A QUALITATIVE STUDY OF THE COPING STRATEGIES USED
BY CAREGIVERS OF HIV-POSITIVE CHILDREN IN A
RESIDENTIAL CHILDCARE SETTING

DESIRÉE LOUIS

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Supervisor : Prof Charles Malcolm

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DECLARATION

I declare that *A qualitative study of the Coping Strategies used by Caregivers of HIV-positive children in a Residential Childcare setting* is my own work; that it has not been submitted before for any degree or examination in any other university, and that all sources used or quoted have been indicated and acknowledged as complete references.

__________________________     June 2008

Desirée Helene Louis
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Sections</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>KEY WORDS</td>
<td>i</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>ii</td>
</tr>
<tr>
<td>DECLARATION</td>
<td>iii</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>vi</td>
</tr>
</tbody>
</table>

**CHAPTER 1: GENERAL INTRODUCTION**

1.0. Introduction 1
1.1. Background to the Study 3
1.2. Rationale for the Study 4
1.3. Significance of the Research 6
1.4. Aims of the Study 7

**CHAPTER TWO: LITERATURE REVIEW**

2.1. The Impact of HIV/AIDS on Children 8
2.2. Paediatric HIV Caregivers 9
2.3. Caregiver Burden, Stress and Burnout 11
2.4. Overview of Coping Theory 13
2.5. Caregiver Coping 15
2.6. Theoretical Framework 19

**CHAPTER 3: METHODOLOGY**

3.1. Research Design 23
3.2. Procedure 24
3.3. Participants 24
3.4. Data Collection 25
3.5. Transcribing of interviews 26
CHAPTER 4 : RESULTS AND DISCUSSION

4.0. Introduction to Research Site 30
4.1. Theme One: One Self: Multiple Roles 31
4.2. Theme Two: The Impact of HIV/AIDS on the Caregivers 42
4.3. Theme Three: Coping with Attachment, Separation and Loss 49
4.4. Theme Four: Interpersonal Relationships and Social Support 65
4.5. Theme Five: Organisational Dynamics 73
4.6. Summary 76

CHAPTER 5 : CONCLUSION AND RECOMMENDATIONS

5.1. Summary of Main Findings 79
5.2. Recommendations for the Research Site 81
5.3. Recommendations for Future Research 83
5.4. Limitations of the Study 83
5.5. Concluding Remarks 84

REFERENCES 85

Appendix 1: Interview Schedule 99
Appendix 2: Consent Form 100
Many sectors of South African society are affected by the human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) epidemic; most vulnerable are HIV positive children as they are often orphaned or abandoned. As the parents of these children are often ill or deceased, the caregivers play a vital role in taking the place of the parents. However, because of factors like stigma, fear of contagion, poverty and high child: caregiver ratios, caregivers of HIV-positive children often experience high levels of stress. The aim of this study was to investigate the coping strategies employed by caregivers of HIV-positive children working in a residential care setting. This study was conducted in Cotlands in the Western Cape; a residential childcare setting caring for mostly HIV-positive children from birth to 6 years. Eight childcare workers were interviewed with respect to their coping strategies and experiences. The study is located within a Positive Psychological framework, using the Salutogenic model. The research design is qualitative, making use of an interpretive approach. Data was collected by means of semi-structured, audio-taped interviews. The data was analysed by means of thematic analysis. The following themes emerged: the challenge of multiple roles; the impact of HIV/AIDS; attachment and loss; and interpersonal relationships amongst staff. The coping strategies employed by the caregivers were situation dependent. They included problem-focused coping; emotion-focused coping; social support; and to a lesser degree passive-avoidant coping. Positive coping strategies were benefit-finding and positive reframing; Salutogenic functioning included sense of coherence and learned resourcefulness. Prayer and religious coping were used by many participants, and on the whole found to be helpful and a source of comfort. An important finding is that many participants progressed from less adaptive to more adaptive coping strategies, and eventually Salutogenic functioning, the longer they worked at Cotlands. In general, the caregivers did not display signs of distress or burnout, enjoyed their work, and appeared to be coping well. Recommendations included further training, role clarification, staff support; provision of counselling and debriefing.
CHAPTER 1

GENERAL INTRODUCTION

1.0. Introduction

The human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) became public knowledge in 1981. No cure has to date been found for this syndrome and in the developing world infection rates continue to increase at an alarming rate. According to Van den Boom, Catalan, Hedge, Fishbein and Sherr (2006), the sharp climb in global HIV infection “has [proceeded] relatively unabated” (p175). Up to the end of 2004, at least 60 million people had been infected with the HIV virus worldwide since the beginning of the epidemic. In 2004 alone, five million people were infected with the HIV virus, “the greatest number of infections in a given year since the beginning of the epidemic over 20 years ago” (Van den Boom et al, 2006, p 175). Every day 14 000 new infections take place, 95% of the latter occurring in Sub-Saharan Africa (Van den Boom et al, 2006).

According to the latest UNAIDS reports, the HIV/AIDS prevalence rates indicate that in Sub-Saharan Africa “an estimated 1.7 million people were newly infected with HIV” in 2007. In addition, 76% of global deaths owing to AIDS occurred in the Sub-Saharan region, the majority of them being women. Of all HIV infected people 35% of them live in Southern Africa (UNAIDS/Sub-Saharan Africa, 2008). Recent UNICEF statistics indicate that at the end of 2005 South Africa had an 18.8%. HIV prevalence rate (UNICEF, 2008). In spite of recent data indicating that the prevalence rates for adults aged 15 to 49 is gradually declining, (UNAIDS/Sub-Saharan Africa, 2008), the problem of HIV/AIDS has had a far-reaching negative impact on South African society as a whole. The number of AIDS-related deaths is
still climbing and in the period of 1997 to 2004, the mortality rate among 20 to 39 year old women has tripled (UNAIDS/South Africa, 2008).

As such a large percentage of the African population is infected, government and health departments have mainly attended to factors like prevention, education, and treatment and addressing stigma and misconceptions related to the illness (Moore & Williamson, 2003). However, a large group of people who are also affected by the AIDS pandemic, viz. the caregivers of people with HIV/AIDS (PWHA), have not received adequate attention. Many of these are doctors, social workers and especially nurses. According to Lehman and Zulu, the latter bear the brunt of the burden (2005), which is exacerbated by the fact that South Africa’s Public Health system is already stretched to the limit regarding available resources (Campbell, Nair, Maimane, & Sibiya, 2005b; Mayers, 2005; Johnson, cited in Orner 2006). Numerous researchers attest to the fact that South African hospitals are overburdened (Quinlan & Desmond, 2002; Van Graan, Van der Walt & Watson, 2007). In some South African hospitals, HIV-positive patients comprise one third of those admitted (Van Dyk, 2007). In many KwaZulu Natal hospitals, the situation is much worse. Hospitals in Pietermaritzburg and surrounding areas are over 110% full because of AIDS admissions (Bateman, 2001). The shortage of human resources has given rise to informal home-based caregivers, who are either family members or volunteers (Melnick, 2002; Orner, 2006; Simpson, 2006, Van Graan, et al, 2007).

One of the groups of people most affected by the AIDS pandemic is the children affected and infected by HIV/AIDS. By 2005, approximately 240 000 South African children aged fourteen years and under were infected with HIV (UNICEF, 2008). According to Leary, all South African HIV-positive children (HPC) admitted to hospital are underweight and most of them have had prior hospital admissions. In each case, hospital admissions are a result of
illnesses like serious diarrhoea or pneumonia. Leary reported that approximately one quarter of Red Cross Children’s hospital beds was occupied by HIV infected infants and toddlers (1998). A paediatric chief of three KwaZulu Natal hospitals reported that 60% of “paediatric respiratory admissions were HIV-positive”. According to Dr McKerrow, before the age of two, HIV infected children were either becoming very ill or dying (Bateman, 2001, p.5). However, overburdened hospitals are often forced to discharge ill HIV-positive children, as they need the room for other patients (Bateman, 2001; Leary, 1998). The assistant director of a Johannesburg Children’s home reported that the “hospitals are completely overwhelmed”, and thus they are “finding it increasingly hard to admit” one of their HIV infected children to a hospital (Galloway, 1997a, p 11).

The plight of HPC is exacerbated by the fact that many of their parents are either dead or unable to care for them. The grandparents are often also unable to care for them, as there are other grandchildren to care for. Consequently, since state hospitals are unable to cope with the growing number of AIDS patients, many HPC will need alternative places of care, like children’s homes or hospice type facilities. One such home is Nazareth house in Cape Town. Sister Margaret of Nazareth house reported that the facility was for children who would not be accepted anywhere else. Therefore, in spite of the challenge of caring for HPC there is a need for facilities where they will be cared for if the hospitals are too full or they do not have family who can look after them. As a director of another children’s home in Johannesburg said “we see an increasing number of children needing care - where are these children going to go?” (Galloway, 1997a).

1.1. Background to the Study
Cotlands in the Western Cape is one of numerous children’s homes, originally established 72 years ago to take in abandoned babies. However, in recent years the focus has shifted to
HPC, because of the growing need. Cotlands is a residential care setting (RCS), which is partly government subsidised, taking in mostly HPC from birth to approximately six years old. They have been brought to Cotlands either because they are recently orphaned, abandoned or neglected. Since its inception five years ago, Cotlands in Somerset West has taken in over 130 children. Apart from their medical treatment, twelve childcare workers (CCWs) are responsible for attending to all their daily physical, emotional and social needs.

This study concerns the CCWs, who work for Cotlands, Western Cape. A key function of their work is caregiving; which involves duties like feeding and playing with the children. However, these CCWs’ roles have been dramatically expanded; and have assumed new proportions by the additional factor of caring for HPC. This at times entails being a nurse, rather than a CCW when a child is ill, as well as being extra careful about the prevention of infection and issues of hygiene. Thus they have much more to deal with than traditional CCWs, and therefore they will be studied as caregivers rather than as CCWs.

1.2. Rationale for the Study

Research that has focused on the care of people with HIV/AIDS (PWHA), has mainly dealt with home-based caregiving (Campbell & Foulis, 2004; Chimwaza & Watkins, 2004; McClausland & Pakenham, 2003; Melnick, 2002; Orner, 2006; Theis, Cohen, Forrest & Zelewesky; 1997; Van Wyk, 2002); nurses working in hospitals or clinics (Gueritault-Chalvin, Kalichman, Demi & Peterson, 2000; Lehman & Zulu, 2005; Mayers, 2005); and family caregivers (Martin, Wolters, Klaas & Wood, 2004; Rose & Clark-Alexander, 1998). In comparison, very little has been written on South African HIV/AIDS caregivers in any type of setting. Furthermore, there is currently a paucity of research on the coping strategies and experiences of caregivers specifically caring for HPC in South Africa (Melnick, 2002). An American study by Bachanas, Kullgren, Schwartz, McDaniel, Smith and Nesheim (2001), focused on the
biological parents of HPC, studying their psychological distress and coping style. According to Rose and Clark-Alexander (1998) - writing about the quality of life and coping styles of mothers and alternative caregivers - the caregivers who provide support to HPC are themselves in need of emotional and physical support. In spite of the vital role they play, South African HIV/AIDS caregivers in general, and their specific needs, have received comparatively little attention (Melnick, 2002; Van Wyk, 2002). Although a few studies done on caregivers have highlighted the rewards of caregiving, the majority of caregiver research has focused on their burdens, or on the negative aspects of caregiving (Theis et al, 1997). Thus, research is needed on possible proactive coping strategies used by caregivers of HPC, as well as the benefits they derive from doing this work.

Prior to the implementation of ARV (Antiretroviral) therapy, sometimes also referred to as ART, HPC became very ill quite soon, usually not living past the age of seven (O’Hare, Venables, Nalubeg, Nakakeeto, Kibirige, & Southall, 2005). Therefore, their caregivers mostly did palliative care. On the other hand, as a result of ARV therapy, babies and children infected with HIV/AIDS will be healthy for longer and will live longer (Brown, Lourie, Pao, 2000; Fischer, 1999). Consequently, those taking care of these children will have different issues and challenges to face (Fischer, 1999).

Therefore current research is required to determine how caregivers cope with the new challenge of caring for HIV-positive children on ART, as well as what type of support and training they are going to need in order to function optimally and to have a better quality of working life (Rose and Clark-Alexander, 1998). Consequently, the researcher is of the view that research on the coping strategies of the caregivers of HPC in residential care settings, who are receiving ARV therapy, is essential.
1.3. Significance of the Research

As more HIV-positive parents die, more children are going to need care. This growing number of HPC and AIDS orphans is putting a huge strain on health care professionals and on affected communities in South Africa, but especially on these children’s caregivers whether home-based or in a residential setting. On the whole, the amount of children who need care far outweighs the caregivers who are willing, available or trained and equipped to look after them (Lehman & Zulu, 2005; Van Dyk, 2007). Furthermore, the national roll-out of paediatric ART is accompanied by various risks, fears, constraints and challenges such as selecting suitable patients and strict monitoring of medication adherence by health workers (Campbell et al, 2005b; McKerrow, 2005). This may place an even greater burden on the caregivers of HPC. In order to help those caregivers who are already involved in caring for HPC it is imperative to minimize their stress, maximize their ability to cope and in so doing to prevent burnout and the subsequent loss of this precious and indispensable human resource.

Since ARV therapy has become more freely available in South Africa in 2004, the HPC at Cotlands have been treated with it. In addition, they have also received the proper nutrition and care. Therefore, they have a chance of living a relatively healthy life for up to ten or even twenty-one years of age (Fischer, 1999). Hence, their caregivers will have to cope with different challenges, like knowing how to prepare these children to live with a chronic illness, and having to deal with the issue of disclosure (Lesch, Swartz, Kagee, Moodley, Kafaar, Myer & Cotton, 2007). Consequently, this study is important in starting the process of discovering the impact that the implementation of ART has on the caregivers of HIV-positive children, and how caring for children within the context of a residential care setting, affects the caregiving experience.
Furthermore, this study enabled the researcher to ascertain the impact on the CCWs of the attachment to the children they care for and the subsequent pain and loss they experience after their departure owing to factors like adoption. Lastly, the study was useful in firstly informing employers regarding the work environment and support structures that the caregivers require in order to function optimally; secondly, to improve the quality of care they provide; and thirdly to improve their own quality of life. Finally, the information obtained from the Cotlands caregivers could be of help in compiling the most effective and comprehensive training programme for caregivers of HPC receiving ART, or HIV-positive children who are cared for in a residential care setting.

1.4. Aims of the Study

No South African research has been conducted focusing on the coping strategies of paediatric HIV/AIDS caregivers (PHCs) working in a residential care setting. Hence, the aims of this study are firstly to ascertain the coping strategies used by these specific caregivers. The second is to discover their unique experiences, including the challenges as well as the rewards inherent in caring for HIV-positive children, especially since the roll-out of ART. The third aim is to determine what impact the working conditions and environment have on the caregivers’ ability to cope with the demands of their work.
CHAPTER TWO

LITERATURE REVIEW

2.1. The Impact of HIV/AIDS on Children

The majority of literature concerning the impact of HIV/AIDS on children focuses on AIDS orphans or children whose parents are HIV-positive (Andrews, Skinners, & Zuma, 2006; Bray & Brandt, 2007; Brookes & Shisana, 2004; Drew, Makufa & Foster, 1998; Freeman & Nkomo, 2006; Germann, 2004; Orr & Patient, 2004; Stein, 2004). When the subject of HPC is dealt with, the topics explored are: mother-to-child transmission (Women and Children with HIV/AIDS, 2006; Brown, Lourie & Pao, 2000); the course and prognosis of the illness (Women and Children with HIV/AIDS, 2006; Brown et al, 2000; Hutton, 2003; O’Hare et al, 2005); treatment and palliative care (Hutton, 2003; O’Hare, et al, 2005; Antiretroviral roll-out in SA: Where do children feature?, 2004); challenges for society and the medical profession (Cooper, 1990); and the implementation of ART (Antiretroviral therapy), including its efficacy and adherence challenges (Women and Children with HIV/AIDS, 2006; Brown et al, 2000; Hutton, 2003; McKerrow, 2005; Obwago, 2002; O’Hare et al , 2005; Antiretroviral roll-out in SA: Where do children feature?, 2004).

Besides the physical impact of the epidemic, HPC also face psychological problems, such as loss, stigma and rejection (Brown et al, 2000; Campbell, Foulis, Maimane, & Sibiya, 2005; Fischer, 1999; Kouyoumdjian, Meyers & Mtshizana, 2005). Social challenges HPC have to deal with include poverty, environmental and social deprivation, social ostracism and discrimination (Fischer, 1999; Halhambo, Hayden, Otaala & Zimba, 2004). One of the biggest needs of HPC that has to be addressed is the probable loss of their primary caregiver. Alternative forms of care mentioned in the literature are grandparents or other relatives (Freeman, & Nkomo, 2006; Linsk, & Mason, 2004; Phillips, 2006). When the children become
very ill, they may need to be treated at clinics or hospitals (Fransman, McCulloch, Lavies, & Hussey, 2000). However, in South Africa, the growing number of AIDS patients needing care, together with the dwindling nursing personnel, has necessitated alternative forms of care like home-based care (Campbell & Foulis, 2004; Melnick, 2002; O’Hare et al, 2005; Olenja, 1999; Uys, 2002) and community-based care (Russel & Sneider, 2000; Van Graan et al, 2007). Nevertheless, with the roll-out of paediatric ART, residential care settings with trained nurses and childcare workers will become vital places of care. In a Zimbabwean study exploring the advantages and disadvantages of residential care centres for PWHA, Jackson and Kerkhoven (1995) argue that in spite of the benefits of receiving care at home many HIV-positive adults and children may require more specialised care, for whom admission to a hospital is not possible. In their case, residential care settings may be the best solution.

2.2. Paediatric HIV caregivers

According to the literature, the primary caregiver of many HPC is their biological HIV-positive mother (Hughes & Caliandro, 1996; Kouyoumdjian et al, 2005; Reidy, Taggert & Asselin, 1991; Rose & Clark-Alexander, 1998). Apart from the stress of caring for an ill child, she also has to cope with her own HIV-positive status and everything associated with it like the fear of dying, repeated hospitalisations, stigma, judgement and isolation (Rose & Clark-Alexander, 1996, Rose & Clark-Alexander, 1998). All these factors combined could result in biological HIV-positive mothers not coping as well as alternative caregivers such as grandparents or foster parents (Rose & Clark-Alexander, 1998). Furthermore, several studies have reported psychological problems amongst mother-caregivers such as a lower quality of life, depression, anger, psychological distress, anxiety and psychological adjustment (Bachanas, et al, 2001; Fischer, 1999; Hughes, Caliandro, 1996; Rose & Clark-Alexander, 1998; Women and Children with HIV/AIDS, 2006).
Some grandparent caregivers also have multiple problems to deal with, such as multiple roles, socio-economic deprivation, as well as having both a child and a grandchild who are HIV-positive (Caliandro, Hughes, 1998; Fisher, 1999; Linsk, & Mason, 2004). In addition, studies have reported poor health amongst some of them (Linsk, & Mason, 2004), which is often owing to advanced age. However, many grandparent-caregivers cope well with the caregiving of an HIV-positive child, because of factors like their maturity (Caliandro, Hughes, 1998).

Another problem many paediatric HIV/AIDS caregivers struggle with is the fear of contagion. A common concern raised by carers, enrolled in a home-based programme, was becoming infected whilst caring for an HIV-positive child (O’Hare et al, 2005). According to Berkowitz and Nuttal, this fear is also evident amongst some nurses. Although overall nursing staff do not feel negative about treating HPC, those who have some negative emotions are more at risk of infection exposure (1996). In a South African study on the experiences of nurses working in a Cape Town clinic, nurses reported living continuously with the fear of infection (Lehman & Zulu, 2005). One of the ways to address problems like negative emotions is to offer HIV/AIDS caregivers social support. The importance of this is evident in an African study investigating the effectiveness of a home-based care programme for orphaned HPC which found that carers benefited the most from “knowing that someone cares” (O’Hare et al, 2005, p446). Other studies support the importance of social support for PHCs (Hansell, Caliandro, Hughes, Russo, Budin & Hartman, 1992; Hughes & Caliandro, 1996). Moreover, according to Linsk and Mason (2004), family caregivers of HPC also require support and interventions from professionals like social workers.

The fear of contagion highlights another caregiver need identified in the literature, which is adequate training (O’Hare et al, 2005). According to Van Graan, et al, although non-
professional caregivers have some knowledge regarding the care of HPC, there exists gaps in their knowledge about such matters as community-based referrals, the caring requirements that are specific to children as well as what measures to take to prevent the transmission of the HIV virus (2007). Lesch and colleagues recommend that primary caregivers of HPC receive information and support regarding how and when to disclose the child’s HIV-positive status (Lesch, et al 2007).

A further challenge that PHCs face, is the implications of ART (McKerrow, 2005). For instance, as not all individuals respond equally well to ART, caregivers have to cope with the disappointment of a patient dying when the patient was expected to recover. Therefore, caregivers also have to cope with loss and grief (Demmer, 2001; Fischer, 1999). According to Hutton (2003), even though an HIV-positive child’s health will improve after receiving ART, caregivers still need to be trained in palliative care “as symptom management is an important component of palliative care” (p. 267).

2.3. Caregiver Burden, Stress and Burnout

Most research on the experiences of caregivers, concur that their work is accompanied by a high degree of stress and often burnout. According to Van Dyk (2007), many South African HIV/AIDS caregivers are left feeling overwhelmed by the apparent “severity and intensity” of the caregiver burden, which often leads to burnout caused by occupational stress (p49). Caregiver burden, stress and burnout have also been reported by several other investigators in South Africa (Lehman & Zulu, 2005; Shebi, 2006; Van Wyk, 2002), Africa (Kipp, Matukala, Laing & Jhangri, 2006) and overseas countries (Baker, Sudit, Litwak, 1998; Bellani, Furlani, Gncchi, Pezzotta, Trott & Bellotti, 1996; Bennett, Kelaher & Ross, 1993; Gueritault-Chalvin et al, 2000; Maslanka, 1996; Ross, Greenfield & Bennett, 1999).
Caregiver stress and burnout is not unique to the disease of HIV/AIDS but is also reported amongst caregivers of other illnesses, both locally (Potgieter & Heyns, 2006; Sardiwala, 2004) and internationally (Aschbacher, Patterson, Von Känel, Dimsdale, Mills, Adler, Ancoli-Israel, & Grant, 2005; Riemsma, Taal, Rasker, Klein, Bruyn, Wouters & Wiegman, 1999). One of the factors that contributes to HIV/AIDS caregiver burden and stress is a sense of despair and hopelessness in the face of the enormous number of patients that need care in comparison to the relatively few caregivers available to care for them (Van Dyk, 2007). According to Simpson (2006), in a study investigating the psycho-social support received by South African HIV/AIDS caregivers, many of the participants reported that they find the pressure of HIV/AIDS caregiving too much as they feel that the task is too great. In a study concerned with how Cape Town nurses experienced the HIV/AIDS epidemic the researchers noted that the nurses reported high levels of stress, feelings of hopelessness, depression, and a sense of being overwhelmed. They admitted they were not coping and their way of dealing with their workload was by withdrawing (Lehman & Zulu, 2005).

All the aforementioned is exacerbated by other factors like lack of social support, and stigma (Campbell et al, 2005; Mayers, 2005; Orner, 2006; Van Dis & Van Dongen, 1993); isolation (Fischer, 1999; Orner, 2006) and multiple roles (Mayers, 2005; Orner, 2006). According to some South African nurses, they also have to perform the role of social worker, besides nursing (Lehman & Zulu, 2005). Furthermore, caregiver burden and stress sometimes results in burnout when there is lack of staff support and inadequate training (Van Dis & Van Dongen, 1993). The results of caregiver stress and burnout, are the development of health and psychological problems like depression and hopelessness, which may ultimately result in high staff turnover (Flaskerud, & Lee, 2001; Stetz, & Brown, 2004; Van Dis & Van Dongen, 1993). Consequently, in order to prevent caregiver burnout, researchers have studied their coping strategies in order to improve caregiver coping.
2. 4. Overview of Coping Theory

The theory of Lazarus and Folkman (1984) is currently used by many researchers when studying stress and coping (Bennett & Kelaher, 1993; Gueritault-Chalvin et al, 2000; Martin, Wolters, Klaas, Perez & Wood, 2004; McCausland & Pakenham, 2003; Melnick, 2002). For example, Rose and Clark-Alexander (1998), investigated whether mother and alternative HIV/AIDS caregivers used confrontive (problem-focused) or emotive (emotion-focused) coping strategies. According to Lazarus and Folkman, in spite of the widespread interest in coping both within the scientific community and the lay community there has been little consensus about how best to conceptualise and study coping strategies (1991). Nevertheless, according to their brief overview of how coping had been viewed and studied in the past, two main trends emerged.

The first was based on the study of animal behaviour, which viewed coping as an effort to “control aversive conditions” and in so doing to “lower drive and activation” by either avoiding or escaping a potentially threatening situation (Lazarus & Folkman, 1984, p.139). The second model of a hierarchical conceptualisation of coping was embedded within the tradition of psychoanalytic ego psychology. Accordingly, individuals employed strategies that were more akin to defence mechanisms progressing from very primitive ones in which there was almost total ego fragmentation to mechanisms that were more mature. The psychoanalytic theorists appeared to judge the efficacy of a coping mechanism by the degree to which the person was still in touch with reality (Lazarus & Folkman, 1984; 1991).

By contrast, Lazarus and Folkman conceptualized coping as the way in which individuals cognitively appraised and then reacted to different potential stress-producing events in their lives. They defined psychological stress as the interaction between the person and the environment that was judged by the individual as challenging or “exceeding his or her
resources and endangering [personal] well-being” (1984, p21). They theorised that before an individual engaged a coping strategy a process of appraising the stressful situation was first involved, divided into three stages; viz. primary appraisal, secondary appraisal and reappraisal. They defined coping as efforts that were both cognitive and behavioural which were employed to manage situations that posed a challenge to a person that might either tax or exceed their personal resources. The two general ways in which people cope are Problem-focused coping or Emotion-focused coping (1984). Problem-focused coping is utilised when an individual believes that a particular problem can be solved, and thus addresses the problem directly. In contrast, emotion-focused coping is involved when a person feels that nothing can be done to solve the problem itself, and thus “coping is directed at regulating emotional responses to the problem” (Lazarus & Folkman, 1984, p.150).

Subsequent to the seminal work of Lazarus and Folkman several studies showed that not only the situation and the cognitive appraisal of it determined which specific coping strategy would be used by an individual but also the interaction of the aforementioned with the individual’s type of personality (McCrae & Costa, 1986; O’Brien & DeLongis, 1996; Watson & Hubbard, 1996). Some of these theorists further broadened the theory of Lazarus and Folkman by the addition of several more coping strategies. For instance, Carver, Scheier and Weintraub (1989) developed 13 scales of coping that were conceptually distinct from each other. O’Brien and Delongis (1996) added to the understanding of coping by incorporating a third coping strategy viz. relational coping, which looked at the role that interpersonal relationships played as well as whether the stressor was work related or interpersonal in nature.

Numerous studies investigating coping and stress have made use of the work of Holahan and Moos and their colleagues. Unlike Lazarus and Folkman they have not focused on the role of
cognitive appraisal in the coping process. Instead, they formulated and refined a theoretical model, which focused on the interaction of factors like life stressors, resistance factors, personal and social context as well as family support, on an individual’s coping strategies (Holahan & Moos, 1985; Holahan & Moos, 1987; Holahan, Moos, Holahan & Brennan, 1997).

In spite of developments in how coping strategies were to be studied, and what influenced them, they were for the most part still viewed from a psychopathology perspective. According to Schwarzer and Knoll, “the term coping [has often been used] in a more narrow sense”, to refer to the way in which people respond to adverse events (cited in Schwarzer and Knoll, 2003, p.393). However, increasingly coping is rather being viewed from a psychological well-being point of view and as possessing numerous positive functions such as personal control, optimism and self-confidence (Greenglass, 2001). Moreover, more recent studies also focus on the rewards of caregiving and consider coping from a more proactive point of view, which is orientated towards the future (Greenglass, 2001; Schwarzer and Knoll, 2003). According to the latter, positive coping is a combination of mastering demands and searching for meaning. They distinguish between four types of coping. These are: reactive coping - which takes place once a stressor has already been encountered; anticipatory coping, referring to when a challenging event is sure to occur, e.g. an upcoming exam; preventive coping, which refers to the preparation an individual undertakes for uncertain future events - such as retrenchment; and proactive coping referring to when a person builds up their personal resources in order to enhance their individual growth. The latter coping strategy is a form of goal management whereas the first three involve risk management.

2.5. Caregiver Coping

Although many researchers of caregivers have used Lazarus and Folkman’s theory of coping strategies, many of them have either added one or more coping strategies or they have
substituted their own constructs. Accordingly, in two studies by Rose and Clark-Alexander, of firstly American mother PHCs (1996) and secondly mother and alternative PHCs (1998), in general both the mother and the alternative caregivers used confrontive coping more than emotive or passive coping strategies. In their study of family caregivers of school age HPC, Bachanas et al (2001) found that family PHCs using palliative coping displayed poor psychological adjustment and reported more psychological distress than those using adaptive coping strategies. Martin et al found that American family PHCs used the passive coping strategies of passive appraisal, religious support and reframing the most. Of concern to the researchers was that they used social support the least (2004).

As far as trained caregivers are concerned, in a study of Australian HIV/AIDS health care professionals, it was found that the two main coping strategies employed were internal and external coping strategies. These are similar to internal and external locus of control, and included factors like positive and active coping for the former, and pessimism, denial and religious strategies for the latter (Bennett & Kelaher, 1993). These authors found that participants who used more internal coping, presented with lower grief levels, whereas higher levels of grief were associated with more external coping strategies. In contrast, in their study of nurses caring for AIDS patients, Gueritault-Chalvin et al (2000) found no direct relationship between internal and external coping, locus of control and burnout. However, nurses who used more external coping strategies were more likely to experience burnout than those using internal coping strategies.

A South African study found that home-based caregivers used family and colleague social support, faith, and self-control, to cope with their work (Melnick, 2002). Coping strategies reported by primary caregivers of PWHA in the Western Cape were: going for walks, reading; attending counselling, as well as choosing to be alone. Many reported holding on to
hope as a means of coping (Orner, 2006). A common coping strategy employed by the caregivers in a study by Simpson (2006) is talking to someone and to God. Coping strategies used to a lesser extent were: working in the garden; watching television and singing. In a study by Shebi (2006) on the coping strategies of HIV/AIDS primary caregivers living in disadvantaged communities, she found that they used instrumental support, information-seeking, humour, denial, acceptance, hope, spirituality and self-control as coping strategies. Contrary to studies supporting the efficacy of problem-focused coping, in her study of hospice workers, Sardiwala (2004) found that those who made use of problem-focused coping suffered from more emotional exhaustion than those using emotion-focused coping. She suggested that this difference could be owing to the fact that hospice caregivers are daily faced with a problem they cannot solve, which is their patient’s terminal illness. In a study on the vicarious trauma experienced by Western Cape caregivers of children admitted to a place of safety, the caregivers reported coping with their distress by withdrawing from both colleagues and family and also by often taking sick leave (Booysen, 2005).

Most research articles concerning the topic of caregiver stress, burnout or coping, include the important role played by social support in the stress and coping process (Bachanas et al, 2001; Blankfeld & Holahan, 1999; Holahan, Moos, Holahan & Brennan, 1997; Marshall & Barnett,1992; Mayers, 2005; O’Brien & DeLongis, 1996; Van Dis & Van Dongen, 1993; Wight, Aneshensel, LeBlanc, & 2003). Several studies on the role of social support in caregiving attest to the buffering and beneficial effects of social support, whether it is from family or colleagues (Blankfeld & Holahan, 1999). For example, in a study by Bachanas et al (2004) they found that instrumental family support reduced the daily hassles experienced by primary caregivers. In their study of social workers and nurses, Marshall and Barnett (1992) found that support at work acted as a buffer against participants’ mental and overall physical health. Furthermore,
family support acts as a buffering effect against financial concerns for informal American male homosexual HIV/AIDS caregivers (Wight et al, 2003); and as a “buffer against intense feelings of grief” for Australian health care professionals (Bennett & Kelaher, 1993, p.216). Lastly, social support may also reduce the risk of burnout (Grossman et al, 1993; Visintini, 1996). In contrast, there are risks associated with impaired social support. For instance, low morale appears to be associated with lack of social support (Bowd & Loos, 1996). In a study on the relationship between social support and mood, it was found that perceived social support played a bigger role than actual social support as a predictor of mood (Soskolne, Acree & Folkman, 2000).

Participants in several studies evidenced difficulty coping with the issue of death and loss. According to Bennett and Kelahar (1993), health care professionals who identified very strongly with their patients – suggesting a strong attachment - experienced more grief when their patients died. The authors suggested that these caregivers should be taught how to maintain “a healthy emotional distance” in their work in order for them to cope better with loss (p.216). Some caregivers have to cope with the multiple losses of a child and a grandchild being HIV-positive (Fischer et al, 1999). Thus, some expressed the need to learn how to cope with loss (Theis, et al, 1997). Other needs expressed by HIV/AIDS caregivers are: social support; training on infection prevention, disease progression and treatment; coping and problem-solving skills and to be provided with a safe space to talk (Bowd et al, 1996; Mayers, 2005; Reidy et al, 1991).

Several studies have referred to spirituality or religious practise as a caregiver coping strategy. (Baker et al, 1998; Bennett, et al, 1993; Cadell, 2007; Martin, et al, 2004; Orner, 2006; Potgieter & Heyns, 2006; Simpson, 2006). Some of these studies report religion as being an ineffective coping strategy (Martin et al, 2004). In a study of American mother and alternative
HIV/AIDS caregivers, the vast majority of them used prayer as a coping strategy. The researchers classified it as a less effective passive coping strategy, in spite of the fact that the caregivers found it very beneficial (Rose & Clark-Alexander, 1998). Furthermore, in another study on PHCs, Christian African American grandparents reported that God and prayer were essential and intrinsic to their ability to cope (Phillips, 2006).

Besides caregivers reporting that their religion helps them to find meaning in HIV/AIDS caregiving, other studies have reported that caregivers have found caregiving itself meaningful and beneficial (McCausland et al, 2003; Milberg, Strang, 2003). This has enabled caregivers to offset the burden, stressors and negative aspects of caregiving with the rewards (Carlisle, 2000). In addition, in two studies by Cadell, some caregivers reported that they had experienced growth as a result of caregiving (2003; 2007). The results of the aforementioned have prompted some researchers to investigate why certain individuals cope well with stress and even flourish in the face of adversity. Consequently, in recent years more researchers on caregiver coping are moving away from focusing solely on caregiver stressors, burnout and reactive coping; to rather concentrating on caregiver strengths, growth and proactive coping (Greenglass, 2001; Simpson, 2006).

2.6. Theoretical Framework

Although the recent shift in focus by various theorists and researchers described above, represented a paradigm shift from a pathogenic approach to an approach concentrating on strengths, health and well-being, Seligman and Csikszentmihalyi (2000) admit that the idea of Positive Psychology was not new. Nevertheless, according to Seligman, Steen, Park and Peterson (2005), Positive Psychology is an umbrella term for studying positive emotions, character traits and enabling institutions. Furthermore, Seligman and Csikszentmihalyi (2000) assert that if psychologists wished to improve peoples’ quality of life and make life
worth living then it was essential for psychologists in the new millennium to begin to move away from the exclusive study of pathology. Without ignoring the former, psychologists also needed to research health and human strengths.

Consequently, the field of Positive Psychology has gained increasing momentum as more and more psychologists have studied, reported and written about human strengths and virtue, both internationally, (Aspenwell & Staudinger, 2003; Cadell, 2003; Cadell, 2007; Carlisle, 2000; Carr, 2004; Folkman, 1997; Greenglass, 2001; Linley & Joseph, 2004; Lopez & Snyder, 2003; Luthens & Jensen, 2002; Maddux, & Lopez, 2004; McCausland. & Pakenham. 2003; Milberg & Strang, 2003; Park, 2005; Phillips, 2006; Schwarzer & Knoll, 2003) and in South Africa (Barends, 2004; Cilliers, Viviers & Marais, 1998; Potgieter & Heyns, 2006; Strümpfer, 1990; Strümpfer, 1995; Strümpfer, 2005; Van Jaarsveld, 2004; Viviers, 1998; Wissing & Van Eeden, 1997). However, Antonovsky was one of the first psychologists who had explicitly and intentionally called for a focus on health rather than on disease, by conceptualising the theoretical framework of Salutogenesis, which was derived from the words saluto (from Latin) meaning health and genesis (from Greek), meaning beginning (Antonovsky, 1979).

Several constructs underpin Antonovsky’s theory of Salutogenesis. Firstly, an individual is not ill or healthy instead each person’s physical condition lies somewhere on a health-illness continuum, which is multi-dimensional as it incorporates factors like one’s subjective perceptions of one’s health. Secondly, people cope with life’s stressors through the utilisation of their ‘generalised resistance resources’. These are internal and external factors such as intelligence, ego strength and social support, that individuals ‘build up’ over time increasing their resilience and resourcefulness (Antonovsky, 1979). Thirdly, sense of coherence (SOC) comprises three components, viz. comprehensibility, manageability and meaningfulness. Comprehensibility refers to the degree to which an individual believes that
the internal and external stimuli in his or her life are mostly predictable, consistent and make
cognitive sense. **Manageability** is the extent to which each day’s tasks and stress is
manageable. **Meaningfulness** refers to the degree to which, on an emotional level, there is
sense to one’s life (Strumpfer, 1990). Lastly, Antonovsky argued that stress is ubiquitous but
neutral, i.e. not necessarily good or bad (1979). Strumpfer expanded on Antonovsky’s
Salutogenic model by adding the constructs of *learned resourcefulness* proposed by
Rosenbaum, and *hardiness* proposed by Kobasa (cited in Strumpfer, 1990). Additional
Salutogenic concepts are self-efficacy, potency, stamina and self-regulation (Strumpfer,
1990).

Themes that are included in Positive Psychology are human strengths, resilience, wisdom,
well-being, hope and courage (Aspinwall & Staudinger, 2003; Lopez & Snyder, 2003; Strümpfer,
1995; Strümpfer, 2005; Wissing, 1997). All the aforementioned positive characteristics are
needed by caregivers of HIV-positive children who work under difficult and stressful
circumstances each day, in order to cope optimally in the face of factors like loss, fear of
contagion, stigma and long working hours. Therefore, the first motivation for using the
Salutogenic model is because it focuses on psychological issues from a health, strength and
well-being point of view, rather than from a disease, weakness and pathology perspective.
(Aspinwall & Staudinger, 2003; Strümpfer, 1990; Strümpfer, 1995; Strümpfer, 2005). Moreover,
although stress is inevitable, the Salutogenic model asserts that well-adjusted people cope
with it in a healthy way and even if the amount of stress is high, many people survive it and
even function well (Antonovsky, 1979). Secondly, while many psychological theories on
stress and coping look at what happens once a potential stressful event has already occurred
the Positive Psychological framework, like the Salutogenic model, looks at ways in which
individuals act proactively in order to either prevent stressful situations from occurring,
lessen their impact or learn and grow from them (Schwarzer & Knoll, 2003).
Furthermore, whilst volunteering at Cotlands, the researcher witnessed that the CCWs enjoyed their work and appeared content in spite of the fact that they worked 12 hour shifts and cared for children who were HIV-positive. It is therefore possible that the CCWs working for Cotlands make use of proactive and positive coping strategies and find their work meaningful. Consequently, the Salutogenic model will be helpful in providing answers to why Cotlands CCWs cope with and enjoy their work, despite the daily stressors of paediatric HIV caregiving. Lastly, the Salutogenic model will offer a more comprehensive picture of the caregivers’ experiences by focusing not only on the negative aspects of the work and caregiver weaknesses but also on the positive side of their work and caregiver strengths.
CHAPTER 3

METHODOLOGY

3.1. Research Design

The research design chosen for this study is a qualitative, exploratory research design. According to Terre Blanche and Durrheim (1999), should the researcher believe that individuals’ subjective experiences are “the reality to be studied”, he or she may make use of interviewing as a methodology as it relies on “subjective relationships between researcher and subject” (p6). The interpretive approach located within qualitative research, is characteristic of this. Consequently, a qualitative research design was used for this study as its focus was on the subjective experiences of CCWs caring for HIV-positive children (Willig, 2001).

Semi-structured interviews were used for data collection as the type of caregivers and caregiving situation, viz. South African caregivers of HIV-positive children on ART, had not yet been researched. Thus, the researcher was interested in whether unique coping strategies emerged given this situation. Furthermore, in a study by Melnick (2002) concerning the coping strategies of home-based HIV/AIDS caregivers, the latter raised a number of concerns regarding the applicability of a number of statements in Lazarus and Folkmans’ ‘Ways of Coping’ questionnaire. One participant in particular reported that the questionnaire was one-sided and that the questions were inappropriate. According to Melnick, other researchers corroborated the fact that the ‘Ways of Coping’ questionnaire has limitations when applied to the context of AIDS care (Smythe & Yarandi, 1996; Stone, Greenberg, Kennedy-Moore & Newman, 1991, cited in Melnick, 2002). As it is possible that other coping
strategy questionnaires, such as the COPE of Carver et al, might have similar problems as it was developed on a first world western population, the researcher thought that a semi-structured interview might yield more reliable results. Furthermore, according to Cohen (1991) context and “situation-specific measures provide a richer portrait” and greater understanding of how individuals cope in certain situations (p. 233).

3.2. Procedure

Having worked as a volunteer at Cotlands in the past, the researcher approached the Director of Cotlands for permission to conduct this study, and to find out if it would be feasible. A meeting was arranged with the director and the head sister to explain the purpose and significance of the proposed study. Both of them were very interested in the research topic and thought it would be very helpful to all working or volunteering at Cotlands and it would help the organisation to improve its service. Therefore, permission was granted for the study. Thereafter the sister informed all the CCWs of the proposed study and the request for them to participate therein. The latter were supplied with an information sheet providing them with the reason and purpose of the study. It also explained issues of confidentiality, anonymity, freedom to terminate at any time and the audiotaping of the interviews.

3.3. Participants

Cotlands employed a total of twelve childcare workers, four of whom are on duty together at the same time. Participants were selected on the basis of their ability to communicate comfortably either in English or Afrikaans as the researcher is unable to communicate in Xhosa. The limited time the participants had to participate in the study made the use of an interpreter impracticable. Eight CCWS volunteered to participate in the study.
3.4. Data Collection

Demographic information was collected from each participant. Data pertaining to the CCWs’ stress, coping and attachment experiences was collected using a semi-structured interview. This format of interviewing was used in order to give some structure to the information collected and consistency in the types of questions asked. At the same time, it allowed the researcher the freedom to collect subjective and personal information and opinions. Other reasons for choosing a qualitative research design and a semi-structured interview is so that no restraints would be placed on the respondents, thereby important information could be captured that might otherwise have been overlooked (Parker, 2005). According to Struwig and Stead (2001), the semi-structured interview allows the researcher to “obtain multiple responses to set questions and allows for detailed responses” (p. 98). The semi-structured interview was used rather than an unstructured interview as it allowed for more control and greater ease of comparison across interviews than an unstructured interview would have.

The interview schedule and questions were compiled after a review of relevant literature and were based on the researcher’s prior involvement with Cotlands as well as the aims of the research study. The researcher conducted an interview with the director of Cotlands in order to obtain further valuable background information. This enabled the researcher to formulate an interview guideline that would be more relevant to the experiences of the Cotlands caregivers. The questions were structured in a logical order, beginning with background information and questions regarding their daily work and stresses, and then progressing to the manner of coping with the latter. The more sensitive topics like attachment, loss, stigma and fear of contagion were left for last, so that by that time the participants would feel more at ease with the interviewing process and with the researcher.
The interviews were conducted on the premises of Cotlands itself. As the participants work twelve-hour shifts, the researcher did not wish to interview them either before or after work. Thus, the only time available was during the children’s afternoon sleep hour. The interviews were conducted in both Afrikaans and English. The researcher translated the former into English. All the interviews were audiotaped. Additional notes were made by the interviewer.

3.5. Transcription of interviews

The interviews were transcribed by the researcher as it facilitated the first process of data analysis, viz. immersion, and it allowed for the listening of the interviews from a different angle. In addition, sounds like laughter, which was important information, might have been omitted by a secondary transcriber (Parker, 2005).

3.6. Data Analysis

The data analysis was located within an interpretive paradigm using thematic analysis (Banister, Burman, Parker, Taylor & Tindall, 1994) as it was a way of coherently organizing interview material in relation to specific research questions so that one could “do justice to both the elements of the research question” and the interests of the researcher (p. 57). The specific method used, was the step-wise thematic data analysis of Terre Blanche and Durrheim, (2002).

Step 1. Familiarisation and Immersion

Once the data had been collected, which includes the transcripts of the audio recordings as well as the field notes, complete familiarisation with the data was facilitated through multiple readings. Whilst the researcher was doing this, progress notes were made as well as diagrams as a way of getting to know the data thoroughly and to ascertain what was being said and what was not being said (Terre Blanche & Durrheim, 2002). Multiple readings also
had the added advantage of allowing for additional insights to emerge (Smith & Osborne, 2003).

Step 2. Inducing Themes

The researcher grouped the interviews into specific themes and categories that emerged from the data itself. At times it was necessary to use the language of the participants as far as possible, thus avoiding merely summarizing the content. In addition, an “optimal level of complexity” was sought ((Terre Blanche & Durrheim, 2002 p.142). Whilst looking for themes, it was also important to make note of instances like contradictions within one interview (Smith & Osborne, 2003).

Step 3. Coding

Data was coded according to themes and then broken down into common clusters (Terre Blanche & Durrheim, 2002) as well as connections between the themes (Smith & Osborne, 2003).

Step 4. Elaboration

The data was re-looked at more finely to discover more, subtler themes that might have previously been overlooked (Terre Blanche & Durrheim, 2002). Furthermore, in the more detailed analysis, the researcher also looked for theoretical connections (Smith & Osborne, 2003), as well as “commonalities across interviews” which facilitated the recognition of varied experiences and ones which were similar (Pollio, Graves & Arfken, 2006, p.258).

Step 5. Interpretation & Checking

Finally the researcher compiled a written account of the interpretations that emerged out of the data analysis (Terre Blanche & Durrheim, 2002).
3.7 Ethical Considerations

Participation in this study took place on a voluntary basis for the participants. They were ensured that their identities would remain anonymous, and whatever they divulged would remain confidential. They were informed that at any point during the interview they could terminate should they not wish to continue, without any penalty to themselves, as well as withdraw from the study at any time. Participants signed a written consent form thereby ensuring their informed consent. The participants were furthermore informed that the interviews would be recorded but that the tapes would be kept in a secure place and that the information would be erased after transcription. The latter would be erased after completion of the study. The participants were assured that whatever they divulged would not in any way be connected to them personally when feedback and recommendations were given to the Director of Cotlands. During the interviewing process, the researcher applied the ethical principles as suggested by the Belmont report of autonomy, respect, beneficience as well as justice (Vadum & Rankin, 1998).

3.8. Reflexivity

A few years prior to the present study, the researcher volunteered at Cotlands by helping to care for the children a few hours each week. During this time, the researcher observed that the CCWs appeared to enjoy their work, loved working with the children and seemed to cope well with their work and the children. Therefore, whilst conducting this study, the researcher was aware of the fact that she might be biased in how the questions were structured; which questions were asked; and how the data was collected and interpreted. The researcher was also aware that her own ethnicity, viz. Caucasian, might have impacted on the interviewing process as the participants, who were not from the same ethnic group, might have been reluctant to disagree with the interviewer or to freely give their opinion (Flores & Obasi, 2003). Nevertheless, the researcher believed that two factors minimised the bias that
might have occurred. Firstly, the researcher conducted the research from the perspective of an objective observer. Secondly, the interview schedule was guided by themes in the literature and the aims of the research. Notwithstanding the aforementioned, the researcher’s previous personal experience with Cotlands may also be regarded as an asset, as it helped in informing an understanding of the organization, and of the CCWs.

3.9. Limitations

One of the limitations of the data collection, was that the participants might have been distracted during the interviewing process, as the children could be heard playing and crying outside. Thus, as the participants knew there were only four of them on duty at a time they may have felt guilty that they were not helping out, and hence their attention may have been divided. However, conducting the interviews on Cotlands premises and in the same passage as the children’s rooms also made the stresses and experiences that the participants experienced on a daily basis very immediate. Whereas if they were interviewed in their homes the challenges they experienced at work might not have appeared so bad to them and their attachments to the children might not have been captured so vividly. The aforementioned location of the interviews might have prohibited the participants from feeling free to be completely honest at all times. Moreover, as the selection criteria for this study was the ability to communicate in English or Afrikaans, those participants whose first language was Xhosa might have found it difficult to express themselves adequately in a language that was not their mother tongue.
CHAPTER 4
RESULTS AND DISCUSSION

4.0. Introduction to Research Site

At the time of the interviews (December 2006), Cotlands had a total staff complement of 25. These included the director, a fund-raiser, a donations co-ordinator, a social worker, two registered nurses, two staff nurses, three housekeeping staff, and a driver. Four volunteer medical doctors come to check on the children four hours per week. The twelve CCWs and the staff nurses were the only staff who worked twelve-hour shifts. Four CCWs and one staff nurse were on duty each shift. The registered nurses worked from 8h00 to 16h30, five days a week. The CCWs were also assisted by approximately 10 volunteers.

Cotlands took in an average of 20 children at a time, with a maximum of 26. At the time of the interviews, 18 children had died since inception. As Cotlands aimed to place the children with families of their own by for example, returning the children to their biological relatives, there was quite a high turnover of children. Although the majority of the children were HIV-positive, some of them came to Cotlands as abandoned children; with other chronic or terminal illnesses or they had a disability like cerebral palsy and were then placed in Cotlands for a brief period of respite care. All the Cotlands caregivers had to care for every age group on a rotation basis. They all worked in the same team for at least a year and might work with a different team for approximately two months. Some of the caregivers had been sent to another Cotlands in the Western Cape to help out there for several months.

Demographic Information

As all CCWs at Cotlands are women, all the participants were female. The highest level of education of six the participants was grade twelve. One of them had grade ten and the other
grade eleven. Only two of the participants had no prior caregiving experience. At the time of the interviews, the longest that a participant had worked at Cotlands was three and a half years, and the shortest one year. All the participants were Christians, and the average age was 31 years. As far as home language was concerned, three of them were Xhosa speaking, four of them Afrikaans, and one of them bilingual. Three of the participants were married, three single, one widowed, and one separated. Three of the participants had no children, two participants had one child each, two caregivers had two children, and one participant had three children (two of whom are stepchildren).

4.1. Theme One: One Self: Multiple Roles

To see that the children are safe and to care for their health; to ensure that they are happy – that they are really healthy would I say (#1)

We must ensure […] they get the correct food and if medication has to be given – some of the time staff nurse will ask us to help with that. When they are ill we must make sure that they are comfortable; if the doctor has to come then the staff nurse has to be informed about it – if the child has to be taken to hospital because he is sick, or has to see a doctor. (#3)

They call us childcare workers […] What we do is we care for the children […] So in the mornings […] they get divided into different age groups. Perhaps you see a child’s condition indicating that he must be in a certain group to be stimulated; and then when a child needs to go to hospital – or they have an appointment, one of us goes with […] so that if the child experiences any problems, we are there to deal with it. (#6)

We have a lot of routines. […] the children must be dressed, cleaned, fed – those who can’t feed themselves […] stimulation must be done – those who must go outside […] those who are older, that should have been in a school, for them there are activities that we do, like colouring in, building puzzles, […] changing and cleaning again; then putting them down for a nap. (#8)

4.1.0. Introduction

Most of the participants reported that the primary responsibility of the caregivers working at Cotlands was that they must look after the children and see to it that they were well cared
for. The specific day-to-day duties that were involved in this were to bathe and dress the children; to see that they were always clean and neat, as well as change the babies’ nappies. They needed to feed them and see that they received the right food for their age group. Many of these duties were done according to a fixed routine. All the aforementioned duties were mostly the same as the duties that would be performed by childcare workers at any children’s home, and was similar to what a primary caregiver, such as a child’s biological mother, would do for the child in their care. Accordingly, several of the caregivers reported that one of their roles was to be a mother to the children at Cotlands. Several of the participants expressed this role as follows: “[we] give them TLC (tender loving care)”; “give them love”; “we are like a mother to them”. Their perceived role of mothering will be discussed under Theme Four.

4.1.1. The Challenge of Caring for Older Children

Owing to the fact that some of the children at Cotlands were there until the age of five the caregivers also needed to cater to their specific needs. Hence, the caregivers had to play with them, did activities like building puzzles and blocks and read to them. Several of the participants found it challenging and at times difficult to work with the older children as they were constantly on the go, needed to be kept busy, and thus had to be watched more carefully. One caregiver said, “when they start walking and talking, then they are active – they are a handful” (#6). Participant #8 found it challenging to cope with the older children as they sometimes misbehaved. She voiced her frustration as follows:

“They sometimes make a person very angry. […] The bigger ones cause a person to talk a lot [laughs]. Because you can’t anymore spank them; you may not shout at them. You may also not say that they are naughty – you may not do anything. You just have to be strong – that’s all. […] With the babies you do not have all these problems.”
Another participant reported that the older children asked too many questions some of which she found difficult to answer. She said:

> Coz the eight years – ooh – they are old now […] but if you say no – [the younger ones] won’t ask you so many questions. So that age group – yoh, huh-uh. […] Why is it that I must not do this? […] But some of the questions are very difficult – you can’t even know and you have to tell them why – you see. So you can’t even explain why you say no – but that thing they are not supposed to do.

In contrast, one of the participants struggled with the fact that some of the older children needed special attention, as they were slow in their development.

> The stimulation of the children (is challenging) - especially with the older ones - the two and three year old ones. About that age, because some of them – how can I say it – they are a bit slow.

**COMMENTARY**

Older children pose a different challenge for caregivers than younger children. Some of the challenges which emerged from the participants’ comments was that the children needed to be watched more carefully once they started walking; they needed to be kept busy and they had lots of questions that needed to be answered. A possible reason why one of the participants found the many questions from the older children somewhat challenging could be because she is Xhosa speaking and several of them spoke Afrikaans. Alternatively, it could also be owing to the fact that she had no children of her own and was thus not used to dealing with all their questions. However, it might be an indication that older children were aware that there was something wrong with them and they wanted to know more about it.

The fact that HPC will have questions that need to be answered is supported by an article on Nazareth House. According to Sister Margaret, they endeavoured to make it clear to the children that all people died. As the children got older, they tried to explain more to them. However, as some of their children were developmentally delayed it was not always possible
to explain to them what was going on. On the other hand, she also said, “As the questions come, we must be ready to answer them” (Galloway, 1997b, p16). In spite of a clear need to answer the questions of the children at Cotlands, the caregivers might not have been adequately trained and prepared to disclose and discuss the children’s HIV status with them. That some form of training was required for the caregivers to deal with the specific needs of older children was evident from the fact that in the Johannesburg Cotlands, the organisation had psychology students and part-time psychologists to help the children understand what was happening to them (Galloway, 1997a). Several studies attest to the difficulties surrounding the disclosure of their HIV status to a child (Brown et al, 2000; Fischer 1999). For example, the primary caregivers of children who attended a hospital in Soweto for care typically refrained from disclosing their child’s HIV status to them even though the children often wanted to know what their illness is. The reasons supplied by these caregivers included a lack of knowledge and skills as well as stigma (Kouyoumdjian et al, 2005). According to Lesch et al, disclosing to children was not a straightforward and easy matter and thus they advocate for a process-oriented approach (2007).

A few studies have noted that HPC may have lowered cognitive functioning, social deficits (Fischer, 1999), attention deficit/hyperactivity, oppositional defiant, conduct disorders as well as other behavioural and emotional problems (Brown et al, 2000; Women and Children with HIV/AIDS, 2006). Accordingly, one of the participants found older children difficult to manage when they misbehaved as the caregivers were not permitted to spank or shout at the children. She likely found “the naughty” children stressful as the caregivers had possibly not been taught effective strategies to discipline or control the children. She could have felt frustrated as she might discipline her own children by spanking them and shouting at them. Nevertheless, this participant reported that she dealt with the discipline problem by being strong, which indicated that she exercised restraint and self-control. Therefore, it could be

In spite of the challenges that were posed by the older children, one of the participants (#3) reported that she found it quite rewarding and more enjoyable to work with the older children as she had the opportunity to teach the children new things like respecting other people. According to Van Jaarsveld (2005), individuals who scored high on the *meaningfulness* component of a SOC would see life as a challenge, and not as burdensome. Consequently, it could be hypothesised that participant #3 found it meaningful to care for the older children as she did not find the task burdensome but rather a challenge. This is also reflective of *meaning-making* coping, which is a Positive Psychology coping strategy (Milberg & Strang, 2003; Schwarzer & Knoll, 2003).

4.1.2. Coping with Very Sick Children

*It is very depressing, coz sometimes you get the child, then his condition is okay, the next minute, then the child’s condition is back where it was. Sometimes you feel it is so unfair for these little children.[…]. It is depressing, coz sometimes I think to myself, how did it go today? Because there are so many things you must attend to […]. So then you cannot unburden yourself. But at times it goes better, and then again it goes worse and worse – until you cannot handle it. […] When you work with such a child, you go sit with the staff nurse, and open up. At first it was not nice, coz we did not know what this involved. But now – I am at a stage – I can now say “Now see sister, the thing is like this. So from here onwards, what is going to happen?” Then she informs me […]. So now you know what to expect. […] But now that you know, I mean, it gives you a chance to use your mind. […] But now it is better that you know what the symptoms are and what is stage one. You know this is coming or that is coming. So now I know and I can try to make the child comfortable. But that time, we did not know what the different stages were. But here you get the children that are terminal, then automatically they go onto ARVs. Then you are prepared - willing to see the child. On oxygen – the child will get very sick, but with that (ARV) the child becomes well – the child becomes beautiful. So you get that time when you see the darkness. But we are now at the stage where we are prepared for these things.*
As the majority of the children at Cotlands are HIV-positive, one of the crucial roles that the Cotlands caregivers have to fulfil is to treat them while they are ill. According to the participants, this means that they sometimes give them medication or accompany a child to hospital so that they are on hand should any problem arise. They also do palliative care and tube-feeding when necessary as well as inform the sister when a child is ill or needs to be taken to hospital. Consequently, they also at times have to perform the role of a nurse. This was evidenced by the fact that two of the participants referred to the children at Cotlands as their patients. Several participants mentioned that they found it stressful when a child was very sick, especially to see the child in pain, suffering or dying. It left some of the participants feeling helpless and powerless, as it seemed as if little could be done about it.

A few of the participants coped with having to nurse sick children through religious coping. In contrast, another participant coped by insisting that a child was too ill to be cared for at Cotlands, and had to be admitted to hospital. The latter caregiver’s coping strategy could be viewed either as an *avoidant* coping strategy, or as a *problem-focused* coping strategy. This depends on respectively, whether the caregiver’s motive for wanting the child admitted to the hospital was to spare herself from having to cope with the child’s illness, or whether she had the proper care and best interests of the child at heart.

Nursing sick children appeared to be more difficult for some participants, as they initially did not know what to expect. As one of them said:

> When I first come here I did not know the Cotlands children were very sick children […] but when I came in I see they are sick children. But I told myself that I would cope, that I will try my best to cope with the work. (#5)

She seemed to have thought that she would be able to cope, however, later in the interview, when she was asked if she had any stressors at work, she admitted:
When a child is very sick – it even make me crazy, because the child is starting to cry, and then you don’t know what is wrong. And then when you touch the child, it seems you make the pains more. It is very stressing.

Participant #5 reported that she coped with this stress by preferring to be alone until she felt “alright” again, which is a passive-avoidant coping strategy. Nevertheless, in the latter part of the interview, when she was asked how she felt about the children being HIV-positive, her response was:

It affect me a lot, because when I see them, when you look at the children – I was thinking of leaving, but at the other end I thought maybe one day there will be a child like this at home; and who’s going to look after them. So I told myself, no I must learn to look after these children, although it is painful to see the children suffering.

Consequently, participant #5 coped with the sick children through benefit-finding, and positive reframing (Carr, 2004, McCausland & Packenham, 2003), as she told herself that what she had learnt at Cotlands would enable her to help other HPC in her own community.

The oldest participant (#1), who had been working at Cotlands almost since its inception, also reported that when she first came to Cotlands she did not know what to expect. This she found very depressing and difficult to cope with. She expressed the uncertainty she was feeling as follows, "because sometimes – at the moment you get the child then he is alright, come the next minute, the child’s condition is again back [where it was]". However, in spite of struggling initially, after having been at Cotlands for a while, this caregiver reported that she enjoyed working with the sick children, because her training had equipped and empowered her to know exactly what to do and how to cope when a child was sick. Moreover, she actually found it rewarding, as she could see evidence of the fact that her care of the child had played a role in the child’s recovery. She said:

*The very sick children. I like it very much because I already know what routine I must follow. It is easier for me as I know now [what to do]. I find it very pleasing. And the most*
beautiful of all is to witness when they start improving. You know what you did. You at least contributed to it. (#1)

According to participant #1, one of the ways in which she coped with it initially, was by seeking information from the sister on what would happen at each stage of the illness. Thus she would know what to expect, and could prepare herself mentally and emotionally for it. Participant #1 also appeared to have gained pleasure from the sense of achievement that she felt at having contributed to the child’s improvement.

COMMENTARY

A large proportion of the challenge of caring for PWHA is dealing with the illness which progressively gets worse. For instance, informal family caregivers of PWHA living in Malawi reported that they did not consider the caregiving itself to be a problem. However, they admitted that it was distressing when after one had done one’s best for the patient that the patient still did not improve (Chimwaza & Watkins, 2004). According to many Cotlands caregivers, caring for very sick children appeared to be one of the most challenging roles of their work. This finding was also observed by Manning (2002) who reported that the impact of HIV/AIDS probably places a considerable “emotional strain” on the caregivers of children “who enter the home HIV-positive” and after a few years “progress through a succession of painful illnesses before passing away at a young age” (p23).

In relating how they coped with sick children, both participants #1 and #5 shared three factors in common. Firstly, both made use of the coping strategy of benefit-finding (McCausland & Packenham, 2003; Schwarzer & Knoll, 2003). Participant #1 noted that her caring of a child had led to its improvement whereas participant #5 found it beneficial that what she had learnt at Cotlands would enable her to help her own community one day. Other studies support the benefit that caregivers derive from caregiving. In a study by McCausland
and Packenham, (2003), some of the caregivers noted that they had benefited from AIDS caregiving as they could see that they had made a difference in the life of the care recipient, while others stated that they their knowledge of HIV/AIDS had increased. A sense of achievement is one of benefits of caregiving mentioned by other AIDS caregivers (Gueritault-Chalvin et al, 2000). The caregivers in a study by Booysen (2005) reported that they found it rewarding when they saw the abused children that had been admitted to the centre getting better – knowing that they had played a role in the healing process.

Secondly, both participants #1 and #5 showed evidence of Salutogenic functioning, specifically SOC (Antonovsky, 1979). One could deduce from participant #1’s explanation of how she dealt with a very sick child that it was not beyond her capability, as she felt able to manage and cope with it. Participant #5’s sense of being able to cope, although initially future oriented, still evidenced confidence in herself to cope. According to Van Jaarsveld (2005), the manageability component of SOC is negatively correlated with a feeling of helplessness. Therefore, one could conclude that as participants #1 and #5 did not feel helpless in the face of treating sick children, that they exhibited a fair degree of the SOC manageability component. Thirdly, both participants reported that initially it was not easy to work with sick children, or to see them in pain, but over time, they learned to cope with it.

One of the coping strategies employed by participant #1, viz. wanting to know the course of a child’s illness, might be illustrative of what Schwarzer and Knoll referred to as anticipatory coping. This is preparing for an event that one anticipates to happen in the future (2003) – also referred to as preventive coping by Greenglass (2001). Both of these are Positive Psychology coping strategies. On the other hand, it could be evidence of the problem-focused coping strategy of information-seeking (Lazarus & Folkman, 1984). Alternatively, the coping strategies evidenced by participant #1 in the above extract, may
also be interpreted as learned resourcefulness and mastery, as she had over time learned how to manage a very sick child through her training, experience, and by asking for information (Kobasa, cited in Strumpfer, 1990). The coping strategy of information-seeking evidenced by participant #1, has also been reported in a study by Shebi (2006), investigating the experiences of HIV/AIDS primary caregivers. According to Shebi, shortly after having discovered the HIV-positive status of their close relatives, the caregivers who would be responsible for caring for them actively sought out both instrumental support and information on what to expect and how to care for their family member.

Although the participants enjoyed working with the children, when some of them became very sick, it could be quite distressing at times. This finding is supported by other South African paediatric HIV caregivers, who have also reported on the challenges inherent for PHCs. For example, when asked what some of the problems were associated with caring for HIV infected children, Sister Margaret of Nazareth House replied, “It’s a very difficult thing to deal with, because you want to see these children running around … it’s awful that this is holding them back. It’s painful” (Galloway, 1997b, p.16).

Religious coping used by a few participants is discussed under theme four.

4.1.3. Feeling Overwhelmed

Apart from the multiple roles that Cotlands caregivers had to fulfil, their description of their day-to-day work also revealed a sense of being overwhelmed at times. They had to take care of five to six children at a time and when one of them was very sick, it was difficult to focus on the other children as well. This problem was further compounded when one of the childcare workers was off sick as well. In the words of one participant:

*If there is someone who - even if us the staff is also sick – that thing will affect the children [...] So now we are four careworkers .. we have to keep – most of the time - we have to look*
after that one, but we do also look after others, you see. But we have to concentrate to that one who is very sick. [...] So sometimes it’s very stressful. (#2)

Another participant expressed her feelings of being overwhelmed as follows:

There are about four or five, and you must give attention to all of them. One child needs stimulation exercises, another cries, and no-one is there - or another child wets his pants. Then you must leave what you are doing and go and see to that child. (#8)

When they felt overwhelmed, most of the participants coped by asking for help from either the other caregivers, or nursing staff. The latter were reported to be very supportive of the caregivers, and were always willing to lend a helping hand.

COMMENTARY

Several studies focusing on caregiving have reported that caregivers often experience feelings of being overwhelmed, especially if the care recipient is very ill, or if the caregivers had many individuals under their care, or if they had an additional burden like insufficient finances (Booysen, 2005; Chimwaza & Watkins, 2004). Some caregivers at times become so overwhelmed, that they feel they are not coping at all (Simpson, 2005). Many nurses in a study by Lehman and Zulu (2005) reported feeling stressed and overwhelmed by the vast numbers of patients that required their attention on a daily basis. When caregivers experience extreme pressure they often burnout or may even experience symptoms of posttraumatic stress disorder (Booysen, 2005). In spite of a few Cotlands caregivers feeling overwhelmed and expressing feelings of helplessness and powerlessness, it was not something that they experienced very often and they did appear to cope with it.

The coping strategy used by most participants when feeling overwhelmed, was the problem-focused coping strategy of instrumental support-seeking. This also indicates the important role that social support plays in the optimal functioning and well-being of caregivers. It is
noteworthy that the participants who made use of staff support felt the freedom to ask for it and believed they would receive it. Furthermore, some of them mentioned that other co-workers would step in and help without being asked; should they notice that more than one child needed attention. The caregivers in a study by Shebi (2006) reported that it was a great help to them that people in their community, such as neighbours would offer their assistance. The importance of this quality of staff support is underscored by Miller, Gillies and Elliot, who noted that health workers needed support which is accessible as and when it is required (cited in Mayers, 2005). The importance and necessity of social support at work was also highlighted by South African nurses (Lehman & Zulu, 2005). Although they also reported feeling overwhelmed, they however did not receive adequate support at work.

SUMMATIVE COMMENTARY

Of all the roles that the participants had to fulfil what they appeared to find most challenging was caring for a very sick child and having to attend to more than one child at the same time. It appeared that they used different coping strategies for the different situations. This seemed to indicate that they appraised the situation of having to help two or more children simultaneously to be more challenging than treating a very sick child, as they could not cope with the former on their own. Nevertheless, when faced with having to manage different roles several of the participants had unique ways of coping with them.

4.2. Theme Two: The Impact of HIV/AIDS on the Caregivers

_Fear of infection lives with nurses continuously … if given a choice, they would not test … occupational exposure contributes greatly to tensions within personal relationships, fuelled by fear and stigma (Lehman & Zulu, 2005, p. 53)_

_I feel that I’m not afraid anymore, because I spoke to my husband about it. Because I felt if he is afraid, then I will have to leave. Coz there was an incident where we heard about one sister who gave an injection, and apparently the patient’s blood went into her eyes. […] my_
husband spoke openly about it to me – that he was aware of this story [...]. So then I asked him: [...] so how do you feel about it? If something should happen, coz you know I work with the children? (#1)

Caring for an HIV-positive person poses unique challenges to the caregiver. Not only does the ‘patient’ have a terminal disease for which there is no cure, but the progression and course of the disease differs from one person to the next and can last from a few months to several years. As the means of transmission is mainly through sexual contact, AIDS is also an illness that is accompanied by stigma, isolation, rejection and fear of infection (Campbell et al, 2005b; Fischer, 1999; Halhambo et al, 2004). These factors have been exacerbated by many misconceptions concerning the manner in which the HIV virus is contracted. Most of the aforementioned issues, like contagion fear, affect HIV/AIDS caregiver to some extent during their time of caregiving. According to Orner (2006), “stigma and prejudice towards caregivers was common, and exacerbated stress levels” (p. 236).

4.2.1. Contagion Fear and Risk of Exposure

When the caregivers were asked to mention some of the challenges that accompany their work at Cotlands, none of them mentioned the fear of infection. However, when the topic was raised at a later stage, several of the caregivers admitted to having some form of contagion fear, which ranged from a mild fear to quite a substantial fear, as evidenced in the words of participant #5:

*Yes I’m afraid of being infected – you can’t say you are happy you are infected ... because it is a dangerous disease – because you can die – very soon.*

She described her way of coping with contagion fear as:

*Sometimes I’m always thinking about it  - but I tell myself, I saw a lot of children who suffer from this disease ... So I think I will also accept it and cope with it, because I have knowledge of it.*
Four coping strategies or human strengths appeared to be evident in this extract, firstly the coping strategy of positive reframing (Carr, 2004). The second might be the passive-avoidant coping strategy of acceptance (MacArthur & MacArthur, 1998; McCausland & Pakenham, 2003; Rose & Clark-Alexander, 1998). The third appeared to be illustrative of an adequate SOC, as the caregiver believed that she has the ability to manage and deal with the situation (Antonovsky, 1979). Lastly, the strength of learned resourcefulness (Rosenbaum, cited in Strumpfer, 1990) also appeared to be evident.

Not only was participant #5 afraid of being infected, but her husband also appeared to be very concerned about it. For example, when she was asked whether her family were concerned about her being infected, she replied:

_Yah, he is worried, and he’s always asking me “use gloves every time” always asking me._ … _[The rest of my family] are also worried. And then they are always, “What are you using to protect yourself? How can you be sure you can’t get infected?”_

Participant #5 reported that she had had herself tested once, but has not had the courage to go again, as “I don’t like to go there – it is not easy”. Notwithstanding, she appeared to have quite a fatalistic attitude about contagion fear as she said, “If it’s meant for me (to be HIV-positive), then it’s meant for me. But I don’t know. It does not bother me”. However, she did afterwards concede to some worry regarding being infected, and that she would some time in the future have herself tested, just to ensure that she was not infected. Another possibility is that participant #5 had a fear of infection as her family had projected their fears onto her. In contrast, Lehman and Zulu (2005) reported that one of the nurses in their study admitted that she had projected her fear of infection onto her family members.

Another participant (#3) described an incident, which had clearly been quite stressful for her. She believed that she might have risked exposure by not wearing gloves when she was handling a child whose nose was bleeding while simultaneously she had a burst blister on
her hand. However, in spite of her fear of infection she avoided having herself tested for the HIV virus, which may be an indication of a passive-avoidant coping strategy (MacArthur & MacArthur, 1998; McCausland & Pakenham, 2003; Rose & Clark-Alexander, 1998).

Unlike the above two participants, another Cotlands participant (#4) has had herself tested many times, despite asserting that she is not afraid of being infected as she wears gloves. It thus appeared as if she coped with contagion fear through denial – which is a passive-avoidant coping strategy. On the other hand, she might have coped with it through trying to control the situation by having herself tested regularly. According to Lazarus and Folkman, personal control forms an integral part of the coping process (1984). Similar to the latter participant, participant #7 also presented with a discrepancy between what she said and what she did. For instance, although she said that she was not afraid of being infected she had herself tested three times in a row even though the clinic had said that it needed only to be done twice. Another participant (#8) stated that she was not afraid of being infected. Yet she admitted that it would be much worse being infected with the HIV virus through rape, than having to live with the virus acquired in another way.

**COMMENTARY**

The possibility of being infected by the HIV virus is a fear with which many HIV/AIDS caregivers struggle. Some South African nurses (Lehman & Zulu, 2005; Mayers, 2005), non-professional South African caregivers (Melnick, 2002; Orner, 2006; Shebi, 2006), and many Ugandan home-based carers (O’Hare et al, 2005), also admitted to experiencing contagion fear. Cotlands caregivers presented with differing attitudes regarding contagion fear and thus coped with it differently. For example, the coping strategies that seemed to be exhibited by participant #5 were positive reframing and acceptance, and the strengths that appeared to be evident were SOC and learned resourcefulness. The aforementioned coping strategies
probably did not occur simultaneously. Instead, they may have developed over the course of her working at Cotlands as she gained more confidence in dealing with the challenges that accompanied her work. Experiencing growth and acquiring greater internal strength owing to AIDS caregiving is supported by other caregiver literature (Cadell, 2003; Cadell, 2007). In a study by Shebi, she noted that some of the primary caregivers acknowledged that because of caring for an HIV-positive person they had become emotionally stronger (2006).

The fact that participant #3 did not have herself tested for the HIV virus may be indicative of a passive-avoidant coping strategy. Another possible reason might be that she realised that there was a possibility of becoming infected, but she did not seem paranoid about it. One could also hypothesize that she did not see the point in worrying about it as she had already too many other things to concentrate on whilst caring for the HIV-positive children. Thus her avoidance of being tested could instead be viewed as a coping strategy proposed by Carver et al (1989), viz. “the suppression of competing activities” (p.269), as she possibly chose not focus on her contagion fear, but rather on her other work responsibilities.

There might be several reasons why there seemed to be a discrepancy between what both participants #4 and #7 said and did. Firstly, there could be factors outside Cotlands that might play a role in their contagion fear such as possibly having had unprotected sex or they could be suspecting their partners of having had unprotected sex. Secondly, they might consciously have believed that they had no contagion fear yet unconsciously they did fear being infected. Hence, they often had themselves tested. Whether the risk of exposure is big or small, real or imagined, caregivers of PWHA still have to take precautionary measures when working with their patients. According to Manning (2002), a residential care organisation in KwaZulu Natal reported that owing to HIV/AIDS there does exist a potential risk for occupational exposure for childcare workers, although the organisation does practise
“universal precautions to protect” both staff and residents (p.23). Thus to a greater or lesser degree many professional and non-professional HIV/AIDS caregivers have to cope with the risk of exposure to the HIV virus.

Lastly, participant #8’s statement regarding rape, could indicate that she probably had a bigger fear of being raped, than of being HIV-positive. This might suggest that rape was a much more prevalent phenomenon in her community than HIV/AIDS. In addition, several of the participants had to wait a long time for transport and others had to walk quite a distance to get to work, which could play a role in participant #8’s fear of being raped. This highlights that not only factors at work impacts on the participants’ effective coping and psychological well-being, but also factors outside of the work environment. Nonetheless, for the participants who admitted to some contagion fear it was worse for them and their families when they first started working at Cotlands than it currently appeared to be.

4.2.2. Misconceptions

Although the majority of the participants appeared to be informed about how one acquired the HIV virus, some of them still seemed to have some misconceptions. For example, one of the participants (#5) thought that one could acquire the virus anywhere, not just when working with HIV-positive individuals. When her family asked her how did she know that she could not become infected (at work), she replied, “you tell them you can get infected anywhere. Maybe around here (in her own community) I can get infected”.

COMMENTARY

All Cotlands caregivers probably received the same training, viz. that the most common route of exposure to the HIV virus is through contact with sexual fluids, but also through contact with an infected person’s blood. Consequently, caregivers of HIV-positive persons
must always wear gloves when working with their patients (Zaidy, Small & Louis, 1997). However, in spite of having received the same training and working in the same place, some of the participants still evidenced misconceptions regarding the risk of contagion and responded to it differently. One of the participants seemed to have a misconception regarding HIV infection as she said that one could get it anywhere.

Very differing attitudes to the possibility of being infected, as well as misconceptions regarding it, is also reported in other studies of HIV/AIDS caregivers. For example, Shebi noted that one of the primary caregivers in her study was afraid to wash the HIV-positive person in her care for fear of being infected, whereas another primary caregiver had not been afraid to handle her HIV-positive family member, whose drip had fallen out and was draining blood (2006).

4.2.3. Stigma, Discrimination and Social Ostracism

Besides having to care for a very sick child, while simultaneously having to manage a fear of infection, HIV/AIDS caregivers also often have to face possible stigmatisation, discrimination, isolation and rejection. Unlike reports from other HIV/AIDS caregivers, none of the Cotlands participants encountered any stigmatisation from either their family or friends; neither did they experience any discrimination, isolation or rejection as a result of working with HPC. However, one of them said that when she and a staff nurse went together to have themselves tested for HIV, she did not want to go to a clinic close to either her work or her home, for fear of someone recognising her from her own community.

COMMENTARY

As far as stigmatisation is concerned, the fact that participant #1 went to a clinic far from her home to be tested, seems to indicate that she did fear being stigmatised if people she knew
were to find out that she either went to have herself tested for the HIV virus or that she was HIV-positive. Nevertheless, although stigma associated with HIV/AIDS is often mentioned in HIV/AIDS literature (Melnick, 2002; Orr & Patient, 2004; Stein, 2004) it does not appear to be much of an issue for the Cotlands caregivers.

SUMMATIVe COMMENTARY

The impact of HIV/AIDS on caregivers of HIV-positive individuals includes factors like social ostracism, discrimination, and rejection, yet none of the participants reported having experienced any of the aforementioned. Stigmatisation appeared only to have affected a few participants, and only in terms of a perception that they may be stigmatised if recognised when going for an HIV test. Some of the participants had a problem with contagion fear. However, their attitudes to it were different – which to a certain degree may be influenced by misconceptions - and thus they responded to it differently. One of them would have herself tested regularly, whilst another avoided having herself tested. Although some of them do fear contagion, it did not cause unmanageable stress, as it did not hamper their work or interfere with their functioning. Moreover, it was not an obstacle to them forming attachments to the children and did not prevent the participants from picking them up, even if they were bleeding.

4.3. Theme Three: Coping with Attachment, Separation and Loss

All the children seem to naturally pick out one caregiver that they virtually look on as their mommy, and with whom they build up a special relationship (Galloway, 1997b, p.15)

The staff usually develop special relationships with certain children (Galloway, 1997a, p.11)

I think I treat all the children the same – I don’t have a child who is very special, all the children are the same to me […] but sometimes you think about them. […] It’s very sad when they take children away (#5)
You form a bond with the child […] but you know when to end it. […] You must have a working relationship with the child; and you must know that it is for the child’s best – it’s not for you. You must not use it for yourself - otherwise it will break you. Because you see, the children become well again […] Her mother had just died, and then she came here […] and she bonded with me – she thought I am now her mother – she gave me the name mommy E. […] I had to tell her “I’m not your mommy, but I am your mommy while you are here”. (# !)

4.3.0. Introduction

Most of the participants reported having formed an attachment to the children – most of them to one or two specific children - especially those who had mentioned that one of their roles was to be a mother to the children and to love them. However, two of the participants reported that they did not form attachments with the children. One of them said that she treated all the children the same, that there was not a specific child who was special to her. The other participant said that she formed a “working relationship” with the children, and coped with the possibility of attachment by keeping her boundaries. In terms of attachment and loss, even though ART has improved the lives of HPC considerably, it makes it quite challenging for Cotlands caregivers to cope with caring for HPC. According to Galloway (1997a), the assistant director of a Johannesburg facility for HPC reported that it was hard for the caregivers to lose a child that for months had been in their care, and whom they had looked after as if they were their own children.

Since the implementation of ART at Cotlands, many of the children live longer and become healthy again. Therefore, the organisation aims to place these children back into homes of their own through for example, foster care. However, not all of them respond equally well to ART as some of them will still die or suffer from opportunistic infections and some of the children are already so ill that it is too late to put them on ART. Moreover, there are much fewer ARV therapies available for children (Women and Children with HIV/AIDS, 2006). Nevertheless, although some of the children at Cotlands still die, the caregivers experience
loss most often when a child leaves Cotlands when placed out. Caregivers also have to cope with being separated from the children when they are not on duty.

4.3.1. Coping with Separation

The participants dealt with separation and loss in numerous ways. When they were asked how they coped with not seeing the children on their days off work the one replied that she played with the children in the area where she lived so as not to miss them too much.

Another participant explained how she coped with missing one of the children as follows:

*Sometimes if I have transport, I just come (to Cotlands). Especially this one she’s 8 months. And this Saturday […] and last Saturday I was missing her so much, […] the whole family of mine, they know her, even though they didn’t see her. (#2).*

A participant whose child lived with his paternal grandparents in a nearby town said that when she saw her own child, she did not miss the children at Cotlands and when she was with the Cotlands children, it helped her not to miss her own child that much. These two participants seemed to make use of a problem-focused coping strategy to cope with being separated from the children at Cotlands. However, participant #3 experienced separation very differently. She said “*I [miss] her terribly … I just bear [not seeing her] till I see her again*”. Thus, she coped with it by waiting, which is an internal coping strategy (Gueritault-Chalvin et al, 2000). On the other hand, participant #7 who had formed a strong attachment to some children said, “*[I] just wanted to take them home for [myself] “.

**COMMENTARY**

Most of the participants for whom separation from the children was an issue seemed to use a more active approach to cope with separation, thus they likely felt there was something specific they could do to deal with separation. Yet participant #7 seemed to think that there was nothing she could personally do to help her cope with the separation from the children
as she appeared to use a passive-avoidant coping strategy of wishful thinking, to cope with it (McCausland & Packenham, 2003). Similarly, caregivers in a study by Hill, Newmark and Le Grange, used wishful thinking in situations they felt could not be changed (2003). According to the Cotlands Director, some of the caregivers had coped with separation from the children by taking the children home with them when first starting to work at Cotlands, but eventually they did not do so any longer. Many of the participants formed quite strong attachments to specific children, some of whom were affected by being separated from them. Yet it did not appear to be overwhelming or distressing, especially as they knew the children were being treated well at Cotlands.

The participants manifested different levels and types of attachment to the children. Some of them only had what one participant referred to as “a working relationship” (#1). Whilst another participant formed such a close attachment to the child that she wanted to take him home. These varied attachment styles is consistent with that reported concerning the CCWs interviewed in a study by Bussey (2005). In his study, the relationships between the CCWs and the children ranged from “personally intimate, through ambivalence, to highly guarded resistance and extreme detachment” (p65). In the case of Cotlands caregivers, one could hypothesize that different attachment styles could explain why they seemingly responded differently to a child leaving Cotlands - thus coping with it differently. According to Parkes (1988), grief intensity is determined by “the quality of attachment” to the person (p.59)

When comparing the participants’ responses to their demographic information it appeared as if in some cases there might be a relationship between the type of attachment and coping strategy manifested by a particular participant and her age and marital status. For instance, it is hypothesized that one of the participants who was single and childless, might have formed
a very strong attachment to specific children and came to visit them on her days off, as she unconsciously wished to fill the longing inside her for her own children.

4.3.2. Coping with Children Leaving Cotlands: Being “Placed Out”:

Although most of the participants had formed close attachments to certain children, they did not necessarily experience the resultant loss when they left Cotlands in the same way. Therefore, they sometimes also managed it differently. For example, one of the participants experienced a wide range of emotions and thoughts in trying to come to terms with the loss of a child leaving. This is how she related the experience:

I felt very unhappy about it. But what could I do about it…… I don’t actually know. When I came in [here] I found she was not [here] anymore….. And there is nothing I can do about it you know. But sometimes, like this morning, then I miss her. Then each of us talks about a child that has been special to us – like she was the child that was special to me. … I was very worried about her, how is she going to be treated … and she is a child if she cries then I know what is wrong, like her nappy needs to be changed, or she’s hungry. … she was very fussy, so if she did not like the food, then I had to get her something else (said laughing and in a light-hearted manner) (#3).

Participant #3 appeared to feel somewhat helpless about how to cope with the loss at first and seemed to struggle with it, especially as she had been away relieving at another Cotlands branch at the time of the child leaving. Nevertheless, she subsequently resigned herself to it and seemed to accept it, thus moving from a less adaptive to a more adaptive passive-avoidant coping strategy. On the days that she missed the child a lot, she coped with it by talking about her to the other caregivers, hence making use of social support and emotion-focused coping. Lastly she coped with it through the use of humour, which can be seen as either a Positive Psychology coping strategy (Vaillant, cited in Seligman & Csikszentmihalyi, 2000), or as an emotion-focused coping strategy (Carr, 2004). Hence, participant #3 progressed from a sense of helplessness to a highly adaptive coping strategy of humour in the process of coming to terms with the loss of
someone special to her. Similarly, another participant coped with a child leaving, by positive reframing and benefit-finding (Carr, 2004; McCausland & Packenham, 2003), saying that it was better for the child to have a family of his own.

Similar to participant #3, other participants also voiced their concerns over how a child was fairing once having left Cotlands. Some of them coped with their concerns over the continued care of the child by seeking information on the child’s welfare from management.

Another participant (#6) initially coped with her concern by wishing to remain in contact with the child. She recalled:

"The one that left, I try to keep in contact. One would like to know how is it going with them. […] You see, we know before the time that child is going to be placed out. So you say to yourself before the time, that the child is leaving – but I cope with it. … In the morning when you get here, the child used to shout “Aunty”, and then you give him a big hug – but he has left now. So the other day I thought to myself, I wonder what he is doing now… I regularly think about him. And when I get home, you see, I have a photo of him standing there – so I often look at it." (#6)

Besides wanting to keep in contact with the child, participant #6 also coped with her ‘special’ child being ‘placed out’ by preparing herself for the child’s discharge – also referred to as anticipatory coping (Schwarzer & Knoll, 2003). She also appeared to evidence a SOC and learned resourcefulness as strengths that she drew from to cope with this loss.

Another participant dealt with a special child leaving in another way. She said:

"So then I thought I’m not going to bond anymore. So I said to the sister. “You know sister, when this child leaves Cotlands – I’m not going to bond anymore”. So she said, “You only think that”… I can’t help it. It just happens. Cause this one – I was on leave from April – and when I came back I [was so upset] … Shuh. I missed her, missed her every time – especially if I don’t know where she is…. And sometimes, I just change the others’ names – and use [her name that] I’m used to." (#2)."
Participant #2 initially believed that the best way in which to cope with the pain and loss that occurred when a child was ‘placed out’, was not to bond with the child in the first place. Although she had mentally decided on this, emotionally she was not able to go through with it. In her attempts to deal with this loss, she also appeared to have sought the advice and social support from the sister. Lastly, she wanted to keep the memory of the child alive by continuing to use her name for other children.

Whether participants coped with a child being placed out through an active coping strategy like *information-seeking*, or whether their coping was indicative of Salutogenic functioning, a caregivers’ experience of attachment and loss possibly was exacerbated by being quite ambivalent about it. An example of this is illustrated in the following participant’s words:

*When a child has been here a long time, and his condition is deteriorating – he gets sick and you know […] he is not going to make it. That is the worst time. And also when a child has become stronger and better, and you see that child has progressed … and you have cared for him, and in the end his condition is so good that he is placed out […] And then you become worried about whether that person is going to take good care of the child.*(#6)

Participant #6 described a child who she knew was not going to make it as “the worst”. Yet at the same time also found it painful when a child whom she had nurtured and cared for so much – possibly investing a lot of time and ‘*Tender Loving Care*’ into the child – becoming so well that he or she left Cotlands.

**COMMENTARY**

It is to be expected that coping with the death of a child would probably be painful and difficult for the caregiver. Yet according to most of the Cotlands participants, it was ‘easier’ to cope with loss owing to a child’s death, than because of a child having left Cotlands when placed out. The former was easier to deal with as they had encountered it less often and they believed that the child was in a better place. In the latter case, they had various concerns
regarding the future of the child, and it was a situation faced more often. The recollections of
the aforementioned participants indicated that there were unique and individual ways in
which participants experienced and coped with their special child having left Cotlands. In
addition, three common themes emerged in the ways that they coped. The first theme was
the desire to keep the memory alive of the child they missed. For instance, one of them kept
a photo of the child, another thought often about the child and a third participant called other
children by the name of the child who had left. Collectively the participants would remember
and reminisce about the children - sharing stories about the children whilst they were
together. Thus they used social support, interpersonal relationship coping or emotion-
focused coping to face the loss they experienced when a child was placed out.

The second theme is connected to the participants’ concern regarding whether a child would
receive the proper treatment and care in his or her new home. Some of the participants coped
with their concern by making sure that the child would still be well cared for. This
‘continuation of care’ was done by seeking information from either management or from the
family that the child went to in order to reassure themselves that the child was alright and
that his or her needs were being met. Thus, the active coping strategy of problem-focused
coping was used in this situation. In a study by Bussey (2005), the CCWs were also
concerned about the quality of care a child would receive once they left the children’s home.
One of their ways of wanting to cope with it was to build relationships with the caregivers
who would be the child’s primary caregiver once they left. However, they were at times
restricted from doing this, as it was actually the role of the social worker.

The third common theme, which involved coping as a process of progressive stages, will be
discussed later, as it also occurs in the next section.
It is noteworthy, that although one of the participants mentioned that she had been told before the time that a child was going to be placed out, other participants seemed to have been unaware of it going to happen. Therefore, the effectiveness of communication between caregivers and management may also affect how the caregivers cope with a child being placed out, especially as this form of loss happens much more often than a child who dies.

4.3.3. Coping with death

One of the painful factors for caregivers, associated with HIV/AIDS, is that several of their patients die and often after a long and painful illness. For some of the Cotlands participants this resulted in them feeling quite powerless. As in the case of coping with children leaving Cotlands, the participants coped with children dying in different ways.

One of the participants when asked how she experienced it when a child died replied, “So this was the best thing for him – he was in pain, so you just let it go, think, Okay the best is to let him go”. She seemed to cope with the death of this child through positive reframing and benefit-finding (Carr, 2004; McCausland & Packenham, 2003). Other participants reported that they coped with a child’s death through passive-avoidant coping strategies such as wanting to be alone; by accepting it; or by just wanting to be quiet. One particular participant reported that it was so painful for her to be present when a child died, that she had to take sleeping tablets to sleep that night. Participant #1 reported that she coped with the children dying by having decided not to become too attached to the children and not to allow herself to become so affected by things. On the one hand, this may be an indication of some emotional blunting. Yet on the other hand, this same participant said that what helped her to cope with a child’s death was to know that she had done her best for a child. She also seemed to cope by having sometimes handed the responsibility of caring for a dying child, in the last stages of the illness, over to the sister and the hospital.
Similar to some of the other participants, participant #6 described a range of emotions and different processes in coping with a child’s death. This is how she recalled it:

You feel bad, and then you will cry if you have now been close to the child. But the more you are involved, and you know the circumstances, and the longer you are here, the stronger you become. [...] And when the parents of the child that died come here, and you talk to them, then the emotions come by themselves automatically – you are sad, especially if you knew the parents. [...] in the beginning it was more difficult, especially when you see the parents, but you get used to it - eventually you learn to be stronger – for the mother or parents. [...] I cope much better now, because one knows now when a child is beginning to deteriorate – so you prepare. You prepare yourself for it at the beginning.

Some of the coping strategies employed by participant #6 were emotion-focused coping strategies such as crying and talking, and anticipatory coping as she prepared herself for what to expect. Furthermore, participant #6 was able to comprehend what was going to happen to the child, and she believed she could manage the stress resulting from the child dying. She had learned to be resourceful by preparing herself for what was to happen next to a dying child. Therefore, SOC components like the comprehensibility and manageability and learned resourcefulness appeared to be evident. The aforementioned coping strategies point to a progression in the participant’s ability to cope, and in the type of coping strategies selected by her, viz. beginning with more reactive coping strategies, and ending with more positive coping strategies and Salutogenic functioning.

In the next extract, it is revealed that some of the participants did not only have to cope with the loss of a child who had died, but they also had to deal with the pain of the child’s family. The participant recounted her pain and the pain of a mother:

I was hurting. It was for me as if it were my own son. And a few years ago I lost my husband – but the feelings are different [...] But with the little boy’s death I felt; the hurt differs. [...] I was very affected by it. [...] The previous day he had his birthday, and that night he died. His mother would have come to fetch him – she was looking forward to it.
And that is what made the pain so bad. How does one explain to such a mother that her son has died? That is what made it so bad for me.

This participant mentioned that the workshops she had attended - which taught them relaxation exercises like meditation - helped her to cope a lot.

Many of the participants used religion and spirituality to cope with the death of a child or when they knew that a child was about to die. For example, one of the participants reported that when she saw a child suffering, she prayed that God would come and take the child. Yet in spite of appearing to believe that God had answered her prayer, she still expressed a sense of helplessness and powerlessness. She talked about it as follows:

I just accept – because there’s nothing I can do, especially as these children are very sick [...]. So sometimes I see that children lying there in all that pain, I just ask God that He can take the children – because she suffer a lot. Although we ask God – but when that thing is happening, it is like you did not mean right now, but there is nothing that we can do.

Although the above participant did not appear to find much comfort or support from praying to God in this specific incident, another participant found prayer to be very helpful to her. She explained it as follows:

[Other caregivers and I ] pray together, discuss problems together [...]. We recently had a child where we felt - we all prayed together for the child, because we felt the case is beyond us – truly, it helped us.

Besides finding prayer helpful, this participant also appeared to find comfort from the social support of collectively praying together. She also coped with a child dying by being able to discuss her problem with other co-workers. According to her praying really helped, even though the child still died, as it seemed to have given her a sense of peace.

Coping by using social and emotional support was also mentioned by other participants. For example, one of the participants said that it helped to talk to someone who could identify with what she was going through. Thus, she made use of an emotion-focused coping strategy
like emotional social support-seeking (Carver et al, 1989; Lazarus & Folkman, 1984; Greenglass, 2001). She expressed her pain and coping in this way:

> It’s sad – because I remember a boy, five years old – I was working night at that time, and he was keep asking me something to eat, it was midnight, and I was wondering, why this child is asking for food – and then I give him the food – but he didn’t sleep the whole night, and when I came back they told me he passed away, and I was very sad, because I didn’t know that time was his good-bye to me […] You see when you talk with the people […] you are not the only one who is working with that children – then you talk with the others and tell them: ”You know, this is very painful” - they will comfort you

In spite of acknowledging that it was very painful when a child was dying or had died, this participant noted that she had found comfort and support from being able to talk to other caregivers. Therefore, she employed social support and interpersonal relationship coping strategies (Marshall & Barnett, 1992; O’Brien & DeLongis, 1996).

**COMMENTARY**

One of the most difficult aspects of AIDS caregiving is accepting that it is a terminal illness. Coping with death and loss is a struggle for many caregivers of PWHA (Rose & Clark-Alexander, 1998; Theis et al, 1997). Ugandan caregivers of family members with AIDS, (Chimwaza & Watkins, 2004) were unable to acknowledge that their relatives would not survive in spite of caring devotedly for them. In contrast, Cotlands caregivers were able to accept the death of a child even though at times it was not easy, by using social support (Blankfeld & Holahan, 1999) and benefit-finding (McCausland & Packenham, 2003). An example of the latter was that the child’s death would be an end to his or her suffering.

As in the case of coping with children being ‘placed out’, coping with a dying child, appeared sometimes to be a process. When first starting to work at Cotlands it was worse and more difficult for some of the participants, but later on they said that they “get used to it”. This process often involved stages of letting go. This seemed to include on the one hand,
keeping alive the memory of the child. On the other hand, after a child had left Cotlands, some of the participants ‘continued their care’ of the child by making sure that the child was still well cared for. Some of the participants used *anticipatory* coping, as they could ‘read’ the signs that indicated that a child was not going to make it (Schwarzer & Knoll, 2003). Therefore, they could prepare themselves for it beforehand - emotionally and mentally. What Schwarzer and Knoll (2003) referred to as *anticipatory coping*, could in the case of loss, be interpreted as *anticipatory grieving* as reported by Shebi in her study on HIV/AIDS primary caregivers (2006).

Lastly, in coping both with death or a child leaving, several participants reported that they could cope better with it as they had become “stronger”. Consequently, it was evident that the participants had grown in their ability to cope and possibly gained in ego strength, although they themselves did not express it in this manner. The finding that caregivers experience growth as a result of the caregiving process, is also supported in other caregiver literature (Cadell, 2003; Cadell, 2007). One of the participants in the study by Shebi, reported that she had grown emotionally stronger as a result of HIV/AIDS caregiving (2006).

4.3.5. Coping with Loss: Maladaptive, Adaptive or Salutogenic Responses?

*There was an emptiness. But I felt that I knew from the beginning, she is not my child […] You don’t take it so badly as if the child had died under your hands – then you may blame yourself – if you were on duty […] but it is one of those things – you know it is your job, […] so I always say to them I feel better if I know I did my best – so then I don’t have any regrets.*

*When I close my eyes – I just see the picture of that baby lying there in the cot. And if there is a child that died and I have to see, I first have to take a pill during the night […] I just accept – because there’s nothing I can do.*

*I was actually happy and relieved, she had suffered a lot. […] I felt at peace.*
It’s very sad when they take children away, but I’m happy to see them going because they are going to have a good life with everything they need … so you just tell yourself, this is the right thing for them also – you don’t just think for yourself, but also for the children.

Although several of the participants mentioned that after having been at Cotlands for a while, it became easier to cope with their work as a result of “getting used to it”, this might actually be an indication of emotional blunting rather than a sign of them “becoming stronger’. However, without exploring it in more detail with the caregivers in question, it is not possible to come to a definite conclusion. According to Schwarzer and Knoll, coping strategies are not easy to determine, as they often change over time and from situation to situation (2003). Nevertheless, judging by these caregivers’ dispositions and love of their work, it did not appear as if they had learnt to cope better by blunting their emotions, but rather by having built up emotional resilience (Colerick, cited in Strumpfer, 1990).

The apparent presence of psychological strengths such as emotional resilience, learned resourcefulness, growth and benefit-finding indicates that the participants evidencing these strengths felt confident about their ability to cope; had made sense of their experiences at Cotlands and regarded the work they did as worthy of their time and investment. According to Van Jaarsveld (2005), “an individual with a strong SOC will experience life as a challenge, as worthy of commitment” (p138). Therefore, one could hypothesize that the Cotlands caregivers had developed a fair to strong SOC, as they evidenced all the SOC components of manageability, comprehensibility and meaningfulness. According to Antonovsky, people with a strong SOC will select the appropriate resources to meet life’s challenges (cited in Strumpfer, 1990). Van Jaarsveld noted that the engineers and scientists in his study who had a strong SOC made use of effective coping mechanisms – such as active coping strategies - to either reduce or eliminate the stressor encountered (2005). Although
some of the participants had employed ineffective coping strategies to cope with loss when they first started working at Cotlands, in general, they did not evidence ineffective coping.

Furthermore, the Salutogenic model enabled the researcher to identify positive coping strategies used by Cotlands caregivers, as well as Salutogenic functioning. Various researchers have made use of the Salutogenic model to focus on health and strength and on the reasons why certain people seem to cope better than others have despite adversity or high stress levels. For instance, it has been used to identify how CBT psychotherapy can facilitate the maintenance and improvement of outcome for people with OCD (Joachim, Lyon and Farrell, 2003); and to investigate how SOC is influenced by factors like stress and recent trauma (Eriksson & Lindström, 2006). Similarly, in recent years the Salutogenic model has been used by many South African researchers (Hutchinson, 2005; Mtsweni, 2007; Oosthuizen, 2005; Sher, 2003) to for example, study the relationship between SOC and effective coping strategies (Van Jaarsveld, 2005)

Many Cotlands caregivers found religious coping to be effective and helpful. Although only a few participants used religion to cope with a very sick child, several participants used prayer or religious coping to deal with a dying child. The use of prayer, religion and spirituality is supported by several other South African studies on HIV/AIDS caregivers (Melnick, 2002; Orner, 2006; Shebi, 2006; Simpson, 2006). An important point to make regarding the use of religion and spirituality as coping strategies is that, as has been mentioned in the literature review, some theorists have classified it as an ineffective and passive coping strategy whereas others have not. Some researchers assert that a coping strategy cannot be classified as either adaptive or maladaptive without taking the context into account (Lazarus & Folkman, 1984; Schwarzer & Knoll, 2003). The researcher also found this to be the case, especially as far as religious coping is concerned.
As mentioned earlier, religious coping did not seem to benefit some of the participants. For one of them it appeared to border on fatalism, which may be an external coping strategy (Gueritault-Chalvin et al., 2000). Nevertheless, in general, the findings of this present research, as well as the observations of the researcher, seemed to support the studies that have reported on the benefits of prayer and religion as a coping strategy (Phillips, 2006). Moreover, according to Flores and Obasi, when interpreting data the researcher should take into account the cultural background of the study participants (2003). Accordingly, the perceptions and interpretations of the participants themselves also indicated that religious coping and prayer contributed to the overall well-being of the participants. This supports the findings of Park, who noted that the degree to which religious coping contributed to psychological adjustment, is predicated on the role it plays in an individual’s life and the meaning he or she ascribes to it (2005). Based on all the aforementioned, it appears as in general the participants made use of effective coping strategies, which is also indicative of Salutogenic functioning.

**SUMMATIVE COMMENTARY**

In general, most of the participants formed attachments to the children. A few of them evidenced less adaptive coping strategies some of the time, yet most of them appeared to cope quite well with the different forms of loss. The temporary separation from the children whilst being off duty resulted in some sadness for a few participants, who mostly used problem-focused coping in that situation. Most of the participants found the loss because of a child leaving Cotlands, the most difficult to process. Most of them reported that one or more children had died to whom they had been attached. Coping with loss in a gradually more adaptive and healthy manner, appeared to apply to many participants. Initially it was difficult and painful for them but later on they adjusted to working at Cotlands, eventually feeling stronger and more confident to cope with it. The most advanced stage of coping appeared to be benefit-finding, positive reframing, growth and SOC functioning.
4.4. Theme Four: Interpersonal Relationships and Social Support

You must get on well with your colleagues – so you must ensure that there is no friction between us. One must work on one’s relationship with - have a good relationship with the staff - [with the] nurse (#3)

4.4.0. Introduction

The important role that interpersonal relationships play in the overall functioning of caregivers, especially in the form of social support, has been widely reported in caregiver literature – especially in terms of its buffering effects against stress and burnout. However, although interpersonal relationships are often addressed in caregiver literature, it mostly focuses on the interpersonal relationships between caregiver and care recipient or between caregiver and his or her family (Wight, Aneshensel & LeBlanc, 2003). This has mostly also been the case in South African articles on caregivers; as the majority of South African HIV/AIDS caregiver literature has focused on home-based carers. There has therefore been little focus on interpersonal relationships amongst the caregivers themselves especially negative relationships and conflict (O’Brien & DeLongis, 1996). Nevertheless, some researchers have pointed out that although social support does play an important role in the stress and coping process, investigators should not overlook the fact that there may also be cases where interpersonal relationships can have a negative effect on an individual (Blankfeld & Holahan, 1999; O’Brien & DeLongis, 1996). When the participants were questioned regarding stress at work, one of the stressors mentioned by a few of them were problems regarding interpersonal relationships amongst staff. This manifested itself in three basic forms, which will be discussed below.

4.4.1. Lack of Teamwork

Teamwork – everyone does not work properly together. You see, we are all divided into groups [...] That one is responsible for those children you see, but the things that must be done, don’t get done. So then you help out there, and at the end of the day think, “Why did
The first problem with interpersonal relationships mentioned by a few of the participants was the lack of teamwork amongst the caregivers. For example, participant #8 said:

You don’t actually get the co-operation as you are supposed to get [...] There’s no teamwork from everyone with whom you work [...] It makes it sometimes unpleasant to come to work.

Besides the lack of teamwork, participant #6 appeared to feel that there was a lack of cooperation from some of her co-workers, as some of them were shirking their responsibilities. Therefore, participants #8 and #6 felt that they had to do some of the other caregivers’ work besides their own. In addition, for the latter participant, managing inter-staff conflict seemed to play quite a big role in her daily functioning at work, as it was one of the responsibilities she mentioned when she was questioned about this aspect of her work.

According to the responses from the participants, some of them coped with conflict and friction between themselves in two basic ways. Firstly, some preferred to confront the person involved directly. Secondly, other participants coped with conflict by withdrawing or by taking some time to be alone. Therefore, the former used a confrontive coping strategy, whereas the latter employed an avoidant coping strategy (O’Brien & DeLongis, 1996).

**COMMENTARY**

As caregiving is such a stressful occupation, it is important for caregivers working in teams to know that they can rely on support from their colleagues. Some researchers have noted that women require support from their colleagues during not only stressful times, but all the time. Not receiving support at work, negatively affects the caregivers’ physical health (Marshall and Barnett, 1992). Although some of the caregivers stated that they did receive support when they needed it, it appears as if either this support may have been inconsistent
or not all the caregivers were equally helpful. Therefore, when some of the participants perceived their colleagues to be unsupportive, it resulted in interpersonal conflict, which resulted in either withdrawing from the person in question or confronting her. Findings by O’Brien and Delongis (1996) support the use of confrontive coping to manage interpersonal conflict, and noted that it was an ineffective coping strategy in the case of interpersonal relationships. Yet Cotlands caregivers appeared to have resolved the interpersonal problems through confrontation.

4.4.2. Communication Difficulties

Another interpersonal problem was mentioned by one of the Xhosa speaking participants. She reported that when she was on duty, the other caregivers on her shift spoke Afrikaans to each other all the time, in spite of the fact that the work policy was that the communication language was English. She said:

> Sometimes they speak Afrikaans also (management) […]. And you know if the boss does that thing then the others will follow […]. So you see they said that the language is English, but now [the caregivers] also speak Afrikaans because they saw the boss do it […]. I believe all of us English is not our home language, it is Afrikaans and Xhosa, but we are supposed to speak English – one language.

It appeared as if she felt that the situation was maintained by the fact that the director of Cotlands also spoke Afrikaans, instead of English. In addition, she reported that it was especially problematic for her as it often related to problems with a specific child. It thus negatively impacted on her being able to do her work effectively. She coped with this problem by ignoring these caregivers, and speaking to the children instead. As she said, “I will just take the child and talk to the child, although the child is not going to respond, but she, the child, is responding by laughing”. Thus she made use of an avoidant coping strategy.
The problem that different languages creates for caregivers is also supported in another South African article. For instance, some nurses working in Cape Town, also complained of their work being affected by a problem with language, which they referred to as “a language barrier” (Lehman & Zulu, 2005). However, the difference between the experiences of the Cape Town nurses and the Cotlands caregivers is that the former had a problem communicating with their clients, whereas the Cotlands caregiver experienced problems with understanding her co-workers. Thus apart from having felt isolated at times, she also missed important information regarding a child.

4.4.3. Problems with Management

The third aspect of interpersonal relationships reported was the lack of involvement and lack of support by some members of management, particularly the social worker and the Director. One of the participants communicated this problem as follows:

We just see them in the mornings [...] we have time here at the back (if they want to talk), I think they don’t set aside time to see us. It feels for me we are here at the back, and they are in the front, and they don’t have a care about us [...] Because many times things happen [...] then they are not even aware of it.

Thus, it seems as if she felt marginalised by management, and thinks that if they were more involved with the caregivers, they would be more aware of what was happening at work.

Those participants, who experienced problems with management, appeared to make use of passive-avoidant coping strategies, as they did not say anything about their concerns to management. According to Lehman and Zulu (2005), some of the nurses interviewed, also did not feel that they were receiving support from management. However, unlike Cotlands caregivers, it seems as if the nurses did try to talk to management about their problems, but
they said, “when it’s us nurses complaining, nobody is listening” (p32). In contrast to the few Cotlands caregivers who perceived management as being unsupportive, the majority of caregivers looking after abused children in a place of safety in Cape Town indicated that they did not feel supported by their management (Booysen, 2005).

It is understandable that some participants felt somewhat upset by the perceived neglect from management, as supervisor support plays an important role in contributing to the psychological well-being of caregivers (Marshall & Bennett, 1992). Nevertheless, according to Soskolne, Acree and Folkman subjective perception of support plays a bigger role in determining well-being, than actual support (2000). The fact that a few participants perceived management to be unsupportive, might have played a bigger role in their apparent unhappiness about it, than did management’s actual involvement.

4.4.4. Supportive Interpersonal Relationships and Social Support

Everyone on the staff are supporting, everyone [...] Like when you’re busy, someone is crying there; sister also coming out of the office and come and help you –and they see you’re busy, [...] so they help you – they attend to that one or clean – they don’t have a problem supporting you. (#7)

We help each other, like if one of the children get sick – but I’m busy – and he is sick on the floor, that colleague is not going to wait till I finish what I’m doing, she will clean it up. [...] We do all things together. [...] They (management) help us when you - maybe you’re busy with other children and then they come; they see but this child is crying and then they see that you are busy, you are not just ignoring the child. They will pick up the child and give attention while you are busy. [...]They (the sisters) are always working with us. They are always on the floor with us. I think they are the most helpful people with us (#5)

They (other careworkers) talk and comfort and offer words of encouragement. (#2)
One of the coping strategies mentioned by most of the caregivers was that of social support, both at work and at home. The majority of participants reported that they received a lot of help and support from the other caregivers. Apart from receiving or being offered help, many of them would also ask for support, both in terms of instrumental or emotional support. For instance, one of the participants when asked whether she received support at work replied:

*Sometimes a person can see on a person’s face that there is a problem. [...] I scold and talk every day. So the days when I am quiet, they can see something is wrong. Then they ask me; then we talk about it.* (#3)

Therefore, according to her on some days, if she was not her usual self, some of the other caregivers would ask her about it – thus showing an interest in her well-being.

As far as nursing staff are concerned, all of the participants found them helpful and supportive. Some of them noted that if the nursing staff noticed that one of the children needed assistance and the caregivers already had their hands full, then they would often step in and help without being asked. However, the type of support that the participants seemed to value the most was being able to talk to the nursing staff about their problems or difficulties at work. Several of them referred to the fact that they used to have one-on-one sessions with the sister, which were very helpful but which unfortunately did not take place anymore. In spite of some of the participants stating that they felt management was not supportive or interested in them enough, the majority of the participants either did not mention having problems with them, or they found them to be supportive and willing to listen or help where they could. One of them even reported that they had given her very helpful advice on how to deal with the financial problems that she had had.

Most of the participants reported having adequate social support at home, and generally described their families as being supportive. However, one of the participants who was sharing a house with two other ladies, reported that her housemates were not really
supportive. Although her own parents were supportive, and she received support from her son’s paternal grandparents – who were taking care of him, they all lived far from her. Fortunately, she perceived her co-workers at Cotlands as her family, and found them to be supportive. She described her relationships with them as follows:

*There is a lot of support […] they are like your own family. You can talk to them about anything; you can trust them with your problems […] and it does not feel so lonely for you – especially for me, I’m not really from this area.*

**COMMENTARY**

As is the case in most caregiver literature, the findings of this present study also indicated that social support played an important role as a coping resource for the Cotlands caregivers, both in the availability of it and in the accessing of it. A number of the participants mentioned that if they felt somewhat overwhelmed by several children needing their help simultaneously, then asking for and receiving support from their colleagues helped them to cope with this stress. Bennett and Kelaher (1993) reported that social support has a protective and buffering effect on caregiver stress, and thus plays a role in reducing the risk of burnout. According to Van Dis and Van Dongen, a spirit of support amongst caregiver staff acts as a buffer preventing burnout (1993). Therefore, the social support that the participants received from each other and from the nursing staff appeared to have prevented the stress that is inherent in their work resulting in burnout. Unlike the nurses in a study by Lehman and Zulu (2005), the Cotlands caregivers mostly found their supervisors to be supportive and helpful. Marshall and Barnett (1992) reported that women employees who had received greater supervisor and co-worker support had reported better physical, as well as mental health. This could explain why only two participants reported any physical ailments, or reported having experienced some depression when first starting to work at Cotlands.
Besides the very important practical assistance that the participants received from their social support resource at work, they also received essential emotional support. They would for instance, unburden to the nursing sister, who would listen to them and encouraged them. This indicates that positive and supportive interpersonal relationships existed amongst the Cotlands caregivers and the nursing staff. Several of the participants mentioned that the support they received from one another helped them to cope with their feelings of loss and grief when a child had died or had left Cotlands. According to Bennett and Kelaher (1993), one of the benefits that social support offers to HIV/AIDS caregivers is that it acts as a “buffer against intense feelings of grief” (p.216).

Numerous research articles noted that the availability of positive social support – not only at work but also at home - is essential for psychological health. For example, according to the caregivers in a study by Chimwaza and Watkins (2004) family and community members provided “social and moral support”, as well as some financial and instrumental support (p805). The majority of participants reported having good relationships at home; and all of them received support from their families. In fact, the coping strategy reported by several of the participants that they used when at home was to talk to family or friends or to seek counsel from someone they trusted in their church. The caregivers in a study by Philips (2006), caring for their HIV-positive grandchildren, reported that the support from their church was very beneficial. It could be hypothesized that the support the participants received from their families and churches contributes to the fact that the Cotlands participants appeared to be very positive and enjoyed their work in spite of the fact that caregiver literature widely reports on the stress and burnout experienced by caregivers. According to Mayers (2005), “social support systems can act as a buffer for the individual and help maintain psychological and physical well-being over time” (p. 39).
In contrast to the support that Cotlands caregivers received from their families, it appeared as
if some nurses in a study by Lehman and Zulu (2005) did not receive adequate family
support. Instead, they were discriminated against and sometimes rejected by their families.
This finding is supported by the caregivers in a study by Shebi (2006) who also perceived
their family as unsupportive, especially when first starting to do AIDS caregiving. In an
American study (Theis et al, 1997), the HIV/AIDS caregivers reported that they did receive
help from family, neighbours and case managers. However, they still wanted help from a
counsellor or companion, possibly indicating that they received instrumental support but not
emotional or moral support. Hence, one could hypothesize that instrumental, social and
emotional are necessary and viewed as important by HIV/AIDS caregivers.

**SUMMATIVE COMMENTARY**

Overall, the majority of participants reported that they worked well with their colleagues and
received adequate support from them, both in terms of practical support and emotional
support and encouragement. All participants reported having supportive families. Some
participants experienced some stress at work caused by negative interpersonal relationships.
This interpersonal conflict was caused by firstly, communication difficulties because of
caregivers being from different ethnic backgrounds; secondly, a lack of teamwork as some of
the caregivers shirked their responsibilities; lastly, perceived marginalisation by
management whom apparently seldom communicated with the CCWs.

**4.5. Theme Five: Organisational Dynamics**

*The children who are healthy, I feel it is just too much to keep them caged in; because you
see we do not have time enough for them to work off all their energy. We do not have
enough time for them. You see our routine does not allow for so much time – and then also
for the other things.*
Based on some of the participants’ comments, it seems as if certain factors inherent in an organisation like Cotlands; may play a role in some of the difficulties they encounter in their work. Some of these factors are the routine they need to follow each day, the time allocated to each task, and the care they need to take to avoid infections. The Cotlands caregivers also had to do stimulation exercises with the children whose developmental milestones were delayed. Two of the participants mentioned that the stimulation exercises that needed to be done with the smaller children, was a task that caused them some stress.

*What I can say - is with the stimulation – if we can only - 30 minutes is alright for the stimulation, but over that 30 min it’s boring [long pause] and we can see the children that they are not now interested anymore […] then when you see the children are bored so – you don’t see what you are doing when they are bored […] so they need a break after 30 min (#5)*

Another participant voiced her frustration as follows:

*Sometimes there is not enough time (for stimulation exercises), because sometimes there come interruptions […] and you can’t sit the whole time with one specific child. There is not enough time for each child – so you don’t get to everyone. (#8)*

She coped with the above situation by waiting, patience and a sense of humour.

*You just have to take time with them, and wait until they are ready to do what you have to do for them […] You also need a sense of humour with them[…] you can’t just […] do the thing with them that you want to do with them – you must have time for them. You must just wait until one day they now want to do what they must do. (#8)*

One of the participants found the time allocated to this task too long, as the child became bored with it, which resulted in her also becoming bored with it as well. In contrast, the other caregiver reported that she found the time too little as one would invariably be interrupted by another child needing one’s attention. According to her, the children took their time with the exercise and thus did not complete the task in the allotted time. Notwithstanding, she said that she had learnt to cope with this task by learning to be patient with the children, waiting for them to complete the task in their own time, and by utilising her sense of humour. She
would also ask the nursing staff for assistance. She said, “We ask if there is not someone extra that can be with us, or can the group be made smaller”. Therefore, apart from coping by waiting and using her sense of humour, participant #8 also made use of *instrumental support-seeking*, as a coping strategy.

**COMMENTARY**

Although none of the participants attributed any stress in their work to Cotlands itself, working in a residential care setting with vulnerable children did play an indirect role in some of the difficulties encountered by a few participants. For instance, it was possible that owing to the fact that Cotlands is a non-profit organisation, they did not have the finances to employ staff like occupational therapists who might normally have done the stimulation exercises. Hence, some of the caregivers might not have felt properly equipped to do them. Yet, despite a few participants finding the stimulation exercises challenging, one of them did manage to cope with it and overcame the restrictions of the routine.

The coping strategies of waiting and patience, which were employed by participant #8, are described as *internal coping* strategies by Gueritault-Chalvin et al (2000). Although according to Vaillant, humour is a mature defence mechanism, it has also been adopted by Positive Psychology as an example of human strength (cited in Seligman, 2000). Carr categorised humour as an *emotion-focused* coping strategy aimed at regulating emotions (2004). In addition, to *emotion-focused* coping, participant #8 also made use of *problem-focused* coping, as she felt that there was something specific that could be done to solve her problem. In contrast to the latter participant, one could hypothesize that participant #5 was not coping as well as participant #8 with the stimulation exercises as she attributed her frustration with this task to external factors related to the organisation. This might indicate
that she had an *external locus of control*, usually associated with *passive* coping strategies by Gueritault-Chalvin et al (2004).

Although the two participants differed in their reasons for finding the stimulation exercises challenging, both of them appeared to be frustrated with the fact that they were dictated to by the programme and routine at Cotlands. One of them was of the opinion that not all the children fitted perfectly into this routine. It therefore appeared as if the routine required by Cotlands was a hindrance to a few caregivers doing their work effectively as well as coping well with the demands of the task. Moreover, the caregivers might have felt frustrated by the fact that they were not given the freedom to use their own initiative, and thus perhaps a sense of personal agency was being inhibited or restricted. In a study on childcare workers caring for children from dysfunctional homes, Bussey noted that they felt that the limitations put in place by the organisation they were working for, was in some instances an obstacle to them working effectively (2005).

4.6. Summary

There were quite a number of similarities but also a few differences amongst the experiences and coping strategies of the participants.

The participants loved their work and enjoyed working with the children, which most often resulted in attachments to the children. One of the issues found most challenging, was the loss the participants experienced when children left Cotlands after having been placed in a family of their own. Hence, one of them protected herself from becoming too attached to the children by maintaining a ‘working relationship’ with them. For most of the participants, the loss itself, and the pain it caused, was easier to process than the uncertainty and concern
regarding whether the child would still receive good and loving care. Most of them coped with this through by seeking information on the child’s welfare.

A task that some of the participants did find quite challenging, was caring for very sick, suffering or dying children. It was especially difficult for them to witness the child’s pain, as they were afraid of causing the child even more pain. By comparison, it seemed to be easier for them to cope with a child’s death; as they believed it was an end to the child’s suffering and he or she was in a better place, although they still reported feeling sad and hurt. In a study by Galloway (1997b), she reported that the caregivers “obviously feel the deaths [of the children] terribly. Particularly if it’s a child who has been there “for a long time, and to whom [they] have bonded with very strongly” (p.16).

Although coping with a very sick and suffering child, as well as a child’s death were challenging, the participants coped with these through social support, benefit-finding and religious coping. Moreover, they believed they could cope with it even though it was often difficult. By contrast, caregivers in studies by Simpson (2006) and Booysen (2005) reported feeling completely overwhelmed and stated that they were not coping. The caregivers in the former study had experienced a couple of symptoms of burnout, whereas the caregivers in the latter study had reported several PTSD symptoms.

There were some instances when a few of the participants did not appear to be coping at work. The one participant was unable to handle the many questions that the older children would ask, whilst another said a crying baby at times made her feel crazy. These examples might indicate the way the participants were feeling at that moment; or it suggests how they felt when first starting to work at Cotlands. A problem that a few participants did not know how to manage was interpersonal conflict. Unlike some participants who did cope with it by
directly confronting the person in question, the former participants just avoided the problem and withdrew themselves. Therefore, although the interpersonal relationships at work were mostly good and a source of social support, there were some instances when they hampered the effective functioning of some participants. Similarly, a few participants noted that the programme and routine of Cotlands also at times hindered them from coping effectively, although other participants found the routine and programme to be helpful.

Consequently, in the case of interpersonal and organisational factors the subjective opinion of the participant played a significant role in how the participants perceived these factors and thus coped with them. Similarly, the manner in which several of the participants both perceived and coped with the fear of contagion was based on their subjective views but also on personal experiences. Their way of coping with contagion fear ranged from either highly avoidant, where they would not have themselves tested at all, to an almost obsessive control where the one participant had herself tested every few months.

Apart from fear of contagion, HIV/AIDS caregiver literature often reports on the social factors connected with the epidemic that the caregivers sometimes have to face, such as social ostracism and isolation. None of the Cotlands participants reported having experienced any rejection or discrimination as a result of HIV/AIDS. Only one of them reported having faced any stigma, but only in the form of perceived stigmatisation.

The participants often used similar types of coping strategies to cope with the same problem. On the other hand, some of them coped with the same problem very differently from the other participants. A very interesting similarity that emerged, which applied to numerous of their challenges, was the utilisation of more healthy and adaptive coping strategies the longer they worked at Cotlands; often resulting in the manifestation of Salutogenic strengths.
According to the findings of this study, childcare workers caring for HIV-positive children working in a residential care setting, have similar experiences and challenges to nurses, community-based caregivers and primary caregivers, such as coping with loss and contagion fear. Nonetheless, caring for HIV-positive children poses unique challenges for the caregiver, calling for flexibility and situation-dependent coping strategies.

5.1. Summary of Main Findings

5.1.1. Caregiver Coping Strategies

According to Schwarzer and Knoll (2003), coping is a difficult concept to assess and one cannot easily distinguish between for instance preventive and proactive coping without considering the context. Furthermore, because of cultural differences, what some theorists might view as maladaptive coping might in fact be adaptive for people from another culture. Having said that, based on the results of the study, Cotlands caregivers evidenced a wide range of coping strategies, which sometimes differed from individual to individual.

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The caregivers mostly used religion and social support as coping strategies when a suffering or dying child was involved. Confrontive coping on the one hand and avoidant coping on the
other were used for interpersonal problems. Many of the caregivers used the positive coping strategy of \textit{anticipatory coping}, and often evidenced Salutogenic functioning when caring for very ill HIV-positive children. Most of them employed active coping and social support to cope with loss owing to a child being placed out. For the most part, the participants made use of adaptive coping strategies with clear indications of strengths like \textit{sense of coherence}. \textit{Avoidant coping} strategies were used less often.

Consequently, although traditionally reactive coping strategies were present, there was substantial evidence of Salutogenic functioning being relied upon by the Cotlands caregivers to cope with their work. Overall, they appeared to be positive, quite resilient, resourceful, and exhibited psychological well-being.

5.1.2. Caregiver Experiences

Prior to the roll-out of ART, HIV-positive children in South Africa seldom survived past the age of two or three years. Therefore, their caregivers had to cope with children who became very ill and died soon thereafter. Since the national roll-out of ART, caregivers have reasons to be hopeful and positive. However, ART does not guarantee good results. This had several implications for the Cotlands caregivers.

Firstly, they had to know how to cope with children who were ill as well as children who were healthy. Secondly, they had to deal with disappointment, uncertainty and loss when some children did not respond equally well to ART. Thirdly, as the purpose of Cotlands is to nurse the children back to health, many do become well. Therefore, Cotlands aims to place these children with families of their own as soon as possible, resulting in a high turnover of children. Although the caregivers had to cope with experiencing attachment and loss on a continual basis, most participants formed close attachments whilst a few did not.
The caregivers found their work at Cotlands rewarding for several reasons. Firstly, all the participants loved working with children. Secondly, they appreciated the companionship and support amongst the staff, although they also had to deal with occasional problems and conflict amongst the caregivers and other Cotlands staff. Thirdly, they experienced that they had contributed towards the children either getting better, or alleviating their suffering. Lastly, they were able to use the knowledge and training they had received at Cotlands, to benefit their families and communities.

5.2. Recommendations for Cotlands

Most of the participants reported that they had good relationships with all the staff and found them supportive. However, several of them had problems with interpersonal relationships for various reasons. These included issues related to communication, teamwork, delegation, role clarification and management.

Examples of these are firstly, owing to the layout of Cotlands premises, some of the caregivers felt marginalised and ignored by management. Several studies have reported on the need that caregivers have for ‘a voice’, and to be recognised or rewarded by management (Booysen 2005; Gueritault-Chalvin et al, 2000; Sardiwala, 2004). Therefore, it is suggested that management make their presence, interest and appreciation more felt to caregivers. Secondly, one of the caregivers sometimes felt that a child was too ill to be looked after at Cotlands any longer and should be hospitalised immediately. Yet she was informed that it was not yet necessary. This highlights the need for factors like “policy guidelines”; “management protocols” (Fransman et al, 2000, p.89); “appropriate referral systems” (Mayers, 2005, p.40); and role clarification (Bussey, 2005). The aforementioned needs could be met by: implementing policies that will clarify the criteria and process under which a child should be
admitted to hospital; stipulating the channels of communication to be followed by all personnel; clarifying job descriptions.

Several researchers and caregivers have expressed the need for caregiver debriefing, grief counselling and support groups (Galloway, 1997a; Hill et al, 2003; Lehman & Zulu, 2005; Mayers; 2005; Melnick, 2002; Rose & Clark-Alexander, 1998; Simpson, 2006; Theis et al, 1997). Numerous participants reported that they found the one-on-one sessions that they had very helpful, whilst others benefited from attending the ‘Care for Carers’ support group. These appeared to have met the need for loss and grief debriefing and counselling. However, some caregivers either may require support on a more regular basis, or may require more intensive counselling – particularly when first starting to work at Cotlands. Consequently, the researcher recommends that accessible and regular support be available for caregivers, such as individual counselling sessions or support groups, especially when new to Cotlands.

Several studies on caregivers report the need for more training (Bachanas et al, 2001; Gueritault-Chalvin et al, 2000; Lehman & Zulu; Mayers, 2005; Melnick, 2002; Sardiwala, 2004). For example, education and training is key in helping caregivers cope effectively with attachment and loss (Bennett & Kelaher, 1993). In spite of the courses that the caregivers had attended, there still appeared to be some unmet needs, especially as some of the participants did not appear to be coping that well at certain times. Consequently, it is recommended that a training needs assessment be done. The researcher recommends that such training includes:

- Comprehensive and clear HIV/AIDS training, for example risk of contagion.
- Different, situation-dependent coping strategies - to be reinforced with follow-up training.
- Effective child management techniques, specifically for older children.
- Interpersonal conflict management and communication skills.
5.3. Recommendations for Future Research

The findings from this study add to the growing awareness that religion can have a positive buffering effect on a caregiver’s ability to cope with stress (Phillips, 2006). In support of other South African research on HIV/AIDS caregiver coping strategies, Cotlands caregivers also made substantial use of religious coping. Consequently, as religious coping seems to be used widely by South African HIV/AIDS caregivers, it would be of value to conduct further research on its efficacy, in order to improve caregivers’ employment and manner of accessing this support.

The value of the study – which took the caregivers’ context into consideration – is that it demonstrated that for many of the caregivers, coping effectively and optimally with their work at Cotlands is a gradual process and takes time. Accordingly, when assessing coping strategies it is important not only to consider the context of coping but the length of time that an individual has been in the situation under investigation and to what extent this determines the type of coping strategy employed. It is further recommended that research be done that will focus on both identifying and distinguishing between Salutogenic functioning, adaptive coping and maladaptive coping strategies from a South African point of view.

5.4. Limitations of the study

The limitation of the study is that it investigated the coping strategies and experiences of only eight paediatric HIV caregivers from only one residential care setting. However, it has begun the process of investigating the coping strategies of PHCs; and how they can improve them. Therefore, it is recommended that this process be continued by comparing these findings to caregivers at other Cotlands childcare settings, as well as other children’s homes like Nazareth House. In addition, it will be of interest to research the coping strategies of PHCs in other settings, such as nurses in hospitals or grandmothers in community settings.
Another limitation is that the caregivers in this study referred to the nursing staff, social worker and director as either being supportive or unsupportive. Therefore it would be valuable to research their perspective on what their role is in the organisation, and thus to acquire a comprehensive understanding of the extent to which they impact on the CCWs’ quality of coping and ability to cope.

5.5. Concluding Remarks

Caring for HIV-positive children in a residential care setting, who are receiving ARV therapy, poses unique challenges for the caregiver. These include issues like coping with frequent loss when the children die and when they are placed back into homes of their own. The coping strategies employed by Cotlands caregivers were found to be mostly adaptive with clear evidence of positive coping strategies. The Salutogenic model was useful in that it aided the identification of caregiver strengths and in determining which coping strategies to teach in order to enable caregivers not only to avoid burnout, but also to find caregiving meaningful, beneficial and rewarding.

I conclude this study with the words of one the Cotlands caregivers:

*I feel, because I have my own children, as a mother it is very painful because like yesterday, the one little boy, he was very ill. So I told E. she must tell the sister that she must phone the hospital so that he can be admitted. And the sister said we must continue with the water, [...] because he had diarrhoea you know. So we continued to care for him and make him comfortable. And then yesterday afternoon it looked as if at any moment he would breathe his last. [...] So then the child was taken to the hospital. It hurts one, because it feels for you that you are powerless, that you can’t do anything. [...] We phoned and there was some improvement. But, but it just feels - sometimes they come in here and it looks as if they are about to die. But with the help of the Lord, and the care we put in, that child shows improvement, and the child becomes so healthy that the child can go home.*
REFERENCES


AIDS Care, 8(2), 183-194


APPENDIX ONE: INTERVIEW SCHEDULE

Introductory Question: Why did you come to work for Cotlands?

A BACKGROUND INFORMATION
1. What do your daily duties involve?
2. Which of them do you find most difficult or unpleasant? Why?
3. Which of them do you enjoy the most? Why?
4. With which age group of children do you prefer working?

B STRESS AND COPING
5. What do you find most stressful about working at Cotlands?
6.1. How do you cope with these stresses?
6.2. How does stress usually affect you?
6.3. How do you usually cope with stress? / What do you do to manage stress?
6.4. What have you found helpful when you face stressful or difficult situations?
7. Do you currently also have personal issues you struggle with or are concerned about?

C ATTACHMENT
8. Are there any of the children you have formed a special bond with?
9. How do you handle not seeing them on your time off?
10. Have you formed attachments to any of the children that have ended?
11. How did you deal with that experience? / How was that for you?
12. Have any of the children you have personally looked after died?
13. If so, how did you feel about it?
14. If so, how did you cope with the loss?

D SOCIAL SUPPORT
15. Do you get support at work from your colleagues?
16. Do you get support at work from your employers / superiors?
17. What type of support do you get?
18. What type of support do you have at home – if any?
19. Is there anyone else that you consider to be a support for you?

E JOB SATISFACTION
20. How long do you intend working at Cotlands?
21. Why?

F PERCEPTION OF HIV/AIDS / CONTAGION FEAR
21. How do you deal with the fact that the children are sick children?
22. What is your view of the possibility of being infected by the children?
23. How do your family feel about the possibility of being infected?
APPENDIX TWO:

UNIVERSITY of the WESTERN CAPE

DEPARTMENT OF PSYCHOLOGY

Private Bag X 17, Bellville 7535, South Africa, Telephone: (021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

CONSENT FORM / TOESTEMMINGS FORM

I have considered the information provided pertaining to the research project for the Master’s thesis of Desirée Louis. I understand that my participation in this research project is voluntary and I retain the right to withdraw from it at any time. By signing this form, I release the information obtained from my participation in this study for UWC institutional purposes with the understanding that it will be kept confidential and at no time will my name be used or connected with any information.

Consent

I, __________________________, do hereby give the researcher, __________________________ permission to use the interview data (if applicable) for the purposes of this research study.

Details (in order to contact interviewees)

Name of participant: __________________________ (confidential)
Contact telephone number: __________________________ (confidential)

Ek is bekend met die inhoud aangaande die navorsings projek vir die tesis van Desirée Louis se Meesters graad en ek begryp dat my deelname daarin vrywillig en dat ek vry is on te eniger tyd van die studie te ontrek. Deur die vorm te teken, maak ek die inligting wat verkry word deur my deelname beskikbaar vir UWK se doelstellings met die verstandhouding dat dat dit vertroulik gehou sal word. Verder sal my naam nooit gebruik word in verband met hierdie inligting nie.

Toestemming

Ek, __________________________, gee hiermee aan die navorser, __________________________, toestemming om die onderhoud data te gebruik [indien van toepassing] vir die doel van hierdie navorsings projek.

Kontak inligting

Naam van deelnemer __________________________ [vertroulik]
Kontak telefoon nr __________________________ [vertroulik]

Signature of participant/ geteken deur deelnemer __________________________ Date ____________
Signature of researcher / geteken deur navorser __________________________ Date ____________