embark on an exhaustive discussion of issues related to grief and bereavement.

## **2.4 Rewards of caregiving**

While engaging in an exploration of aspects of caregiving that are stressful, there exists an equally important need to examine aspects that are rewarding and personally enhancing in the lives of caregivers. Hendrick's (2000) research on the impact of HIV on caregivers found that family members involved in the process of caregiving reported deriving a sense of meaning to their lives. In addition, during the course of caregiving, they were able to show their competence under difficult circumstances.

The aforementioned author also includes learning more about oneself and an increased awareness of one's own mortality, thereby engendering a greater appreciation for life as a potential reward. According to Guinan's et al., (1991) study, for the most part participants found the volunteer process rewarding if they were able to use groups, friends or religion as a form of support. However, it was found that regarding the work as rewarding did not preclude perceptions of it being less stressful.

### **2.5. Intervention strategies employed at an organisational level**

Because of the significantly high incidences of stress and burnout among AIDS care workers it is imperative to review the different intervention strategies that may be utilised at both an organisational and personal level. Armstrong (2000) concluded that providing stress management programmes for caregivers working with people with HIV/AIDS should not be regarded as a luxury, but a necessity. She recommended that the following measures for managing stress form part of the general routine for maintaining the well being of caregivers. These include:

- Setting realistic work targets for caregivers
- Regular time off for caregivers
- Annual retreats for caregivers
- Provision of healthcare and paid sick leave
- Team work and regular meetings to discuss issues and share problems
- The appointment of a carer's counsellor
- An effective voice for caregivers in decisions that concern them
- Regular training and refresher courses for caregivers

According to Sadock & Sadock (2003), self – help support groups have been reported to be helpful because a group of people sharing similar experiences provides an individual with mutual support, empathy, and understanding and enable members to adopt an adaptive manner of dealing with various issues. Cho & Cassidy (2001) assert that in sharing their experiences with each other, caregivers can provide much needed support to each other.

## **2.6. Coping strategies employed on a personal level**

On a personal level, caregivers may use various coping strategies incorporated into their everyday lives to prevent them from becoming overwhelmed with the demands of their work. Cho & Cassidy (2001), assert that caregivers need to make time and space for their own needs by indulging in leisure activities such as reading, taking holidays, participating in sport and getting together with friends. Caregivers should also be able to attend the funerals of people under their care and have the opportunity to interact with the family of the deceased. It is crucial that caregivers acknowledge and work through the loss of a relationship, instead of ignoring it.

### **CHAPTER THREE**

#### **CONCEPTUAL MODEL**

##### **3.1. Transactional model of stress and coping**

The conceptual model adopted for this study is based on Lazarus and Folkman's (1984) transactional model of stress and coping. It was deemed appropriate as it provides an explanation for the ways in which caregivers evaluate and cope with the stressors that they face in their jobs on a daily basis. The focus in the review of this conceptual model will thus be on aspects of coping.

According to this model, the individual and the environment are said to exist in a dynamic and mutually reciprocal relationship. This view of the constantly altering environment, individual and his/her relationship with the environment is pertinent to the research being undertaken. Care giving in the context of HIV/AIDS is not an event but rather a process. Many changes occur for the child as well as the caregiver during the progression from HIV infection to an AIDS stage. Different stages of the disease are accompanied by diverse emotions as well as different means of coping for the caregiver. As the disease progresses, the demands made on the caregiver increases. These increasing demands may increase stress levels of caregivers and thus necessitate greater and diverse coping resources.

Lazarus and Folkman (1984) emphasize primary and secondary appraisal as important concepts in understanding how people cope with stressful situations. Primary appraisal focuses on the individual's evaluation of harm, threat and challenge in the environment. Secondary appraisal involves assessing both personal and environmental resources available for dealing with a stressful situation. When a caregiver engages in primary appraisal of the environment and perceives it to be one in which there is the potential for stress, he/she would then take stock of the resources that are available or set about procuring the resources for dealing with the stress. Thus, both primary and secondary appraisals operate concomitantly to determine the amount of stress and the strength and quality of the emotional reactions.

### **3.2. Coping**

Lazarus & Folkman (1984) define coping as the constantly changing cognitive and behavioural efforts that an individual makes to deal with internal and external demands that he/she perceives as exceeding the resources that he/she possesses.

These authors identified problem-focused coping which is directed at managing or altering the problem causing the distress and most likely occurs when conditions surrounding the problem are appraised and amenable to change. Emotion-focused coping is directed at regulating the emotional response to the problem and occurs when the evaluation of the problem yields the view that nothing can be done to modify the challenging environmental circumstances. According to O'Neill & McKinney (2003), problem-focused coping strategies include information gathering, planning, and taking



direct action, while emotion-focused strategies include efforts to escape or avoid problems, emotional outbursts, and self-accusation. These distinctions between the two coping strategies are not meant to imply that problem- focused coping is positive and emotion- focused coping is negative. Rather it is a question of which form of coping is more adaptive given the appraisal of a situation as being changeable or unchangeable. Therefore problem focused coping would be more adaptive if one felt that the conditions surrounding the problem could be changed and emotion focused coping would be more adaptive if the problem was deemed unchangeable.

### **3.3.Coping resources**

Being able to cope with a situation depends to a large extent on the resources that a person is able to draw on (Lazarus & Folkman, 1984). In secondary appraisal, the individual evaluates the personal and environmental coping resources around him/her in order to manage the situation (Naughton, 1997). The resources that are regarded as characteristically existing within the individual may be divided into physical resources and psychological resources. Rather than being regarded as mutually exclusive categories, these resources should be regarded as being connected. Caregivers may find that some resources are more available than others. Furthermore the levels of the resources tend to fluctuate at different times depending on the circumstances. These will be outlined in greater detail below.

### **3.3.1. Health and energy**

Physical well-being has been found to play a relevant role in coping with problems and stress. While Lazarus and Folkman (1984) have attested to people's capability of coping despite poor health and depleted energy, they state that having good health and higher levels of energy make it easier to cope with stressors. This implies that if the caregivers in this study are experiencing low levels of energy or poor health themselves, this compromises their ability to cope with stressors as effectively as they would if they enjoyed optimal energy levels and good health.

### **3.3.2. Positive beliefs**

According to Lazarus & Folkman (1984), holding positive beliefs is a crucial psychological resource that can be utilised in coping with stress. Beliefs that pertain to how much personal control one perceives to have are of particular significance in moderating the effects of stress as well as facilitating coping. If caregivers feel that they are able to have control over the outcome of a situation, they should be able to cope better than if they feel as though nothing they do will change the outcome. For example if a caregiver believed that her care helped to ease a child's physical discomfort, then she would be able to cope better rather than if she felt that her intervention would have no effect on the child's level of comfort. Thus the more personal control one feels one has, the greater the ability to cope.

According to the aforementioned authors, religious beliefs also play a significant role in coping. One's religious belief may be regarded as a positive belief if one's religion subscribed to the notion of a benevolent higher being. Thus a caregiver who believes that there is a merciful God is able to cope better than one who does not hold such beliefs. This may seem paradoxical in view of the above statements about the amount of personal control one perceives to have diminishing the effects of stress and facilitating coping. The implication when one subscribes to the notion of a higher being is that all the control resides with the higher being and not with the individual. Therefore it would seem that the notion of having no personal control would increase the effects of stress and diminish the ability to cope. However when individual perceives that the control lies with a *benevolent* higher being rather than one which would not be merciful, they are able to cope better.

### **3.3.3. Problem solving skills**

Even though different researchers and authors conceptualise problem solving skills in different ways, there is the general consensus among these authors that people who possess skills necessary for solving problems, are more likely to be able to cope with stressful situations and events than people who do not possess such skills (Lazarus & Folkman, 1984). Accordingly, caregivers in our study who possess and apply problem-solving skills should be more adept at coping with stressors. People whose problem solving skills are deficient would benefit from programs which would help them develop such skills.

### **3.3.4. Social skills**

Social skills, which may be defined as socially appropriate and effective means of communication and behaviour, have been implicated as a resource in helping people to attain greater control over their social interactions (Lazarus & Folkman, 1984). This means that a person with good social skills is more adept at communication with others people and is therefore more likely to be able to enlist their help and support which is important in facilitating coping.

### **3.3.5. Social support**

Lazarus and Folkman (1984) have attested to the fact that supportive social relationships mediate the effects of stress and facilitate coping. Social support may also change with alterations in a person-environment relationship. This means that the kind of social support a person seeks out may change at different stages as the encounter progress. As changes in the process of caregiving occur, caregivers may find themselves seeking out different sources of social support to help them cope. For example, initially caregivers may informally seek out the help of family and friends to help them to cope with the demands of their work. As demands and stressors increase, caregivers may find themselves requiring greater support. Thus they may find themselves seeking help from colleagues and supervisors within the organization or even health care professionals such as Psychologists.

### **3.3.6. Material resources**

Material resources refer to money and the goods and services that can be procured therewith. According to Lazarus & Folkman (1984), being in possession of monetary resources provides easier and more effective access to professional assistance and increases the coping options available to an individual. Furthermore they state that simply being in possession of financial resources decreases an individual's vulnerability to threat and thus facilitates effective coping. For the caregivers in the current study, this means that having access to money makes it easier for them to cope with stressors.

### **3.4. Constraints against utilising coping resources**

Constraints refer to the factors that inhibit the way a person copes (Lazarus & Folkman, 1984). These include personal and environmental constraints which will be elaborated on below.

#### **3.4.1. Personal constraints**

Personal constraints allude to cultural values and beliefs that a person has been raised with, as well as products of a person's unique personal development that influence their behaviour and emotion (Lazarus & Folkman, 1984). This means that, cultures and societies have their own set of rules of what they perceive to be appropriate behaviours

and feelings. According to the aforementioned authors, despite individual differences in people as well as situational differences, it is found that culturally derived values and norms function as crucial constraints. This means that we need to take into consideration that the experiences of the caregivers in our study and their ways of coping may be influenced by their cultural contexts.

#### **3.4.2. Environmental constraints**

According to Lazarus & Folkman (1984), constraints that may exist in the environment and be out of the control of the individual may thwart his/her best efforts to cope with stressful situations and events. For the caregivers in this study environmental constraints may refer to the conditions under which they work as well as live. Specifically this may refer to the actual physical environment in which they find themselves working in on a daily basis. If the physical environment at the home is not conducive to the kind of work being attempted, this may hamper efforts at coping. Similarly, if their living quarters at the home are poor, they may find their efforts at coping impeded.

## **CHAPTER FOUR**

### **METHODOLOGY**

#### **4.1. Method**

The interpretive research paradigm was selected for the present study. This research model operates under three key assumptions. The first assumption is that people's subjective experiences are authentic and should be taken seriously. The second assumption is that people's experiences can be understood through interaction with the researcher as well as empathetic listening by the researcher. The third assumption is that qualitative research techniques are best suited to this task (Terre Blanche & Kelly, 2002). Of importance in the interpretive paradigm is the frame of reference of the observer (Henning, van Rensburg & Smit, 2004). In other words, rather than the existence of an objective reality, it is understood that reality can be influenced by the observer and the process of observation.

According to the abovementioned authors, the interpretive research paradigm endeavours to generate descriptive analyses that emphasise profound interpretive understanding of social phenomena. As the current research endeavours for a deep, rich and meaningful exploration and understanding of the experiences of caregivers working with children with HIV/AIDS as well as their perception of their experiences, the interpretive research paradigm was regarded as the most suitable approach.

In keeping with the interpretive framework, a qualitative methodology that utilised in-depth interviews had been adopted to allow for the exploration of experiences of caregivers within the context of a children's home. Through the interviews, rich descriptions of their experiences as influenced by their unique circumstances have been generated. These descriptions serve to provide substantial data from which perceptions regarding stressors, rewards and coping may be identified as themes and categories. These themes will be used to provide a collated examination of the experiences of caregivers with the view to providing recommendations and interventions.

#### **4.2. Sample**

The sample comprised of four women employed as House mothers and caregivers at a children's home in the Durban area. This is the house within the children's home which accommodates children with life threatening illnesses, particularly those suffering from HIV and other associated opportunistic infections. The number and gender of people interviewed was influenced by the focused nature of the study. This means that although the chosen home had other caregivers and people of both sexes, it was only the four ladies interviewed who worked specifically with children with HIV/AIDS. The four participants were Black Africans, affiliated to the Christian faith, ranging in age from 25 to 40. None of the women were married but three of the four were involved in a relationship with a significant other. One of the four women had two children, with the rest being childless. All of the caregivers had a high school level of education. None of the caregivers lived in the Durban area except for purposes of work. One of the



caregivers has worked in that particular house in the children's home for a period of five years. Two of the caregivers have worked there for three years and one of the caregivers has worked there for a period of a year. This particular Children's Home is one of two such facilities in the Durban area and this sample will serve as a pilot sample for further research in this area.

#### **4.3. Instruments**

Data was obtained through in-depth interviews to facilitate the collection of information. The questions that were asked in the interview are outlined on the interview schedule (See Appendix A). As interpretive research aims to explore phenomena within a particular context, observation served the purpose of describing the context (Terre Blanche & Kelly, 2002). Caregivers were observed carrying out their duties as well as in their interaction with the children under their care. Observations as well as the researcher's interpretations of observations were recorded as field notes. Interviews were conducted in English. This language medium was chosen as it is the first language of the interviewer. In addition, the participants reported that they felt sufficiently conversant in English to answer the interview questions. Answers to the interview questions were recorded on a dictaphone and transcribed verbatim.

#### **4.4. Procedure**

The director of the children's home was approached and an appointment was made with her to discuss conducting research at the home. She was provided with an outline of the scope and purpose of the proposed research before the meeting. At the meeting with the director, she was given an opportunity to ask questions pertaining to the research. She also reviewed the consent forms that would be given to the house mothers. The director awarded the researcher written permission to conduct research using participant observation and in-depth interviews. At their weekly meetings, the director provided the house mothers with the consent forms which they filled in and returned to the researcher. Participant observation and interviews commenced in the last week in May and ended in the last week of June.

#### **4.5. Data Collection: In-depth interviews**

In-depth interviews were conducted on a one to one basis with each caregiver. The interviews were conducted in English and averaged approximately one to one and a half hours in length. An interview schedule was utilised (See Appendix A). All interviews were tape recorded and transcribed verbatim.

#### **4.6. Analysis**

The text generated from the in depth interviews was analysed using thematic content analysis (Mayring, 2000). Thematic content analysis was employed in order to generate thematic categories to enable a description of the experiences of the caregivers. The initial step in thematic analysis entailed inducing and identifying a range of themes. The following step in the analysis was to code the data which according to Terre Blanche and Kelly (2002) entails marking different sections of the data as being examples related to one or more of the themes that have been generated. The thematic categories that had been generated were difficult aspects of the job, reactions to deaths of children under their care, issues of emotional attachment and detachment, attitudes of other people towards their work, rewards of caregiving and coping strategies utilised by caregivers. After coding, the themes were elaborated on and explored in greater detail in order to uncover implications that had not been captured by the coding system. The final stage in the analysis of the data was the interpretation and checking and finally generating a written account of the experiences of caregivers using thematic categories as subheadings.

## **CHAPTER FIVE**

### **RESULTS AND DISCUSSION**

This chapter presents a summary of the findings of the data collected through observation as well as in depth interviewing. In keeping with the qualitative paradigm, “thick descriptive data” will be used to substantiate the findings. This means that the caregiver’s responses will be quoted verbatim. Findings based on data collected will be presented in terms of the stressors and rewards of caregiving in the Children’s home as well as coping strategies employed to deal with stressors. Issues of emotional attachment and detachment on the part of caregivers will also be elaborated on.

In addition this chapter presents a discussion of the findings and compares the findings of the present study to previous studies and theoretical contributions mentioned in the literature review. At this point it is important to revisit the focus of enquiry in the study. The aim is to explore the experiences of caregivers working with children living with HIV/AIDS in the context of a children’s home. The objectives of the study is to investigate the stressors experienced by caregivers, the rewarding aspects of caregiving as well as the ways in which caregivers cope with challenges associated with working with children living with HIV/AIDS.

### **5.1. Observations**

Observations at the Children's Home were conducted over a period of four days.

The residence in which the children are housed is split over 2 levels and includes rooms for groups of children as well as rooms for the caregivers when they are on night duty. In addition caregivers have rooms outside of the actual house which affords them a bit more privacy should they feel they require it. The children eat their meals in a dining room which has tables and chairs arranged in groups. Children also have access to a rather large common room which has a television, video recorder as well as a "hi-fi" system. There are also specific playrooms in which the children play with toys that are specifically kept there. Children have a large outdoor area which is well equipped with playground equipment for outdoor play as well as access to a swimming pool. Meals are prepared by the caregivers in a large kitchen. The home also has a "remembrance garden" in which the names of children and caregivers who have passed away are displayed. At the end of the year a prayer ceremony is held at the home to remember and pay respect to all the people who have passed away during the year.

There are four caregivers allocated to the house and at any given time there will always be two caregivers on duty. Caregivers work every alternate week.

Interaction between the caregivers and the children under their care appeared to be characterised by familiarity, affection, warmth and genuineness. The caregivers appeared to be at ease with their charges and displayed no tension or anxiety. Children had unrestricted access to the caregivers. The day's routine is written out and pasted on the wall of the common room.

Routines were followed and the children seemed to understand what was expected of them. Although cleaning staff are employed in that capacity at the home, children are also allocated certain responsibilities such as the cleaning of their rooms and tidying of the areas around their beds and personal cupboards. In addition children were allocated other cleaning duties such as the sweeping of certain rooms that were in use by all of the children around the home or helping to tidy up after meals. The children complied with these duties and did not have to be reminded by the caregivers. The level of neatness and cleanliness in the living areas attests to the earnestness with which the children undertake such responsibilities. The children appeared to be treated alike except for the youngest child who was about two years old and whom everyone including the other children paid a bit more attention to. At times the children did clamor for attention from caregivers and at such times the level of noise did escalate dramatically. Even though children did sometimes play roughly with each other during free play times, the caregivers were able to maintain order.

## **5.2. Interviews**

In- depth interviews conforming to the questions on the interview schedule conducted on a one on one basis with the caregivers yielded the following themes.

***Theme One: Difficult aspects of the job***

- **Hours of work**

Caregivers reported that the hours of work tended to be tiring and sometimes disorientating, as they had to be on duty for a week at a time including night duty. They reported the long hours as being a source of difficulty in the job.

*“Sometimes you wake up tired because everything is going by the time. It’s a long day from morning to night when everything is going by the time.”*

and

*“Sometimes when you work night shifts you always get tired because we wake you early in the morning and we sleep late.”*

The caregivers in the study reported that while they did find working such long hours in a shift stressful, working every alternate week gave them the opportunity to spend time away from their duties and recuperate. Consistent with Lazarus and Folkman’s (1984) assertion that good health and higher levels of energy make it easier to cope with stressors, was the findings of how the caregivers felt when their health and energy was not at an optimal level. The caregivers in the study reported that although they were generally in good health, the long hours of work during their week long shifts made them feel disorientated, irritable and tired at times. They reported that their lowered levels of energy at the end of a shift predisposed them to greater susceptibility to the effects of stress such as feelings of depression and anxiety and a lowered ability to cope as effectively with stressors. During times of minor illness the caregivers felt less able to

cope effectively with the demands of their work and opted to take leave. The leave did allow them to recover the necessary energy they needed to deal with their daily tasks.

- **Disciplinary problems**

The two caregivers with the least number of years of experience also expressed feelings of uncertainty with regards to disciplinary matters and felt that they needed training in disciplining the children more effectively. There existed feelings of hesitancy and guilt in disciplining them and the caregivers were afraid of being too harsh on them given their medical conditions and their relatively short life spans.

*“Sometimes I find it difficult to discipline the children. I know they are sick and that makes me to not want to shout at them. But when they are naughty we have to do something.”*

The caregivers found themselves having to contend with uncertainty and difficulty in disciplining the children. While they revealed an understanding of the fact that children would sometimes behave in a naughty, disruptive manner, they experienced conflict when they had to discipline the children under their care. This conflict arose because they felt as though harsh discipline would serve to exacerbate the children’s existent medical conditions. Furthermore their own sense of guilt about punishing children who were ill and had a shortened life span made things even more difficult. These conflicting emotions effectively resulted in mounting frustration leading to them realising that they would require clarity and support on this issue. According to Lazarus and Folkman



(1984), the possession and application of problem solving skills is associated with enhanced coping. The caregivers felt that they needed a greater understanding of how to deal with issues of discipline involving the children. They felt that they would benefit from a program directed at this issue. Thus enhanced knowledge and skills in areas which were perceived to be deficient was associated with an increased ability to cope. This is also consistent with Armstrong's (2000) assertion that regular training and refresher courses for caregivers would be a helpful measure in managing stress and thereby maintaining the well being of caregivers.

- **Feeling of helplessness**

Caregivers also described feeling a sense of helplessness when children are ill or in pain and they are unable to do anything to alleviate the suffering.

*"It is too difficult if you find that the child is sick and that is the last stage -when you give the medication and you see it doesn't help. The child is still complaining about something. Sometimes when the person has died you blame yourself and say maybe I did not give them enough things that I have to do but inside you worry what can I do now. Even then you don't know how to help but the sickness is inside already and you can't do anything. That is difficult."*

This is consistent with Lazarus and Folkman's (1984) assertion that a person's perception of how much personal control he/she has is of significance in moderating the effects of stress and facilitating coping. The caregivers felt that despite their efforts at providing the child with the necessary care, they were unable to stop the child from feeling pain or discomfort. This tended to increase the levels of stress and lessen their ability to cope.

- **Fears pertaining to possible infection**

The caregivers also testified to initially having fears related to their own state of health and the possibility of being infected with diseases as a result of their work.

*"...I don't know what I can get. Some of the people got TB and you could get that. We used to bathe the children without gloves and after that we used gloves but we don't know what we have got by then."*

However being educated about the mode of transmission of HIV helped the caregivers to allay these fears.

*"It used to worry me when I started working but I'm fine now. We did HIV training and that helped me. I know how the virus spreads and I can't get it like that."*

As mentioned in the literature review, Makhaba and Memela's report (2002) alluded to the sense of uncertainty that caregivers felt regarding their safety from possible infection when working with children living with HIV/AIDS. This was despite the training that they had received. In the current study, however, caregivers reported that the HIV/AIDS

training that they had received assuaged their initial fears of possible infection. Through training they had learnt to take the necessary precautions such as wearing gloves when bathing the children with open sores. It is important to note that in the three years between the report released by Makhaba and Memela and the current study, there have been ongoing HIV/AIDS campaigns and educational programs in the various forms of media. This could partly account for the difference in findings regarding the caregiver's fears of infection in the report and the current study. Overall, the current study revealed that fear of infection did not appear to be a significant source of concern and did not preclude their physical interaction with the children.

### ***Theme Two: Reactions to death***

- **Reactions to impending deaths in the home**

Caregivers recounted intense emotional reactions to the impending deaths of children. This was exacerbated when the child appeared to have been aware of his/her own impending death and when the child suffered physical pain at the time nearing death. However paradoxically, for the caregivers, the impending death of a child in pain appeared to bring a sense of relief and release for a child in agony. Some caregivers reacted by doubling their efforts at providing comfort for the child.

*“...you think about your own children and also the pain the child is feeling but the other side you feel the child is relieved. If she suffered for so long you feel she is being released.”*

Some caregivers reacted by increasing their efforts at providing comfort and support for the child whose death was imminent.

*“...one child I knew he was dying. I wanted to give him the most attention, love, caring that I can give. I remember there was this child who was very strong but I knew that something could happen at any time he was so strong. He used to come to the kitchen and pour water in the tap and drink just a little bit and throw the rest away. When I was looking at him, I could sense he was watching me. This feeling, sixth sense or what it made me see this child does need that attention from me. He kept on coming to the kitchen by that year the child care workers on the weekends were the ones who were cooking. I always liked cooking so I invited him over to sit with me. I saw that he was happy but he was scared to ask if he could stay. So he kept coming for the water as an excuse. He was asking me questions and he wanted to talk just talk. He was telling me about his family and different stories. He was telling me about the good times. That relationship that he wanted from me, I did give him. He could sense he was dying. That boy was very clever. He was nine years old and he was scared to die. He didn't say anything. But the social worker once called him and told him he is HIV positive and I'm not sure if they told him he was going to die. In the kitchen he was asking me about HIV. He asked me do you die. I was telling him what I know but he wanted another person to tell him about it. I did sense he was scared and looking to me for answers and some I did not know. I was very sad when he died. I formed a bond with him but after these days in the kitchen he became very*

*sick where he was just lying there not eating, vomiting, feeling pain. I was sensing he was feeling a lot of pain, every movement was pain. Painkillers wasn't helping so before he died I did accept it and I prayed for him in my room. Please God it is time for him to go. The pain is too much for him. Take him now or make him better, I did accept but I was very sad. I also said thank God it is almost over."*

Caregivers appeared to be particularly moved as they recounted their feelings about the impending deaths of children. Furthermore they recalled more intense personal reactions when a child appeared to have been aware of his/her impending death and when the child was experiencing increasing physical pain that medication failed to relieve. Instead of withdrawing emotionally from the sick child, the caregivers reported intensifying their efforts at making the child feel special and loved. Their motivation appeared to be to ease the child's suffering as well as providing themselves with a feeling that they had done their best for the child and thus prevent a sense of guilt after the child has passed on. Thus instead of prematurely separating and withdrawing from the child in preparation for the parting, caregivers felt more close to the dying child. However in contrast to the literature on anticipatory grief (Sadock & Sadock, 2003) which stated that a strong sense of closeness to the terminally ill person could have the effect of amplifying the impact of the loss at death, the feeling of closeness that the caregivers in the study felt had the effect of relieving any feelings of guilt after the child's death and making acceptance of the child's death easier. Caregivers also reported that the impending death of a child was sometimes a relief for them as it meant that the child would be released from his/her pain.

- **Reactions to the deaths of children at the home**

Two of the caregivers who had experienced the deaths of children under their care in the home attested to the difficulty in coping with the deaths of children particularly when they occurred in quick succession. Difficulties arose not only in coping with their own feelings of helplessness and loss but also in trying to keep the other children in the home from feeling the loss of the children. Reactions to the death were manifested not only emotionally but somatically as well such as the loss of appetite and weight.

*“You can’t help the feelings. You feel so sad, you feel sick. You can’t cry in front of the others especially the other children because they will feel sad. But you have to talk to release yourself because if you keep it inside you get sick. You have to talk about it. Sometimes it happens like if you thinking about it by yourself you can get sick.”*

and

*“I knew that I had to be strong especially since we are working with children. The children saw that these others were sick and they used to sense what was happening even though they didn’t know the children were dying but I had to be strong. . . On the first day I took the children to the swimming pool and I was pretending that nothing happened although I was thinking that in the house this thing happened but I had to be strong for the sake of the other children so they could not see what was happening. In my room things did happen. I used to think and cry but that was healing to me. It was like a month before I got through it. I also became sick; I lost appetite and a lot of weight. It affected me badly...”*

Sukovaty's (2004) examination of how healthcare workers are affected when working with people in pain stated that when patients die, the caregiver has little opportunity to mourn or complete the process of grieving particularly when the losses are simultaneous or within a short space of each other. Mallinson (1997) alluded to "bereavement overload" which may cause a person to become emotionally overwhelmed, physically exhausted and spiritually demoralised when facing losses in this manner. In the current study, the two caregivers who had experienced the deaths of children under their care in the home attested to the difficulty in coping with the deaths of children particularly when they occurred in quick succession. Their feelings of helplessness and loss were exacerbated by the difficult task of having to keep the other children in the home from feeling the loss of the children who had died. This is consistent with Cho and Cassidy' (2001) assertion that caregivers may have little opportunity to attend to their own grief reactions as there are others whose needs ought to be addressed. Thus they felt that they had to put on a brave face and provide containment for other caregivers as well as maintain a sense of normality for the other children. Reactions to the deaths of children were manifested not only emotionally by thoughts of the deceased and crying when alone in their rooms but also somatically such as the loss of appetite and weight. However rather than becoming spiritually demoralised, caregivers reported that they resorted to prayer to help them to cope and make sense of the deaths of the children. One also needs to make reference to the importance of the wall of remembrance that is found in the home. This wall serves to commemorate the lives of children and caregivers who had died. For the caregivers, it provides an important function of knowing that even though

the children did not have any families, their lives were of significance. Even though caregivers cannot interact and mourn with family members of these deceased children as advised by Cho and Cassidy (2001), they can constantly visit the wall when they need to.

***Theme Three: Emotional attachment/detachment***

For the caregivers working in such close proximity to children, many of whom had no other family to depend on, it was inevitable that close bonds would develop. The caregivers however stated that although they were close to the children, functioned as and were regarded by the children as maternal figures, they understood the limits of this relationship and the potential difficulties of getting too attached to the children. This feeling did not preclude the development of meaningful relationships with them.

*“... If I start to feel like a parent to them then they will start to believe that I am their mother. But I am not their mother. I can’t take them to my home. I want to comfort them and make them feel special because their lives are very short. I get close to them but I tell myself that I am not their mother and I can’t be their mother...”*

and

*“... We don’t encourage them to call us their mothers because some of them still remember their mothers. They know that they once had mother and then they passed away. We encourage them to call us aunty but that relationship that we have with them that is why I say it is like they see us as mothers. I will make an example of one of the other children. She does have mother but she once asked me one day can you be my mother. I don’t know what she was thinking but I think that the care that I give*



*to her the attention that I give to her, that relationship that I have with her even though I don't show any favouritism but she liked me and she looked at me as a mother."*

While caregivers admitted to developing a meaningful and close bond with the children under their care and revealed such attitudes in their interactions with them, they were conscious of the inherent difficulties of allowing the children to regard them as parental figures. The caregivers revealed an awareness of their role in the lives of the children and at the same time understood the importance of providing a warm, caring and nurturing relationship for them. While they did not make attempts to detach themselves from the children, they also did not encourage relationships that resembled too closely the parental relationship. They did admit to being cognisant of the dangers of appearing to prefer one child over the others and endeavoured to create an environment in which all the children felt as though they were treated equally. While issues of attachment were discussed at meetings with supervisors and adopted as a matter of protocol, there also existed an element of self-preservation on the part of caregivers who understood how devastating it could be to watch a beloved child die.

#### ***Theme Four: Attitude of other people towards work***

- **Attitude of Family to work**

Caregivers reported that at the outset their families expressed reservation and fear at the fact that they were working with children who were infected with HIV/AIDS. However after educating their families about HIV/AIDS and what their jobs entailed, their fears

were assuaged. Thereafter they enjoyed support and encouragement from their families for their work.

*“... my mother. In the first year she was very worried that I might contract AIDS by accident. She did not have knowledge of how you get AIDS. She is a woman from a rural area and she was very scared for me. Every time, she was concerned Remember I told you I lost weight- she thought I might have AIDS. I did a lot of explaining. Now she is comfortable and is even willing to come here and see the children.”*

and

*“...In fact my mum was asking how do you work with people like that and then I did explain to her that they are normal people. There are people that can live with them. There is no difference between a normal person and an HIV person. Then she understood.”*

and

*“I educate my children about HIV and AIDS and they know what it is about. They are fine that I work here. In fact we have family that passed away and they know about it. The work in this home helps us at home with the people who are sick. Because we get training here we know what to do when the people are sick.”*

For the caregivers in the study relationships with family members did not appear to be jeopardised as a result of their involvement with children with HIV/AIDS. In fact when families were educated by the caregivers not only did they have their fears of infection assuaged, but they also tended to play a supportive role and were even willing to become

involved in activities in the home themselves. Consistent with Lazarus and Folkman's (1984) assertion that supportive social relationships mediate the effects of stress and facilitate coping is reports from the caregivers of how they have and continue to benefit from the support of family, friends and colleagues in navigating the stressors inherent in their duties. The support of these people gives them the feeling that they are understood and are not alone. Thus they are better able to cope with the stressors of caregiving.

- **Attitude of community to work**

While caregivers had freely divulged the nature of their work to people in their family, they were less candid with members of the communities in which they lived. They reported that members of their community were aware of the fact that they worked with children in a Children's Home but did not know that the children were infected with HIV/AIDS. When asked about whether they anticipated discrimination in their community should the exact nature of their work be revealed, the caregivers said that there existed the possibility of being discriminated against. However they also felt that their communities were becoming more educated and aware of information regarding HIV/AIDS and modes of transmission.

*"...Maybe they will think I have HIV too. Some people say people who work here have HIV too. I don't tell the people I work with HIV children because they might say I have HIV."*

and

*“...people say you work here because you are HIV positive. But it’s fine. If they are saying that it is fine. It doesn’t bother me because I know what I am doing here. But at first it used to affect me because I know I don’t have the disease. But even if I have HIV it’s not their business.”*

and

*“... most of the people are aware although I don’t spend that much time with them. They are educated about HIV now...”*

The current study confirmed Makhaba and Memela’s (2002) report which stated that caregivers had to deal with negative community perceptions surrounding their work. Members of their community often believed that they worked as caregivers for children with HIV because they were also infected with HIV. In the current study the caregivers avoided telling members of their community the exact nature of their jobs as they feared that they would be labelled as being infected with HIV/AIDS and thus be discriminated against. According to Lazarus and Folkman (1984), culturally derived values and norms function as crucial constraints to effective coping. Initially cultural beliefs or misconceptions about the spread of HIV and the stigma attached to people who are HIV positive as well as those who are in contact with those who are HIV positive played a significant role in the caregivers disclosing the nature of their jobs to people in their family and community. Lack of disclosure restricted the kind of support that they could access from their communities and hence was an impediment to coping. However education and training that they received and

disseminated to their friends and families made it easier to disclose the nature of their jobs as well as dispel some of the myths and misconceptions surrounding HIV/AIDS.

***Theme Five: Rewards of caregiving***

Caregivers reported that they did find their job rewarding. However they cited different reasons ranging from the educational gains in the job being conveyed to their communities to being awarded divine rewards for undertaking such work.

*“You learn about HIV so you can help other people in your community. It is good to help the children as well because they have no one else to take care of them. Some of them have no parents and no family. I can help them to feel they have people and they are not alone in the world.”*

and

*“I think I am a religious person I believe that I am making a difference in the lives of these children; I will be rewarded with blessings from God.”*

Caregivers reported different reasons for regarding their jobs as rewarding. They found that they were able to convey information of HIV/AIDS issues to the people in the community because they had received training on these matters. They also felt that they were able to make a positive difference in the lives of the children under their care by providing them with nurturance and comfort in a safe and secure environment. Of particular importance was the spiritual rewards that they anticipated receiving as a result of caring for children with HIV/AIDS, a job which they felt required one to have

compassion and dedication. They felt that they would be blessed by God for taking care of children in such need. This is contrary to what Hendrick (2000) reported, where she argued that family members involved in the process of caregiving reported deriving a sense of meaning to their lives and were able to show their competence under difficult circumstances as a result of caregiving. In contrast, the caregivers in the current study reported that the greatest reward of their job was being able to use the knowledge that they had gained through their work and HIV/AIDS educational and training courses to help educate their respective communities in matters pertaining to HIV/AIDS. This revealed that they viewed their contribution to their communities as being more rewarding than the rewards that they would gain as individuals. This revealed that they placed a high premium on how they were viewed by their communities. It also seemed to reveal a need for acceptance for the work that they had undertaken as well as the children that they were taking care of.

### ***Theme Six: Coping strategies***

- **Personal coping strategies**

Caregivers utilised a range of personal coping strategies which included taking walks, playing with the children, electing to be alone, taking time off from work, listening to music and interacting and talking with family as well as other members of staff.

*“On my own I take a walk and go shopping. Sometimes I like to be alone to think about my problem. I like my space to be alone with no one. We have outside buildings for ourselves....”*

and

*“I listen to music, Gospel music most of the time or just the radio. I also walk around the area and I also talk to people. When I am stressed out, there are some people I go to, like my colleagues around here who I can just go to and talk to relax. I like talking and listening to the radio and it depends on how I feel on that day. Most of the time it is the music. I like the slow songs. I lie on my bed on my back and just listen to them. Then there are those songs when I am happy when I just shut the door of my room and dance. Sometimes I call my mother when I am stressed. Not that I tell her that I’m stressed. But just talking to her helps me. Just because she is a member of my family it makes me feel better.”*

Cho and Cassidy (2001) asserted that caregivers needed to make time and space for their own needs by indulging in leisure activities such as reading, taking holidays, participating in sport and getting together with friends. Personal coping strategies employed by the caregivers in the current study included taking walks, playing with the children under their care, electing to be alone, taking time off from work, listening to music and interacting and talking with family as well as other members of staff.

According to Lazarus and Folkman (1984), simply being in possession of financial resources decreases an individual’s vulnerability to threat and thus facilitates effective

copied. Although the caregivers in the study reported that the remuneration they received was of an adequate level, they did find that financial resources did impact on their coping indirectly. In addition to geographical distance of the place of work from their homes, their financial situation precluded the possibility of them visiting their homes and family as often as they would have liked. Therefore financial resources did play a role in precluding access to the family members who provided emotional support. Furthermore financial constraints meant that recreational activities that may have aided in coping needed to be limited to those that were financially viable.

Cho and Cassidy focused on healthcare professionals working with people living with HIV/AIDS who would have received higher remuneration and greater benefits than the population in the current study and would thus be more likely to afford to indulge in the kind of activities that they suggested. The kinds of activities that the caregivers in the current study were able to undertake, was influenced to a large extent by financial resources. Financial constraints meant that they could not indulge in vacations away from home and thus had to tailor their activities to their budgets. Caregivers also reported that at the end of the year a prayer meeting is held for all the people who had died during the year. This was particularly important for the caregivers in whose lives religion played a pivotal role. Furthermore, as previously mentioned, the home had a "Remembrance Garden" which serves as a monument to all the people who had died. This helped them to acknowledge the deceased and come to terms with their deaths.



Methods of coping with issues related to grief and bereavement have been cited by various authors. These include understanding grief and bereavement theory, completing bereavement tasks and using available support are able to cope constructively with losses (Saunders and Valente, 1994) as cited in Sukovaty (2004). At an organisational level, education and training of caregivers should be broadened to include issues of bereavement, marginalized loss and personal awareness (Cho, 1997 as cited in Cho & Cassidy, 2001). The caregivers in the study reported that a heightened awareness of issues of grief and bereavement which they received in their training helped them to understand and normalise their feelings and cope more effectively.

- **Organisational coping strategies**

Caregivers also felt that the team within which they worked as well as other member of the organisation such as the social workers, supervisors and the director facilitated open, honest communication and provided support on an ongoing basis and thus found that they were able to discuss and navigate through difficulties.

*“...we have the support from the office. They come to support us and talk to us and then the people come from outside. One year they came from university to talk to us about how we cope in the job. There at the office they allow us to talk about it. And they said if you are feeling tired to work with the children, you have to ask for a break to go to another place and then after a few weeks you can come back here.”*

and

*“When there is something I do not understand I go directly to my director or social worker and I explain there is something I don’t understand. Then they help me a lot. They even ask if they must come to the unit and talk maybe about the children, the problem. My supervisor helps me too. They are supportive.”*

In the current study, the principle coping strategy employed by all the caregivers was discussing their feelings and concerns with other caregivers as well as with their supervisors. Caregivers reported that being part of a supportive team which was continuously available to them, helped them to cope with situations that were potentially stressful as well as navigate through difficulties that they were already experiencing. In addition, discussing their feelings and experiences in a group format gave them a better understanding of how other caregivers coped and helped to normalise their feelings. This is consistent with Sadock and Sadock (2003) and Cho and Cassidy’s (2001) assertion that sharing experiences with other people in similar circumstances enhances support for individuals. This is also in agreement with Lazarus and Folkman’s (1984) assertion that people with good social skills are more adept at communicating and are therefore more likely to be able to enlist help and support which is important in facilitating coping. The caregivers in the study felt that they were able to effectively communicate with other caregivers in the home as well as the social workers, supervisors and director of the home. They felt confident of enlisting the help of others in the home when they had a problem. Furthermore they were able to speak to their families and access help and support from them. This interaction with other people and help-seeking behaviour was

cited by the caregivers as being crucial in enhancing their ability to cope. Furthermore as levels of stress increased, so did their help-seeking behaviour.

- **Role of religion in coping**

All four of the caregivers belonged to different denominations of the Christian faith and said that their religious beliefs helped them to cope with and make meaning of the day to day as well as the more difficult aspects of the job such as the deaths of children and colleagues.

*“If I pray for God to help me he does. When you ask God, the reply comes quickly. When we lost a lot of children we prayed to God to give us a break and then for a long time we did not lose children. We prayed to God to help the children suffering. We say to God if it is better to take them so they don’t suffer the pain, then take them quickly. We see it later and then we say this is the reply...”*

and

*“I belong to church of the Holy Ghost and when I go home I go to church every Saturday. ... Being able to pray helps a lot. Every day when I wake up I pray and ask God to help me face the challenges of the day to help children to be able to listen to me. I ask God to help me manage the behaviour and with the job. Before I came here I pray for guidance and to do positive things to help the children grow. I grew up with my granny and she had that strong faith in God and she used to accommodate people in the house and believe all people are the same sick or well rich or poor. And she*

*taught me all people are equal in the eyes of the lord and I must treat them equal. It did help me a lot. I must always respect other people and have faith in God."*

The caregivers in the study reported that they held strong positive religious beliefs that helped them to cope with impending deaths of children under their care. Although the caregivers acknowledged that whether a child lived or died was ultimately out of their control and determined by God, they were comforted by the belief that the child would be relieved of earthly suffering and be at peace in heaven. Their belief in a benevolent God also helped to ease their grief when a child died. Therefore having no control over the outcome of the child illness and at the same time placing their faith in God helped them to cope better than if they had not held such religious convictions.

## **CHAPTER SIX**

### **REFLEXIVITY**

One cannot undertake a study of this sensitive nature without embarking on a process of reflexivity. Reflexivity refers to the recognition and examination of the role that the researcher plays in the process of conducting research. This includes the assumptions that the researcher works under, the people in the study that he/she identifies or does not identify with and the influence of the researcher on the research process (Terre Blanche & Kelly, 2002).

#### **6.1. Personal Reflexivity**

I am a 30 year old female of Indian descent. I am a wife and mother of a young daughter. This research forms part of the requirements for a Clinical Psychology Masters Degree. In selecting a topic, I had to bear in mind that a topic that I was interested in and felt strongly about would not only hold my attention but would also stand a good chance of being completed within the required time. Furthermore it would have to be in an area of interest that would warrant further investigation and which would generate debate and discussion. My interest in this area of research was influenced by my combined interest in the areas of experiences of caregivers in caring for people with chronic and terminal illnesses as well as issues pertaining to HIV/AIDS. This pointed me in the direction of

my current research. In reviewing the literature on caregiving, I encountered much on professional, familial as well as community based caregiving. However there was little literature on non-familial, non-medically trained caregivers working with children. The scarcity of research in this area helped me to make the decision to research the experiences of caregivers in a children's home. My intention was to provide as authentic an account as I could from the perspective of the caregivers. In doing so I had to be cognisant of my own assumptions and lay myself open to what the caregivers were experiencing and feeling. My initial tendencies were to focus on the difficulties inherent in the job and my initial assumption was that issues of grief and bereavement would predominate. My supervisor pointed out these tendencies and assumptions to me and cautioned me on structuring my interview questions to reveal mainly the negative aspects of the job and neglect positive aspects and opportunities. Her comments and guidance helped me to find a balance in the questions that I asked so that I covered a vast range of experiences and emotions connected therewith. My supervisor also provided clarity regarding qualitative research whenever it was needed. My association with the caregivers at the children's home left me with a great deal of admiration for the work that they do and the ways in which they cope with it as well as gave me an excellent opportunity to re-examine my own stance regarding issues of caregiving.

## **6.2.Functional Reflexivity**

It was imperative that the impact of the research on the participants be examined. The interview questions were of a nature that required participants to reveal personal and

sensitive topics. Hence my approach had to be respectful of their feelings and the difficulties inherent in revealing such emotions. The caregivers were co-operative, friendly, accommodating and seemed to enjoy the opportunity to talk about their experiences. Being a first language English speaker of a different cultural group, I had to take into account that they may not have been as forthcoming about certain issues related to culture as they might have been with a researcher who belonged to the same cultural group as them. Although the women appeared to be comfortable conversing in English, I also had to consider that richer information might have been obtained had they been able to converse in their mother tongue.

### **6.3. Implications of the findings**

As outlined in the introduction, there is a paucity of research into the experiences of caregivers working with children living with HIV/AIDS in the context of children's homes. The aim of this research is to highlight their experiences with the objective of addressing the difficulties they experience at a personal as well as an organisational level. The difficulties identified can be used to devise strategies to facilitate more effective caregiving and prevent already existent caregivers from leaving this line of work altogether. As mentioned previously, when addressing aspects of caregiving for people with HIV/AIDS, there is a tendency to focus on the stressful rather than the positive rewarding aspects. Thus this study serves to point out that while there are indeed difficulties inherent in such work, there are also rewarding aspects. This is important knowledge for people wanting to undertake such work but find themselves discouraged

by the perception that there are no positives inherent in such work. For caregivers already engaged in such work, it serves as a reminder of the rewards. Therefore within children's homes, rewarding aspects of caregiving need to be highlighted and enhanced. This study may have implications at an organisational level. There exists the opportunity for the development of ongoing training programs which address areas of difficulty or deficit, teach effective coping strategies as well as enhance positive aspects of the job for caregivers. There is also the opportunity to provide recommendations and interventions for caregivers who find themselves overwhelmed by the demands of their jobs.

#### **6.4.Limitations of the study**

Although the current study has served to highlight the experiences and important aspects of caring for children with HIV/AIDS in a children's home, the applicability of the findings to a broader population of caregivers within children's homes is questionable. It is crucial to take into account organisational and environmental factors which may differ vastly across children's homes in South Africa. However while the outcome of the study may not be generalised to populations of caregivers as a whole, it has provided a deeper understanding of the experiences of caregivers from their perspective. As this research functions as a pilot study, it is recommended that this study be replicated with a larger sample of caregivers to make the findings more applicable to the general population of caregivers who work in children's homes. Furthermore, all of the participants in this study belonged to the Black African population group. This was largely a function of the fact that all of the caregivers employed at this particular house within the home were of



the African Indigenous group. It is thus recommended that when the study is replicated the participants be more heterogeneous. Finally all the interviews were conducted in English. Although the caregivers appeared to have had little difficulty expressing themselves in English, they should be given the option to express themselves in the language of their choice.

### **6.5. Concluding remarks**

The present study has been able to highlight the difficult and rewarding aspects of caregiving from the perspective of the caregiver. It has been established that while the caregivers do experience difficulties as a result of the nature of their jobs, that being caring for children who are sick and are known to have a limited life span, they also find many rewards inherent in their work. Difficulties of the job included the long hours of work, disciplinary problems that they faced from the children under their care, their feelings of helplessness and fear of possible infection. The training that they had received not only helped dispel their own fears of infection but also allowed them to disseminate this information and educated members of their family on issues pertaining to HIV/AIDS. However they felt that further and on going training was required to help them to deal with other issues in their job such as issues of appropriate discipline for the children under their care. Caregivers also provided crucial insight into their feelings regarding the deaths of children under their care and the ways in which they had dealt with it. This was closely linked to their feelings of attachment towards the children. Caregivers testified that although their roles as non-familial caregivers may have led to

initial feelings of ambivalence regarding their role in the lives of the children, it did not preclude the development of close, warm and caring relationships between them.

The caregivers revealed their opinions about the attitudes of other people, particularly the members of their family and community towards their line of work and how this aided or impeded coping. According to them, close supportive family relationships played a crucial role in aiding coping, while negative attitudes from members of their community prevented disclosure of the nature of their jobs and precluded the opportunity for greater social support. Caregivers alluded to the rewards of caregiving which, according to them, was more emotional and spiritual than material. In exploring coping strategies, caregivers revealed how they utilised personal coping strategies as well as the support from other members of the organisation to traverse the difficulties in their work. They also attested to the vital role that religion played in helping them to cope. Finally caregivers revealed that their jobs provided opportunities for them to educate their families and communities about issues related to HIV/AIDS and in doing so provided a community service.

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**APPENDIX A: Interview schedule**

- For how long have you been working in this Children's Home?
- What is your job description / what does your job entail?
- Why did you get into this line of work?
- What makes you stay in this line of work?
- What do you find difficult about this job?
- What is rewarding about this job /Are there any rewards?
- How do people in your family/ friends/ community feel about you working in this field?
- Have you experienced discrimination as a result of your job? (If yes please elaborate).
- Has any child died while you were working here?
- How many children are lost per month?
- Have you ever lost a child you were taking care of? What is that like? /How do you feel when that happens/ how does that affect you?
- How do you feel when you know a child is going to die soon?
- Have you ever lost more than one child within a short space of time?
- How do you feel when that happens?
- How do you usually cope with the loss/death of a child?
- What support structures does your employer provide?
- Who do you speak to about how you feel?
- How do you cope with the demands of your job?
- Do you have any concerns about working in this field? (If yes, what are they?)
- What do you think would help you manage the demands of your job better?

## **APPENDIX B: TRANSCRIPT OF INTERVIEW**

Gender: Female

Age: 26

Duration of work at DCH: 4 years

### **What does your job here involve**

I am a child care worker, a caregiver. My job here involves taking care of children like taking them to the hospital, giving them care, being like a teacher, like I am a teacher to them. Kind of a parent to them and a nurse to them. When they are sick I am the one taking care of them. I bath them I prepare them to go to school every morning and when they come from school I give them lunch & do homework with them and activities with them

### **When you work with the children do you feel like a parent to them?**

Yes I do. I feel like since they don't have parents, they don't have mothers I am the person who they look to look after them, like a role model or a mother.

### **Do they look at you as a mother figure?**

Yes sometimes. Although we don't encourage them to call us their mothers because some of them still remember their mothers. They know that they once had mother and then they passed away. We encourage them to call us aunty but that relationship that we have with them that is why I say it is like they see us as mothers. I will make an example of one of the other children. She does have mother but she once asked me one day can you be my mother. I don't know what she was thinking but I think that the care that I give to her the attention that I give to her, that relationship that I have with her even though I don't show any favouritism but she liked me and she looked at me as a mother.

### **What made you get into this line of work?**

It was an accident. When I was growing up I wanted to be a social worker and I always liked to be around children especially younger ones. I grew up in the rural areas and I didn't have any knowledge about children's homes or any other places that were keeping children. When I was growing up I developed that love especially in matric and standard nine. I wanted to work with children and I didn't know how or where because I did not have knowledge of these places. Then I came to Durban and I was staying with my cousin. I wanted to be a social worker but I did not have enough money to go to university. My uncle who was going to pay for my fees decided that because I wanted to work with children it would be a good idea if I become a teacher. I went to Edgewood college for an interview but they did not take me because it was full and I had to stay home and while I was at home with my cousin in Durban, she was asking me what other thing I would like to do and I said there is nothing else I would like to do but to work with children. She told me there are places called children's homes and places of safety and then there are course you can do in Technikon SA. We went there and they gave me books and then I was reading about these things and then I was interested and then I had to think about it. I was reading pamphlets and one day I went and registered. The course was residential child care. While I was doing my practical in Lakehaven's Children's home and realised this is what I wanted to do to make a difference in the lives of young people who have no hope. I knew these children have no parents and are children at risk and I want to help them and make a difference in their lives.

### **What makes you stay in this line of work?**

To work with children I enjoy every minute. Even though children are not always sweet. When I was thinking of working with children I did not think of children with difficult behaviours or problems I just thought of children. Just children so even with those things those difficult behaviours to solve those problems not to correct but to model and encourage the changes in those children, It does help me to enjoy my job and see there is hope and they can be there I look at the best in them. I can see there is a future in them and I am the tool who will influence them to change in life in the community in SA as a whole.

### **What do you find difficult about this job**

When you see them getting sick especially when the child is very sick and lying down on the bed, not eating, vomiting, losing weight. It is very touching, Even though I am not a very emotional person. I remember my

first weekend working in this house one of the children passed away on that Sunday and it was very sad to me and although I did not cry in front of the children but when I was in my room. I was thinking do I have to continue doing this. How long is it going to happen that these children are getting sick every day? Is it going to happen every day or what? By that time when I came to this house a lot of children were very sick and I was thinking oh my God is this going to happen. Is this the life I chose? I was having second thoughts. This work is taking the other direction. With patience, I know that as these children are getting sick and dying they do need love and special attention they do need to be cared for especially in the last days. They are still like other children. That year was very challenging to me. It was the year that where I had to decide. I decided this is where I need to be – to help the children to die in peace. Like to feel the temperature- just a touch is what they needed most. I said I can do it. Let me do it

**Since you started working here how many children have you lost?**

Five. Especially on that first week. One died on Sunday, my first weekend working here. The second on Tuesday morning. The other on Thursday and the other one on Friday in the same week.

**How did you handle the death of so many children in one week?**

I knew that I had to be strong especially since we are working with children. The children saw that these others were sick and they used to sense what was happening even though they didn't know the children were dying but I had to be strong. Then there was this childcare worker who was in her fifties or early fifties so she was the one who was taking over and preparing the body and all that and I was given the task of taking the children out. On the first day I took the children to the swimming pool and I was pretending that nothing happened although I was thinking that in the house this thing happened but I had to be strong for the sake of the other children so they could not see what was happening. In my room things did happen. I used to think and cry but that was healing to me. It was like a month before I got through it. I also became sick; I lost appetite and a lot of weight. It affected me badly

**Did you experience any times when you knew a child was going to die**

Yes although I was not sure. One child I knew he was dying. I wanted to give him the most attention, love, caring that I can give. I remember there was this child who was very strong but I knew that something could happen at any time he was so strong. He used to come to the kitchen and pour water in the tap and drink just a little bit and throw the rest away. When I was looking at him, I could sense he was watching me. This feeling, the sense or what it made me see this child does need that attention from me. He kept on coming to the kitchen by that year the child care workers on the weekends were the ones who were cooking. I always liked cooking so I invited him over to sit with me. I saw that he was happy but he was scared to ask if he could stay. So he kept coming for the water as an excuse. He was asking me questions and he wanted to talk just talk. He was telling me about his family and different stories. He was telling me about the good times. That relationship that he wanted from me, I did give him. He could sense he was dying. That boy was very clever. He was 9 yrs old and he was scared to die. He didn't say anything. But the social worker once called him and told him he is HIV + and I'm not sure if they told him he was going to die. In the kitchen he was asking me about HIV. He asked me do you die. I was telling him what I know but he wanted another person to tell him about it. I did sense he was scared and looking to me for answers and some I did not know. I was very sad when he died. I formed a bond with him but after these days in the kitchen he became very sick where he was just lying there not eating, vomiting, feeling pain. I was sensing he was feeling a lot of pain, every movement was pain. Painkillers wasn't helping so before he died I did accept it and I prayed for him in my room please god it is time for him to Go The pain is too much for him. Take him now or make him better, I did accept but I was very sad. I also said that God it is almost over.

**Are you a religious person?**

Yes, I belong to church of the Holy Ghost and when I go home to Mandeni I go to church every Saturday. Our children here go to Methodist Church and I take them every Sunday and leave them with the Sunday School teacher and I attend church for one hour. Being able to pray helps a lot. Every day when I wake up I pray and ask god to help me face the challenges of the day to help children to be able to listen to me. I ask god to help me manage the behaviour and with the job. Before I came here I pray for guidance and to do positive things to help the children grow.



**Is there anything in your culture that helps you in this job?**

In my culture I believe in the culture my family and the way I was brought up. I grew up with my granny and she had that strong faith in God and she used to accommodate people in the house and believe all people are the same sick or well rich or poor. And she taught me all people are equal in the eyes of the lord and I must treat them equal. It did help me a lot. I must always respect other people and have faith in God

**How does your family feel about the fact that you work with children with HIV/AIDS**

They are fine. Except for my mother. In the first year she was very worried that I might contract AIDS by accident. She did not have knowledge of how you get AIDS. She is a woman from a rural area and she was very scared for me. Every time, she was concerned. Remember I told you I lost weight- she thought I might have AIDS. I did a lot of explaining. Now she is comfortable and is even willing to come here and see the children

**How do the people in your community react to your working with children with HIV/AIDS**

They don't know I did not get the chance to tell them. Only the people in my family and those who are very close to me. I go home once a month and then it's far so when I finish her at twelve I reach home when it is dark. On Saturday I go to church on almost the whole day and then spend time with family, Then On Sunday I visit a few friends and prepare to come back. I don't spend much time in the community

**Do you think your community would discriminate against you if they knew that you worked with children with HIV/AIDS?**

No I don't think so because most of the people are aware although I don't spend that much time with them. They are educated now

**Do you have a boyfriend?**

No

**Do you want to have children of your own someday?**

Yes very much

**What support do you have at work?**

I get a lot of support for the team especially in this house. I am working with people who have experience like maybe more than 10 years of experience. So I do get support from them and my supervisors. And the principal and social workers.

**What kind of HIV/Aids training did you have?**

I went for adherence counselling at King Edward Hospital where I was told how to care for a person with HIV. How to take drugs. It was one day and I also read a lot of books and pamphlets about HIV.

**Do you worry that because you are in such close contact with children that there is possibility of your being infected yourself?**

I don't worry about getting AIDS because I know you get it from blood. When you are dealing with rashes, wounds, I use gloves. I don't have that worry.

**What are some of the rewards of this job?**

I think I am a religious person I believe that I am making a difference in the lives of these children; I will be rewarded with blessings from GOD.

**How long do you see yourself working in the home?**

Long years.

**Do you ever think you will get to a stage where you are unable to perform your duties?**

I have not thought about it. I think I am still fresh now.

**What advice would you give?**

They need to be dedicated people with love and not do this job for the sake of the money. To me it is like a calling. You must do it because you love it.

**How did you feel losing colleagues?**

It was very hard especially since we did not know how they died. And people were asking why and talking. Because we did not know why and we were worried. And we started thinking maybe we could get something. This one lady, I got very close to her and she taught me everything and guided me and when she died I was very sad. I cried a lot.

**What do you find difficult about this job?**

Sometimes I find it difficult to discipline the children. I know they are sick and that makes me not want to shout at them. But when they are naughty we have to do something. There are these times when they do something naughty and we say go and sit on that chair in the corner and they do that but they look at you with that look and you feel so bad because you know they are sick children. Then you just say come here and sit with me now and then they are happy again.

**Is there anything that your organisation can do to make working here easier?**

Maybe if we can learn some ways to discipline the children, some courses or something like that or someone to come and show us how to discipline them properly. It would also help to have a nurse to help us when the children are sick. Even though we know about the medicines and what to do we would feel safer having a nurse here who we can call if we don't know what to do.

**What do you do to relax?**

I listen to music. Gospel music most of the time or just the radio. I also walk around the area and I also talk to people. When I am stressed out, there are some people I go to, like my colleagues around here who I can just go to and talk to relax. I like talking and listening to the radio and it depends on how I feel on that day. Most of the time it is the music. I like the slow songs. I lie on my bed on my back and just listen to them. Then there are those songs when I am happy when I just shut the door of my room and dance. Sometimes I call my mother when I am stressed. Not that I tell her that I'm stressed. But just talking to her helps me. Just because she is a member of my family it makes me feel better.

**APPENDIX C: Consent Form**

University of Kwazulu Natal  
Durban Campus  
King George V Avenue  
Glenwood  
Durban  
4041

**MINI-DISSERTATION: THE EXPERIENCES OF CAREGIVERS WORKING WITH CHILDREN LIVING WITH HIV/AIDS**

**CONSENT TO PARTICIPATE IN RESEARCH**

Dear participant, we are asking you to take part in this research so that we can explore the experiences of caregivers working with children living with HIV/AIDS.

This research will be conducted by Nemsha Naidu and supervised by Ms N Memela.

If you agree to participate in the study, the researcher will spend time with you during working hours and observe your work-related tasks. In addition the researcher will at times ask you questions related to your experiences of caregiving.

If you agree to participate, you will be increasing the understanding of the experiences of caregivers working with children living with HIV/AIDS.

Your participation is completely confidential. The results will be reported in a group category.

If you decide to participate, you can withdraw at any stage of the process.

You may ask questions about the study. Nemsha Naidu is available on 0842936434. Ms Memela may be contacted on 031 260 7428.

Signing your name means that you agree to participate in this study.

I, .....agree to participate in this study exploring the experiences of caregivers working with children living with HIV/AIDS. I understand that my participation is entirely voluntary, confidential and that I can withdraw at any time and that the nature of the research has been explained to me. If I have any questions I can call Nemsha Naidu on 0842936434 or Ms N Memela on 031 2607428.

.....  
Signature

.....  
Date



## Appendix D: Ethical Clearance

RESEARCH OFFICE (GOVAN MBEKI CENTRE)  
WESTVILLE CAMPUS  
TELEPHONE NO.: 031 – 2603587  
EMAIL: ximbap@ukzn.ac.za

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06 OCTOBER 2005

MS. N NAIDU (9300224)  
PSYCHOLOGY

Dear Ms. Naidu

ETHICAL CLEARANCE APPROVAL NUMBER: HSS/05079A

I wish to confirm that ethical clearance has been granted for the following project:

**"Experiences of caregivers working with children with HIV/AIDS"**

Yours faithfully

MS. PHUMELELE XIMBA  
RESEARCH OFFICE

PS: The following general condition is applicable to all projects that have been granted ethical clearance:

THE RELEVANT AUTHORITIES SHOULD BE CONTACTED IN ORDER TO OBTAIN THE NECESSARY APPROVAL SHOULD THE RESEARCH INVOLVE UTILIZATION OF SPACE AND/OR FACILITIES AT OTHER INSTITUTIONS/ORGANISATIONS. WHERE QUESTIONNAIRES ARE USED IN THE PROJECT, THE RESEARCHER SHOULD ENSURE THAT THE QUESTIONNAIRE INCLUDES A SECTION AT THE END WHICH SHOULD BE COMPLETED BY THE PARTICIPANT (PRIOR TO THE COMPLETION OF THE QUESTIONNAIRE) INDICATING THAT HE/SHE WAS INFORMED OF THE NATURE AND PURPOSE OF THE PROJECT AND THAT THE INFORMATION GIVEN WILL BE KEPT CONFIDENTIAL.

cc. Faculty Officer

cc. Supervisor (Ms. Zethu Memela)