Caregivers' experiences of stress while caring for orphaned and vulnerable children in an institution

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by

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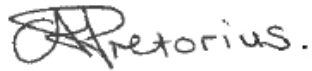
Prof Kesh Mohangi

PRETORIA
2013

This dissertation is dedicated to my remarkable family:
My Mom Memory, Dad Koos and Sister Michelle

Thank you for your unwavering love, support and encouragement.
It is because of your influence, patience, guidance and understanding
that I have been able to achieve my dreams.
Thank you for being my rock.

DECLARATION

I, Chereen Ann Pretorius (student number 21091596), hereby declare that all the resources that were consulted are included in the reference list and that this study entitled *Caregivers' experiences of stress while caring for orphaned and vulnerable children in an institution* is my original work.

C.A PRETORIUS
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ABSTRACT

The context of working and living in a care institution is accepted as challenging for all concerned, yet there is a dearth of studies into the stress experiences of caregivers. This study investigated caregivers' stress and coping in an institution where care was provided to children affected by HIV and AIDS. The study was informed by a qualitative and case study design within an interpretivist paradigm. In addition, it was guided by a theoretical framework derived from Folkman and Lazarus' (1984) transactional model of stress and coping. A focus group discussion and individual interviews were utilised to gather data, and to clarify and probe responses on caregivers' experiences of stress.

Thematic analysis of the data yielded the most significant themes and subthemes from caregivers' subjective experiences and perceptions of the stress that they experienced in their daily work situation. The results of the study indicate that caregivers' stress experiences need to be addressed if caregiving is to be provided effectively. This will require not only training and management support for caregivers in institutional context (e.g., to deal with challenges such as appropriate discipline for the children under care), but also personal support and counselling for caregivers in order to enable them to assess the signs of burnout and cope with stress effectively.

KEYWORDS

HIV and AIDS

Caregivers

Stress

Coping

Orphaned and vulnerable children

Institution

CONTENTS

FIGURES

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TABLES

CHAPTER 1:
CONTEXTUALISING THE STUDY

1.1   INTRODUCTION

Chapter 1 of this study provides a framework within which I set out the aim, rationale, and purpose of my research, which was to gain an in-depth understanding of caregivers' experiences of stress while fulfilling their duties in the context of an institution for orphaned and vulnerable children affected by HIV and AIDS. I proceed to present the research questions and clarify several concepts used in this study. Furthermore, I discuss the research methodology and design with specific reference to paradigmatic choices, participant selection, and data gathering strategies, as well as the analysis and interpretation of data. Finally, I present the ethical considerations and quality criteria of the study, and conclude by outlining the chapters that follow.

1.2   BACKGROUND TO THE STUDY

This study forms part of a broad research project initiated in 2009. The need for this study was identified in an investigation conducted by Dr K. Mohangi into the well-being of children affected by HIV AND AIDS who were being cared for in a residential care facility (institution) at a major provincial hospital situated on the outskirts of Pretoria (Mohangi, 2008). One of the findings of Dr Mohangi's study indicated that the well-being of institutionalised HIV- and AIDS-affected children was to a large extent dependent upon the quality of caregiving experiences. Thus, an assumption of the broad study would be that raising the psychosocial emotional awareness of adult caregivers could possibly increase the well-being of vulnerable children.

This study aligns with the first track of data collection during which data were collected from participating caregivers by this researcher in the role of fieldworker, and, once I had been granted ethical clearance, more in my role as researcher. My research was conducted at a children's centre at a major provincial hospital situated on the outskirts of Pretoria. The centre is a children's home for orphaned, HIV-infected and abused children (see Figures 1.1 and 1.2).

Figures 1.1 and 1.2: *The institution at which the research was conducted*

1.3   AIM AND RATIONALE OF THIS STUDY

In systematic reviews of the literature on the challenges faced by carers of AIDS-orphaned children in South Africa, Kuo and Operario (2009; 2011) discovered a need for investigating the career-related well-being of such caregivers since few studies address the issue of their health in context of their work milieu. In view of the particular socio-economic difficulties touching on upliftment in previously disadvantaged communities in post-apartheid South Africa, one component that requires particular attention is that of emotional well-being in caregivers of young children. As orphan numbers and HIV prevalence increase, support systems begin to weaken. As a result of the inability of extended families to take care of and support affected children, the number of South African children who will need to be accommodated within children's homes and other care facilities will rise (Makiwana, Schneider, & Gopane, 2004).

Studies conducted on carers of AIDS-orphaned children in South Africa are far and few between (Freeman & Nkomo, 2006; Kuo & Operario, 2009; Schroeder & Nichola, 2006; Townsend & Dawes, 2004, 2007). There is, however, existing literature that reveals a rising concern with regard to the possible negative impact that caring exerts on caregivers of orphaned and vulnerable children. Several studies have documented poor health outcomes associated with caring in this field, including elevated levels of stress, chronic illness, and

poor nutritional regimens (Kuo & Operario, 2011; Rotheram-Borus et al., 2002; Ssengonzi, 2007). More information is needed on caregiver health as these carers play a significant role in supporting orphaned and vulnerable children. The focus of this study was on caregivers in institutions where care is provided to children affected by HIV and AIDS, specifically with a view to exploring the effects that caring for affected children has on the stress and coping levels of caregivers. By striving to make a contribution to filling this gap in the literature, this research may lead to a better understanding of caregiver stress, needs, and improvements in the caregiving environment.

1.4   PURPOSE OF THE STUDY

The purpose of this study was to explore and describe the factors contributing to stress experiences of caregivers who work within an institution where they care for orphaned and vulnerable children. The investigation is aimed at adding to and expanding upon the limited body of knowledge that exists with regard to this phenomenon and to raise awareness of the effects of career-related stress on caregivers and the elements that may contribute to their experiences of stress.

1.5   RESEARCH QUESTIONS

1.5.1 Primary research question

In light of the rationale and purpose of this study as explained above, the primary research question guiding this study is:

What are the stress experiences of caregivers working in an institution caring for orphaned and vulnerable children?

1.5.2 Secondary research questions

In addressing the primary research question, the following secondary research questions arose:

- ♦ *What constitutes stress for caregivers?*

- ♦ *How do caregivers cope with stressful experiences arising in their work environment?*

1.6   CONCEPT CLARIFICATION

In order to attend to these research questions, it is essential to define and clarify several key concepts relevant to this study.

1.6.1   Caregiver

According to Davies (1995), caring work is characterised "as attending physically, mentally and emotionally to the needs of another and giving a commitment to the nurturance, growth and healing of that other" (pp. 18–19). The Family Caregiver Alliance (as cited in LoboPrabhu, Molinari, & Lomax, 2006) view formal caregivers as "professionals, paraprofessionals, or volunteers associated with a service system whom provide care at home, in community agencies, or to institutions or residential facilities" (p. 25).

For the purposes of this study, caregivers are considered to be individuals who are compensated for their care-giving duties in an institutional context. Furthermore, these individuals are seen as the primary caretakers of the children under their care, being responsible for the children's daily needs, development, and emotional well-being.

1.6.2   Orphaned and vulnerable children

In this study, children who are affected by HIV and AIDS are delimited in accordance with the widely used definition by UNAIDS (2008) as being under the age of 18 years, and being either orphaned by AIDS, or rendered vulnerable by living with one parent or both parents diagnosed as HIV-positive. If orphaned, the status of such children is further categorised in terms of being paternal, maternal, or double orphans (the last-mentioned of course referring to the loss of both parents to AIDS) (Skinner et al., 2013).

1.6.3   Institution

Institutional care is defined as "a group living arrangement for children in which care is provided by remunerated adults who would not be regarded as traditional care-givers within the wider society" (Rayneke-Barnard, 2005, p. 23).

In relation to this study, an institution is seen as a group living arrangement with the aim of providing either temporary or permanent care to children who have been affected by HIV and AIDS where there is no alternative placement for them.

1.6.4 Stress

Stress can be defined as a person–environment relationship (Folkman, 1984; Lazarus, 1966). The experience of stress is the manifestation of negative emotions triggered by danger, threat or challenge, and which signal to the body the need to prepare for actions of defence and protection (Slaski & Cartwright, 2003).

Matteson and Ivancevich (1987) define stress as an adaptive response to an external action. Stress within this study will be viewed as a transactional stimulus–response referring to the evaluation that the individual makes of the fit/unfit that exists between environmental demands and his or her capacity to confront them. It also emphasises the perception that the individual forms about the situation (Edwards, 1988; Harrison, 1978; Lazarus & Folkman, 1984; McGrath, 1970).

In the context of this study, stress was understood as arising when a caregiver appraises a situation as challenging, threatening or otherwise too demanding, and is unable to respond as the appropriate coping response is not available (Cohen & Wills, 1985).

1.6.5 Coping

Lazarus and Folkman (1984) define coping as the constantly changing cognitive and behavioural efforts that an individual makes to deal with internal and external demands that he or she perceives as exceeding the resources that he or she possesses. It is this definition that will serve for the term *coping* in the current study.

1.7   PARADIGMATIC PERSPECTIVE

1.7.1 Metatheoretical paradigm

I conducted this study from a qualitative approach embedded in the interpretivist paradigm. Berg (2001) describes qualitative research as seeking answers to questions by examining various social settings and the individuals who inhabit these settings. Qualitative research is defined by Denzin and Lincoln (2005) as the studying of phenomena in their natural settings and seeking answers to questions that stress how social experience is created and given meaning. In this study, the central phenomenon being explored was the perception that

caregivers had of their experiences of stress in the setting of the institution where they worked.

The interpretivist paradigm as followed in this study is concerned with individual participants, their experiences, and the meaning they assign to their experiences of stress. Nieuwenhuis (2007) states that the ultimate aim of interpretivist research is to provide insight into the way in which a particular group of people make sense of their circumstances, and this insight is achieved by offering a perspective on a situation and by analysing those aspects under study. Through using the interpretive approach, I set out to understand rather than explain caregivers' interpretations of the "world around them", i.e., their view of the effect of their working environment on their personal lives.

1.7.2   Methodological paradigm

I conducted this study from a qualitative perspective. Qualitative researchers collect information through spoken or written language, or by observations that are recorded in language, and then analyse the information by recognising and categorising themes (Durrheim, 2006). Berg (2001) states that qualitative research refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things, but viewed in the context of seeking answers to questions by examining various social settings and the individuals who inhabit these settings. Denzin and Lincoln (2005) affirm these basic tenets in considering qualitative research to be the studying of phenomena in their natural settings and seeking answers to questions about the ways in which social experience is created and given meaning. In this study, the central phenomenon being explored was the caregivers' experiences within the setting of the institution where they worked.

1.7.3   Theoretical framework

A number of theorists (e.g., Cohler, Groves, Borden, & Lazarus, 1989; Haley, Levine, Brown, & Bartolucci, 1987; Schulz, Tompkins, & Rau, 1988) have proposed stress models that share common features. These models provide a framework for organising the large number of variables relevant to understanding the process of caregiving (Schulz, Gallagher-Thompson, Haley, & Czaja, 2000).

In the current study, Lazarus and Folkman's (1984) transactional and cognitive appraisal model of stress and coping is used to conceptualise and examine the experiences of stress and coping resources of caregivers. This model developed by Lazarus, Folkman and other researchers (Folkman, Lazarus, Pimley, & Novacek, 1987; Lazarus & Folkman, 1984) has three primary elements: a potential activator, an individual's reaction to the activator, and the consequences to the reactions. The stress and coping model includes the following categories of variables:

♦ context variables such as gender, age, socio-economic status, and caregiving history;

♦ demands on the caregiver;

♦ the caregiver's appraisal of demands as stressful or satisfying;

♦ the potential mediators between appraisal and outcomes, their coping styles, and social support;

♦ the consequences of caregiving demands (Olshevski, Katz, & Knight, 1999).

The transactional model of stress provided by Lazarus and Folkman (1984) is a highly appropriate one for considering the effects of stress, particularly regarding individual differences in adapting to demanding environments such as those in caregiving in institutions. The central assumption of this theory is that stress reflects the individual's understanding of his or her place in the world. Stress develops from unfolding person–environment interactions that exceed the person's perceived capacity to cope with environmental demands (Matthews, Zeindner, & Roberts, 2004).

1.8 OVERVIEW OF THE RESEARCH METHODOLOGY

In the following section, I introduce the selected research design, selection of participants, data collection, as well as data analysis and interpretation. The selected research methodology will be discussed in detail in Chapter 3.

1.8.1 Research design: Case study

This study made use of a case study design as typified by Yin (1984) in order to explore caregivers' experiences with regard to stress within an institutional milieu. In addressing the

question of how a case study can be described, Cohen, Manion and Morrison (2005) employ the view of Nisbet and Watt (1984) when they consider a case study to be a specific instance that is designed to illustrate a more general principle. In the current study, the experience of caregivers in managing stress is described with the aim of contributing to the improvement of stress management in caregivers through participation in stress management training.

In terms of methodological advantages and disadvantages, Nisbet and Watt (as cited in Cohen et al., 2000, p. 184) consider the capacity to provide insight into other similar situations and cases, thereby assisting in the interpretation of similar cases, as one of the strengths of a case study design. In addition, given the in-depth examination of a particular case as proposed by this study, the case study design allows for the capturing of the uniqueness of the features of the case, which might not have received similar attention in a larger-scale research design. This feature of case study design is also considered one of its notable advantages (Nisbet & Watt as cited in Cohen et al., 2000).

Yin (1984) argues that a case study design is to be preferred when the object of the study is a contemporary phenomenon in a real-life context, while Stake (as cited in Schwandt, 2007) emphasises the aim of case studies to be the generation of knowledge of the particular. One of the fundamental aspects of this study relates to gaining an understanding the stress experiences of caregivers working in an institution where they care for orphaned and vulnerable children. Given the uniqueness of the situations, as well as the contemporary and real-life character of the context, the preceding arguments by Yin and Stake support the use of a case study design in this research project.

A significant limitation of case study design is the caveat on the universal validity of findings, since generalised results may not be directly transferable to other contexts or applications (Bassey, 1999; Nisbet & Watt, 1984). A further limitation noted by Nisbet and Watt (as cited in Cohen et al., 2000, p. 184) is the possibility of a case study design not being amenable to cross-checking, hence being selective, personal, subjective, and biased.

1.8.2 Selection of participants

A sample comprises the elements of the population considered for actual inclusion in the study (Arkava & Lane, 1983). For this study, the selection of participants was based upon

their participation in the broad research project mentioned at the beginning of section 1.2. From those who participated in the broad study, seven participants were purposively selected to participate in the current study based on their role as caregivers in the institution.

Therefore, the sampling technique used in this study is purposive. Purposive sampling is based entirely on the judgement of the researcher and the sample is composed of elements that contain the most characteristic, representative, or typical attributes of the population as recommended by Singleton et al. (1988) and Strydom and Delport (2011).

Relevant information pertaining to the research participants is outlined in Tables 1.1 and 1.2.

Table 1.1: *Details of participants in the focus group discussion*

Participant	Age group					Working experience at institution (years)
	20–29	30–39	40–49	50–59	60–69	
Caregiver 1			✓			3
Caregiver 2			✓			11
Caregiver 3		✓				2
Caregiver 4			✓			5
Caregiver 5			✓			4
Caregiver 6				✓		11
Caregiver 7			✓			11

Table 1.2: *Details of participants involved in individual interviews*

Participant	Age group					Working experience at institution (years)
	20–29	**30–39**	**40–49**	**50–59**	**60–69**	
Caregiver 2			✓			11
Caregiver 3		✓				2
Caregiver 4			✓			5
Caregiver 7			✓			11

1.8.3 Data generation strategies

I employed multiple data collection and documentation strategies, relying on methods such as a focus group discussion, individual interviews, and a research journal in which I recorded field notes and personal reflections. As the selected data collection strategies are discussed fully in Chapter 3, the table below is intended as a brief overview of the data collection strategies.

Table 1.3: *Data collection*

Method of data collection	Descriptions of the process
Focus group discussions with Caregivers 1–7	Open-ended questions were asked and the discussion was moderated in order to gather information. Discussions were recorded and transcribed.
Semi-structured individual interviews with Caregivers 2, 3, 4, and 7	Semi-structured, open-ended interviews were conducted, recorded, and transcribed.
Research journal	Field notes, observations, and personal reflections were documented in a research journal.

1.8.4 Data analysis and interpretation

Cohen et al. (2005) describe data analysis as "making sense of the data in terms of the participants' definitions of the situation, noting patterns, themes, categories and regularities" (p. 147). Analysis of the qualitative data of this study was approached through the process of making sense of the raw data by observing patterns, interpreting such patterns to discover concepts and relationships, and then organising them to arrive at the formulation of substantive findings. For the purposes of this study, I conducted a thematic content analysis in view of its being, in the words of Anderson (2007), "a descriptive presentation of qualitative data".

My data analysis focused on the participants' subjective experiences and perceptions, as well as their understanding of the stress that they experienced as caregivers in an institution for orphaned and vulnerable children. By implementing thematic analysis, I was able to search for key words, meanings, and themes that emerged as important to the description of the phenomenon (an approach advocated by Cohen et al. (2005), and Babbie and Mouton (2001).

1.9   QUALITY CRITERIA

1.9.1 Credibility

The goal of credibility according to Lincoln and Guba (as cited in De Vos, et al 2002) "is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described" (p. 351). One of the most valuable techniques for establishing trustworthiness is through member checking (Lincoln & Guba as cited in Seale, 2003, p. 172). This entails verifying the researcher's comprehension of members' statements with the participating members in the endeavour to guard against any potential researcher bias being reflected in the description of the data. In this study, member checking was addressed during the semi-structured interviews by the facilitators of the focus groups and interviewers through continually verifying and summarising the participants' remarks. This provided the participants with an opportunity to clarify any misconceptions with regard to their statements.

1.9.2 Transferability

Context is seen as central to transferability. Findings from qualitative research can rarely be directly transferred from one context to another and depends on the similarity of the contexts (Mackey & Gass, 2005). In this regard, I acknowledged the context-specific features of this study and used thick descriptions as a reporting method by availing myself of multiple perspectives to explain insights collected from the study. Mackey and Gass (2005) state that if researchers report their findings with sufficient detail for the audience to understand the characteristics of the research context and participants, they will be able to evaluate whether the study can be appropriately transferred to their setting.

1.9.3 Dependability

In terms of dependability, the aim was to characterise fully the research context and relationships among participants (Mackey & Gass, 2005). In order to augment the dependability of this study, participants were asked to review the patterns in the data.

Triangulation of multiple sources of data was employed to ensure that issues from all feasible perspectives would be explored. Using triangulation can aid in credibility, transferability, and dependability (Mackey & Gass, 2005). Johnson (as cited in Mackey & Gass, 2005) notes that "the value of triangulation is that it reduces observer or interviewer bias and enhances the validity and reliability (accuracy) of the information" (p. 146).

1.10 ETHICAL CONSIDERATIONS

Strydom (2011) defines ethics in social sciences research as "a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students" (p. 63). Whenever human beings are the focus of investigation, the implications of what researchers propose to do must be looked at closely (Leedy & Ormrod, 2005). As the researcher, my subjectivity also played an important role during the qualitative study, as I became the main instrument of data generating in the research process as typified by Cohen et al. (2005). I was involved in all aspects concerning the study, and therefore, needed to

remain aware of, as well as submit to, the ethical standards as stipulated by the Ethics Committee of the Faculty of Education at the University of Pretoria.

Accurate and complete information was conveyed to participants in order for them to fully comprehend the investigation and consequently be able to make a voluntary, thoroughly reasoned decision regarding their participation in the study (in accordance with guidelines provided by Strydom (2011)). Participants were made aware of the goals of the research and the procedures to be followed. Since this study formed a component of a broad study, the credibility of all the researchers concerned was rendered to the participants, who were informed that if they agreed to participate, they would have the right to withdraw at any time and that participation was entirely voluntary. Special care was taken to ensure, as Delport and De Vos (2011) recommend, that the participants did not feel coerced into participating. The caregivers subsequently provided their written informed consent to participate in the broad study, which included the current one.

Confidentiality was maintained and respected throughout the research process, and the anonymity of all participants was preserved. Confidentiality was respected by not discussing with anyone the specifics of what was seen or heard (Glesne, 2006). Although the researcher and study supervisor knew who provided the information and were able to identify participants from the information given, they did not disclose any particulars publicly (Cohen, et al., 2005).

The consequences of the study needed to be addressed with regard to the possible harm as well as the expected benefits of participating in the study. Researchers should not harm their participants and the risk of harm should be minimised (Brinkmann & Kvale, 2008; Marczyk, 2005). No part of the study intended to cause any purposeful physical or psychological harm to participants. The possibility exists that the participants may have disclosed more information during the focus group discussion or individual interviews than they had intended or wished to, but the protection of their anonymity should limit the impact of any consequent regrets to some extent.

1.11 OUTLINE OF CHAPTERS

Chapter 1: Contextualising the study

This chapter provides a broad overview and explanation of the rationale and aim of the study. The purpose and the research questions are stated, and the main concepts are defined. The paradigmatic choices and the research methodology are also discussed. In conclusion, ethical considerations and quality criteria adhered to in this study are briefly addressed.

Chapter 2: Literature review

In this chapter, the current literature on orphaned and vulnerable children, the caregivers of these children, and the stress related to their role as caregivers in an institution are explored. The theoretical framework for this study in terms of stress and coping is also discussed.

Chapter 3: Research process

Chapter 3 provides a detailed outline of the research design, research methodology, and research process. The data collection, data analysis, and interpretation methods are explained. Throughout this chapter, the limitations and strengths of the research process are identified. The quality criteria utilised in this study to meet the requirements necessary for validity and reliability are also described. This chapter concludes with an overview of the ethical considerations adhered to in the research process.

Chapter 4: Results and findings

Chapter 4 presents the results of the study in terms of the themes and subthemes that emerged during the thematic analysis of the raw data. The discussions of themes are enhanced by including direct quotations from participants and excerpts from a range of selected data for further explanation and reference to existing literature, as introduced in Chapter 2. Furthermore, the inclusion and exclusion criterion for each theme is presented.

Chapter 5: Final conclusions and recommendations

This concluding chapter links the results of the study with the research question posed in Chapter 1. The challenges and limitations are mentioned, followed by recommendations for further research, practice, and training.

1.12 CONCLUSION

The current chapter provided an overview of the research enquiry in order to orientate the reader regarding the research that follows. The chapter further provided the rationale, aim, and purpose of the study, as well as the relevant research questions and key concepts. The paradigmatic choices that I employed as researcher in this study are explained, as well as the chosen research design and methodology. The quality criteria and ethical considerations adhered to in this study were also highlighted.

In the next chapter, I present the literature review guiding this study. I discuss the existing literature that I consulted on stress and coping pertaining to caregiving of orphaned and vulnerable children affected by HIV and AIDS. I also delineate the HIV and AIDS pandemic in South Africa in terms of its societal effects.

CHAPTER 2:
LITERATURE REVIEW

2.1 INTRODUCTION

In the previous chapter, I provided a broad overview of the research problem, defined the purpose and rationale for the study, and outlined the research questions that guided it. In addition, I briefly discussed the research design and methodology, while also unpacking the key concepts germane to the research.

The current chapter encompasses a presentation of a literature review and a summary of the sources that I consulted. I will, moreover, profile the relevance of these sources to specific aspects of the study. Perusing the literature on any subject in a particular field requires a critical, selective approach aimed at identifying material that will first aid in providing a "placement framework" for the study as a whole. Second, the literature review can be considered the milieu in which the study is critically reviewed. For example, in the section below, the macro-context of the HIV and AIDS pandemic serves as the general setting in which "critical backlighting" will reveal a specific aspect, namely the micro-context of this particular study. The micro-context at issue is the stress experienced by caregivers of children and young people whose lives have been affected by HIV and AIDS. Third, the literature review provides a criterion foundation for comparing conceptions and delimiting definitions to be used in the study.

2.2 THE HIV AND AIDS PANDEMIC

As research studies worldwide have affirmed repeatedly (e.g., Actuarial Society of South Africa, 2005; Brown & Cameron, 2002; Miller, 2007; Nyambedha, Wandibba, & Aagaard-Hansen, 2003; UNAIDS, 2010), HIV and AIDS are global phenomena that have devastating social effects on the populations of developed and developing countries alike. Moreover, the pandemic has assumed cataclysmic proportions in Africa, more particularly in countries of the sub-Sahara. As of 2009, it was estimated that 33,3 million people (range 31,4–35,3 million) worldwide were living with HIV and AIDS, and that 2,6 million people (range 2,3–2,8 million) were newly infected with HIV (UNAIDS, 2010). In sub-Saharan Africa, it was estimated that 22,9 million adults and children were living with HIV and AIDS at the end of

2010 (UNAIDS, 2011). The total number of people living with HIV in South Africa was estimated at 5,38 million in 2011. An estimated 16,6% of the adult population aged 15–49 years was HIV positive. Aside from the ravaging effects on the lives of infected people themselves and societal structures in general, one of the most disturbing concomitant outcomes of the AIDS pandemic in sub-Saharan Africa has been the unprecedented number of children left orphaned or otherwise vulnerable (Nyambedha, Wandibba, & Aagaard-Hansen, 2003; Thurman, Jarabi, & Rice 2012). In view of South Africa's being one of the countries that have been most severely affected by the pandemic, unique dimensions and characteristics have come to pose intense challenges in meeting the needs of vulnerable children (Brown & Cameron, 2002; Maritz, 2002; UN Press release, 2001).

2.3   HIV AND AIDS: ORPHANED AND VULNERABLE CHILDREN

The most recent global report of the Joint United Nations Programme on HIV and AIDS (UNAIDS, 2010) has estimated that the number of children orphaned by AIDS increased from 10 million in 2001 to 16,6 million in 2009 worldwide. Of these children (aged 0–17) who had lost one or both parents to AIDS, 14,8 million were in sub-Saharan Africa. South Africa has the highest HIV and AIDS prevalence, together with the largest number of children orphaned and made vulnerable by the pandemic in the world (Anderson & Phillips 2006; UNAIDS, 2010). According to a report on mid-year population estimates by Statistics South Africa (2011), there were an estimated 2,01 million AIDS orphans in South Africa in mid-2011, an increase from an estimated 1,99 million in 2010. In 2005, it was estimated that 2,3 million South African children would have been orphaned by HIV and AIDS by 2020 (Actuarial Society of South Africa, 2005), but UNICEF South Africa's Annual Report for 2012 set the number of all orphaned children in the country at 3,6 million, of whom 2 million in the age group 0–17 years had already been orphaned by AIDS (UNICEF, 2013).

In view of the foregoing statistics, it stands to reason that the literature on orphaned and vulnerable children in South Africa lays particular emphasis on the seriousness of the role of the HIV and AIDS pandemic in adversely affecting these children not only directly but also indirectly (Journaids, 2009; SaSix, 2009; Smart, 2008; UNAIDS, 2008; UNICEF, 2003; UNICEF 2013). For the purposes of this literature review, children who are affected by HIV and AIDS are delimited in accordance with the widely used definition by UNAIDS as being under the

age of 18 years, and being either orphaned by AIDS, or rendered vulnerable by living with one parent or both parents diagnosed as HIV-positive. If orphaned, such children is further categorised in terms of being paternal, maternal, or "double orphans" (the last-mentioned referring to the loss of both parents) (Skinner et al., 2013). Given the nature of HIV transmission, the infection of both parents is a frequent occurrence and, consequently, disproportionately large numbers of children of deceased parents are left as double orphans (International Adoption, 2008; Skinner et al., 2004; Thokomala, 2008). The majority of these orphaned children are resident in Southern Africa and it has been estimated that if there are no effective interventions to bring about changes in sexual and social behaviour (Johnson & Dorrington, 2001), by 2015 approximately one third of children under the age of 18 in South Africa will have lost one or both parents to AIDS (Bradshaw et al., 2002).

In fact, during South Africa's census of 2011, the total number of children aged 0–17 who reported that they had lost one or both parents constituted 18,8%, and the UNICEF South Africa Annual Report of 2012 notes that one out of every five of all children were orphaned (UNICEF 2013). The growing number of vulnerable children, and especially orphans, is one of the most tragic long-term consequences of the HIV and AIDS pandemic (Guvava, 2011).

Vulnerable and at-risk children constitute a large sector of the South African population as a result of factors such as poverty, disease, inequality, and HIV and AIDS (UNICEF, 2003). The *Children on the Brink 2002* publication by UNAIDS, UNICEF and USAID (2002) highlighted a universal conceptualisation of the term *orphan* to include at-risk and vulnerable children. This can be viewed as a significant improvement on previous studies, which adhered to the principle of distinguishing among children only according to orphan status, with the result that children with ailing parents were grouped with non-orphans and thus excluded from being identified as vulnerable (Miller, 2007).

There is no single agreed-upon definition for the term *orphans and vulnerable children* or *orphaned and vulnerable children* (frequently abbreviated as OVC in the literature), since this particular formulation can be viewed as involving *all* social phenomena that may pose a risk to children or render them vulnerable (Miller, 2007; Skinner et al., 2006; Smart, 2003); in other words, not the social or community effects of HIV and AIDS only. Moreover, as *Children on the Brink 2004* (UNAIDS, UNICEF, & USAID, 2004) cautions: "*Children on the*

Brink also avoids using acronyms such as 'OVC' (for orphans and vulnerable children) or 'CABA' (for 'children affected by HIV and AIDS'). Experience has shown that such jargon eventually becomes used at the community level to identify particular children" (p. 6). This approach is understandable for high-level reports with a worldwide distribution such as UNAIDS ones, and although there may be some justification for using such abbreviations in the academic field for the sake of brevity, their use will also be avoided in this study.

"Vulnerability" has been conceptualised in studies as involving not only individuals who are *affected* by HIV and AIDS but also those who are *infected* by it (Skinner et al, 2006; Smart, 2003). Gillespie et al. (2005) categorise vulnerable children in such a way that it encompasses the most important aspects of the impact of HIV and AIDS on them:

♦ "Children who have lost one or both parents to AIDS (maternal, paternal and double orphans) wherever they live, including on the street;

♦ Children whose parents are alive but who live with relatives or non-relatives under strained capacity (often identified as social orphans);

♦ Children living in households with adult caregivers (parents or non-parents) or other siblings who are chronically ill, possibly due to HIV and AIDS;

♦ Children who are HIV-positive or living with HIV and AIDS, some of whom may be orphaned;

♦ Children in poor households who are not orphaned but experience an adult death; and

♦ Children living with their parents in fostering households, which may have recently taken in an orphaned child" (p. 2).

It is perhaps significant that *Children on the Brink 2002* (UNAIDS, 2002) initially used "under age 15" as the limit for defining "orphans", but increased this limit to "under age 18" in the 2004 follow-up version (UNAIDS, UNICEF, & USAID 2004). This may be indicative of increased sensitivity to the wider scope of vulnerability in age cohorts, since the effects of HIV and AIDS strike wider than initially assumed. It may also have been done in view of a

more realistic correlation between age and the capacity to support oneself. A further highly significant aspect of this upward shift of age limit that must be borne in mind is that it leads to a statistical increase in the numbers of at-risk and vulnerable children to be considered. This cannot be viewed as a merely theoretical or "academic" matter, since it has practical effects in real-life situations—especially in terms of forecasting and planning. It is necessary, for example, to consider statistics realistically in the question of social caring in all its facets (e.g., community and national level), and age-related benchmarks that governments should strive to adhere to in deciding on social support-service expenditure.

Regardless of "virtual" estimates and their potential ramifications, in real terms the elevating number of children affected by HIV and AIDS and their psychosocial well-being remain a vast concern in global society (Guo, Li, & Sherr, 2012). Caring for the estimated 15 million children orphaned by AIDS will constitute a significant challenge for communities across the world for generations to come (UNAIDS, UNICEF, & USAID, 2004). Even if HIV prevalence should be stabilised or decreased, it is anticipated that orphan numbers will continue to grow, reflecting the time lag between HIV infection and death (UNICEF, 2003). It is thus still necessary to develop strategies to manage the predicted surge of AIDS orphans within the next decade (Freeman & Nkomo, 2006; Guo, Li, & Sherr, 2012).

2.4   SUPPORT FOR ORPHANED AND VULNERABLE CHILDREN

2.4.1 Challenges facing orphaned and vulnerable children

A study by Jackson et al. (2004) on early childhood care and development in relation to the HIV and AIDS pandemic in Africa has noted that there are very few reports focusing on the specific challenges that young orphans and vulnerable children have to face, particularly in sub-Saharan Africa. Although the authors concentrate on the age group from birth up to the age of eight, some of these challenges remain valid for older children as well. The high-risk obstacles that these authors identify are the following:

- *Survival risks.* In view of the lack of adequate treatment regimens to prevent HIV transmission at birth or later, approximately 30% of children born to HIV-positive mothers in sub-Saharan Africa are likely to be infected. In addition to this, they face

a secondary survival threat if their mothers die, since they are at greater risk of morbidity and mortality.

♦ *Increased morbidity*. This entails greater susceptibility of AIDS-affected children to all forms of health-related stressors such as malnutrition, diarrhoea, pneumonia, malaria, and HIV infection. Circumstances of impoverishment may prevent access to even the most basic forms of health care. Follow-through on home-based care is often not feasible, and elderly family members or other children functioning as heads of households frequently lack the knowledge to supervise the special health care requirements of very young children, with the result that the normal development of these children is impeded.

♦ *Malnutrition*. Although these researchers have already mentioned malnutrition under "increased morbidity", it is a problem of such vast scope that they also consider it separately. Since HIV and AIDS reduce the ability of ailing adults to work, the family's food production or acquisition is reduced. In a situation of under-nourishment, younger children are especially at risk. Nutrition-related diseases may mimic the symptoms of AIDS (e.g. weight loss), which may lead to distancing from and neglect of younger children by caregiving household members. Once severe malnutrition sets in, irreversible stunting of all developmental aspects may occur.

♦ *Psychosocial trauma*. Very young children, who are unable to express themselves verbally, may be deeply traumatised by the suffering they see around them and fall victim to feelings of grief, anxiety, helplessness, insecurity, and depression. Moreover, being deprived of consistency in caregiving and interpersonal and environmental stimulation may lead to negative long-term cognitive and psycho-social consequences.

♦ *Abandonment*. The researchers consider abandonment to be the far end of the spectrum of inadequate care. In Kenya (Jackson et al., 2004), some HIV-positive women abandon their newborns in the hospital immediately after birth, although such infants may not even be HIV-positive. The same phenomenon is observable in Johannesburg (Jackson, et al., 2004), where in 1998 two thirds of such babies were

indeed HIV-positive. However, irrespective of HIV status, such children have reduced chances of survival because of inadequate resources to sustain them.

♦ *Delay or lack of entry into formal primary education.* Children are frequently prevented from attending school by household poverty, isolation, and despair. In Zambia, for example, one study reported that 32% of orphans (compared with 25% non-orphans) in urban areas were not attending school, whereas the figure for orphans in rural areas was as high as 68% (in comparison with 48% for non-orphans).

♦ *Child labour.* Orphans and vulnerable children frequently have to take up adult responsibilities by caring for ailing parents and younger siblings. They are obliged to help with farm and domestic labour (for their families), or to earn some income for their households in other ways. Jackson et al. (2004) note that "as the death toll of the HIV AND AIDS pandemic continues to mount, the once extraordinary phenomenon of child-headed households is becoming more and more commonplace in Sub-Saharan Africa. There are now orphaned children as young as 6 or 7 attempting not only to negotiate the challenges of their own survival without adult care or supervision, but also to care for younger siblings, some of whom may be infected with HIV. Children in these circumstances are highly vulnerable to exploitation" (p. 81 ff.).

Although further exploration of these specific challenges falls outside the scope of this study, they provide significant background to several aspects of the present investigation. Among other things, they serve to cast more light on the specific problems that caregivers of orphans and vulnerable children need to understand and deal with, and they may also provide general points of reference when considering the pros and cons of institutional care.

2.4.2 Care of orphaned and vulnerable children in the family context

Miller et al. (2006) remark upon the fact that a growing number of households locally are saturated with what they term "orphan responsibilities". One of the greatest challenges facing South Africa today is the increase in the number of orphaned and vulnerable children living in communities and the lack of adequate support available to these children. With this

growing number of orphaned and vulnerable children, the country is presented with a serious challenge for the education, health, and other social systems. As a result, different approaches to care will have to be extended to avoid the potentially rapid increase in child-headed households and street children (Desmond et al., 2002).

Outcomes for children who are orphaned or vulnerable are usually dependent on a number of factors such as the ability of members of the extended family to care for them, available resources, age, government policy, and community-based interventions. Institutional care for orphaned children is uncommon in South Africa because of cultural/traditional considerations being fundamental to the placement of orphaned and vulnerable children (Kuo & Operario, 2011). Family care for orphaned and vulnerable children is usually preferred by children and families, and highly regarded by policymakers (Bhargava et al., 2003; Smart, 2003; UNICEF et al., 2004). Yet, a preferred solution may evolve into an additional complication when the burden of care and support falls on increasingly vulnerable guardians, including elderly grandparents, young siblings, and relatives who are often themselves infected with HIV, thus leaving fewer available caregivers and a growing number of overwhelmed and dissolving households (Foster, 2002; Miller, 2007).

Further to the above, the study of Jackson et al. (2004) observes that the AIDS pandemic in its devastation of family structures tends to leave behind the elderly and the very young. Lydia Nyesigomwe, the Director of Action for Children in Uganda, in summing up the situation of care responsibilities being shifted onto grandparents, coined the memorable phrase "the vulnerable care for the vulnerable" (p. 81 ff.). This described a one-year pilot project that was launched to strengthen grandparents' capacity to provide care to children younger than eight, to improve the overall welfare of families who have to take care of the children, and to involve the broader community in quality care for orphans and vulnerable children in early life (Jackson et al., 2004). These initiatives were undertaken in household and community context, however, without any specific mention of the option of institutional care.

A project was undertaken in Zambia to assess the quality of the care provided by orphanages that wished to apply for UNICEF assistance. Particularly notable was the project rationale for having to look towards institutional care:

While the vast majority of orphans in Zambia are still being absorbed by the extended family network, the ever-increasing number of AIDS-affected children in Zambia has resulted in a growing demand for alternative care options. [Margaret] Akinware [Project Officer and researcher] describes the current struggle in Zambia, as in other Sub-Saharan countries, to come to terms with the seemingly inevitable transition to ever larger numbers of young children requiring institutionalized care as the extended family system becomes taxed beyond its coping capacity. The assumption among social scientists and development workers was that orphans who were taken care of by members of the extended family network received better care and affection than their counterparts in orphanages or in such residential facilities (Jackson et al., 2004, p. 81 ff.).

In spite of these assumptions, and irrespective of their validity or not, the fact remains that certain environmental and systemic stressors, along with overstretched financial resources, have resulted in families and communities in sub-Saharan Africa becoming overwhelmed and under-resourced (Foster as cited in Freeman & Nkomo, 2006; Lugalla, 2003; Miller, 2007). The quality of care that children receive depends on who provides care and the resources, time, and motivation that caregivers have for giving such care. Because both the number of caregivers and their resources are limited, this results in an increase in the number of street children, child-headed households, and child labourers. The last-mentioned grouping in particular may involve girls and older children, which means that infants and young children left at home (while their older siblings are working) are at increased risk of neglect when caregivers are unable to step forward when the need arises (Foster as cited in Freeman & Nkomo, 2006; Miller, 2007).

The traditional African practice of caring for an orphaned or vulnerable child by a relative of the parents' extended family is therefore being challenged, and alternative placement has become essential as the extended family network may no longer be the safety net that it once was, although it still remains the primary source of care for orphans in Africa (Mohangi, 2008; Shetty & Powell, 2003).

Succouring orphaned children will therefore pose long-term challenges to families and communities in so far as traditional support systems weaken because of an increase in orphan numbers and HIV prevalence (Kuo & Operario, 2011; Makiwana, et al., 2004). This steady erosion of traditional systems in turn heightens the pressures on extended families in

that the vast majority of them can ill afford the required caregiving because of the indigent socio-economic circumstances in which they find themselves. The inevitable outcome is an increase in the percentage of orphans and vulnerable children who will need to be accommodated in institutional care systems such as orphan, foster, residential care, and children's homes. It is therefore crucially important to lay the groundwork for making such institutions available to countless children (Makiwana et al., 2004; Subbarao & Coury as cited in Levin & Haines, 2007).

2.4.3   Care of orphaned and vulnerable children in institutional context

In many countries, a considerable number of children are temporarily or permanently cared for in what the literature frequently refers to as "residential care". Evidence suggests that the phenomenon of residential or institutional care has been growing in recent years due to a complex interplay of different factors, among them HIV and AIDS (Dunn & Parry-Williams, 2008; Williamson & Greenberg, 2010). South Africa is faced with the challenge of not only providing adequate institutional space for vast numbers of orphaned and vulnerable children, but also ensuring that the institutional care is able to facilitate the healthy, holistic development of these children (Makiwane et al., 2004; Morrison, 2008).

One definition of institutional care considers it "a group living arrangement for children in which care is provided by remunerated adults who would not be regarded as traditional care-givers within the wider society" (Rayneke-Barnard, 2005, p. 23). Tolfree (2003) states that "institutional care involves large numbers of children living in an artificial setting" (p. 7). In the United Nations' *Guidelines for the alternative care of children*, it is viewed as "care provided in any non-family based group setting, such as places of safety for emergency care, transit centres in emergency situations, and all other forms of short and long term residential care facilities, including group homes" (UN, 2010, Article 29a (iv)). In South Africa, these are legal, formal institutions that function with government support under the supervision of the Department of Social Development (DoSD). Residential care facilities tend to be large and staffed by several caregivers in various capacities.

Institutional care is aimed at providing either temporary or permanent care to children for various reasons such as being orphaned, originating from a seriously unstable home, being chronically ill, etc. Orphanages and child villages are the major types of institutional care

models (Beard et al., 2001). The word "artificial" as used in Tolfree's definition in the preceding paragraph may imply a contradistinction with the word "natural" ("artificial" being defined in the *Concise Oxford English Dictionary* (Soanes & Stevenson, 2004) as "made as a copy of something natural", and may therefore bear an implied negative connotation of "contrived or false . . . insincere or affected" (p. 74). The "artificiality" of residential care, in contrast with a "natural" setting of familial care, may in some measure account for—as noted by Mohangi (2008) and Maclean (2003)—the fundamental differences that can be found among researchers in their attitudes towards placing a child in an institution. According to Christian Aid and UNICEF (2006), while "institutions for orphan and vulnerable children might be perceived as the most recent symbol of modernization, researchers and aid organisations generally consider institutions as the 'last resort' for the placement of children" (as cited in Mohangi, 2008, p. 49). The reasons for considering institutions as a last resort may be divided into two major categories: cost and quality.

The practical matter of costs of institutional care must of necessity be juxtaposed with the more theoretical question of quality. There is a vast amount of literature associated with institutional care in Europe and continental North America (Bowlby, 1969; Frank, Klass, Earls, & Eisenberg, 1996; Golfard, 1945; Morrison, 2008; Spitz, 1965) that warns against the use of orphanages because of traditional models of institutional care. These institutions have been found to cost more per child than family care and are potentially unsustainable because of a heavy reliance upon charitable donations (Subbarao, Mattimore, & Plangeman, 2001; UNICEF, 2003).

The cogent financial arguments in the costs category appear to be supported by research into the quality of care within institutions, which is generally thought to be inconsistent, and thus the type of care and environment that a child experiences can vary from one facility to another (Mohangi, 2008; Maclean, 2003). In addition, research preponderantly favours the view that institutional care generally lacks the capacity to meet children's emotional needs and is associated with aggressive and antisocial behaviours, hyperactivity, inattention, indiscriminate friendliness, poor quality of peer relationships, depression, anxiety, and emotional regulation difficulties. Institutional care may furthermore lead to poor health, growth, and development, and is usually associated with stunted physical development, in particular with significantly delayed growth, weight, and head circumference (Astoints,

2007; Beckett et al., 2002; Fisher, Ames, Chisholm, & Savoie, 1997; Johnson et al., 2006; Maclean, 2003; Miller, 2005; Roby & Shaw, 2006; UNICEF, 2004;). Adverse developmental outcomes such as these have been ascribed to aspects of institutional care that fall short in providing the expected experiences necessary for normal development in infancy and early childhood (Vashchenko, Easterbrook, & Miller, 2010).

The study by Jackson et al. (2004) mentioned above (see 2.4.1), focused on risk factors for very young orphaned and vulnerable children under the age of eight, while a study undertaken by Adejuwon and Oki (2011) in Nigeria concentrated on the emotional well-being of 7- to 18-year-old orphans and vulnerable children in sampled institutions. Their study investigated aspects such as stigmatisation or discrimination, sexual involvement, and school enrolment as predictors of emotional well-being in these children, and the findings revealed that more than half of them suffered from emotional instability because of feelings of unhappiness, lack of appetite, anger, a desire to run away, fear of new situations, and worry.

Although Adejuwon and Oki (2011) caution that their findings cannot necessarily be generalized, these findings, read together with those of the study by Jackson et al. (2004), may serve to provide a fair indication of the experience of orphans and vulnerable children in the context of the HIV and AIDS pandemic. It also appears possible in consideration of the above factors to refer to a grouping of *external situational* and a grouping of *internal psychological experiences* of children. Ultimately, in having considered the potentially negative effects of residential care up to this point, it needs to be borne in mind that caregivers themselves, especially in a regular institutional or residential work environment, also undergo daily exposure to negative experiences or perceptions as reflected by the children in their care. (This might possibly exert some influence on caregiver characteristics mentioned in the next paragraph.)

At the other end of the literature continuum, few authors appear to cite positive effects of institutional care. Since the effects of institutionalisation are far too complex to be amenable to "standardisation" and are dependent on numerous variables, the outcomes and experiences are not the same for every child who is institutionalised (Morrison, 2008). According to Minde (2003), the degree of difference that may be detected between

institutionalised children can be the result of a myriad of factors such as individual characteristics (genetic predisposition, basic personality, attractiveness, prenatal risk factors), caregiver characteristics (training, motivation, and attitude), institutional characteristics (child-to-caregiver ratio, quality and degree of programming), and personal history (the age of the child when entering the institution and the length of time in the institution). Positively, though, children are thought to possess—by nature and by situation—an innate capacity for resilience that allows them to adapt to the institutional environment and protect themselves from further threat (Mohangi, 2008).

There are those researchers (McKenzie, 1999; Morrison, 2008; Vorria et al., 2006; Whetten et al., 2009) who have presented research on the positive aspects of child development in residential care that points out that institutional rearing may be less harmful, or at least no more so, than other approaches. A follow-up exploration conducted by Vorria et al. (2006) has shown a decrease in attachment and behavioural problems that children at first displayed when taken into institutional care. From his survey of nearly 1 600 respondents from nine orphanages, McKenzie (1996) has concluded that many such children manage to achieve success in life, and that institutional care, although not the ideal solution, does indeed fulfil a helpful function in nurturing many disadvantaged children. The implication is, as McKenzie notes, that there are several orphanages that do indeed succeed in removing great numbers of children from the vicious cycles in which they were initially caught up. Whetten et al.'s (2009) study of children aged 6–12 reared in institutions has revealed that the growth and overall health of children in institutions are no worse than those of children in community care. (It needs to be pointed out that this is in contrast with the investigative conclusions on stunted physical development mentioned four paragraphs earlier.) Furthermore, the findings of Whetten et al. have indicated that institution-based children scored higher on intellectual functioning and memory, and had fewer social and emotional difficulties. The authors of this study have explicitly stated that their findings challenge the policy recommendations to use institutions only as a last resort. Morrison (2008), too, has argued that children living in a well-controlled and well-monitored environment such as that of institutional care have a higher chance of having their physical needs met versus those who are in community-based care.

However, whether supported by policy or not, and whether advocated by research or not, in practice there are an increasing number of children being placed in institutional care as a result of being orphaned by AIDS, or the loss of family due to other diseases or natural causes, or as a result of abuse and domestic violence, as noted by UNAIDS (2004). The role that institutional care can play in the context of HIV and AIDS should not be negated, especially in supporting vulnerable children with no one else to care for them (Desmond & Gow, 2001).

If one turns to the study of Jackson et al. (2004), it would appear that a golden mean might be found in the suggestion of Susan Sabaa, National Coordinator of the Ghanaian NGO Coalition on the Rights of the Child, that a flexible alternative care model be considered. The proposed model emphasises child rights and national policies aimed at initiatives providing training in and monitoring of early childhood care and development. Notably, she advocates "pragmatic support for the overburdened extended family system of care for young . . . [orphans and vulnerable children], so that institutionalization becomes the 'last resort' choice" (p. 81 ff.).

This brings one to the crucial role that caregivers play in institutions for orphaned and vulnerable children. Studies such as those of Adejuwon and Oki (2011) emphasise with great justification the need for better-quality support for vulnerable children and family-system caregivers, but not necessarily for caregivers *per se* in institutional context. The study by Jackson et al. (2004), however, goes further than this by pointing not only to the urgent need for pragmatic support for extended-family caregivers, but also for staff of institutions in order to improve care for (at least) young orphaned and vulnerable children. Still, a subtle point needs to be emphasised here: the "pragmatic" support to caregivers that the authors advocate is aimed at improving service-rendering to the children as "clients"—it is not dedicated specifically to fostering the psychosocial well-being of the caregivers themselves. In other words, reference is made to empowering caregivers in rendering better service to others, but not to supporting caregivers as such. (See also 2.5.2 below.)

The type of stress experienced by the caregivers of these children is the main focus of the current research. Unlike children reared outside of an institution, orphaned and vulnerable children are reliant on the institution as a "home" environment, and therefore it follows

that institutions and institutional personnel are proxies to parental and familial care (Smyke et al., 2007).

2.5 CAREGIVERS AND CAREGIVING IN THE INSTITUTIONAL CONTEXT

2.5.1 Introduction

Caregivers as defined by Kools and Kennedy (2001) are considered to be the primary caretakers of children in institutional care. These caregivers have the responsibility of seeing to the children's daily needs, their development, and nurturing of life experiences (Barker, 1988; Kools & Kennedy, 2001). Such professionals or paraprofessionals are often known as residential workers or house parents (Barker, 1988).

The definition of caring work formulated by Davies (1995) characterises it "as attending physically, mentally and emotionally to the needs of another and giving a commitment to the nurturance, growth and healing of that other" (p. 18–19). This definition is particularly germane to orphans and vulnerable children being cared for in an institutional environment, as well as to the role that their caregivers fulfil in that context.

In South Africa, caregivers of orphans and vulnerable children preponderantly comprise family members, particularly women, who provide in-home care on an unpaid basis and who can be described as informal caregivers. Formal caregivers, by contrast, include AIDS-care programme volunteers, health care professionals, social workers and traditional healers. Caregivers in this category are trained and compensated for their caregiving activities (O'Neill & McKinney, 1999; Primo, 2007; Van Dyk, 2008).

2.5.2 The institutional context as working environment

The dearth of appropriate investigations in sub-Saharan context in the research area of the current study has frequently necessitated the use of examples from further abroad. One such example is that of the investigation undertaken by Vashchenko et al. (2002), who surveyed staff in three Ukrainian baby homes in order to learn more about caregivers' attitudes towards the nature of their work and the needs of the children in their care. Their findings revealed that caregivers' reasons for working in this context included benefits and convenient work shifts, morality and affection for children, as well as professional satisfaction. These researchers' findings further indicated that caregivers perceived their

work difficulties as including conflicts, lack of cooperation, and little administrative support. An important theme that emerged during their qualitative analysis of the responses was work-related stress. Lack of support and respect, perceived negativism, and lack of trust in the workplace were cited as aspects of the job that caregivers hoped would change. Other researchers such as Evans et al. (2004) and Colton and Roberts (2006) have noted that contributing factors to high staff turnover rates include dissatisfaction with low wages, high child-to-staff ratios, poor perceived professional status, and long or unstable work hours.

The report *Setting quality standards for residential child care* issued by the Central Council for Education and Training in Social Work (CCETSW, 1992), a regulatory body for social work education and training in the UK, identified essential features of residential child care in which there had been a history of failure:

♦ failure of national and local government to provide appropriate salaries and conditions of service and to fund comprehensive training programmes;

♦ a failure of will on the part of employers, who have only rarely invested sufficient professional expertise and managerial commitment to sustain a fully professional residential child care service;

♦ failure of the social work profession as a whole (and of the social work training "establishment" in particular) to take responsibility for the training of residential child care workers or other equivalent groups; and

♦ failure of the social work profession to remedy the stigma and discrimination against residential child care that persist within some parts of the profession and that disadvantage those living and working in such settings.

Researchers have remarked on the lack of adequate investigations into the impact of care standards and economic resources on care institutions, which can only flourish if standards are high and proper resources are provided. However, the research that does exist indicates that quality of practices must be taken into account, as well as quantity of economic support, if the stakeholders in institutional care context—children, caregivers and the institution itself—are to be sustained (Perry et al., 2006). In sub-Saharan context, reference

can be made to the research of Akinware (Jackson et al., 2004), who piloted the use of an established qualitative assessment instrument, the Inclusive Quality Assessment (IQA) tool, in a selected orphanage in Zambia. This initiative was undertaken *inter alia* to assess its potential for monitoring the quality of orphan and vulnerable child care throughout the country. IQA emphasises both child participation and institutional self-reflection in formulating a proactive action plan to improve overall quality of care, but it appears once again that personal caregiver support (in contradistinction to caregiver training or "empowerment") is not a major component as such. Nevertheless, it is possible (as implied in the following paragraph) that institutional training may well contribute significantly to a sense of personal self-validation in caregivers.

A study conducted by Castillo et al. (2012) on the perceptions of caregivers in an orphanage in Ghana has revealed that participants reported an absence of a formal system for staff training and expressed a strong desire for training. The authors posit that through training, the personnel working in institutions might feel more empowered and motivated to work in such an environment. Furthermore, through appropriate training, caregivers may then acquire the necessary knowledge and skills to communicate effectively with the children and respond to their physical, psychological, and emotional needs. Appropriate training of caregivers may also assist them in better communication with colleagues and administrators within the institutional setting (Castillo et al., 2012). Evans et al. (2004) state that one of the most important avenues for bettering the status of professional childcare is that of improving the training, skills, and expertise of professional childcare workers.

It appears, therefore, that however rewarding caregiving may be, it remains a highly demanding and stressful job or commitment (Ohaeri, 2003; Pavalko & Woodbury, 2000).

2.5.3 Experiences of caregivers

In general, caregiving professions have been associated with experiencing escalated amounts of stress (Khan, 2005). Working in the caregiving profession increases the likelihood of adverse psychological outcomes for caregivers (Figley, 2002; Sabin-Farrell & Turpin, 2003). Stressors have been linked with negative mental health outcomes such as depression and anxiety (e.g., Ellison, 1995; Folkman, Lazarus, & Pimpley, 1987).

Hayden and Otaala (2005) have found that caregivers in AIDS care centres in general (i.e., not only for children) were prone to high levels of stress as a result of their work. In terms of the current study, it may therefore be expected that demands on caregivers will be even higher in the field of caring for orphaned and vulnerable children, given that an increased sensitivity to their need for nurturing in all respects may come into play. Prior research in this area of caregiving suggests that caregivers are subject to a sense of bearing an extra or heavier burden because of the physical and psychological costs of caring for children affected by HIV and AIDS (e.g., Hayden & Otaala, 2005; O'Neill & McKinney, 1999; Van Dyk, 2008).

Specifically in the milieu of caregiving for orphans and vulnerable children, caregiver stress can be divided into primary and secondary components. Primary stress arises from having to care directly for these children and is experienced as a result of everyday caregiving duties such as assisting the children with bathing, toileting, managing behaviour, and planning of daily care. Secondary stressors are indirectly related to caregiving and comprise caregiver conflict with relatives of the children, exposure to the economic hardship suffered by the children and their families, as well as caregivers' personal experience and limitations on their own family life, leisure, and social activities (Pearlin & Aneshensel, 1994; Primo, 2007).

Curbow et al. (2001) describe work-related stress as predictors of burnout, internal conflicts, staff turnover, and dissatisfaction. Evans et al. (2004) state that prolonged exposure to chronically unstable and stressful work conditions leaves childcare professionals vulnerable to burnout.

As a result of society's "unrealistic expectations" of caregivers (Rowe, 2003, p. 17), a considerable amount of stress is placed on them, compromising their health both physically and psychologically. This may lead to decreased psychological health and life satisfaction, and increased levels of caregiver burden, role strain, and depression (Figley, 2002; Fredriksen-Goldsen, 2007; Sabin-Farrell & Turpin, 2003).

2.5.4 Burnout and caregiver burden

The term "caregiver burden" is used in professional context to describe the physical, emotional, financial, and social problems associated with caregiving (Given et al., 2005;

O'Neill & McKinney 2003), which in turn may lead to burnout. Burnout is defined as a multidimensional syndrome that is characterised by emotional exhaustion, depersonalisation, and reduced personal accomplishment (Maslach & Pines, 1977). Emotional exhaustion, which represents the basic stress dimension of burnout, is viewed as exhaustion and loss of energy leading to feelings that emotional resources are inadequate in providing care for others. The second component, depersonalisation, which represents the interpersonal dimension of burnout, is the negative attitude of dehumanising perception whereby caregivers detach themselves from those under their care and manifest cynicism, apathy and withdrawal. The final component of this multidimensional syndrome, namely lack of personal accomplishment, leads caregivers to feel that they are incompetent and perceive themselves as unable to reach work-related goals and as incapable of achieving in the workplace. This is evident in decreased efficiency at work, difficulty in concentrating and increased irritation with colleagues (Evans, et al., 2004; Lakin, Leon, & Miller, 2008).

The concept of caregiver burden furthermore relates to resources that are used and pressures created by working in an environment of caring. The burdens are predictors of the measure of stress that caregivers themselves perceive to undergo. The assumption is that if caregivers have fewer caregiver burdens, they would also experience less caregiver stress (DiBartolo & Soeken, 2003; Pruchno, Kleban, Michaels, & Dempsey, 1990).

In their investigation into ethic differences in burnout, coping strategies, and intervention as relating to childcare professionals, Evans et al. (2004) were surprised by the low levels of personal accomplishment reported by the participants. The researchers combined their findings with those of other studies (Fuqua & Couture, 1986; Sears, Urizar, & Evans, 2000) in suggesting that experiencing low personal accomplishment may be the most common component of burnout and that childcare professionals in particular are vulnerable to this element (Evans et al., 2004).

Caregiver stress may manifest itself in various ways. For example, in Kenya research by Mutiso, Chesire, Kemboi, Kipchirchir, and Ochieng (2011) found that caregivers experienced frequent headaches as a result of long working hours, work pressure, tension among staff and multiple directives from senior staff members. Memory problems, anxiety, depression, and aggression are equally some of the effects of stress on child caregivers, and the

resultant high staff turnover in itself may add to stressor factors (e.g., training and assisting new members). Further deleterious effects in child caregiving environments may include absenteeism, heart disease, high blood pressure, and substance abuse. High emotional involvement without adequate social support or feelings of personal work accomplishments (e.g., job satisfaction) may leave caring professionals vulnerable to job burnout (Adams, Boscarino, & Figley, 2006). It may therefore be assumed that if caregiving staff are adversely affected, the care and support of children in children's homes will suffer because of a decrease in quality of service (Mutiso et al., 2011).

2.5.5 The caregiver and coping

Although negative consequences are present in caregiving, there are also personal psychological rewards and satisfaction to be derived from it. If a sense of achievement is indeed attained, it may, for example, stimulate caregivers' motivation, which in turn may play an important role in having a positive impact on the quality of caregiving (Pavalko & Woodbury, 2000). It is vital for caregivers to have effective coping strategies, given the elevated number of contributing factors discussed above. Through being equipped with adequate coping techniques and being provided with sufficient social support, caregivers will be better able to negotiate the effects of stress on their physical health, psychological health, and life satisfaction (McClendon, Smyth, & Neundorfer, 2004). Considering the high pervasiveness of stress associated with caregiving specifically in an HIV and AIDS milieu, focusing on the caregivers' experience of stress and the outcomes resulting from it could be useful in finding ways to ameliorate it. In this respect, there are various intervention strategies that may be considered for utilisation in appropriate circumstances.

According to Armstrong (2000), it is essential to provide stress management programmes for caregivers working with people with HIV and AIDS—or, for that matter, working with family and relatives of infected people (i.e., the affected ones, as mentioned before). Sadock & Sadock (2003) consider self-help support groups for caregivers to be particularly useful since people sharing similar experiences in a group are able to provide one another with mutual support, empathy, and understanding. Such a milieu is conducive to capacitating members to implement an adaptive manner of dealing with the various stressors they experience.

Social support refers to access to and use of individuals, groups or organisations in dealing with the needs related to caregiving activities (Pearlin et al., 1981). Social support refers to the actual receipt of some emotional, tangible, or informational help from others, and the subjective perceptions of support (Krause, 1986, 1987). The ability to modify the caregiving environment is closely linked with actual and perceived available social support networks (Grant, Elliott, Giger, & Bartolucci, 2001).

It is not only, as the research of Cho & Cassidy (2001) indicates, a question of sharing experiences with others to provide much-needed mutual support, but caregivers should also be aware of the necessity to make time and space for their own needs by indulging in leisure activities such as reading, taking holidays, participating in sport, and getting together with friends. (The necessity of receiving support in seeing to personal needs was touched upon in the last paragraph of 2.4.3 in respect of "pragmatic" support.)

In recent decades, there has been increasing interest in the role of spiritual beliefs and religious participation as factors promoting successful coping (e.g., Ellison & Levin, 1998; Fehring, Miller, & Shaw, 1997; Yoon, 2004). Results suggest that religious or spiritual beliefs and religious participation may improve coping with a variety of stressors. Folkman (1997) in his research attests to the importance of spiritual practices and beliefs in helping HIV caregivers to cope with their situations. Religious beliefs can also provide comfort and hope in distressful circumstances (Musick, 1996). People with high levels of religiosity often use their religious patterns for coping (e.g., prayer, rituals, and religious objects), and spirituality can foster a greater sense of wholeness (Fehring et al., 1997). Given that persons in a care-giving working environment tend to be sensitive to psychological and spiritual matters, the value of privately held religious beliefs can aid caregivers considerably in structuring an inner self-support system.

2.6 THEORETICAL FRAMEWORK—STRESS AND COPING

2.6.1 Introduction

The foregoing sections provided a brief overview of stress and coping strategies for caregivers, but it is evident that a coherent framework or appropriate model is required for analysing and ordering research material and data. In the current study, Lazarus and

Folkman's (1984) transactional and cognitive appraisal model of stress and coping has been used to conceptualise and examine the experiences of stress and coping resources of caregivers.

This model provides an explanation for the stressors and ways in which caregivers evaluate and cope with the stressors that they face in caring for orphaned and vulnerable children. Its theoretical foundation suggests that specific types of situation result in positive and negative perceptions for the individual, usually in terms of the perception of reward or threat. When stressors that can have a negative impact on caregiver well-being are assessed, it is important to consider not only primary, secondary, and other life stressors, but also the way in which caregivers actually appraise these stressors, as well as the internal and external coping resources that they choose to utilise.
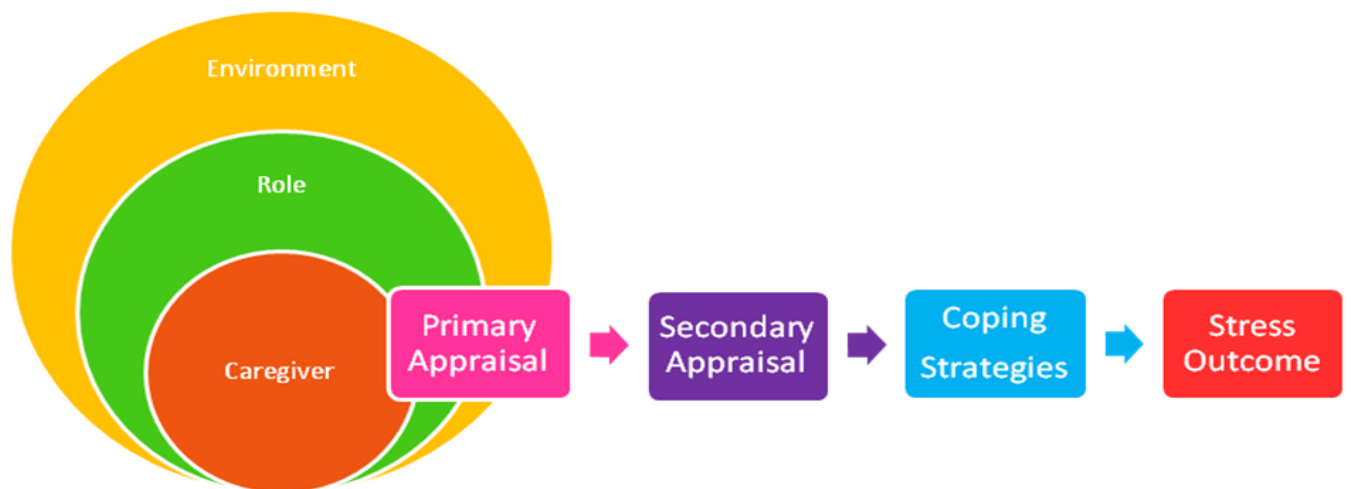
Figure 2.1: *Model based on Lazarus and Folkman's (1984) transactional model of stress and coping*

2.6.2 Stress

Folkman and Lazarus (1985) define stress as the result of a disturbed relationship between the person and the environment because of external and/or internal demands, and his or

her resources or ability to cope with those demands. Depending on the imbalance between the person and the environment, more or less stress is experienced (Lazarus & Lazarus, 1994; Zakowski, Hall, Klein, & Baum, 2001). This definition describes the relationship between the person and the environment, which takes into account characteristics of the person on the one hand, and the nature of environmental events on the other. Psychological stress is therefore seen as a relationship between the person and the environment appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984; Mayers, 2005).

In the context of this study, stress can therefore be said to arise when a caregiver appraises a situation as challenging, threatening, or otherwise too demanding and is unable to respond since the appropriate coping response is not available (Cohen & Wills, 1985). The individual's ability to cope with stress is usually not compromised by a single event and the demands associated with it, but rather by persistent and ongoing events and demands— such as the role of caregiver in an institution— that overstrain personal coping resources and problem-solving capacities (Cohen & Wills 1985; Ryan 2001). Stressors can range from minor annoyances to fairly major pressures, problems, or difficulties (Kanner, Coyne, Schaefer, & Lazarus, 1981).

In the literature, two types of stressors are distinguished, namely primary and secondary (O'Neill & McKinney, 2003; Pearlin, Mullan, Semple, and Skaff, 1990). Primary stressors arise from the actual day-to-day care tasks (e.g., managing challenging behaviour, and bathing, feeding, or dressing care recipients), the number and intensity of caregiving activities, role overload, and the perception of being coerced into caregiving due to needing work or money. Secondary stressors are spillover effects from the primary caregiving role, and include marital disharmony, stress in own family relationships, exacerbation of family conflicts and issues with occupational roles.

Caregivers are also not impervious to other "ordinary" life stressors and strains outside of their caregiving roles (e.g., personal bereavement, or house or work relocation). Based on the transactional view described above, caregiver stress can be defined as the result of a cognitive imbalance between the perceived nature of the demand and the perceived capabilities of the person (Hunt, 2003; Nolan, Grant, & Ellis, 1990). Caregiver stress is thus

experienced when life events, caregiving roles, self-concept, and coping mechanisms, together with the presence or absence of coping mechanisms and social support, come together to form an environment that challenges the caregiver's capacity to adapt to the situation.

Despite a stressor being perceived as a challenge or a threat, theory suggests that coping strategies employed by individuals differ in accordance with the stressor type (Pearsall, Ellis, & Stein, 2009). Perceived stress can be defined as the extent to which situations in the caregiver's life are appraised as stressful (Cohen, Kamarck, & Mermelstein, 1983; Hunt, 2003). Lazarus and Folkman (1984) theorise that two critical processes, namely cognitive appraisal and coping, mediate the potentially stressful transaction between person and environment. These two processes will be discussed next.

2.6.3 Cognitive appraisal

Cognitive appraisal is viewed as an evaluative process in which individuals assess their environmental demands and determine whether it is threatening to their well-being, after which they appraise their resources for meeting the demand (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus & Folkman 1984). Oberst et al. (1989) define appraisal as caregivers' assessment of both the nature of the stressor and their resources for coping with it. The appraisal of a caregiving-related event as stressful will likely generate stress that may exceed the coping resources available to the carer (Pakenham, Chiu, Bursnall, & Cannon, 2007). The relation between the stressful events and outcomes may be altered by the cognitive appraisal processes and efforts to manage the situation (Ptacek et al., 2002).

Lazarus and Folkman (1984) furthermore distinguish between primary and secondary appraisal as important concepts in understanding how people cope with stressful situations. They elucidate these forms of appraisal as follows:

♦ Primary appraisal involves individuals' judgement of the situation as either irrelevant or harmful. The stressful situation is evaluated and the individual determines if the stressor is harmful, threatening, or challenging—a process that highlights the wide range of everyday situations that could potentially be stressful to an individual. An appraisal of harm means that damage has already occurred, whereas an appraisal of

threat refers to harm that will likely happen in the future. The concept of *challenge* refers to a condition of high demand in which emphasis is on mastering the demands and overcoming obstacles. In relation to the current study, caregivers decide through primary appraisal whether the stressor (e.g., caregiving duties) is irrelevant, benign-positive, or stressful. An encounter deemed to be irrelevant has no effect on caregivers' well-being and they consequently have no gain or loss from the outcome. A benign-positive encounter implies that positive results are possible. If caregivers appraise the stressor as stressful, it implies threat, challenge, or harm-loss. However, should caregivers decide that the circumstance does not imply any danger, the coping process is stopped. Events that are appraised as stressful, however, receive further appraisal.

♦ Secondary appraisal follows primary appraisal. The secondary appraisal is not only an evaluation of whether anything can be done, but also serves as an evaluation of coping resources (psychological and social) and the benefits and consequences of a particular coping strategy. This involves a determination, in other words, of which coping option will accomplish what it is supposed to do, and whether it can be applied effectively. Coping options are chosen as a result of the appraisal process and caregivers will then reappraise the situation in so far as coping strategies and resources are activated and the person-environment relationship changes. Short- and long-term outcomes are then determined by the coping options chosen.

It is worth noting that the sequence of influence between primary appraisal and secondary appraisal does not always present itself as one being more important than the other (i.e. primary vs. secondary), or that one always precedes the other (Lazarus & Folkman, 1984). Caregivers' perception or appraisal, particularly as it relates to the caregiving role, is what differentiates caregivers who exhibit adaptive coping from those who display maladaptive coping (Taylor, 2008).

What may be called a balance-tilting mechanism is operative in this appraisal process in that Perkins, Lynn, and Haley (2007) have noted that whereas high levels of stressors on the one hand can increase the likelihood of negative caregiver outcomes, high levels of resources on the other hand can help to decrease the likelihood of caregiver distress. In terms of Lazarus

and Folkman's (1984) model, it could be postulated that if a caregivers' colleagues should assist her in deciding that a situation is for example not necessarily threatening but indeed challenging, then stress can still be expected to result. However, should the caregiver believe that support is available at the institution, then perceived coping resources are increased and therefore any supposed threat associated with the stressor is less likely to be harmful.

2.6.4 Coping

Lazarus and Folkman (1985) define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Coping includes responding actions, a change in thinking, redefinition of the situation, or any other appropriate subjective solution, or anything else deemed appropriate by individuals after a primary and secondary appraisal (Lazarus & Folkman, 1984). Coping resources involve those aspects of individuals' environment—either external or internal—which are not directly or completely under their control (Shapiro, 1983). Such environmental aspects may be health and energy (a physical resource), utilitarian resources (socio-economic status, money), social networks or skills (close interpersonal relationships), general and specific beliefs (self-efficacy, mastery, self-esteem) and problem-solving skills (Folkman & Lazarus, 1979; Gottlieb, 1997; Jang & Haley, 2002). The activities or efforts chosen depend on the array of personal and environmental resources that individuals have at their disposal (Schafer, 2000). In other words, caregivers' evaluation of coping strategies are subjective in terms of whether there are coping resources and options available.

To return to the internal and external aspects of coping resources as identified by Lazarus and Folkman (1984), they categorise as *internal* the use of benign appraisals, sense of meaning, problem-solving skills, previous experience, personality, etc., and as *external* the effort to modify an environment appropriately, social support, money, etc. Internal resources are inherent within individuals themselves, whereas external resources are accessed by changing the environment or utilising assistance from others.

Lazarus and Folkman (1984; 1980) furthermore note that coping has two widely recognised major functions:

♦ The first function, termed problem-focused coping, is aimed at problem-solving or doing something to alter the source of the stress; in other words, managing the stressful situation. Although most stressors elicit both types of coping, problem-focused coping tends to predominate when people feel that something constructive can be done. Examples of problem-focused coping efforts include positive reappraisal, planful problem solving, accepting responsibility, as well as seeking social support.

♦ The second function, which is termed emotion-focused coping, is aimed at reducing or managing the emotional distress that is associated with the particular stressor facing the individual. Emotion-focused coping tends to predominate when people feel that the stressor is something that must be endured. Emotion-focused coping strategies include distancing, self-controlling, confrontive coping, and escape-avoidance.

Coping is also contextual, as it changes over time and across different stressful situations (Lazarus, 1993). Perceiving a situation as harmful and uncontrollable, and resources as being unavailable, promotes emotional-focused coping, while appraising the situation as less harmful and controllable encourages problem-focused coping (Lazarus & Folkman, 1984; Ptacek et al., 2002). Skarsater, Denker and Bergbom (2003) are of the opinion that most types of stress usually require a combination of the two types of coping. Caregivers may then use problem-focused coping when they feel that they can do something constructive to deal effectively with the stress. However, emotion-focused coping is utilised when the caregiver feels that the stress is overwhelming and unmanageable, and makes efforts to modify the distress that accompanies the stress by denying it.

In terms of coping, Folkman and Moskowitz (2000) reviewed evidence from their studies of AIDS caregivers, which helped to explain how individuals under chronic stress and those under essentially uncontrollable chronic stress sustain and create a positive affect. Here it should be mentioned that meaning-based coping processes of positive reappraisal,

problem-focused coping, and the infusion of ordinary life events with positive significance are of particular importance. Examples of meaning-based coping include using one's spiritual beliefs, re-evaluating the caregiving experience, and revising one's goals to regain purpose and control.

In terms of specific coping strategies, Folkman and Lazarus (1984) argue that the coping process and strategies selected are not inherently good or bad. Rather, it is proposed that the adaptive qualities of the coping effort should be evaluated within the context of the specific situation in which it occurred. A particular coping process may be successful within one context and not in another. Also, as the context of the situation is dynamic, what may be determined to be successful at the beginning of the process could turn out to be ineffective at the end.

2.7   CONCLUSION

In this chapter, I explored literature that supports the nature of this study. I further explored the transactional model of stress and coping as the vehicle for understanding how caregivers in a specific context, namely caring for orphaned and vulnerable children infected with and affected by HIV and AIDS in an institutional setting, experience stress and manage the stress outcomes emanating from the caregiving process.

In the next chapter, I will discuss the research paradigm, design, approach, and methodology associated with this study.

CHAPTER 3:
RESEARCH DESIGN AND METHODOLOGY

3.1   INTRODUCTION

In Chapter 2 I provided an overview of the theoretical framework that underpinned my research. In the current chapter, I discuss the purpose of this study and explain the paradigmatic approaches, as well as the designs and methods employed in gathering and analysing data. I conclude this section by justifying my methodological choices and their limitations. Thereafter, I outline the quality criteria followed to ensure that the study would comply with the necessary requirements for trustworthiness. The ethical considerations that I adhered to are also discussed.

3.2   PARADIGMATIC PERSPECTIVE

A paradigm is viewed as being "a set of assumptions or beliefs about fundamental aspects of reality which give rise to a particular world-view" (Nieuwenhuis, 2007, p. 47). Terre Blanche and Durrheim (2006) state that a paradigm is an all-encompassing system that defines for researchers the nature of their enquiry through three dimensions, namely ontology, epistemology, and methodology. In this research study, I applied a qualitative approach embedded in the interpretive paradigm—along the three dimensions of enquiry—as represented in Table 3.1.

Table 3.1: *Three dimensions of the interpretive paradigm*

INTERPRETIVE PARADIGM	
Branch of knowledge	**Dimension involved**
Ontology	♦ Internal reality of subjective experience
Epistemology	♦ Empathy ♦ Observer subjectivity
Methodology	♦ Interactive approach ♦ Interpretive approach ♦ Qualitative approach

3.3.1 Metatheoretical paradigm – interpretivism

To arrive at an understanding of the subjective world of human experience, interpretivists predicate their research approach on the need of human beings to assign meaning to various phenomena (Cohen et al., 2005; Nieuwenhuis, 2007). The interpretivist researcher, according to Bassey (1999), conducts research in order to advance knowledge by describing and interpreting phenomena of the world in an attempt to establish shared meanings with others.

An interpretivist paradigm was eminently suitable for this study because of its concern with individual participants, their experiences, and the meaning that they assign in particular to their experiences of stress. As Nieuwenhuis (2007) notes, the ultimate aim of interpretivist research is to provide insight into the way in which a particular group of people make sense of their circumstances. This objective is achieved by offering a perspective of a situation and analysing those aspects under study. In my employment of the interpretive approach, I set out to understand rather than explain caregivers' interpretations of the world around them. The implication for me as a researcher was that I embarked on an attempt to reconstruct or co-construct the reality (Manson, 2002; Schwandt, 1998) that I investigated, as viewed by the participants.

Interpretivist approaches provide rich, substantial, broad descriptions of issues and events by uncovering and capturing not merely *what* people think or feel or do, but also the *why* and *how* of their social reality. This is a particular advantage of interpretivism, since elements of this nature cannot be accessed by quantitative research (Denzin & Lincoln, 2003). Folkman and Moskowitz (2000), in referring to coping with stress-induced events, suggest that quantitative accounts usually only reveal superficial descriptions of experience and that narrative accounts offer more insight.

In this study, I interacted with the research participants by conducting research in collaboration *with* them and not *on* them—the latter being a risk pointed out by Schurink (2000). This approach offered me the opportunity as researcher to be involved in the social world of the research participants by making close contact with them and sharing in their "presence". Through focus group discussions and individual interviews, I was able to gain a better understanding of the stress experiences of these participants (Terre Blanche & Kelly,

2002; Babbie & Mouton, 2001). I relied on first-hand accounts relayed to me by the caregiver-participants in order to uncover the meaning that they attached to their experiences of stress and the manner in which they coped with it. A major objective of interpretivism is to build a coherent, holistic, contextualised image of individual experience, which, as a construct, may yet be subjective, complex, confusing, "messy" and contradictory (Creswell, 2003; Deetz, 1996; Mason 2002; Richards, 2005).

Every approach to social enquiry has its specific strengths and limitations. As a researcher, I had to recognise that all participants involved (including myself) bring their own unique interpretations of the world or construction of a situation to the research. Therefore, I had to be open to the attitudes and values of the participants or, more actively, defer personal prior cultural assumptions (Mackenzie & Knipe, 2006) where they might inadvertently lead to misapprehension. An interpretive paradigm recognises the self-reflective nature of the researcher, which entails interpreting the data and subsequently presenting the information (Creswell, 2007). I ensured that I maintained a contemplative stance on the interpretation of data and concentrated on understanding the meanings created by the participants during the data-gathering and analysis process.

3.3.2 Methodological paradigm – qualitative approach

I conducted this study from a qualitative perspective. Qualitative researchers collect information through spoken or written language, or by observations that are recorded in language, and analyse the information by recognising and categorising themes (Durrheim, 2006). Berg (2001) states that qualitative research refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things, but viewed in the context of seeking answers to questions by examining various social settings and the individuals who inhabit these settings. Denzin and Lincoln (2005) affirm these basic tenets in considering qualitative research to be the studying of phenomena in their natural settings and seeking answers to questions about the ways in which social experience is created and given meaning. In this study, the central phenomenon being explored was the caregivers' experiences within the setting of the institution where they worked.

Flick et al. (2004), in turn, summarise qualitative research very aptly as the description of life-worlds from the viewpoint of the people who participate in attempts aimed at

contributing to a better understanding of social realities and to draw attention to processes, meaning patterns, and structural features. Therefore, the approach of qualitative research with its aims of sharing in the understanding and perceptions of others, as well as to explore how people structure and give meaning to their daily lives, speaks to the purposes of this investigation. In the study, I sought to answer questions and gain an in-depth understanding of the caregivers' experiences of stress while caring for the children within the institution.

3.4   RESEARCH METHODOLOGY

Another crucial requirement for any research project is the selection of an appropriate methodology. In this section, I discuss the coherent group of methods that complement one another in order to convey the data and findings that will reflect the research questions and suit my research purpose (Henning et al., 2008). I discuss the type of research design that I followed, the reason for its selection, and possible challenges or limitations that may be involved.

3.4.1   Research design – case study

A research design "involves a set of decisions regarding what topic is to be studied among what population with what research methods for what purpose" (Babbie, 2007, p. 112). As such, it links with the description of Henning et al. (2008), who speak of research design as a "design type" (p. 36) that they view as the consideration of the methodological requirements of the research question and consequently of the type of data that will be elicited and processed.

I selected a single case-study design as it would allow me to focus attention on a specific aspect of a social phenomenon (Babbie, 2005) with the objective of capturing the circumstances and conditions of an everyday situation (Yin, 2003). Yin points out that a case study design is an "empirical inquiry" (p. 13), which is preferable when the object of the study is a contemporary phenomenon in a real-life context, while Stake (as cited in Schwandt, 2007) emphasises the aim of case studies to be the generation of knowledge of the particular. Yin also argues that research questions such as "What?" and "How many?" are best answered by survey research, whereas questions such as "How?" and "Why?" are appropriate for case study, history, and exploratory designs. My research questions

pertained to the latter type. One of the fundamental aspects of this study was exploring and understanding what elicits stress in caregivers and how they cope with it. Given the uniqueness of the situation, as well as the contemporary and real-life character of the context, the preceding criteria recognised by Yin (2003) and Stake (as cited in Schwandt, 2007) supported the use of a case study design in this research undertaking.

This case study aimed to gain an in-depth understanding of and insight into the life-worlds of the selected participants (Mouton, 2003). Interpretivist inquirers working with qualitative data share the assumption that people interpret events, contexts, and situations, and act on the basis of those interpretations. The assumption can therefore be made that there are multiple interpretations and perspectives on single events and situations. Moreover, events that individuals experience are unique and are therefore generally non-generalisable (Cohen et al., 2005). Employing a case study design allowed me to obtain a view of the participants' stress experiences as caregivers. I considered the unique life-world of the participants (Janesick, 2000) in an attempt to refine my understanding of their perceptions of their life experiences and the consequent meanings that they ascribe to them, which provided me with a frame of reference analogous to that of the participants being studied (Cohen et al., 2005; Fouche & Schurink, 2011).

In sum, the strengths of case studies facilitate the exploration, description, or explanation of a research topic in some depth and enhance the possibilities for the building of theory (Gummesson 2000). Furthermore, case studies allow for new ideas and hypotheses to emerge from careful, detailed observation (Lindegger, 1999). Despite the benefits of a case study design, the design also entails some challenges. One such potential limitation is that the findings will not be open for cross-checking, as biases and subjective decisions might play a role (Cohen et al., 2003). I attempted to address this limitation through member-checking (Janesick, 2000) through sharing my viewpoints and understanding with the caregivers involved in the focus group discussion and semi-structured interviews, requesting feedback from them on my understanding and initial interpretations. I tried to remain objective by reflecting and thereby expressing my awareness of my possible subjective opinions in my reflective journal. A further limitation of a case study approach according to Somekh and Lewin (2005) is that it is not possible to generalise statistically from only one case or a small number of cases to the population as a whole. The purpose of my study,

however, was not to formulate generalisations on the basis of the findings but to present the case and reflect the experiences of caregivers in an institution in order to arrive at a deeper understanding of the "matrix" of these experiences.

3.4.2 The research process

In the following section, I discuss the manner in which I sampled participants for this study, selected the method for data collection, and decided on the techniques for the data analysis and interpretation. Figure 3.1 outlines this process.
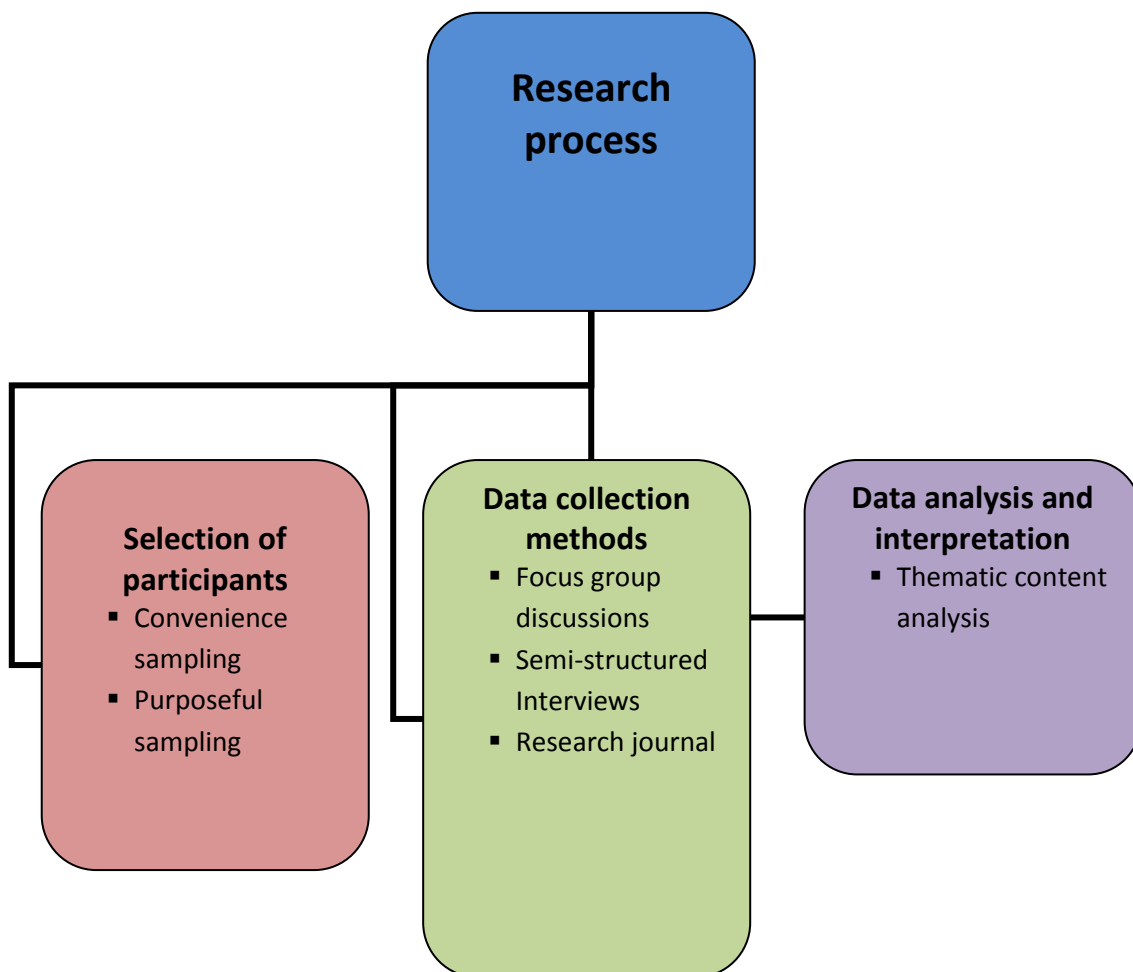
Figure 3.1 *The research process*

3.4.2.1 Selection of participants

To address the purpose of my research, I used both convenience and purposeful sampling. Initially, participants were conveniently selected for this study based upon their

participation in a broad research project[1] in which I had also participated as a fieldworker. Convenience sampling, also known as opportunity sampling, involves the selection of individuals who are easily accessible. This form of sampling was an appropriate strategy to use as it is usually selected for case studies. Moreover, since it does not seek to generalise about the wider population, the parameters of generalisability are negligible (Cohen, et al., 2005).

By utilising purposive sampling, I selected participants according to the criteria of their suitability, experience, availability, and willingness to participate (Creswell, 2003). This form of sampling is based entirely on the judgement of the researcher, and the sample is composed of elements that contain characteristics that are most likely representative or typical attributes of the population (Babbie, 2005; Strydom & Delport, 2011).

From those caregivers who participated in the original broad study, seven were purposively selected to participate in the focus group discussion (see Table 1.1 in Chapter 1). The sample was chosen for a specific purpose, namely to refine an investigation into the perceptional experience of caregivers of vulnerable and orphaned children in an institutional environment. From these seven participants, I purposively chose a further four participants to participate in individual interviews (see Table 1.2 in Chapter 1). These participants were selected because of their ability to communicate in English, their rich verbal participation in the focus group discussion, and their experience and involvement as caregivers.

All the participants were females in the age ranges of 35 to 59. Although none of the participants spoke English as a first language, the focus group discussion was conducted in both English and Sesotho with the help of an interpreter. The individual interviews were conducted in English since it served as *lingua franca* between the participants involved in this research project. (Relevant information pertaining to the research participants is outlined in Tables 1.1 and 1.2.)

3.4.3 Data collection

Mouton (2003) recommends that the researcher should focus on the participants and their worldviews when collecting data and should guard against the pitfall of imposing any

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[1] See Chapter 1, section 1.2.

preconceived theory, notion, or explanation on research material. Henning et al. (2008) consider research to be dependent on the researcher's ability to gather, analyse, and conceptualise the presented data, to which can be added the proviso of performing these actions "sensitively" yet "objectively" in terms of the interpretive approach. In the current study, the data needed to be presented in a manner, as recommended by Henning et al., in which the reader would gain a clear understanding of the research process.

I employed multiple data collection and documentation strategies, relying on methods such as a focus group discussion, individual interviews, and a research journal in which I recorded field notes and personal reflections. (See Table 1.3 in Chapter 1 for a summary of the different methods of data collection.)

3.4.3.1 Focus group discussions

Krueger (as cited in Greef, 2011) defines focus group interviews as "carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (p. 361). Focus group interviews have the potential to produce data-rich detail. They serve as a method of data generation that brings together a group of people to discuss a particular topic or range of issues (Schwandt, 2007). Typically, a focus group discussion consists of a small number of participants under the guidance of a facilitator or moderator (Berg, 2001). Focus group discussions address a particular topic of interest or relevance to the group or the researcher, or all of them. Since the participants interact with each other, the opportunity is created for their views to emerge more readily (Berg, 2001; Cohen, et al., 2005). According to Maree (2007), the goal is to hear participants' general perspectives and to ease them into a process whereby they debate issues actively. Such interaction among the participants according to Kvale (1996) "often leads to spontaneous and emotional statements about the topic being discussed" (p. 101). I regarded focus group discussions as an eminently suitable data collection strategy for my study, as I attempted to explore the experiences of stress of a group of seven caregivers working in an institution.

The main advantages and disadvantages of focus group discussions can conveniently be summed up in the differences between *sharp* and *narrow* focus, paradoxically being the two aspects produced by the same "lens". Regarding its main strength, focus group discussions

are *sharply* focused on a particular issue and, therefore, will yield insight and vital data that might not otherwise have emerged in the environment of a formally structured interview (Berg, 2001; Cohen et al., 2005; Hatch, 2002). They are economical in the use of time, producing a large amount of data in a short period, as compared with observations and individual interviews that tend to require protracted periods (Cohen et al., 2005; Hatch, 2002). Berg (2001) notes the following additional advantages associated with focus group discussions:

♦ they can be highly flexible;

♦ they permit observation of interactions;

♦ they allow researchers access to substantive content of verbally expressed views, opinions, attitudes, and experiences;

♦ they can produce speedy results;

♦ they place participants on a more even footing with each other and the investigator.

Sharp as the focus of these discussion groups may be, their main weakness on the obverse side is their *narrow* focal point in terms of extrapolation potential. As many researchers have pointed out (Berg, 2001; De Vos & Strydom, 2011; Denzin & Lincoln, 2003; Hay, 2005), the invariably limited number of participants causes the findings not to be readily generalisable to a wider population. It should also be taken into consideration that the group members' level of participation can be either very high or very low (Morgan, 1997). The latter was evident during the focus group discussions conducted in this study, which required ample probing during discussions and with preponderantly the same participants (four out of six) contributing to the discussion.

The focus group discussion lasted approximately two hours and was conducted on the premises of the care institution in Pretoria (see Figure 3.2 for an illustration of the setting). In view of my working under the aegis of a broad study, I was able to avail myself of the assistance of four fellow students as facilitators in the focus group discussion. As moderator, my responsibility was to elicit information from the caregivers regarding the manner in which they experienced stress. The informal group discussion atmosphere (Berg, 2001)

appeared to allow the caregivers an opportunity to express their opinions so freely and completely that they often became animated about a certain topic to the extent that they had to be redirected to the discussion on hand.

Figure 3.2: *Setting of the focus group discussion*

The focus group discussion was audio-recorded in order to produce a basis for the data[2] as recommended by Maree et al. (2007). Audio-recordings allow a much more comprehensive record than do notes taken during an interview, as the recordings can be transcribed later for close analysis. The recording done for this study was indeed transcribed; that is, a written account of what respondents said in conversation (Schwandt 1997) was typed out with the aim of preparing a record of the participants' own words. Field notes (Hay, 2005; Maree et al., 2007) and visual data in the form of photographs were used as secondary methods to capture the data collected during the focus group discussion.

3.4.3.2 Semi-structured interviews

The purpose of a qualitative interview is to obtain qualitative descriptions of the life-world of the participants (Kvale, 1996). One of the most important aspects of qualitative research is the assumption that the perspective of participants being interviewed is meaningful and allows them to express their experiences openly (Patton, 2002), which in the present study involved their experiences of stress as caregivers.

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[2] Appendix C

Individual semi-structured interviews were conducted after the focus group discussion with four of the participants to collect further information about the caregivers' experiences of stress. In conducting semi-structured interviews, researchers know the overall themes on which they wish to collect data but remain open to the unexpected, provided that it is broadly relevant to their research (Coles & McGrath, 2010). Producing an itemised schedule prior to the interview allowed me as researcher to contemplate the issues that might be encompassed in the interview and consider difficulties that could be encountered (Eatough & Smith, 2008; Greef, 2005). I was guided by open-ended questions focusing on the participants' points of view (Bryman, 2001), perceptions, and beliefs (Greef, 2011) about stress. The interview process was flexible, with the emphasis on how the participants understood issues and events, thereby allowing for a continuous process of engagement and the opportunity to gain rich, detailed answers (Bailey, 2007; Bryman, 2001; Greef, 2011).

The audio-recording of all interviews allowed me to concentrate on the topic and dynamics of the interview and ensured that the participants' answers were captured in their own terms (Bryman, 2001; Greef, 2011; Kvale, 1996). Audio-recording is preferable to taking notes as it decreases the risk of interviewer bias and ensures that complete data are available for analysis (Greef, 2005; Hancock, 1998). The recording approach also facilitated an easy flow in interviews since it allowed me to be more attentive to participants as I was not hampered by the distraction of having to take detailed notes. The audio-recordings were then transcribed to facilitate closer scrutiny and analysis[3] as suggested by Kvale (1996).

The utilisation of semi-structured interviews allowed for the integration of the interpretive paradigm (Bailey, 2007). This approach enables not only the researcher to investigate certain aspects or areas within the research scope, but also the participants to elaborate on their own experiences as caregivers and to make use of an "opportunity to tell their own story" (Smith, 2003, p. 57). During the interview process, I had to be scrupulously attentive to each participant since every response would inform the research topic at hand. Kaplan and Maxwell (2005) also explain that researchers need appropriate communication skills to

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[3] See Appendix D

ensure that the conversation is focused on the relevant topic. I therefore made use of my experience as an interviewer and relied strongly on my interviewing skills to make certain that I communicated effectively with the selected participants.

3.4.3.3 Research journal

In addition to the data collected by means of the focus group and individual interviews, I also generated field notes[4] in the form of a research journal during the course of the study, which were included as an additional data source. Although the interviews were audio-recorded, the need for note-taking was not entirely eliminated (Patton, 2002). Delamont (2004) states that it is vital that researchers record what they see, usually in the form of field notes, but that this may also be done in audio format or film "because anything not recorded is lost" (p. 235). Mouton (2003) proposes that researchers keep a record— in the form of field notes—of their data collection activities and of the main decisions and events as the research unfolds, in order to compile a record of the research proceedings. Greef (2002) explains field notes as the written account of things the researcher sees, experiences, and thinks about in the course of the interviewing. Schwandt (1997) views field notes as raw data consisting of notes made in the field based on observations and conversations, lists of terms, and rough diagrams and charts, for example.

For the purpose of this study, I used field notes to inform the transcription process of the focus group discussions as well as the individual interviews. The field notes were continuously compared with the transcripts in order to increase the accuracy of the transcripts. Henning et al. (2004) recommend that verbatim transcripts be supported with the field notes of the researcher's experience in the interview.

3.4.4 Data analysis and interpretation

Data analysis according to Mouton (2003) entails "breaking up" (p. 108) the data collected during fieldwork into manageable themes. Cohen et al. (2005) describe data analysis as "making sense of the data in terms of the participants' definitions of the situation, noting patterns, themes, categories and regularities" (p. 147). Analysis of the qualitative data of this study is seen as the process of making sense of the raw data by observing patterns,

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[4] See Appendix E

interpreting such patterns to discover concepts and relationships, and then organising them to arrive at the formulation of substantive findings. Figure 3.3 depicts the analysis interpretation process.
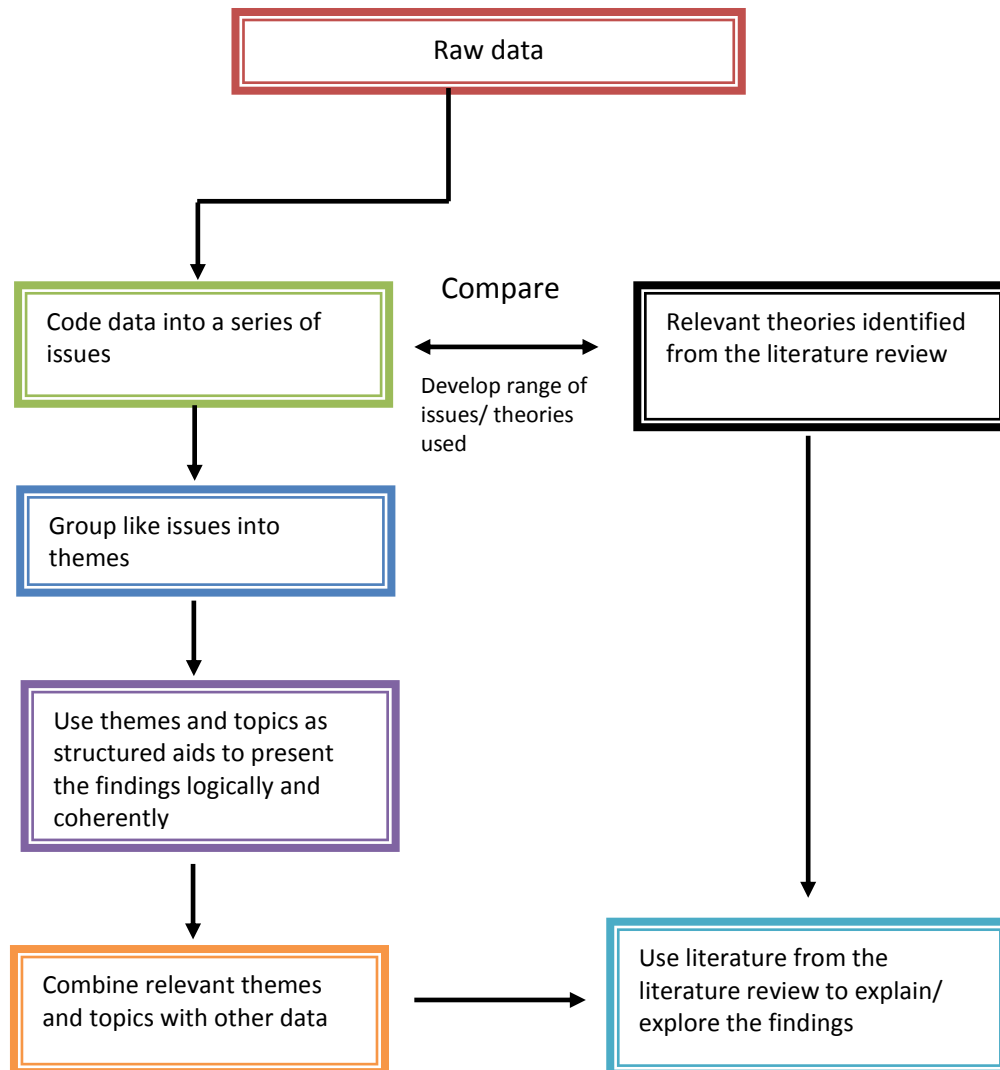
Figure 3.3:   *Data analysis and interpretation process*

For the purpose of this study, I conducted a thematic content analysis in view of its being "a descriptive presentation of qualitative data" (Anderson, 2007). In Milward's (2006) view, qualitative content analysis tends to be more subjective and less explicit about the processes of interpretation, placing emphasis more on meaning than quantification. My data analysis focused on the participants' subjective experiences and perceptions, and their

understanding of stress experienced as care workers in an institution for vulnerable and orphaned children. By implementing thematic analysis, I was able to search for key words, meanings, and themes that emerged as important to the description of the phenomenon (Cohen et al., 2005; Babbie & Mouton, 2001).

The advantages of using content analysis in this study are that this method is accessible, flexible, and relatively uncomplicated to understand and utilise for the novice researcher in the field of qualitative research. Furthermore, the result of the content analysis offers easy comparison with other studies that are undertaken within a similar framework (Braun and Clarke, 2006; Wilkinson, 2003).

In this study, I chose to use the method of Braun and Clarke (2006) (see Figure 3.4) to complete the thematic content analysis, because it was found to be well organised, clear, and suitable for answering the research question. Braun and Clarke (2006) state that analysis is not a linear process, but is instead a recursive process in which the researcher can move back and forth as required throughout the phases.

During the first phase, I familiarised myself with the data by transcribing the audio-recordings. Initially I experienced this process as time-consuming and burdensome, but soon came to realise its value in acquainting me with the specifics of the research material (Riessman, 1993). I immersed myself in the data that I collected by first reading through the entire data set with the purpose of stimulating the formation of potential ideas and patterns. I reinforced this process by repeated re-reading aimed at marking ideas for coding, as well as searching for meanings and identifying emergent themes and patterns that would contribute to organising the data (Braun & Clarke, 2006; Kelly 2002; Wells, 2007).

Once I had familiarised myself with the data, I embarked on Phase 2 of my analysis. This entailed deriving codes from the data by way of identifying as many potential features of the data that that could be assessed in a meaningful way with regard to the study at hand (Boyatzis, 1998; Braun & Clarke, 2006). My literature review served the purpose of informing the process of identifying and coding meaningful pieces of information (Ryan & Bernard, 2000). I coded the data during a systematic line-by-line scrutinisation, which aided me in identifying significant aspects that formed recurring ideas, patterns, and concepts

(Braun & Clarke 2006). Afterwards, I consulted with my supervisor about the process followed up to that point[5]

Phase 1

Familiarising yourself with the data

Transcribing the focus-group discussion and semi-structured interviews. reading and re- reading the data, making notes of intial ideas

Phase 2

Generating intial codes

Coding interesting aspects of the data in systematically accross the data set , grouping data relevant to each code

Phase 3

Searching for themes

Grouping codes into potential themes, collecting all data relevant to each potential theme

Phase 4

Reviewing the themes

Reviewing the themes to ensure they work in relation to the coded extracts and the entire data set

Phase 5

Defining and naming themes

Ongoing analysis to refine the particulars of each theme, generating clear definitions and names for each theme

Phase 6

Producing the report

Final analysis, selection of extract examples, relating the analysis back to the research question and literature

Figure 3.4: *Phases of thematic analysis (Braun & Clarke, 2006)*

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[5] See Appendix F

Having completed the initial coding of Phase 2, I moved on to Phase 3 of my analysis. During this phase, codes that revealed a similarity in meaning were organised into larger units. This merging operation continued until virtually all the codes had been "clustered" satisfactorily. At this point, I was able to consider how the various code groupings might be interpreted in order to arrive at the formulation of overarching themes (Braun & Clarke, 2006). A theme, according to Braun and Clarke, "captures something important about the data in relation to the research question, and represents some level of *patterned* response or meaning within the data set" (p. 10). The interpretive analysis of the data could be initiated during this phase (Boyatzis, 1998) of my analysis, and concepts about the phenomenon of caregivers' stress experiences began to emerge more clearly.

Having devised a set of themes, I proceeded to Phase 4, which entailed a review and a refinement of the individual ones. In view of Braun and Clarke's (2006) dictum that clear and identifiable distinctions should be evident between themes, I conferred with my supervisor to decide on the research validity and viability of each theme, for example whether a particular theme could be justified as sufficient unto itself or revealed discrete elements indicating the necessity of a further thematic division.

The identification and review of the themes facilitated the analysis of their appropriateness of "fit", after which Phase 5 of naming and defining them could continue. I identified the main narrative or "story" of each theme and considered the particular aspect of the data that the theme captured. I also concentrated on identifying any potential subthemes within each theme, since these could be useful in providing structure to and demonstrating hierarchy of meaning within the data (Braun & Clarke, 2006). At this stage, I had to consider appropriate designations for themes, bearing in mind the guidelines by Braun and Clarke (2006) that, in the final analysis, designations or nomenclature for themes had to be concise and immediately provide the reader with a sense of what a particular theme signified.

Phase 6, the final one of my analysis, namely producing a report on my findings and reviewing the results, concluded my thematic analysis. I shall discuss these results in Chapter 4.

3.5   MY ROLE AS RESEARCHER

My intent as researcher in this study was to arrive at meaningful and insightful descriptions of the stress experiences of participants in their working world as caregivers to orphaned and vulnerable children. I strived as researcher, within an interpretative field, to be an active participant throughout the process of data collection (Wimmer & Dominick, 2000). I was responsible for all data collection and analysis. I fulfilled the role of interviewer whereby I conducted a focus group discussion and semi-structured interviews to explore the experiences of the caregivers. This entailed that I as researcher formed a dynamic part of the data as my subjectivity also played an important role in view of my functioning as the instrument of data generation in the research process (Cohen et al., 2005). Stiles (1993) states that in qualitative research, the researcher develops a relationship with participants and is purposely subjective; however, as researcher, my biases and beliefs needed to be made clear and I needed to keep them in mind. By making use of member-checking and my research journal, I attempted to reduce bias in this study.

3.6   ETHICAL CONSIDERATIONS

Strydom (2011) defines ethics in a research context as "a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students" (p. 114). Whenever human beings are the focus of investigation, the implications of what researchers propose to do must be looked at closely (Leedy & Ormrod, 2005). During the study, I gave thorough consideration to all the issues of informed and voluntary participation, participant anonymity, researcher deception, and the consequences of the study.

Consideration of such issues necessarily involved a form of self-scrutiny in my role as researcher and my personal attitude to the question of ethics and ethical conduct. My set of moral principles in terms of Strydom's (2011) definition first involved a fundamental respect for other human beings in whatever capacity I encountered them, *inter alia* in the various main research-role categories identified by Strydom.

3.6.1 Informed consent and voluntary participation

Accurate and complete information must be conveyed to participants so that they are able to comprehend the investigation fully and make a voluntary, thoroughly reasoned decision regarding their participation in the study (Strydom, 2011).

Participants in this study were made aware of the goals of the research and the procedures to be followed. The credibility of the researchers was rendered to the participants by familiarising them with the researchers' credentials. Participants were informed that if they agreed to participate, they would have the right to withdraw from the study at any time and that participation in the study was voluntary.

The caregivers were given an informed-consent declaration describing the nature of the research project as well as the nature of their participation in it. By signing this form, caregivers granted their written, informed consent to participate in the broad research study, of which this proposed study formed a component (see Chapter 1, section 1.2). Special care was taken to ensure that explanations of the process were also provided to participants in their mother tongue via the services of an interpreter. The participants were furthermore given the opportunity to ask for clarification of any matters not entirely clear to them.

3.6.2 Anonymity, confidentiality, and privacy

To protect the participants from potential harm, I considered anonymity, confidentiality, and privacy throughout the duration of my study (Berg, 2001). Participants had the right to expect that when they granted their permission to be observed and interviewed, their confidences would be protected and their anonymity preserved. Anonymity involved keeping the identities of the participants undisclosed (Babbie, 2005; Berg, 2001; Creswell, 2007), whereas confidentiality entailed not revealing to any unauthorised parties the specifics of what was seen or heard (Glesne, 2006).

The study respected the participants' right to privacy and they were informed about their entitlement to this from the outset. Under no circumstances was the research report presented in such a way that others would become aware of the manner in which a particular participant responded or behaved.

3.6.3 Deception

Deception occurs when the researcher intentionally misleads subjects by way of written or verbal instructions, the actions of other people, or certain aspects of the setting (Neuman 2000). Regarding the operative term "intentionally", it should be noted that (2011a) draws a distinction between deliberate deception and deception of which the researcher was not aware (which may be termed unwitting deception). To avoid the pitfalls presented by unwitting deception in the present study, care was taken to discuss unforeseen incidents, circumstances, or developments with the respondents during or immediately after the debriefing interview. In respect of this ethical consideration, too, I made a conscious effort to forestall any potential of deception from the outset by informing the participating caregivers about the goals and procedures of the project, and reminding them that their participation in this study was voluntary.

3.6.4 Consequences

The consequences of a study need to be addressed in particular with regard to any possible harm to which participants may be exposed, but also with respect to the benefits that they may derive from their participation. Researchers should not harm their participants and the risk of harm should be minimised (Brinkmann & Kvale, 2008; Marczyk, 2005). During the course of this study, every effort was made to avoid any physical or psychological harm to participants. In a more positive vein, they were made aware of potential benefits by mentioning to them the psychological advantages that could arise through discussing repressed feelings and thoughts in an open interview setting.

3.7 QUALITY CRITERIA

Every qualitative-approach researcher should be concerned about validity and reliability when designing a study, and consequently analysing or judging its quality (Patton, 2002). Trustworthiness is of prime significance in qualitative research (Maree, 2007). Therefore, it was of utmost importance that I as researcher could vouch for and ensure the trustworthiness of this study by demonstrating quality, rigour, and accountability in the scientific research processes in which I engaged.

3.7.1 Credibility

The goal of credibility according to Schurink, Fouche, and De Vos (2011) "is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described" (p. 419). In addition to this requirement of establishing exact parameters of delimitation and investigation, it should be evident, as pointed out by Huberman and Miles (2002), that researchers were not engaged in fabricating or distorting what they had seen or heard—in other words, adhering to irreproachable standards of ethical observation and reporting.

Credibility in this study was achieved by ensuring that the thoughts, ideas, perceptions, emotions, and experiences expressed by the participants were accurately portrayed, thereby connecting with the interpretive approach of the study. This study strived to provide a candid description of care workers' experiences of stress, which implies that scrupulous identification and elucidation had to be applied.

3.7.2 Transferability

Results or conclusions are not always generalisable to the broader population in qualitative research (Terre Blanche & Durrheim, 1999). Transferability of results in qualitative analysis relies on the resemblance of the original context of the study to the context to which results are to be transferred (Lincoln & Guba, 1985). In view of this premise, context is of necessity central to validating the transferability of research results. It proves, indeed, that findings from qualitative research can rarely be transferred *directly* from one context to another since so much is dependent on the similarities of such contexts (Mackey & Gass, 2005). In this regard, I as researcher am fully aware of and acknowledge the context-specific features of this study.

Thick descriptions were used as a method of reporting; that is to say, multiple perspectives were employed to explain insights collected from the study. Mackey and Gass (2005) have observed that if researchers report their findings with sufficient detail for the audience to understand the characteristics of the research context and participants, that audience will be able to evaluate whether the study could be appropriately transferred to their particular setting. Although only a single institution served as a research source for investigations in

this study, the depth or "thickness" of data from the focus group discussions conducted with participants was enhanced by means of information garnered during four individual interviews. (This "cross-referential" or triangulation aspect also has relevance to dependability, which is discussed in the next section.) Thus, the multiple cases used in this study added to the external validity—and consequently the transferability—of the results, in accordance with the technique recommended by Mertens (2005).

3.7.3 Dependability

Research is considered dependable to "the degree to which the reader can be convinced that the findings did indeed occur as the researcher says it did" (Terre Blanche, Durrheim, & Painter, 2006, p. 93). In terms of dependability, the aim is to characterise fully the research context and the relationships among participants through rich detailed descriptions showing how actions and opinions develop and are rooted in contextual interaction (Mackey & Gass, 2005; Terre Blanche et al., 2006).

In using triangulation of the data that I collected by means of focus group discussions and individual interviews, I was able to produce rich detailed and descriptive data pertaining to the research question. This links to the interpretive approach of the study, which was aimed at exploring and understanding the personal meanings assigned by participants to their experiences in a particular context, and not at generating data to test or prove hypotheses. As an interpretive researcher, I was aware that I was not investigating a stable and unchanging reality and, consequently, that the results of a study of this nature, as noted by Terre Blanche et al. (2006), could not be expected to be found repeatedly.

3.8   CONCLUSION

In this chapter, I discussed in detail the research design, paradigm, and methodology that I employed during my study. I justified my methodological choices in terms of discussing advantages and disadvantages as well as suitability for this study. I also discussed both ethical considerations and quality criteria applied.

Chapter 4 will be devoted to the results of the study. Furthermore, I will situate the findings within relevant literature on this topic in accordance with the conceptual framework guiding this study.

CHAPTER 4:
REPORTING THE RESULTS AND DISCUSSION OF FINDINGS

4.1   Introduction

The current chapter encompasses a presentation of the research findings of this study with a view to formulating an answer to the main research question: "How do caregivers working in an institution caring for orphan and vulnerable children experience stress?" Themes and subthemes salient within the data were identified during the thematic content analysis process. These themes, which were formulated on the basis of the information and knowledge obtained, revealed the underlying meaning of the accounts of the participants. Where necessary, I have made use of direct quotations to add rigour to this study, as well as to support and substantiate the themes identified from the participants' responses. I guarded against the danger of predetermining themes (that is, to project preconceived ideas and notions on data and research material) by allowing them to unfold as I engaged with the transcripts in my research. I then discuss my findings, situating them in terms of the literature study that I conducted, and conclude the chapter by revisiting the theoretical framework (as addressed in Chapter 2) and providing a summary of the findings.

4.2   Presentation of results and findings of the study

Several themes could be formulated from the analysis of the raw data, which were then clustered into three main groups with their related subthemes. These main themes, subthemes, and further categories and criteria, as presented in Table 4.1, are explored in detail for the purpose of data analysis and interpretation in this study.

Table 4.1: *Themes and subthemes on caregivers' stress in an institutional environment*

Theme 1 Contextualising caregiving as a working milieu		
Subtheme	**Inclusion criteria**	**Exclusion criteria**
1.1 Caregivers' motivation for involvement in caregiving	Reasons provided by caregivers for choosing caregiving as a profession	Reasons that do not pertain to caregivers' decision to become a caregiver

Theme 1		
Contextualising caregiving as a working milieu		
Subtheme	**Inclusion criteria**	**Exclusion criteria**
1.2 Caregivers' views of their formal role in institutions	Role of a caregiver within an institution caring for orphaned and vulnerable children	Role of a caregiver in settings outside of an institution
Theme 2		
Stress viewed through the eyes of caregivers		
Subtheme	**Inclusion criteria**	**Exclusion criteria**
2.1 Manifestations of caregiver stress	Caregivers' understanding and views of stress and the symptoms associated with it	Views and symptoms that do not include those associated with stress
2.2 Challenges faced by caregivers	The stress experienced by caregivers caring for orphaned and vulnerable children in an institutional setting	The stress experienced by caregivers outside of that of their caregiving role in an institution
Theme 3		
Coping with stress		
Subtheme	**Inclusion criteria**	**Exclusion criteria**
3.1 Religious beliefs	Prayer and belief in a higher power as a coping mechanism used by caregivers in overcoming stress	Internal coping and other external coping mechanisms utilised by caregivers in coping with stress
3.2 "Lean on me"	External support experienced by caregivers that aid in coping with stress	Internal coping and other external coping mechanisms utilised by caregivers in coping with stress
3.3 Internal coping	Internal coping mechanisms that caregivers utilise in coping with stress	External coping mechanisms that caregivers utilise in coping with stress

The themes set out above hinge on two broad approaches that were utilised for clustering them. The first considered the factors that might aggravate or alleviate stressors in caregiving as a work environment within the milieu of an institution. The second considered the coping strategies that caregivers cultivated in relation to these experiences. Together the themes provide a holistic understanding of the stress experienced by caregivers situated within an institutional context.

4.2.1 Theme 1: Contextualising caregiving as a working milieu

The first theme that could be clustered from patterns in the data related to placement or localisation in a caregiving environment; in other words, the reasons provided by participants for becoming involved in this particular working context or choosing it as a profession. This theme, furthermore, explores how participants construct their role of caregiving in an institution for orphaned and vulnerable children.

4.2.1.1 Subtheme 1.1: Caregivers' motivation for involvement in caregiving

This subtheme explores the reasons for participants having chosen a career or profession in caregiving at an institution. Most of the participants indicated that they began working as caregivers because they had a love for children and considered themselves to have an ability to care for them. Interviews yielded the following relevant responses (quoted verbatim throughout this study, with parenthetical clarification where necessary):

> "It's because if you love kids, that's why you come to work. There are so many work [other jobs] which we can do, but because you love kids that is why we are here" (FGD, P1: 60–62)[6]

> "Now, I've realised that I've got this thing of [for] working with kids because even at church I am a Sunday school teacher . . . I have this thing of [for] kids so I started working with kids" (FGD, P4: 158–159/160–161).

> "I'm quite sure, some of them [caregivers at the institution] have worked for so long here, because of the love of kids. You see, if you don't love the child you can't even stay for five years, you can't stay for six years [will not last so long in this type of employment], but some of us we've stayed here for five years" (FGD, P1: 578–583).

> "And what pushes [encourages] me to work with the kids is that I just realised [was aware] I have this ability to work . . . or potential to work with kids" (Indiv Int 1: 280–282).[7]

> "Yes I enjoy working 'cause I like the kids" (Indiv Int 3: 14).

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[6] The abbreviation *FGD* stands for "Focus Group Discussion" (the source of the extracts), and *P1* for the particular participant in the focus group. The numbers after the colon represent the line numbers in the transcription pages.
[7] *Indiv Int* is an abbreviation used for "individual interview", followed by the number of the interview and the line number where it can be found in the transcription.

For the majority of the participants, the choice to work as caregiver appears to have arisen from a strong altruistic drive, and their love or passion for the well-being of children. It is clear that the caregivers were initially motivated and driven by an awareness of what they considered to be a talent (e.g., "I have this ability"; "I've got this thing"; "potential to work with kids"), and from this formed a vision of working with children in a spirit of dedication (e.g., "love of kids"; "thing of [for] kids"; "why you come to work"; "working with kids"; "stayed here").

It is also evident, however, that in contrast to the positive tenor of caregivers' responses about their original motivation for deciding on their particular profession, they had in the course of time become aware of an incongruity between their early positiveness and a current sense of indifference. This dissonance in feelings was so strongly apparent that I could record the following impression in my Researcher Journal:

> Towards the end of the discussion, it became clear that they [caregivers] do not derive much joy from their work environment anymore and that they are just there for the sake of having a job and some sort of income (Researcher Journal, 3 Sep 2010: 25–27).

Several of the caregivers expressed disillusionment in sentiments similar to "It [doing caregiving work] ends up not being with love now" (FGD, P2: 1277–1278), and "We just sacrifice ourselves to come and work. That love [dedication we used to possess] is no longer in us now, it's just because we've got something [a job] to do" (FGD, P4: 1313–1346). The participants appeared to feel trapped in their jobs and role as caregivers, as expressed in the statement that "I'm just working for the sake of working" (Indiv Int 1: 445–446), due to a lack of alternative job opportunities and the need to care for their own families, as the examples below illustrate:

> "Mostly, if I can say, we're coming to work, but everybody's wishing to get another job and go [elsewhere]. It's just, now, you can't find the [new] jobs easy [easily], but everybody's wishing to get the job [a different job] somewhere" (FGD, P8: 1606–1609).

> "Sometimes it is because we have our own needs, it ends up not being [at the workplace] with love now. It ends up with just . . . going to be there [at the workplace and doing my job], because I've got this and this and this and this [private responsibility]. Like, on my side, I've got five kids to put bread onto the table. And you know, if I'm just going to decide now

that this is too much for me, [that] I can't carry on living like this, what about those five kids? They need bread every day. What would happen about my life? Because you see, now, it's difficult to find a new job. So you just come with [hold onto] this [hope], ah, maybe today it will be better. On the other hand, you are thinking about the other people who are on my side [dependants], who are relying on me to put something on the table" (FGD, P4: 1277–1292).

"I have children; what if I leave the job today? My children, what is going to happen to them? So it's no longer love [for my work]; you just come [to the workplace]" (FGD, P8: 1310–1313).

The above responses reflect a sense of despondency among the caregivers that appears to border on depression. Escapism from current work circumstances is evident in phrases such as "to get another job and go [elsewhere]"and "everybody's wishing to get the job [a different job]". Demotivation to the point of despondency is mirrored in phrases such as "it ends up with just . . . going to be there [at the workplace and doing my job]" and "it's no longer love [for my work]; you just come [to the workplace]". A claustrophobic sense of being trapped can be read into phrases such as "you can't find the [new] jobs easy [easily]", "if I'm just going to decide now that this is too much for me, [that] I can't carry on living like this", "it's difficult to find a new job", and "it's no longer love [for my work]; you just come [to the workplace]". In general, this appears to lead to an attitude of perfunctoriness in carrying out tasks and fulfilling work requirements. Especially in the field of caregiving for orphaned and vulnerable children, a desultory, indifferent, and uninterested approach may give rise to a form of benign neglect and lack of proper nurturing.

Disillusionment and lack of motivation, especially as compared with earlier memories of being inspired and dedicated, and feelings of being trapped in a particular work situation may serve as a matrix for "nurturing" stressor elements. Farber (2000) warns that when the satisfaction derived from work is not sufficient to balance the stressors and is perceived to be inconsistent with the demands made of the caregiver, the results may be emotional and physical distress, ceasing to care, loss of motivation to work hard, and eventually burnout.

Burnout is defined in terms of three components namely, *emotional exhaustion*, which represents the basic stress dimension of burnout; *depersonalisation*, which represents the

interpersonal dimension of burnout that manifests itself in cynicism, apathy, withdrawal and detachment; and *reduced personal accomplishment*, which is evident in decreased efficiency at work, difficulty concentrating and increased irritation with colleagues (O'Neill & McKinney, 2003). When one takes into consideration these components and the responses of the caregivers towards their work, it could be inferred that it is not so much the lack of "love for the kids" but the stressors and associated burnout that have led the participants to feel despondent, apathetic, indifferent, and uninterested.

4.2.1.2 Subtheme 1.2: Caregivers' view of their formal role in institutions

The second subtheme provides insight into caregivers' view of their formal role in an institution. This understanding is essential in order to arrive at an adequate conception of the stress associated with being a caregiver. In coding the data gathered for this study, it became apparent that caregivers conceptualised their role preponderantly as being the routine activities in which they were engaged rather than the emotional subjectivity of providing care. Participants highlighted their caregiving role as follows:

> "Taking care of them [children], [involves] cleaning them, feeding them, taking them to the hospital, to doctors, giving them the medication, cooking for them during the weekends" (FGD, P8: 614–617).

> "We bath them in the morning, we give them breakfast. If there is someone who is sick, we take them to the clinics and the hospital. Things like that" (FGD, P6: 680–683).

> "We have to prepare uniforms for them, and lunch boxes" (FGD, P8: 792–793).

> "What . . . I first do when I come in the morning, I feed them, I bath them, feed them breakfast . . . Those who are going to school, I have to look that they are clean. Those who can't dress themselves, I dress them, I'm giving them food . . . Looking that everything is nice and clean when they are going to school. Those who are here [younger children], we look [whether they] are . . . clean because they also go to preschool to Mama X, so we have to prepare everything for them and then [at] eight o' clock we take them to Mama X. And then if maybe it's at night when they come from school, we must teach them [help with their] homework—those that didn't finish their homework—and sometimes we read Bible stories to them" (Indiv Int 3: 22–35).

From these commentaries, it appeared that the caregivers tended to take a strong practical view of their duties and activities in terms of routine daily activities such as hygiene, nutrition, medical care, and educational care. Since such activities are likely to predominate in an institutional setting, and particularly in view of the considerable numbers of children involved, it is possible that the caregivers' first thoughts about their role would focus on practical daily matters. Yet, other responses indicated that the caregivers were aware of the linkage between quotidian activities and the more subtle aspects of a parenting role; in other words, they also perceived and defined their role construct on the same tenets as that of a parental figure:

> "Meaning it's like a housewife, you know, housewife? Ja, doing everything, attending to the kids. Make sure that they have food. Make sure they are clean. Make sure they are going for checkups. Whatever else is going on in the house" (Indiv Int 1: 16–20).

> "I'm a mother: I have children, and these also are children. I treat them like my own children" (Indiv Int 3: 42–43).

> "We want to help them. Even if you are away from them, you feel that there is something that's missing, you're missing something" (FGD, P7: 898–901).

Although the first response above still reflects a strong predisposition towards a practical, workaday view, the repetition of the word "housewife" indicates a perceptual step beyond the formal caregiver role into that of "homemaker" and, consequently, a role with a more emotional denotation. In the second response, the participant fully accepts and steps into the mother role, which is underscored by the deep sense of concern expressed in the third response by the participant's intense emotional bonding with the children. In these three cases, it may be possible to discern three main levels of bonding commitment in different persons ranging from "housewife/homemaker" awareness to that of a maternal role, and from there to seeing beyond instrumental needs and a pseudo-parental role to a consciousness of deep-seated emotional commitment.

Discussion

As is pointed out in the literature, caregivers are considered to be the primary caretakers of the children under their care by attending to their physical, mental, and emotional needs

(Davies, 1995). Caregiving relates to the contextual and environmental factors that influence the conception of caregiving (Leira, 1994; Uren 2009). In a formalised view, caregiving can be considered preponderantly as a job and caregivers who assume this perspective can thus be depicted as significantly more focused upon the activities conducted than the emotional connection involved in their work (Uren, 2008). During the interviews conducted for this study, it became evident that the caregivers in the institution concerned fulfilled a role beyond the limits of routine, practical or "instrumental" caregiving, but also assumed what Mohangi (2008) refers to as a pseudo-parental role. Fyhr (2000) has proposed that since children living in residential institutions require the same kind of care as those living in families, the institution should become an "artificial family institution" where caregivers fulfil the parental role, thereby "providing physical care and a psychological parent-child relationship as well as a model of morally sound behaviour" (Fyhr, 2000, p. 62). This view correlates with the perception of the ideal role that the participants in this study had *initially* constructed for themselves, but which they had come to abandon in the course of time to assume a more formalised, routine view.

4.2.2   Theme 2: Stress viewed through the eyes of caregivers

It may be expected that individual caregivers will perceive their working environment in an individual way and consequently experience stress in a unique manner. However, it may also be expected that common salient points will be identifiable in these experiences and perceptions. This second theme incorporates the experience of stress in relation to the institutional context in which caregivers work in caring for orphaned and vulnerable children.

4.2.2.1 Subtheme 2.1: Manifestations of stress

The highly demanding nature of caregiving, in particular for orphaned and vulnerable children, places a considerable amount of stress on caregivers, compromising their health both physically and psychologically. In this study, many of the participants stated that they experienced headaches, a lack of energy and increased blood pressure as a result of working as a caregiver in an institutional setting. The following examples depict both the physical and emotional symptoms that the participants experience:

"Sometimes it is physical: you feel like you must [just take a] bath and [go to] sleep. I don't want to see anyone" (FGD, P5: 1028–1029).

"When I'm stressed too much, then my high blood pressure comes. My headaches started to be, eish, I don't feel all right. But what can I . . .[do?] I just take my medicine" (FGD. P8:1030–1033).

"If you feel stress, you can feel inside you[self that] today I'm not feeling well; maybe [a] headache or a pain somewhere, feel[ing] dizzy, [experiencing] tiredness. You feel like sleeping, be[ing] alone" (Indiv Int 2: 104–106).

"For me, maybe sometimes I'm stressed. I don't want to talk, nè, I'll just go to bed and sleep and I'll feel like now I'm sick. I don't feel all right. [It's] like I'm saying my heart, my blood pressure goes high; my headache is paining now. Ja . . . most of the time when I feel like I'm stressed, then my heart, blood pressure goes high very quickly, and then I hear that it is high, now my headaches start paining too much. Even if I can drink . . . [a headache pill] it won't stop" (Indiv Int 3: 236–243).

"I was helpless you know, like I didn't have energy, I felt like I can sleep" (Indiv Int 1: 901–902).

What is significant in the above responses is the common theme of lethargy and psychosomatic symptoms leading to avoidance behaviours in the form of withdrawal and a desire to sleep. The implication of this is that if caregivers find their own coping resources failing, or if they lack the energy to cope with their work surroundings, it cannot bode well for their primary task of caregiving to the vulnerable. It was apparent that some participants in this study was fully aware of this, as one remarked: "If I'm thinking too much and I'm having the headache, I won't [be able to] concentrate to [on the needs of] the children. Now [when] I'm with me [by] myself, [and when] I'm feeling pain . , . I say, I just say I want to go to the hospital or I want to go home because I'm not feeling all right, I'm sick" (Indiv Int 3: 351–355).

It is all the more ironic that the home, which should ideally be considered as a safe haven or harbour of refuge, can become "compromised" by the spillover effects of stress experienced in the work environment. Participants in this study appeared to experience a spillover effect in that their work stress was carried over into other spheres of their lives. This phenomenon

was discernible not only in the psychosomatic effects noted above, but also by behavioural symptoms within participants' home environment. Some of the caregivers experienced difficulty in separating work from home, as is echoed in their comments:

"I am going to shout [at] everyone here [I know that when I go home, I will shout at everyone]. They [my children] say, we are the children of me and my husband. We are not the children [at the institution], don't shout at us. We are not the children of [institution X]. I'll shout [at] everyone like I'm crazy" (FGD, P3: 1046–1050).

"Even me, I didn't use to shout, but these days I shout [because of] everything [that may happen] at my house. My children say, 'Why do you shout? You shout too much'" (FGD, P8: 1051–1054)

"One day my child said to me, 'Mama, since you are [started] working at [institution X], you are shouting at me.' I said, 'Whew, I am [so] used to shouting. I thought maybe I'm just talking'" (FGD, P7: 1060–1063).

"Sometimes we're angry, so you come home, you start shouting at innocent people, you know, [because of] that anger to you [within you], you see". (FGD, P5: 1450–1452)

"Sometimes when you're not shouting [do not wish to shout], you just come home, because of that thing happened here [something unpleasant happening at the institution]. You go home, you look sad and the children can see: 'Mommy what happened today?' I say [that] I don't want to talk to them, [but I feel that] maybe [I] just [want to] go there [somewhere] and sleep. They say, 'Come and eat food,' [but] you don't want [to]. The children they get worried now. Something happened at work. You don't want to eat, you don't want to talk to them. It affects them, they get worried: 'What happened?' They start worrying, you see" (FGD, P8: 1458–1468).

The above examples of pent-up work stress that is released in spillover at home reveal that such stress mainly appears to find expression in externalised, outwardly directed aggression through shouting at close members of the family. In the majority of these cases, the participants were aware of what they were doing ("you start shouting at innocent people"), but in one case the participant was not even consciously aware of the way in which she was behaving ("'Whew, I am [so] used to shouting. I thought maybe I'm just talking'"). Once again, a strong element of irony is present in this phenomenon, since caregivers who ideally

have to concentrate on a "mothering" or "homemaking" role at the institution display behaviour in their own home environments that their own children find disconcerting (e.g., "don't shout at us"; "you shout too much"; "you are shouting at me"; "Mommy, what happened today?"). In contrast to the majority of cases of externalised "stress release", one participant consciously avoided shouting but appeared to internalise her negative feelings, which expressed themselves in lethargy, loss of appetite, withdrawal from her children, and a desire to sleep (an escapism indicator). It is significant that the issue of sleep (the traditional metaphor for death, even though expressed unconsciously), was mentioned more than once by participants. In this context, such mentions serve to indicate the seriousness of feelings of despondency and depression:

> "Because this thing [problems], it becomes more emotional issues [so] that you don't feel like wake [waking] up some days" (FGD, P4: 1157–1163).

Rowe (2003) refers to society's "unrealistic expectations" (p. 17) of caregivers, which places great demands on them in their daily work environment. Being in the caregiving profession, caregivers often experience escalated amounts of stress (Khan, 2005). Studies have shown that caregiver stress may manifest itself in various ways and may lead to caregivers experiencing increased levels of caregiver burden, burnout, role strain and decreased psychological health and life satisfaction (Adams, Boscarino, & Figley, 2006; Figley, 2002; Fredriksen-Goldsen, 2007; Given et al., 2005; Mutiso et al., 2011; O'Neill & McKinney 2003). These phenomena were evident in the responses of the participants in the current study, which reflected stress experiences that were expressed in lethargy, withdrawal, various psychosomatic symptoms such as headaches and increase in blood pressure, loss of appetite, outwardly directed negative feelings (aggression), internalisation of negative feelings (depression), avoidance and escapism behaviours (depersonalisation), and so forth. These findings regarding physical and emotional symptoms in the current study corroborate those from other studies in which caregivers with similar symptoms were found to be experiencing burnout (Given et al., 2005; Evans et al., 2004; O'Neill & McKinney 2003; Maslach & Pines, 1977; Mutiso, 2011; Van Dyk, 2007).

As various researchers (e.g., Cohen & Wills, 1985; Folkman & Lazarus 1985) have noted, the ability of caregivers to manage stressful situations are influenced by their experience of

their particular situation as demanding or challenging. If caregivers feel that their health and energy are not at an optimal level, it makes it more difficult for them to cope effectively with stressors both primary and secondary resulting from the demands of their work (Lazarus & Folkman, 1984). The primary source of stressors, as identified by Pearlin et al. (1990), can be found in the day-to-day care tasks and activities ("formal" role) in which caregivers are engaged (as described in subtheme 1.2 in subsection 4.2.1.2). Secondary stressors result from the spillover effects from the primary caregiving role engaged in at the institution. These effects may include marital disharmony, stress in own family relationships, and issues with occupational roles. Pearlin et al. (1997) have used the term "proliferation" to describe the spillover effect of stressors from the work milieu into the home environment. Considering the definition of the word "proliferation" as "rapid reproduction or increase in numbers" (Soanes & Stevenson, 2004, p. 1148), one may note the feeling, as reported by several participants in the current study, of being overwhelmed at home by stressors originating in the work environment.

4.2.2.2 Subtheme 2.2: Challenges faced by caregivers

HIV and AIDS-related caregiving, especially to children, places unprecedented demands on the carers, since the breadth and intensity of problems with which they have to deal are unique. This phenomenon was aptly summed up by a participant who remarked: "But everything is stress, twelve months of the year" (FGD, P4: 1132–1133). Analysis of participants' responses revealed three broad categories of stress-inducing problems or subjective, personal challenges relating to:

- the institution's management aspects;

- maintaining discipline among the children;

- lack of authority as (pseudo-) parental figure.

Participants' responses on the institution's management aspects

It could be assumed that caregivers should be encouraged to perceive the institution and its management team, as well as aid from the national department, as a means of support and a buffer to the stress they experience. However, in this study, many if not most of the

caregivers voiced that this was not the case. Caregivers felt that they were not given the support that they needed in terms of training, advice or debriefing, as the following responses reveal:

"I can't say we [are] getting the support from management so much" (Indiv Int 3: 398).

"I don't feel that [we] get enough support. If you talk [complain] to the social worker [about] the children do[ing] this and that, they talk to the children, but you don't get to that point where you can say you can maintain them [manage their behaviour]" (Indiv Int 2:41–44).

"Ah-ah-ah, even [whether] you talk to the manager or social worker, they say [the] same: 'I will make a day to come talk with the children,' but they take a long time to come" (Indiv Int 2: 100–102).

"Ja, maybe even if I can talk to the social worker, she will tell you, 'No, do whatever is best for you'. On the other hand I must do what suits me, [yet] . . . if I . . . do something wrong to these kids, I'm the one to be blamed. So you see, I'm in between two things. I'm doing this one, I'm wrong; I'm doing this [that] one, I'm wrong. So I must sit with it. What must I do? So, that is why most of the time I just keep quiet" (Indiv Int 1: 200–207).

"So now I just 'uh ah' hands off, I can't, I can't really, I can't [cope with this]" (Indiv Int 1: 129–133).

"It's for my own baby [up to me] to go see what can I do" (Indiv Int 1: 85–87).

In the above instances, a sense of abandonment may be detected: the caregivers perceived themselves to be left to their own devices (e.g., "It's for my own baby [up to me] to go see what can I do"), burdened with responsibility, but not empowered to maintain order (e.g., "So you see, I'm in between two things. I'm doing this one, I'm wrong; I'm doing this [that] one, I'm wrong"). For example, it may be inferred that the carers are held responsible for children's (mis)behaviour, but are not permitted to address children themselves (e.g., "If you talk [complain] to the social worker [about] the children do[ing] this and that, they talk to the children, but you don't get to that point where you can say you can maintain them [manage their behaviour]"; "they say [the] same: 'I will make a day to come talk with the children,' but they take a long time to come"; "On the other hand I must do what suits me, [yet] . . . if I . . . do something wrong to these kids, I'm the one to be blamed").

In spite of an awareness of being caught on the horns of a dilemma ("So you see, I'm in between two things"), which may encourage a position of inertia ("So, that is why most of the time I just keep quiet"; "So now I just 'uh ah' hands off"), some caregivers also appear to be aware of solutions for such problems through improved communication strategies and mechanisms:

> "It is so difficult. I think maybe we need something like debriefing" (FGD, P4: 210–211).

> "No, they don't want to help us to take a meeting, to handle a meeting somewhere in the centre" (FGD, P4: 389–391).

> "So far we don't have any, any, any training. Nothing. Even at debriefing session[s] we don't have [any]. It's for my own baby [up to me] to go see what can I do" (Indiv Int 1: 85–87).

> "She [social worker] offers but one hour [of guidance and advice]. I think . . . it's not enough, especially because sometimes we have issues and they [the children] have this tendency of fighting with old people, these kids. So now I just 'uh ah' hands off, I can't, I can't really, I can't [cope with this]" (Indiv Int 1: 129–133).

> "I've never had any training; that's why I said I have my own way to it [have to find my own solutions]" (Indiv Int 1: 197–198).

Caregivers appear to be able to identify weaknesses and needs in the system (for debriefing, training, guidance and advice), but also the means to arrive at solutions (meetings, discussions). One participant in particular identified the great value of self-initialised seeking of peer support:

> "Maybe if there's somebody [a colleague] to share [problems with] and then maybe she can tell me. You know, if maybe we are cooking in there, she will advise me, 'No, man, you mustn't do this, maybe try this.' But with someone who's professional. Because this thing [problems], it becomes more emotional issues [so] that you don't feel like wake [waking] up some days" (FGD, P4: 1157–1163).

Discontent between caregivers and management, at least as seen from the viewpoint of the caregivers, was highlighted throughout the interviews. There were strong indicators that management and the caregivers were not communicating well, as may be gathered from

the responses already quoted above. Additional responses in this respect were the following:

"We don't discuss the issues, they tell us [merely inform us about them]. The board members, they don't even come [to see us]" (FGD, P8: 1661–1662).

"If you talk, they say they don't want to hear about that" (FGD, P2: 1669–1670).

"We are not allowed to talk. If you talk, then you are the enemy" (FGD, P8: 1676).

"If you can raise your hand and say I don't understand, you are now the target. You have got the attitude [displaying a bad attitude]. Seriously" (FGD, P3; 1680–1682).

"It feels bad. You want to say something and they don't want you to say it. You feel useless because your words are meaningless to them. Maybe I am going to talk something that is not useful" (FGD, P8: 1687–1691)

"Although sometimes you feel oh, you can't say anything because I am not educated. They are educated [and] that means I can't tell them anything. So maybe [even if] they are asking you a question, which looks like this [you get the impression that], they say you must not talk. When you talk, you are wrong" (FGD: P6: 1692–1697).

"But what is not good to us is the things which come from the Management. I think if the management can listen sometimes to what we want from them, then everything can be all right. But then many of the times, the Management does not get what we want. So it's difficult. And here, we don't strike. Even if we want something they don't give us, we just come to work. We can't strike. If you strike, you are fired. So we just come, even if it's difficult, we just come." (FGD, P8:1640–1650)

As perceived by the participants, a serious gulf—even to the extent of victimisation—appeared to exist between them and management (e.g., "If you talk, then you are the enemy"; "you must not talk. When you talk, you are wrong"; "they don't want to hear about that"; "you are now the target"; "If you strike, you are fired"). This challenge of authoritarian, one-sided communication as indicated by the participants seemed to be a major source of stress to them. The caregivers indicated that they were not awarded an opportunity to discuss their experiences, except during meetings held once a month. The caregivers indicated that at these occasions the management speak and they listen, too

apprehensive to air their opinions or voice any problems, which can only have a negative effect on their cognitive appraisal of the situation.

Neither do caregivers have any opportunity outside of these meetings to gather and share experiences: "No, they [management] don't want to help us to take a meeting, to handle a meeting somewhere in the centre" (FGD, P4: 389–391). The participants felt that such meetings were needed "because each and every one has a problem with the children" (FGD, P7: 400–401). Being able to discuss their feelings and experiences in a group format would give the caregivers a better understanding of how their colleagues cope and help to normalise their feelings.

During the collection of the data, it appeared from the participants' responses that most of them no longer derived satisfaction from their work, finding it stressful and demotivating. (Compare also the *Discussion* under subsection 4.2.1.1.) They seemed to display symptoms of despondency and demoralisation—that is, depersonalisation as discussed in subsection 2.5.2— because of being so overwhelmed and overworked that they viewed their work as merely another job:

> "I think there is no longer [any] good. We are now enjoying [experiencing only] the bad things. We are no longer enjoying it [our careers] for you can't enjoy it; [you] just [do your] work" (FGD, P6: 1517–1518).

> "We're no longer having [any] joy. Because if I can [may] say [so], there is nothing good here starting from [with] the pay; it's a problem" (FGD, P8: 1535–1537).

> "At first I do [did] enjoy working here, but now, things are becoming difficult and then you start to say, 'No, I think I'm on the wrong track. This is not what I want" (FGD, P6: 1549–1552).

> "There is nothing that I can tell you [that] I enjoy. As I'm saying, you know, if I can get the opportunity to quit, hey-hey–hey, I'm going to use it" (Indiv Int 1: 495–497).

It also became apparent during the focus group discussion and the individual interviews that the caregivers were dissatisfied with insufficient salaries. Several of them reported that they had been employed at the institution for a number of years without being granted any salary increase, having to live from month to month without being able to save:

"[A] problem otherwise: the problem that I'm having is the money I'm getting here" (Indiv Int 3: 94–95).

"It's not all right for me or for the years I've worked here and for the work I'm doing. They said I'm working all right [my work quality is acceptable], but the money they are giving me is not all right" (Indiv Int 3: 97–99).

"Because at end of the month I have to get my salary, and there are many things I want do. That salary is not going anywhere. It's not helping me with anything" (Indiv Int 3: 103–105).

"I don't earn not even three thousand, [but] two thousand seven hundred for [the last] thirteen years [working at the institution]. That one [particular problem] gives me too much stress. Because when I think, what is going to happen when [if] I [should] leave the job here? I'll [have to] go and stay at home without anything" (Indiv Int 3: 437–441).

They were, moreover, concerned about a lack of benefits. As two of them noted:

"And when you work with NGO there is nothing [are no] benefits" (Indiv Int 2: 257).

"NGO, they don't have money. Our many stress when today I say I'm leaving the job I won't go with anything here because we don't have pension fund only the provident fund here, and the money I'm getting is very little I can't manage to put to the bank [save]. When I go like today, I just go like this [leave in the same state as I arrived at this institution]. I don't have anything. That one is the thing I don't like about [name of institution]" (Indiv Int 3: 429–434).

This quandary of being unhappy in the work situation but having at least some measure of security, and consequently being afraid of risking any change, was reflected in the confusion expressed by one participant:

"Because everything you want here, you can't find it easy. It's either you want to go on leave, it's a problem, there's nothing. I don't know how to explain. Everything is difficult" (FGD, P8: 1553–1556).

Discussion

In the main, the problems experienced by caregivers (*as reported from their point of view*) in the "management aspects" category entailed the following:

- lack of adequate support by management as evidenced by a lack of guidance, advice and training;

- poor communication as evidenced in reported one-sided communication from management and lack of true dialogue with caregivers in proper meetings and debriefings;

- an authoritarian and even threatening management style displayed by management to the extent of giving rise to a perception of victimisation by caregivers;

- management's tendency to leave staff to their own devices, but placing them in a quandary by depriving them of the right and means to formulate and implement their own solutions to daily problems, thus in effect smothering any positive initiative among caregivers;

- loss of inner drive and personal motivation among caregivers, giving rise to a sense of despondency and purposelessness, which in turn may engender depersonal-isation;

- inadequate remuneration and benefits for staff.

The findings in this category correlate significantly with the strategy proposed by Van Dyk (2008) in preventing occupational stress and burnout among HIV and AIDS caregivers:

- a supportive working environment;

- professional supervision and mentoring;

- emotional support and therapeutic counselling;

- stress reduction and coping skills;

- ongoing training.

Van Dyk (2008) states that both caregivers and management should work as a team in order to address HIV and AIDS effectively in their interventions. This necessity was underscored by the responses obtained from participants during the current study, considering the

problems that arise when communication between management and caregivers is poor. Management will consequently remain unaware of the problems that caregivers experience and the challenges that they have to face, whereas the caregivers themselves will feel disregarded, even negated, and thus lose their initial motivation. As discussed in subtheme 2.1 in subsection 4.2.2.1 on the manifestations of caregiver stress, the literature indicates that positive and effective caregiving—as experienced by the carers—is commonly associated with career satisfaction and altruistic components of the caregiving process.

Meeting the participants' need for training and knowledge would provide them with the ability not only to manage the children under their care, but also to manage the emotional component of their work environment. This would provide the means for caregivers to understand and deal with the situation without being overwhelmed in the process. If provided with advice, training, and guidance, the caregivers may be able to utilise such reinforcement as a personal resource that they could rely upon for support and, at times, a sense of relief (Kramer, 1993). An additional important advantage would be the buffering of the effects of stress within caregiving and the institution through effective problem-focused coping.

Caregiver burden, as Frank (2008) has pointed out, can also be extended to social and financial problems. Regarding the social aspects, the findings from this study corroborate those of studies done in other countries, for example the United Kingdom, Ukraine, and Ghana (Castillo et al., 2012; CCETSW, 1992; Vashchenko, et al, 2002). The current study echoes in particular findings regarding caregivers' experiences of work difficulties involving management conflicts, lack of cooperation, little administrative or general support, an absence of respect, a general spirit of negativism, and lack of trust in the workplace.

In finding a bridging example between the social and the financial aspects of caregiver burden as identified by Frank (2008), one may turn to the failure in setting quality standards for residential child care, which the CCETSW (1992) ascribed to the failure of national and local government to provide appropriate salaries and conditions of service, and to fund comprehensive training programmes for caregivers. It may be considered a universal given that financial means and support are essential for survival, whether for an institution or an individual. At institutional level, as one participant remarked, "NGO, they don't have

money" (Indiv Int 3: 429–434). Lack of financial means at "macro" level will in all likelihood devolve downward to lack of financial support at "micro" level for employees, namely the caregivers. Especially within the community context and acknowledging the implications of the current South African economic climate and unemployment rate, this appears to impact on the emotional experiences of the caregivers. For the participants in this study, caregiving was a means of financial income. As illustrated by their comments, they considered this aspect of their jobs as one of the spheres which caused major additional stress within their personal lives and, therefore, on their abilities at work. Strongly motivational as altruism and personal dedication may initially be for caregivers, the pressures of financial burdens appear to have an equally strong corrosive effect on their sense of purpose.

Participants' responses on maintaining discipline among the children

Many of the participants in this study expressed feelings of uncertainty with regard to disciplinary matters and felt that they needed training in maintaining discipline (i.e., orderliness and good behaviour) among the children more effectively. Data collected revealed that discipline is an area in which caregivers felt unsupported by management:

> "Like when we used to go here [when we began working here], they [management] said we are [acting as] the parents; see to it that you discipline them [the children] in which way [you see fit]. Don't wait for a social worker. So, but if you can discipline them, they [the children] say you are abusing them, so we don't know where to go [what to do]" (FGD, P8: 1143–1148).

> "[A] child she is doing this and this and this [a child may be misbehaving]. The social worker will say, 'Ei, I don't know [what to recommend]. You are [acting as] the mamas [and] you must see what you can do,' [As for] me, these children—I'm tired with them [of their misbehaviour]. So if I take the problem to the social worker, it means I can't manage the thing that child is doing. So if she is saying, 'You can do what you want', but [my] doing this [what I think best, the] child doesn't understand. So I, I don't know what to do. I can't beat the child [or] they [will] fire me. So it's maybe [best] to just leave the child like that" (Indiv Int 3: 401–408).

It is significant that, in one instance at least, a participant's first thought about exercising discipline, in the given context, is to have recourse to corporal punishment ("I can't beat the

child"; "[but otherwise] I don't know what to do"). This is not to say that corporal punishment is in any way tolerated at the institution, but it does tie in with the perception of other caregivers who felt that they lacked the knowledge necessary to exercise discipline among the children appropriately and implement effective means of punishment. The children's attitudes towards the disciplinary measures used by caregivers left the participants helpless and frustrated:

> "I don't know what punishment I can give them [the children], because we don't allow to beat [any beating of] the child—we [are] not allowed [to do this], and maybe [if] you give them [the children] this [kind of] punishment, they say, 'No, why?' So, I don't know which punishment I can give the child. So, I don't know what to do now. I'm [be]coming stressed. I must leave the child like this, or what[ever]. So, I don't know what to do by that time now" (Indiv Int 3: 258–263).

> "They [the children] don't worry anymore about the punishment [being punished]. They say they are used to the punishment. They do something wrong, and then you say, 'I am going to punish you!' or 'I am going to beat you!' then they will [merely] dismiss you. They have got that mind [they think] that they are going to fire you [have you dismissed]. They know very well that you are not going to beat them" (FGD, P7: 412–419).

> "There is nothing that I can do, 'cause like I have said, this is not my own kids. There is no way. Even my kid at home I can punish her . . . but with this one [in the institution] I am trying, I am trying to punish [discipline] them. Most of the time I will take away from them [withhold] their pocket money, but they [are] used to it. They know [that] 'if I [the child] can just do this. She [the carer] will just gonna take my pocket money for [a] week and the next week life goes on [things carry on as usual with the pocket money being returned].' That's the way, and there is no way I can punish them. There is no way" (Indiv Int 1: 183–193).

As can be inferred from the above, the caregivers' sense of helplessness about exercising discipline or maintaining good behaviour among the children was exacerbated by the fear that the children would report them to the management for abuse in an attempt to escape the consequences of their actions. This stratagem of the children seemed to be fairly common:

> "Once you do something wrong, [the children say,] 'We are going to tell the manager' . . . So it is difficult: how are you going to punish these children?" (FGD, P8: 867–869).

"[I am too] scared even to tell the child [to] leave this [not to do something unacceptable], because she is going to scream and run downstairs to report you, and [whereas] you have done nothing wrong. And there they [managers] come [and ask], 'What did you do?' Sometimes they believe you, sometimes they say you're lying [and think that] maybe you beat the child" (FGD, P8: 1252–1258).

"Maybe, let's say [assume that] I've got something to say [to the children], to talk to them, say [for instance] if the child make[s] a mistake [misbehaves] and if we can [should] shout [at them], they say it's abuse. They [managers] are going to write a warning for [issue a written warning for the incident], you see. That makes me to stress, we can't [even] talk [to] them [the children] loudly, we can't. Maybe [even if] we can [only] say, 'Hey!' then they [the children] say you are naming [insulting] them" (Indiv Int 4: 65–69).

Responses such as these once again reflect situations in which caregivers find themselves in a quandary. They are burdened with the responsibility of maintaining orderliness and discipline among the children, but are not equipped with the necessary approaches to do so. The stress that the caregivers experience in such cases may result in a withdrawal response, which could culminate in a persistent feeling of indifference to their work and the children—typical of the manifestation of depersonalisation mentioned in subsection 2.5.2.

Participants' responses on lack of authority as (pseudo-) parental figures

Discussions with the participating caregivers yielded data that revealed a strong undercurrent of resentment from the children against their carers. This feeling, which manifested as a lack of respect particularly among the older children, arose from the children's attitude to the caregivers in their parental or pseudo-parental role particularly when attempting to maintain discipline. Participants reported feeling helpless, unwanted, and unappreciated by the children in their care, who used the caregivers' position of authority as a weapon against them:

"They don't respect us because we are not their parents or what" (Indiv Int 2: 17).

"This thing of saying like 'You're not my mother; you can't tell me this and that.' So it's very difficult. It's really, really difficult" (Indiv Int 1: 63–65).

"If they don't listen to me [and] if I [try to] talk to them, they make me upset. They make me feel like they don't respect me" (Indiv Int 2: 186–187).

"More especially, some of them, they do not appreciate things. Instead of appreciating, they will tell you a lot of hard words like 'You are not my mom'. Then you end up saying, 'If I am not your mom, I don't think I will [there is no need for me to] sacrifice my time to be with you.' Sometimes it is hurting because you are doing your best for them but some of them, they don't see [this]" (FGD, P4: 191–198).

"Because they have this, this like [habitual way] of saying, 'This is not my mother', because they use to [usually] tell me that 'you are not my mother, you are not going to tell me what to do'" (Indiv Int 1: 513–516).

"This is difficult. 'You are not my mother', [the child says to] the person who makes sure that she [the child] eats healthy, she, she, she gets everything; everything for her is perfect. [I] make sure that she gets everything . . . clothes and whatever, school things, whatever, but then at the same time she tells you, 'You know, you are not my mother.' You make sure that she takes her medicine on time, [that] she goes for checkups, give her whatever she wants, but then at the same time she tells you, 'You are not my mother.' The efforts that you are putting on [into] helping that poor kid, it seems like it is nothing—you are just doing nothing" (Indiv Int 1: 524–536).

Three crucial, interrelated elements can be isolated from the above responses:

♦ a sense of sacrifice ("sacrifice my time to be with you"; "doing your best for them"; "she gets everything"; "give her whatever she wants"; "efforts that you are putting on [into] helping");

♦ lack of appreciation ("instead of appreciating"; "they don't see [this being done for them]"; "the efforts . . . it seems like nothing");

♦ rejection as expressed in rebelliousness ("they don't respect us"; "you can't tell me this and that"; "they don't respect me"; "you are not going to tell me what to do").

It appears that the caregivers in general felt that they were making efforts and sacrifices that were not only *not* appreciated, but thrown back in their faces through disrespect and rejection. This "nexus" of elements had a strong negative impact on the caregivers as

reflected in responses such as "they don't respect us"; "it's very difficult. It's really, really difficult"; "they make me upset"; "sometimes it is hurting"; "it seems like it is nothing—you are just doing nothing". The feelings and perceptions expressed here can be considered to range from resignation to despondency. The most piercing hurtful phrase used by the children, as perceived by the caregivers, was "not my mother", "not my mom".

It may be surmised that the children, with their lack of life experience, have little or no conception of the negative effect of their words on their caregivers. Yet, this attitude is a primary source of stress for the caregivers, who also have to cope with the children's unwillingness to listen to them or respect them even in matters of daily routine. It would appear that this encourages a situation in which caregivers begin to disengage themselves from their work situation and experience emotional discord:

> "I'm not enjoying it [my job] because these children don't respect us anymore. Sometimes we must shout at them, you see. It's not nice" (Indiv Int 2: 22–24).

As has been noted (see 4.2.1.2), many caregivers take their pseudo-parental role seriously: "Like a housewife . . . doing everything, attending to the kids" (Indiv Int 1: 16–20); "I treat them like my own children" (Indiv Int 3: 42–43). Although the children at the institution call them "mama", the caregivers are not given the respect associated with that role, as one participant commented:

> "They call us 'mama', nè, but when that boy said to me, 'You did not carry me in your stomach; you are not my mother,' I said to him, 'But you say "mama" when you call me.' They say [he said], 'Ja, [but] I have my own [real] mother'" (FDG, P3: 875–879).

The participants indicated that the children displayed an attitude of entitlement by regarding the caregivers as merely being there to work for them and clean up after them. Participants indicated that they experienced this as more stressful than the demands placed on them by their own children at home:

> "You know, sometimes like these kids who are difficult, who do not want to listen . . . So at work, sometimes, they have this tendency of doing it [unacceptable behaviour] because like they know that [are aware of it]. And they will say, 'You will work for us'. They used to tell us, 'You are here to work for us'" (FGD, P6: 864–866).

"You know, talking and talking . . . [by] itself is a stress . . . Even if you can go to their rooms, they [the children] just wake up. You know, it's a mess. Each and every day I teach them when you wake up after you've bathed, [tidy up] everything, take, pick up everything on the floor. They will leave their underwear, trousers, just go [get] out of the trousers and leave them the way it was. Bath towels, everything, they will just leave it there and when we ask them [to tidy up], they say, 'No, [the institution] is paying you [to do it]" (Indiv Int 1: 93–103).

In view of the rejection that caregivers have already experienced in their attempts to fulfil a "mothering" or "homemaking" role, they have to suffer the further insult of being regarded as mere "paid cleaners". The words "talking and talking [by] itself is a stress" reflect the exhausting futility of attempting to convince the children to do something themselves to improve their living environment. Such stress can in all likelihood only add to feelings of despondency and emotional blunting.

Discussion

Lazarus and Folkman's (1984) assertion that a person's perception of how much personal control she or he has is of significance in moderating the effects of stress and facilitating coping. The caregivers in this study felt that despite their efforts at maintaining discipline among the children they were unable to do so with the desired result. Moreover, they considered themselves to be caught on the horns of a dilemma between management and the children: on the one hand, they were instructed to maintain orderliness, but on the other, the children tended to accuse them of abusive conduct. Inconsistency between instructions given by management and lack of support from management in complying with those instructions gave rise to considerable tension in the caregivers. This tended to increase their levels of stress and lessened their ability to cope.

The need for training of caregivers has been remarked upon in a great range of other studies, for example those of Castillo et al. (2012), Evans et al. (2004), Colton and Roberts (2006), Jackson et al. (2004), and Van Dyk (2008). The current study, however, highlights in particular the need for training in behaviour management in order for the caregivers to discipline and respond effectively to the children in their care. Knowledge would provide confidence within their position and identity as caregivers (Richardson, 2002), as well as

competence in their abilities to manage difficult situations rather than to feel overcome by a sense of helplessness (Scott & Brown, 2004). If exposed to the appropriate training, caregivers' appraisal (Lazarus & Folkman, 1984) of the challenge of behaviour management should alter positively and they should be able to apply appropriate problem-solving strategies and, consequently, avail themselves of problem-focused coping. Simultaneously, appropriate training may assist them in improving their communication with colleagues and administrators within the institutional setting (Castillo et al., 2012).

4.2.3 Theme 3: Coping with stress

This theme considers how caregivers cope with the challenges they encounter in working with the children in the institutional setting. Coping is defined as "the cognitive and behavioural efforts made to master, tolerate or reduce external and internal demands and conflicts among them" (Lazarus & Folkman, 1980).The caregivers reported coping in three major ways with the stress that they experienced. Firstly, religious beliefs were pointed out as a major coping strategy. Secondly, participants highlighted the importance of the support that they received from fellow-caregivers at work and from their family members at home. Thirdly, caregivers utilised a range of personal coping strategies.

4.2.3.1 Subtheme 3.1: Religious beliefs

The majority of the participants in this study indicated that their religious beliefs played a key role in enabling them to cope with the stressful situations that they were faced with daily. Their Christian faith (the preponderant form of faith in the institution's locality), served as a source of strength for the caregivers in that they believed that it was by God's grace that they were able to cope:

> "God's grace. Truly speaking, it is God's grace because after a kid swears onto [at] you and then you go back to her and [in a] loving [manner], you know how difficult is it? It's really difficult, but I just told myself that it's really God's grace to do all of those things to accommodate them, to give them what they need, to do everything for them each and every day" (FGD, P4: 223–230).

> "And that's why I used to say maybe you know it's God's grace to be in this house and managing some of the things[, which] on my own I cannot [do]" (Indiv Int 1: 222–224).

Additionally, the participants indicated that the act of prayer helped them to cope with the stress associated with caring for the children:

> "I'm sort of just praying, praying to God, God must give me strength to come to work and communicate with the children" (Indiv Int 2: 276–277).

> "I cry and then, after crying, then I pray: 'O my God, help me to handle this because really, really, really, on my own I cannot. I cannot'" (FGD, P4: 1107–1109).

> "When I'm at home, I always pray to God. I say: 'God, it is You who makes me to love the children, it is not by my grace, it's by your grace, it's by Your power. Give me love and strength to work with them'" (FGD, P3: 320–324).

> "I always, I'm, uh, sometimes going to the toilet and praying. I [am] used [to] pray[ing] when I'm stressed. Even if I'm at work, I go to the toilet and pray so that I can control my temper" (Indiv Int 4:187–189).

The intensity of stress that the caregivers experience is reflected in the fact that they have to reach into the deepest recesses of their inner resources, of which faith is a vitally important one for many individuals, in order to cope. Coping seems to focus on two elements: asking for energy to deal with difficulties ("give me strength to come to work"; "help me to handle this"; "give me love and strength"), and asking for the power to exert self-control over feelings of aggression ("give me love"; "so that I can control my temper"). These elements tie in with two of the manifestations of stress mentioned under the *Discussion* in 4.2.2.1, namely internalisation of negative feelings as reflected in depression, and outwardly directed feelings of helplessness as reflected in aggression. It should be noted that these two elements are not necessarily mutually exclusive.

Discussion

The high value of a sense of faith in coping with feelings of depression and aggression, as found in the current study, correlates with Folkman's (1997) emphasis on the importance of spiritual practices and beliefs in coping with stress. As can be seen from the responses of the participants in this study, religion or spirituality can be viewed as a strong source of support for the caregivers in providing them—as noted by researchers such as Bussing, Fischer, Ostermann, and Matthiessen (2008), as well as Musick (1996)—with a sense of strength,

reassurance, comfort, and hope in distressful circumstances. For caregivers who can take recourse to faith, like several participants in this study, God and the religious or spiritual beliefs that they hold can serve as a highly significant support system (Blinderman & Cherny, 2005).

4.2.3.2 Subtheme 3.2: "Lean on me"

A support system that appeared to be of equal value to religion was having recourse to the assistance of colleagues, which can be typified as "lean on me". Participants in this study indicated that they received support from their fellow-caregivers at work to help them cope with stress. If one caregiver was experiencing difficulties in dealing with a particular situation, she could ask her colleagues for ideas or help. The quotations below indicate the manner in which the participants perceived having someone to share with as a positive means of coping:

> "Monday like this, [colleague X] was busy cleaning, and then we were busy discussing [became engaged in discussing] things like if I have experience [of] a difficulty on duty, we used to discuss [started discussing options to take, such as] 'Ah, this one and this, and this and this [can be done]" (Indiv Int 1: 897–900).

> "Upsetting problems, it's just waiting for [colleague Y, who was absent]. When my colleague can come at [return to] work, maybe on Sunday, then I say [told her], 'You know, today he [a child] was doing this, [and] this [that], and I don't like it the way he act [and I didn't approve of the way he acted]" (Indiv Int 2: 92–95).

> "We talk, we talk [discuss things among ourselves]. Like these mamas [caregivers] who are crying, I tell them, 'If you see it is difficult for you, then call somebody. If you can see that you can't manage this, call somebody to come and help you'" (Indiv Int 3: 394–396).

> "I just explain it to my colleague, 'This and this is not good for me or how can I cope,' and she will explain it to me" (FGD, P6: 1443–1445).

> "Sometimes you feel like I can have a shoulder to cry on. Like maybe if we share with, me and [colleague Z] we share some of the things, but there are those things that are deep, that needs a special person to say [to], you know, 'I've got this and this and this [these problems],' if she can say something [give advice], we'll be like be lively [up and running] again" (FGD, P4: 1124–1132).

Two issues in particular are striking about the above responses. The first is the naturalness with which help is sought and granted, which is indicative of a generally healthy collegial working relationship among the caregivers. Care is extended not only to the children, but also to fellow-workers. The second matter is the awareness expressed by at least one participant that some issues may be too complex to be resolved at "grassroots" level among caregivers themselves, and that expert help and advice may be required.

Participants also indicated that they found comfort in sharing their experiences of stress with their family members.

"Eish, maybe I talk to someone close to me, maybe when I'm going home. With my daughter, say You know today maybe he [somebody at work] do this, [and] I don't like the way he do unto [behaved towards] me'" (Indiv Int 2: 115–117).

"Mmm, I used to, to talk to my daughter, and then cause she knows these kids. She said, 'Okay, it's who?' [who caused difficulties today?], and then I'll talk to her. I always used to talk to them [family]" (Indiv Inter 4: 303–305).

"I just go home and talk to my children and say, 'Hey, you know, at work maybe [person A] or [person B] just hurt me,' so just talk to my family. It helps me" (FGD, P5: 280–282).

In these cases, sharing the experiences of the day seemed to have a positive effect on the person's ability to cope, especially if a family member is mature enough to understand and has the ability to listen ("'Okay, it's who?' [who caused difficulties today?]". In other cases, this avenue may not be open, for example to the respondent mentioned under 4.2.2.1 regarding manifestations of stress:

". . . You go home, you look sad and the children can see: 'Mommy what happened today?' I say [that] I don't want to talk to them, [but I feel that] maybe [I] just [want to] go there [somewhere] and sleep . . . The children they get worried now. Something happened at work . . . It affects them, they get worried: 'What happened?' They start worrying, you see" (FGD, P8: 1458–1468).

Participants also indicated that working together allowed them to take time off if they were feeling stressed and to help one another in difficult circumstances:

"Ja, at the work, ja, some of the mamas—like when I'm stressed and when my headache is very paining for my high blood pressure—then they can say, 'Mama [X], don't work; just go home or go to the doctor'" (Indiv Int 3: 361–364).

This may be considered a particularly good example of the "lean on me" principle by taking on an extra burden on a colleague's behalf.

Discussion

Social support is defined as "helpful functions performed by significant others such as family members, friends, co-workers and neighbours and thereby enhances the individual's physical and psychological well-being" (Throits as cited in Petersen, 2000, p. 10). This is well illustrated in the responses from participants in this study, but with the proviso that a balance should be maintained between sharing and burdening. Sharing should be done with those capable of providing support, such as professional counsellors ("a special person to say [to], you know, 'I've got this and this and this [these problems] (FGD, P4: 1124–1132)"), colleagues and mature family members. A measure of irony is present in the case of Participant 8, whose reluctance to discuss work problems with children who are possibly still too immature to understand actually gave rise to increased anxiety at home (FGD, P8: 1458–1468). This example may reflect a small aspect of what Cohen and McKay (1984) refer to as the intricacy of the role that social support plays in caregivers' ability to deal with stressful situations. However, in the main it appears that caregivers in this study made good use of such support to ameliorate the stress they experienced in their caregiving duties. This did not necessarily imply that they were coping adequately.

4.2.3.3 Subtheme 3.2: Personal coping strategies

Strategies in this subtheme involve those of a type that one participant, at a loss for words, tried to explain as "I'm just coping, but I don't know how, but I'm just coping" (Indiv Int 2: 112). They are of a more personal, *ad hoc* nature, and during the individual interviews and focus group discussion caregivers shared how they developed a variety of personal coping strategies, for example: "I've got my own [way] to deal with the things. Some of the things are difficult, and I've come to such an extent that I've just told myself that I'm going to do that whatever that suits me because these kids are very, very difficult" (Indiv Int 1: 160–164).

Participants' responses

As noted in the previous subsection (4.2.3.2), the majority of caregivers appeared to avail themselves of a social support system. Other participants, however, indicated that they internalised the stress they experienced by keeping it to themselves: "I just keep quiet and do my things [carry out my tasks]" (Indiv Int 1: 560–565). Several caregivers also seemed to experience a sense of helplessness in coping with distressing situations and thus made use of use passive and emotive coping as can be seen in the following examples:

"When I feel like I can't say anything, I feel like I can [should] just keep quiet or sleep, or maybe I can just go out [leave]" (Indiv Int 1: 546–548).

"Sometimes I just ignore [everything]" (Indiv Int 1: 92).

"I deal with it within myself, until that time maybe [when] I forget about it, but it will take time for me to forget" (Indiv Int 1: 265–266).

"Ja, if I'm not having a stress, then I'm all right. I'm doing my work, I'm laughing, I'm happy, I'm laughing with everyone, but now when I'm stressed sometimes I feel I don't want to talk with people. I'm just keeping quiet. So when I'm not stressed, then I just talk to everybody. I'm happy" (Indiv Int 3: 250–254).

"Some of the things I just let them [the children] get away with now" (Indiv Int 1: 705).

"Sometimes I'm just going outside, maybe to the gate, [and] look [watch] cars [driving by]" (Indiv Int 2:61–62).

"I'm talking maybe alone [to myself, saying], 'Eish I must take things easy. I must [get] used to it because I work [constantly] with these children" (Indiv Int 2: 71–72).

"Like I'm saying, I just ignore them [the children] or you'll become a wreck" (FGD, P7: 994–995).

"So you do your job. You just go into your room and you cry, you satisfy yourself that you let all out, do whatever is needed for that day. So that helps you to release some of the stress you're feeling. So you use that as one of your coping means. You isolate yourself and you cry and you give off your emotion and then you're OK" (FGD, P4: 265–271).

What appears to be particularly predominant in the above responses is a need for withdrawal ("I feel like I can [should] just keep quiet or sleep, or maybe I can just go out [leave]"; "Sometimes I just ignore [everything]"; "I deal with it within myself"; "I feel I don't want to talk with people"; "I'm talking maybe alone [to myself]"; "you isolate yourself"). Another form of stress relief and self-protection is crying ("so that helps you to release some of the stress"), which appears to help to some extent ("you give off your emotion and then you're OK"). However, what may also develop in some caregivers is a desire to withdraw ("maybe I can just go out [leave]"; "Sometimes I'm just going outside"; "You just go into your room") to such an extent that in a few instances a loss of interest, accompanied by indifference, may ensue ("I feel like I can [should] just keep quiet or sleep"; "Sometimes I just ignore [everything]"; "I just ignore them [the children]").

Discussion

A sense of despondency among caregivers, frequently originating in feelings of helplessness, has already been remarked upon several times throughout this chapter. A perception of impotence or powerlessness appears to be an important motivation in this respect, perhaps resulting from certain avenues to solutions being closed or adequate support not being available. This may well form the basis for the development of a sense of depersonalisation over a period of time.

Emotion-focused coping, also known as passive and emotive coping, is the avoidance of a problem that can be used to maintain hope and optimism; however, in the case of the participants in this study it was used to deny both the situation and its implications. At times, some participants displayed attitudes and reported avoidance behaviour (as if what had happened did not matter), which Rose and Clark-Alexander (1999) have identified as a stratagem to avoid addressing the impact and consequences of situational events. This approach is generally used when individuals believe that they are unable to change a stressful situation, as many of the participants in this study have reflected in their feedback. Their emotion-focused responses corroborate those found by Folkman et al. (1994), which include cognitive escape-avoidance, behavioural escape-avoidance and distancing.

4.3 SUMMARY OF THE FINDINGS OF THIS STUDY

Findings from this study indicate that participants experience caregiving in an institution as stressful, demotivating and an emotional burden. Caregivers working in an environment of HIV and AIDS are constantly experiencing challenges. Within the context of this study, caregivers' stress experiences included numerous organisational and management factors, especially lack of emotional and practical support, inadequate training, discipline difficulties, and lack of respect and appreciation from the children in their care. It further appeared that the above challenges have begun to overwhelm the caregivers in this study, leaving them feeling exhausted, and with a sense of depersonalisation and reduced personal accomplishment as a result of stress. It can therefore be inferred that the caregivers who participated in this research are experiencing burnout, or are at least displaying significant signs of it, as described in various studies on the subject (e.g., Curbow, Spratt, Unagaretti, McDonnell, & Breckler, 2001; Dorz et al., 2003; Oktay, 1992; O'Neill & Mckinney, 2003; Ross, 2001; Visintini & Campanini, 1996).

4.4 CONCLUSION

In this chapter, I have discussed the results of this study in the format of themes and subthemes. Emerging themes that were relevant to the research question were supported by the participants' accounts. The findings were discussed with specific reference to relevant theory and literature.

The following chapter concludes the study by providing possible answers to the posited research questions. In addition, I highlight possible limitations within this study and potential recommendations for future research.

CHAPTER 5:
CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In Chapter 4, I presented the results of my study in terms of themes and subthemes that emerged. I then interpreted my findings against the backdrop of Chapter 2.

In this chapter, I present an overview of the previous chapters, followed by my final conclusions, as I revisit my research questions formulated in Chapter 1. I also reflect on the potential contributions of my study, discuss the limitations I identified, and make recommendations for training, practice and further research.

5.2 OVERVIEW OF PREVIOUS CHAPTERS

In Chapter 1, I presented the introduction to this study, discussing the purpose and rationale, keeping in mind the primary research question guiding the study, namely "What are the stress experiences of caregivers working in an institution caring for orphaned and vulnerable children?" I also provided orientation regarding definitions of the key terms referred to in the study. Lastly, I presented the adopted research paradigm, a basic overview of the research methodology, including quality criteria and the ethical considerations applied to this study.

In Chapter 2, I discussed existing literature regarding HIV and AIDS and addressed support for orphaned and vulnerable children. Furthermore, I explored the literature with regard to caregivers and caregiving in the institutional context in terms of experiences, burnout and coping. I concluded the chapter with a discussion of Lazarus and Folkman's (1984) transactional model of stress and coping, which formed the theoretical foundation for this study.

In Chapter 3, I described and elaborated on the research methodology applied in the study. I commenced the chapter by discussing the qualitative approach that I followed, anchored in an interpretivist paradigm. The chapter included a discussion on the strengths and limitations of using a case study design, as well as the choice in selecting the participants. I continued the chapter by discussing the data collection methods I employed and the

manner in which I thematically analysed and interpreted the data. I concluded the chapter by discussing the quality criteria followed in the study to meet the requirements necessary for validity and reliability, as well as the ethical considerations I adhered to in striving to enhance the rigour of the study.

In Chapter 4, I presented the results of the study with reference to the specific themes and subthemes that emerged from the data analysis process. The three main themes that I identified were:

♦ contextualising caregiving as a working milieu;

♦ stress through the eyes of caregivers;

♦ ways of coping.

I then interpreted and discussed these themes in terms of the relevant literature and the theoretical framework.

In the next section, I present a summary of the themes elicited from the data analysed. I subsequently address the research questions in accordance with the results of this study, as well as with reference to the theoretical framework utilised in the study.

5.3   OVERVIEW OF RESEARCH FINDINGS IN RELATION TO THE THEORETICAL FRAMEWORK

The results and discussion in the previous chapter provide an understanding of how caregivers experience stress while working within the context of an institution. In this study, stress was understood as arising when a caregiver appraises a situation as challenging, threatening, or otherwise too demanding, and is unable to respond because the appropriate coping response is not available (Cohen & Wills, 1985). The findings from this study suggest that the caregivers experience an imbalance between the resources, capacities, and managerial support available to them on the one hand, and the demands imposed upon them by their working role and job environment on the other.

The persistent demands on caregivers in an institution were shown in this study as causing strain on their coping resources and problem-solving capacities (Cohen & Wills, 1985; Ryan,

2001). The caregivers that participated in this study appeared to exhibit high levels of stress, as well as burnout associated with their experiences. They used a variety of coping strategies that included problem-focused coping (seeking social support) to deal directly with challenges, but for the most part took recourse to dysfunctional coping and avoidance, as reflected preponderantly in refraining from taking any action in difficult situations (see Figure 5.1). It was therefore noticed that the majority of the participants exhibited signs and symptoms of burnout as discussed in Chapter 2. This suggests that support is needed to help caregivers to deal with challenges of caregiving. Training in problem-solving skills, exposure to different forms of coping, counselling, and psychosocial support will help caregivers to face their challenges without masking their stress or pretending to be coping well.
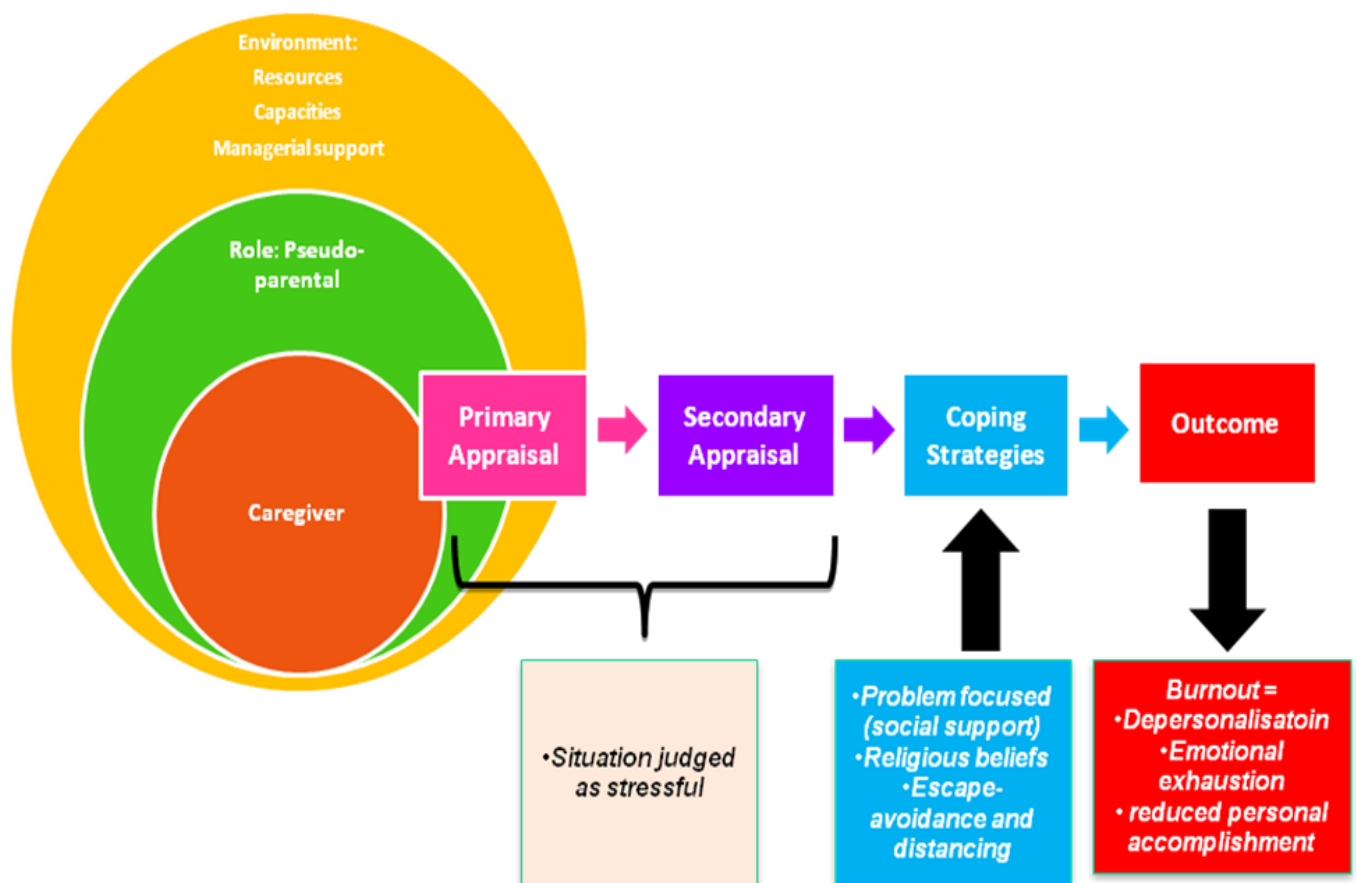
Figure 5.1: *Stress and coping model within the context of this study*

5.4 ADDRESSING THE RESEARCH QUESTIONS

In this section, I answer my primary and secondary research questions, as formulated in Chapter 1.

5.4.1 Primary research question

♦ *What are the stress experiences of caregivers working in an institution caring for orphaned and vulnerable children?*

HIV and AIDS-related caregiving, especially for children, places unprecedented demands on the carers, since the breadth and intensity of problems with which they have to deal are unique. The findings from this study indicated that the following aspects were central to the stress experiences of the caregivers: the institution's management aspects, maintaining discipline among the children, and a lack of authority as (pseudo-) parental figure.

The findings of this study indicate that caregivers experience the following as stress-inducing in terms of their dealings and relationship with the management of the institution

♦ lack of adequate support by management as evidenced by a lack of guidance, advice and training;

♦ poor communication as evidenced in reported one-sided communication from management and lack of true dialogue with caregivers in proper meetings and debriefings;

♦ an authoritarian and even threatening management style displayed by management to the extent of giving rise to a perception of victimisation by caregivers;

♦ management's tendency to leave staff to their own devices, but placing them in a quandary by depriving them of the right and means to formulate and implement their own solutions to daily problems, thus in effect smothering any positive initiative among caregivers;

♦ loss of inner drive and personal motivation among caregivers, giving rise to a sense of despondency and purposelessness, which in turn may engender depersonal-isation;

♦ inadequate remuneration and benefits for staff.

Based on the findings from this study it became evident that there is a need for training for caregivers especially in terms of maintaining discipline (i.e., orderliness and good behaviour) among the children more effectively. Caregivers appear burdened with the responsibility of maintaining orderliness and discipline among the children, but are not equipped with either the necessary approaches to do so or the required support from management. The stress that they experience in such cases results in a withdrawal response, which culminates in a persistent feeling of indifference to their work and the children. Once again, this may be conducive to depersonalisation.

A prominent theme in the stress experiences of caregivers is related to respect, or rather, a lack of respect. This is evidenced particularly among the older children, and the children's negative attitude to the caregivers in their parental or pseudo-parental role. The findings of this study indicate that caregivers feel helpless, unwanted, and unappreciated by the children in their care, who used the caregivers' position of authority as a weapon against them. Findings also indicated that caregivers experienced a general feeling of their efforts and sacrifices not only being *not* appreciated, but also thrown back at them through disrespect and rejection through the hurtful phrase "not my mother".

It was also found that in view of the rejection that caregivers experienced in their attempts to fulfil a "mothering" or "homemaking" role, they also seemed to suffer the further insult of being regarded by the children as mere "paid cleaners". It can be concluded that such stress can in all likelihood only add to feelings of despondency and emotional blunting.

5.4.2 Secondary research questions

♦ *What constitutes "stress" for caregivers?*

Findings from the study indicate that most of the caregivers associated stress with the physical symptoms that they experienced; that is to say, they understood headaches and feelings of general malaise as stress. What was particularly significant was the common theme of lethargy and psychosomatic symptoms leading to avoidance behaviours in the form of withdrawal and a desire to sleep. The implication of this is that if caregivers find their own coping resources failing, or if they lack the energy to cope with their work

surroundings, it cannot bode well for their primary task of caregiving. The caregivers manifested their stress in various ways that corroborate the findings of various other studies in which caregivers displaying similar symptoms were found to be experiencing burnout. The responses of the participants in the current study reflected their conceptualisation of stress in the form of lethargy, withdrawal, various psychosomatic symptoms such as headaches and increase in blood pressure, loss of appetite, outwardly directed negative feelings (aggression), internalisation of negative feelings (depression), and avoidance and escapism behaviours (depersonalisation). This perception or conceptualisation of the experience of stress in terms of frustration, depression, inadequacy, helplessness, aggression, and depersonalisation as observed throughout this study, could indicate future difficulties in caregiving for orphaned and vulnerable children in South Africa.

♦ *How do caregivers cope with stressful experiences?*

In the exploration of coping strategies during the focus group discussions and individual interviews, caregivers reported coping in three major ways with the stress that they experienced. Firstly, religious beliefs were pointed out as a major coping strategy. The intensity of stress that the caregivers experience was reflected in the fact that they had to reach into the deepest recesses of their inner resources, of which faith is a vitally important one for many individuals, in order to cope.

Religious beliefs in this study constituted a supportive element for the caregivers by allowing them to draw on what they considered "God's grace" in order to attain a sense of meaning and hope. This means of coping seemed to focus on two elements: asking for energy to deal with difficulties and asking for the power to exert self-control over feelings of aggression. It was found that when caregivers were struggling to find meaning in what they were doing or were faced with challenges, they would turn to prayer in order to help them find strength and a means to cope with the stress they experienced.

Secondly, findings from the study highlighted the importance of the support that caregivers received from fellow-caregivers at work and from their family members at home in managing those challenges that they experienced as stressful. When faced with challenges, caregivers found great value in self-initialised seeking of peer support. Fellow caregivers

appeared to support each other by allowing their colleagues to take time off when they felt stressed and by taking on an extra burden on a colleague's behalf. In interacting with their peers, and by sharing their experiences and the challenges that they faced within the realm of caregiving, the caregivers ultimately also shared ways of coping with each other in their striving to deal with similar circumstances and types of stressors.

Caregivers found that sharing their experiences of the day with members of their family seemed to have a positive effect on their ability cope. The findings indicated that caregivers found a way of mediating stress through having someone outside the working environment listen and provide understanding. Caregivers thus receive emotional and informational help—which serves as a buffer against potential and actual negative influences—from both family and peers who help them to promote both strength and coping within the institutional working milieu.

Thirdly, the findings indicated that caregivers utilised a fairly restricted range of personal coping strategies. Whereas many of the caregivers appeared to avail themselves of a social support system (e.g., family and colleagues), the majority made use of passive and emotive coping when experiencing a sense of helplessness in coping with distressing situations. Thus, the predominant coping mechanisms to which caregivers took recourse when faced by stressful situations appeared to be withdrawal and isolation through sleeping or physically leaving the immediate work environment, self-protection through crying, deciding to deal with problems on their own terms and according to their own lights (whether effective and appropriate or not), and emotional indifference to excessive or unfair demands from others. It can be concluded that, in the main, caregivers internalised the stress they experienced in order to cope and would rather utilise emotion-focused responses such as behavioural escape-avoidance and distancing as identified by Folkman et al. (1994).

Finally, a particularly important strategy that some participants in this study strongly hinted at, and which can be subsumed under the subtheme of "personal strategies", was the eminently "pragmatic" one of withdrawing from the field of stress by seeking other employment. A measure of irony is attached to this strategy, since it could only be commented on fully by those who had already used it and, consequently, were not present anymore. Although it was mentioned that new employment was not easy to find and that

the participants were reluctant to leave their current work, stressful as they might experience it, it was mentioned that the standard period of remaining at the institution was approximately five years.

5.5   POSSIBLE CONTRIBUTIONS OF THE STUDY

The qualitative nature of this study allowed for an in-depth analysis of caregivers' perceptions regarding their experiences of stress within an institutional setting caring for orphaned and vulnerable children. Considering the dearth of research in this field of enquiry worldwide, the current study may serve to add to the existing knowledge base as relating in particular to sub-Saharan Africa.

The research data highlighted the needs of caregivers in relation to their vocation, which should be taken seriously by institutions in view of the crucially important role that these caregivers fulfil in ameliorating the devastating societal effects of the AIDS and HIV pandemic on children in South Africa. It is, therefore, a strength of this research that the needs of caregivers were identified, and that this identification can be used to devise strategies to facilitate more effective caregiving and prevent existent caregivers from leaving this line work. A subtle distinction needs to be emphasised here (as mentioned earlier in this study). Effective caregiving may be enhanced by various training and "empowerment" courses that will help caregivers to cope better with work-related problem situations in their routine tasks. This aspect may help to improve their sense of competence and well-being, but it is still focused mainly on the improvement of services rendered to others, i.e., the children. It is also necessary, at a highly personal level, to make provision for matters such as regular individualised counselling and guidance to ensure that caregivers possess sufficient inner resources to cope with longer-term difficulties. It may be assumed that such initiatives could be used to address and promote areas of positive development throughout the institution.

The fairly short stretch of remaining in employment at the institution, as mentioned by the participants in the group and individual discussions, was significant. If further research should indicate that this pattern is repeated at other institutions, it could be a cause for concern. The current study may have made a contribution by noting this aspect in particular.

5.6   LIMITATIONS OF THIS STUDY

One of the potential limitations of the current study relates to its sample size. The results may therefore only be applicable to the sample under investigation, and cannot be generalised to the general population. However, considering that my research stance was that of interpretivism, generalisability was not one of the aims that I wished to achieve by the study. For the purposes of qualitative research, however, the sample size did suffice and participants yielded in-depth, rich and insightful information as the aim was to gain insight into the experiences of caregivers in a specific context.

The second limitation is that I made use of convenience sampling. The sample was therefore not randomly selected, and therefore it cannot be claimed that the selected participants are representative of the general population. However, while the outcome of the study may not be generalised to populations of caregivers as a whole, it has provided a deeper understanding of the experiences of caregivers from their perspective.

The qualitative nature of this study called for me as researcher to interpret data according to my own perceptions. This fact may be considered a limitation, since the data gathered may be interpreted differently according to other researchers. The qualitative process, however, required subjective interpretation and therefore was not perceived as a significant limitation. In order to guard against self-biases, I strived to counter such influence through reflexivity. In this respect, my researcher journal served as a valuable instrument for recording my thoughts, which allowed for critical reflection on them afterwards. I also had discussions on my viewpoints with my supervisor in order to probe and reassess my ideas and perceptions.

Although the participants in the current research were able to communicate in English, it is important to acknowledge that it was not their first language. Participants encountered difficulties at times to convey their experiences adequately. Thus, on certain occasions the meanings of the questions being asked had to be explained to the participant, which may have influenced the participant's response to the questions. I relied on the assistance of my fellow researcher for interpretation and member checking of the given information to address this challenge.

5.7   RECOMMENDATIONS

Based on the findings of this particular study, I propose the following recommendations for training, practice and further research.

5.7.1   Recommendations for training

Based on the findings of my study, I recommend that caregivers be given the opportunity to engage in professional development and training opportunities. Informal or formal training/workshops can be developed in order to train them in behaviour management techniques that they can implement in the institution. Furthermore, if all caregivers are trained in the same techniques, it should add to the continuity and effectiveness of managing the behaviour of the children in the institution. Training can play a key role in the management of stress and burnout in caregivers, since they may gain sufficient knowledge and skills to empower them and give them a sense of control over challenging situations.

In addition to "training for work", it is crucially necessary to "guide for self-capacitating". It appears that a great need exists for ongoing training programmes that teach effective coping strategies to caregivers who find themselves overwhelmed by the challenges of their jobs. It is equally essential that opportunities be granted to them for regular "debriefing" and personal guidance counselling in which their physical and psychological well-being is the primary focus. Such initiatives in self-care and self-awareness skills training may contribute significantly to the prevention of burnout. Caregivers can only derive benefit from being able to access psychological and emotional intervention in relation to the difficulties that they experience.

5.7.2   Recommendations for management practice

It is recommended that managers of HIV and AIDS care institutions should be in constant interaction with the caregivers in order to avoid miscommunication and feelings of discontent or depersonalisation that might eventually lead to burnout. Caregivers should be given the opportunity to voice their concerns and be consulted frequently to identify their needs and address them adequately.

Supervision and debriefing sessions from the organisation and management are necessary to help and maintain caregiver morale. In addition to such initiatives, support groups or

support sessions may be beneficial in helping caregivers to share and discuss work-related issues and emotional experiences that have arisen, after which they may have recourse to personal counselling (as mentioned above) if they should feel the need for it.

5.7.3 Recommendations for future research

Future research could further assess formal caregivers' access to coping resources and interventions within an institutional environment, as well as undertake evaluations of the effectiveness of strategies for managing various work-related stressors.

Further investigations are needed to elucidate how care challenges within an institutional setting impact upon carer well-being. This may even be expanded to encompass the familial context of caregivers' lives, considering the importance that several participants assigned to family life in their emotional well-being and handling of stress.

A particularly pertinent issue is that of research that could be conducted into interventions to help caregivers identify the appropriate fit between coping strategies and specific sources of stress in order to assist them in the management of occupational stress.

5.8 CONCLUDING REMARKS

The present study highlighted the challenging aspects of caregiving within an institutional setting from the perspective of the caregiver. In order for caregivers to execute their care-giving effectively, the findings of this study indicated that that the caregivers' stress experiences need to be addressed not only in an institutional framework but also in a person context. This thesis suggests that more training and education is needed for the caregivers; for example, to deal with challenges such as issues of appropriate discipline for the children under their care. Furthermore, caregivers need to be equipped to assess the signs of burnout and be able to cope with stress effectively. Work support group initiatives in tandem with personal guidance counselling may serve particularly well in this respect.

Finally, an arresting impression gained from this study was the dissonance between the positive idealism with which caregivers initially embarked on their careers, and the disillusionment even depersonalisation, by which they currently felt overwhelmed. Their

loss of interest in what they used to consider a special calling, is reminiscent of the words of the poet Khalil Gibran (1926):

> Work is love made visible.
>
> And if you cannot work with love but only with distaste, it is better that you should leave your work and sit at the gate of the temple and take alms of those who work with joy.
>
> For if you bake bread with indifference, you bake a bitter bread that feeds but half man's hunger.
>
> And if you grudge the crushing of the grapes, your grudge distils a poison in the wine.
>
> And if you sing though as angels, and love not the singing, you muffle man's ears to the voices of the day and the voices of the night (n.p.).

It is cause for concern that the caregivers' earlier love made visible in their work should in several cases later have produced "bitter bread" and "poison in the wine". This reflects a tragic waste of goodwill, enthusiasm, and inspiring humaneness—a waste that should not be allowed to continue since it is they, the caregivers, who first and foremost give ear to the voices of the children.

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APPENDICES

Appendix A: Ethics clearance certificate

RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE	**CLEARANCE NUMBER :** UP 10/03/01
DEGREE AND PROJECT	M.Ed
	Caregivers' experiences of stress while caring for orphaned and vulnerable children in an institution
INVESTIGATOR(S)	Chereen Pretorius
DEPARTMENT	Educational Psychology
DATE CONSIDERED	19 August 2013
DECISION OF THE COMMITTEE	APPROVED

Please note:

For Masters applications, ethical clearance is valid for 2 years

For PhD applications, ethical clearnace is valid for 3 years.

CHAIRPERSON OF ETHICS COMMITTEE	Prof Liesel Ebersöhn
DATE	19 August 2013
CC	Jeannie Beukes
	Liesel Ebersöhn
	Prof K Mohanji

This ethical clearance certificate is issued subject to the following conditions:

1. A signed personal declaration of responsibility
2. If the research question changes significantly so as to alter the nature of the study, a new application for ethical clearance must be submitted
3. It remains the students' responsibility to ensure that all the necessary forms for informed consent are kept for future queries.

Please quote the clearance number in all enquiries.

Appendix B: Informed consent

Letter of Informed Consent: Participant

Faculty of Education

Department of Educational Psychology

February 2010

Dear participant

Arising from the findings of my PhD study entitled: *Finding roses amongst thorns: How institutionalized children negotiate pathways to well-being while affected by HIV&AIDS*, I found a need to examine the emotional responses of adults who care for children with a view to enhancing their emotional awareness.

I would therefore like to invite you to participate in a study that looks at caregiver's emotional response while working with and caring for children who are living with HIV&AIDS. Your participation in this research project is voluntary and confidential. It is proposed that in the first stage of the study, you would be completing a questionnaire (test) that explores your emotional intelligence. Thereafter, you will be required to form part of a focus group, the members of whom will be interviewed individually and collectively. During the second stage of the study, you will be invited to assist in the planning and actively participating in a group discussion that is aimed at emotional awareness and enhancing the emotional responses of the participants. Participation in a workshop aimed at stress management is also expected. During this research process, the primary researcher will be assisted by research field-workers (also known as research assistants) who will co-facilitate the focus groups and the group discussions. These research field workers will be students. It is possible that the field workers will utilize part of the information gained to embark on their own individual projects under the supervision of Dr Mohangi. The students are: Ms Chereen Pretorius, Mr Andreas Baron and Mrs Lolo Mosia.

Should you declare yourself to be willing to participate in this study, confidentiality will been assured. The data that emerges from this study will be shared with you to ensure the trustworthiness. Furthermore, the information gained from this study will be

published in the form of journal articles and/or conference presentations. You may decide to withdraw at any stage should you wish not to continue with your participation.

If you are willing to participate in this study, please sign this letter as a declaration of your consent ie. That you participate in this project willingly and that you understand that you may withdraw from the project at any stage. Signing this form also means that you give permission for all interviews and activities to be recorded by means photographs and digital voice recordings. Should you have any enquiries, please feel free to contact me.

Yours sincerely

_____

Dr Kesh Mohangi

Tel: 012 420 5506

kesh.mohangi@up.ac.za

_____

Consent to participate in the research project

I, _____ agree to participate in the research project as outlined in the letter and as explained to be verbally. I am aware that I may withdraw from the study at any stage. I am also aware that my identity will be restricted to only the members of the focus group, the researcher and the research field workers. In all other instances, my identity will remain anonymous. I agree to maintain confidentially will regard to the information shared and identity of other group members during focus group discussions as well as during the workshop.

I also agree to the research field workers (students) utilizing a part of the data from this study to explore their own individual projects under the supervision and guidance of Dr Mohangi. I will contact Dr Kesh Mohangi, should I have other queries.

_____

Participant's name   (please print)

_____   _____

Participant's signature   Date

Letter of Permission: Institution

Faculty of Education
Department of Educational Psychology

February 2010

Dear Sir/ Madam

Re: Permission to conduct research

I am a lecturer at the Department of Educational Psychology at the University of Pretoria. Arising from the findings of my PhD study entitled: *Finding roses amongst thorns: How institutionalized children negotiate pathways to well-being while affected by HIV&AIDS*, I found a need to examine the caregiver's emotional responses to children with a view to enhancing their emotional awareness.

Thus, I would like to invite your institution to participate in this longitudinal research project that is ultimately aimed at enhancing caregiver emotional awareness and responses with the intention that the caregivers themselves as well as orphan and vulnerable children who are in the care of the institution, could benefit.

Your institution's participation in this research project is entirely voluntary and the name of the institution will remain confidential. It is proposed that the study will proceed in different stages: the first stage will be the administration of a psychometric questionnaire (test) that explores the participants' emotional intelligence. Secondly, the participants will be invited to participate in a focus group interviews (individually and collectively); the next stage will be in the form

of a participatory intervention that will be aimed at exploring and developing emotional awareness as well as enhancing the emotional responses and stress management of the caregivers. In addition, further focus groups are envisaged with the participants in order to reflect on their care-giving experience. During this research process, the primary researcher will be assisted by research field workers (also referred to as research assistants) who will co-facilitate the focus groups and the workshop. These research field workers will be students. It is possible that the field workers will utilize part of the data gained to embark on their own individual projects under the supervision of Dr Mohangi.

Should you declare your institution to be willing to participate in this study, confidentiality and anonymity will be guaranteed. I therefore, request your permission to conduct this research study at your institution during the first and second terms of 2010.

I trust that my request will meet with a favourable response.

Yours faithfully,

_____

Dr Kesh Mohangi
Department of Educational Psychology
University of Pretoria
Tel: 012 420 5506
Email: kesh.mohangi@up.ac.za

Faculty of Education

Department of Educational Psychology

Declaration of responsibility: Research Assistant

Title of research project: A COHORT STUDY ON THE PSYCHOSOCIAL AND EMOTIONAL AWARENESS OF ADULTS WHO CARE FOR CHILDREN IN AN INSTITUTION

I, _____, in my capacity as research assistant to the above mentioned research project, do hereby declare that I am cognizance of the goals of the Research Ethics Committee in the Faculty of Education.

I subscribe to the principles of *privacy*, meaning that the confidentiality and anonymity of human respondents and the information they provide shall remain protected at all times; *safety in participation*, that all participants should not be placed at risk at any time and *trust,* which implies that participants will not be respondent to any acts of deception or betrayal in the research process.

_____   _____   _____
Research Assistant (Name)   Research Assistant (signature)   date

_____   _____   _____
Researcher (Name)   Researcher (signature)   date

Focus Group Interview

P4	134.	working here in 1999. The group that I have started	
	135.	in last year.	
	136.	I started working with kids in 2004. I was	
	137.	working for an organisation called Children	
	138.	(word unclear). I started to work with kids there	
	139.	because sometimes we do visits, you find out	
	140.	there is a need at home, so we just organised a	
	141.	group of kids so that we keep them busy after	
	142.	school. Some of them we were talking to them,	Motivation for becoming caregiver
	143.	sort of counselling. I can say that I'm a good	
	144.	counsellor, but I don't have a profession in	
	145.	counselling. Because there is a lot of kids that I	
	146.	have helped, even today, they have made my	
	147.	life better. I am somebody because of you. So I	
	148.	started to love the job even though I was not on	
	149.	that track. Because of the challenges that I	
	150.	used to get when I go to the house, you will find	
	151.	that they are all with the granny, the granny will	
	152.	shout at them, they don't have space for these	
	153.	kids. So for me to them I was like a mentor for	
	154.	them, the mother at the same time. Even when	
	155.	they come to the centre even when they won't	
	156.	find me it's like they have something they've	
	157.	lost. So I started working with these kids from	
	158.	2002. Now I've realised that I've got this thing of	
	159.	working with kids because even at church I am	
	160.	a Sunday school teacher, I play games with	
	161.	them, then it is nice. I love kids. But the	
	162.	challenges, yo, these kids have challenges.	Challenges faced by caregivers
	163.	More especially the teenagers. You know I just	
	164.	told myself no, no, I won't work with kids	
	165.	because some of them, more especially these	
	166.	ones who are vulnerable, you have stress, you	

Kesh P4	167. 168. 169. 170. 171. 172. 173. 174. 175. 176. 177. 178. 179. 180. 181. 182. 183. 184. 185. 186. 187. 188. 189. 190. 191. 192. 193. 194. 195. 196. 197. 198. 199.	must learn to listen to them. Some of them, even if you want to listen to them they are so difficult in a way that you can't handle them. So that is the challenge I have with the kids. Otherwise I have space for kids, I can listen. Even though now I am harsh but to my surprise I just saw kids love me. Even when I am at home, before I wake up. Ko ko ko ko, we want to see ***, you see maybe I have this thing of kids and I am harsh. If I say I am going to beat you, I am going to beat you. I have this thing of kids so I started working with kids. *You say you are harsh. Tell us more about that.* *Why do you say you're harsh?* No, if I am angry, I'm angry. You know sometimes like these kids who are difficult, who do not want to listen. Serious, let me tell you. Even at home I have five kids, my brother's kids they know that if I say I don't want this, I don't want it. So at work, sometimes, they have this tendency of doing it because like they know that I don't have the authority to beat them or whatever. So that is the challenge that I have, because sometimes it is difficult working with kids. More especially, some of them they do not appreciate things, instead of appreciating, they will tell you a lot of hard words. Like "you are not my Mom". Then you end up saying if I am not your mom I don't think I will sacrifice my time to be with you. Sometimes it is hurting because you are doing your best for them but some of them they don't see. But what I like is some of them they see, because they will come	Motivation for becoming caregiver Challenges faced by caregivers Challenges faced by caregivers

	200. to you and say they saw that you have this	
	201. thing. So I saw I have the potential to work with	
	202. kids. There are challenges, but challenges...I	
	203. don't know how to explain it. Any work has it's	
	204. own challenges.	
Kesh	205. *But what helps you cope, P4? What makes*	
	206. *you, despite what the children say to you*	
	207. *sometimes, but you still go back and you still*	
	208. *love the children. What's giving you that*	
	209. *strength to continue?*	
P4	210. It is so difficult. I think maybe we need	Challenges
	211. something like debreifing. You just go into your	
	212. room, cry and after that I tell myself no I am	Coping (internal)
	213. going back there. There is nothing that you can	
	214. do, more especially if it's for your life. You think	
	215. I am going to benefit something for my kids	
	216. anyway. You just cry and thereafter you dry	Coping
	217. your tears and you go back to them. And	
	218. sometimes it's not easy because sometimes	Challenges faced by caregivers
	219. you'll have that feeling that you know these kids	
	220. the way is so difficult. I feel like I will hate them,	
	221. but you will never. And sometimes I've told	
	222. myself that I am not doing it because I'm clever	
	223. enough, but it is God's grace. Truly speaking it	
	224. is God's grace because after a kid swears onto	Coping (religious beliefs)
	225. you and then you go back to her and loving,	
	226. you know how difficult is it? It's really difficult	
	227. but I just told myself that it's really God's grace	
	228. to do all of those things to accommodate them,	
	229. to give them what they need, to do everything	
	230. for them each and every day. I don't say no,	
	231. yesterday you've done this. But when it comes	
	232. to punishment I don't want to lie, I punish. If I	

Appendix D: Excerpts from individual interviews

Participant 1 Individual Interview

	67.	Saying you know I feel like I just go out of this	
	68.	Premise and run away, run nonstop. Sometimes	
	69.	I'll just feel like I'll climb the mountain and be there	
	70.	And shout! So it's not easy.	
Int2	71.	And how long have you been here?	
	72.	Since 2008, October	
Int2	73.	So that's already a good three years or so.	
PAR	74.	Ja...	
Int2	75.	Almost three years	
PAR	76.	Ja, it's almost three years but we are not at the	
	77.	Same page you see. I think maybe with your own	
	78.	Kids you can manage because it's your own kid	
	79.	You can do whatever you want.	
Int1	80.	Ja...	
PAR	81.	With your own kid but with these ones you cannot.	
	82.	You can't, you can't, you can't.	
Int1	83.	Do you get any support from outside, that helps	
	84.	You with training or...	
PAR	85.	So far we don't have any, any, any training.	Challenges
	86.	Nothing. Even at debriefing session we don't	Lack of support
	87.	Have. It's for my own baby to go see what can I do	
	88.	If I have stress I must just make sure it doesn't	Coping

	89.	affect me to an extent that I can't do anything.	
	90.	But now I think I've got some tactics on how to deal	
	91.	with. I've got some tactics on how to deal with.	
	92.	Sometimes I just ignore because sometimes I just	
	93.	Can't, can't. You know talking and talking on it's	
	94.	Self is a stress. I can't say to you take that trunk.	Challenges facing
	95.	Even if you can go to their rooms, they just wake	caregivers
	96.	Up. You know it's a mess. Each and every day I	
	97.	Teach them when you wake up after you've bathed	
	98.	Everything, take, pick up everything on the floor	
	99.	They will leave their underwears, trouser, just go	
	100.	Out of the trouser and leave it the way it was, bath	
	101.	Towels, everything they will just leave it there and	
	102.	And when we ask them they say no mohau is	Lack of authority
	103.	Paying you so... and then even when you are	
	104.	Telling them it's not for my own benefit, it's for your	
	105.	Own benefit.	
Int1	106.	Ja	
PAR	107.	Cause even if you are a grown up you'll behave	
	108.	Like the way you behave now because you must	
	109.	Start treating yourself like a old person now you	
	110.	can't Wait until you are twenty one then say you'll	

	111.	Teach yourself to pick up things. You know what	
	112.	I've realised even if they were telling me that uh	
	113.	I'm getting paid for this, there's a kid at home she,	
	114.	He's four years old, after bathing, he is four years	
	115.	He knows that he must take everything but with	
	116.	This ones it's very very very difficult because they	
	117.	Have this like of saying you are getting paid. You	
	118.	Must do whatever.	
Int1	119.	Ja	
PAR	120.	So it's difficult.	
Int2	121.	You mentioned a talk to the social workers?	
PAR	122.	No, she will talk to them, try to explain real life	
	123.	Even myself I try to explain real life to them. But ja	
	124.	After that back to square one.	
Int2	125.	Ja, so you have the social worker that comes in?	
PAR	126.	Ja, every Monday even today she will be here.	
Int2	127.	Is it, okay.	
Int3	128.	And does she offer any support?	
PAR	129.	Ja she, she offer but one hour I think it's, it's not	Challenges facing
	130.	Enough especially because sometimes we have	Caregivers
	131.	Issues and they have this tendancy of fighting with	Lack of support
	132.	Old people these kids. So now I just "uh ah" hands	

Participant 1 Individual Interview

	133.	Off, I can't, I can't really I can't.	
Int1	134.	Does the social worker support you in anyway?	Support
PAR	135.	Ja, she perfectly 100 percent, 100 perecent she is	
	136.	Trying 100 percent.	
Int1	137.	In what kind of, does she give you advice or how	
	138.	Does she...	
PAR	139.	Ja, because most of the time we will sit here	support
	140.	Discussing, most of the time she can't even go	support
	141.	To the kids because we can sit down and discuss	
	142.	You know I have this problem and this and this	
	143.	And this and we discuss. No I wonder if you can	
	144.	Do this and then she will advise me and then	
	145.	Some of things I will tell her no I decided to do this	
	146.	But she will tell me if you benefit from that thing	
	147.	Then you can do it but if I can see I cannot then	
	148.	I contact her again and tell her no I can't do this.	
Int2	149.	And you find those sessions helpful?	
PAR	150.	No, I even develop my own tactics to deal with	
	151.	These things.	
Int1 and int2	152.	What sort of tactics do you have?	
PAR	153.	Like ah maybe I've used the wrong word to say	

	176.	Have this thing of, I think it's a tendancy or a habit	
	177.	On to them. Even if you talk to them nicely they	
	178.	Don't understand they don't see, they don't	
	179.	Differentiate being politely and I don't know.	
Int1	180.	And how does it make you feel when they speak	
	181.	To you that way?	
PAR	182.	Sometimes I just keep quiet, let me just, what can	
	183.	I say. There is nothing that I can do, cause like I	
	184.	Have said this is not my own kids. There is no way	
	185.	even my kid at home I can punish her my kid	
	186.	I can punish her, but with this one I am trying,	Challenges facing
	187.	I am trying to punish them most of the time I will	Caregivers
	188.	Take away from them their pocket money but	Lack of authority
	189.	They used to it they know if I can just do this she	And discipline
	190.	Will just gonna take my pocket money for week	
	191.	And the next week life goes on, that's the way	
	192.	And there is no way I can punish them, there is no	
	193.	Way.	
Int1	194.	And you've had no training on sort of disciplining	Challenges facing
	195.	Them or that mohau has given you support in how	Caregivers
	196.	To handle those situations?	Lack of support
	197.	I've never had any training, that's why I said I have	

Participant 1 Individual Interview

	198.	My own way to it.	
Int1	199.	Yes because no one has ever given you advice.	
PAR	200.	Ja, maybe even if I can talk to the social worker	
	201.	She will tell you no do whatever is best for you. On	
	202.	The other hand must do what suits me, on the	
	203.	Other if I can do something wrong to these kids I'm	
	204.	The one to be blamed. So you see I'm in between	
	205.	Two things. I'm doing this one I'm wrong, I'm doing	
	206.	This one I'm wrong. So I must sit with it what must	
	207.	I do so that is why most of the time I just keep quiet	
	208.	And I just told myself that know what, it was on	
	209.	February the other one she was shouting at me	Challenges facing
	210.	And telling me I'm a bitch. I said you know the way	Caregivers
	211.	I understand the word bitch maybe I don't know	
	212.	English let me just consult, check in the dictionary	
	213.	Check oh bitch but that's the way I know. And then	
	214.	If somebody told you, you are a bitch then what	
	215.	Can I say? What can you do?	
Int1	216.	How did you handle the situation?	
	217.	I can't say ah you know even now, even now even	
	218.	If I look at that kid eish hey hey hey it's so	
	219.	Difficult and I can feel that this thing it almost	

Int1	1.	We going to use the recorder, but when wetype out the things	
	2.	In our studies we don't use any names, so no one will know	
	3.	Who you are. *** what is your role at the centre?	
PAR	4.	I'm a helper and I'm also relieving on weekends for **** as a	Role as caregiver
	5.	House mother.	
Int1	6.	As a helper what does your job consist of?	
PAR	7.	Cleaning, laundry things	Role as caregiver
Int2	8.	And relieving over weekends?	
PAR	9.	Just maybe medication and cooking, look after children.	Role as caregiver
Int1	10.	What do you enjoy about your work?	
PAR	11.	I like work with kids, but now teenagers they have got a lot	Reason
	12.	Of things on their mind, you can't control them anymore	
Int1	13.	When you say you can't control them anymore what do you	
	14.	Mean?	
PAR	15.	If you talk to them nicely they you know just talk to you the	Challenges
	16.	Way they like and they don't respect us because we are not	Lack of authority
	17.	Their parents or what	
Int1	18.	Is there anything else that you enjoy about your work?	
PAR	19.	I don't know what to say about that.	
Int1	20.	Would it be easier for you to tell us what you don't enjoy	
	21.	About your work?	
PAR	22.	I'm not enjoying it because these children don't respect us	Challenges
	23.	Anymore. Sometimes we must shout at them you see, it's not	Lack of authority

	24.	Nice.		
Int1	25.	Is there anything else about your work that you don't enjoy?	
PAR	26.	Ja, eish you know if you got problems you don't enjoy	
	27.	Anymore you just work because there is no work anywhere.	
Int1	28.	Can you identify anything in your work environment that	
	29.	Causes you stress?	
PAR	30.	It's these children give us stress because they don't listen if	Challenges
	31.	You say you don't come late at home maybe at five o'clock	
	32.	On Fridays they came late, we get worried about them. If you	
	33.	Ask them where were you? Ah with friends. So become	
	34.	Scared where's the children at this time.	
Int1	35.	And what else causes you stress?	
PAR	36.	Boys are coming here now a days to look for girls	
Int2	37.	Okay so you worried about them	
PAR	38.	If you refuse some time, they mustn't go out they come	
	39.	Aggressive to you and you see all these things.	
Int1	40.	And do you feel that you get enough support?	
PAR	41.	I don't feel that get enough support. If you talk to the social	Challenges
	42.	Worker the children do this and that, they talk to the children	Lack of support
	43.	But you don't get to that point where you can say you can	
	44.	Maintain them.	
Int1	45.	Do you feel not getting enough support causes you to	
	46.	Experience stress as well?	

Individual Interview 2

PAR	47.	Ja, ja we not get enough support	
Int1	48.	Do you feel like you have any control over your work	
	49.	Environment, the things that cause you stress?	
PAR	50.	Sometimes I can control myself, say ei it's not my own	Internal coping
	51.	Children and I must just stay like that work with them	
Int1	52.	How do you approach it then, what do you do to cope with the	
	53.	Stress?	
PAR	54.	You know sometimes it is tough to talk with them because if	Caring for children
	55.	You talk to them nicely they shout at you, you see that's the	
	56.	Problem. In the morning they want to wake up on weekends	
	57.	Maybe we say they must wake up maybe 8:30 until 9:00.	
	58.	They want to sleep until late you see?	
Int1	59.	And how do you yourself cope when you are stressed, what	
	60.	Do you do?	
PAR	61.	Sometimes I'm just going outside, maybe to the gate, look	Coping
	62.	Cars.	
Int1	63.	How do you know when you feeling stressed?	
PAR	64.	You feel no, I'm not the same level	
Int1	65.	What do you mean the same level?	
PAR	66.	You become, eish I don't know how to explain it	
Int1	67.	Tense?	
PAR	68.	Mmm others are not the same, others they behave good,	
	69.	Others they don't behave good. They not the same.	

Int1	70.	How do you behave when you stressed?	
PAR	71.	I'm talking maybe alone, eish I must take things easy I must	Coping
	72.	Used to it because I work with these children.	
Int1	73.	So you cope by going out, taking a walk and coming back?	
PAR	74.	If, if I'm going out, they inside there is a lot of trouble, become	Challenges
	75.	Fighting do funny things. They see maybe I'm going out,	
	76.	Jumping the sofa, doing things you don't want they must do.	
Int1	77.	You can't really leave, just go...	
PAR	78.	Ja, maybe just a minute and come back, not a long time.	
	79.	Because they eight some go to study, others go to their room	
	80.	Maybe here watching TV you see they do funny things.	
Int1	81.	So you don't really feel there is a place you can go for a	
	82.	Couple of minutes just to de-stress or find some quiet time?	
PAR	83.	No, not able to work like that.	
Int2	84.	Do you have your own room here or do you go home?	
PAR	85.	If I'm in I stay this room, so even if you here during the day	
Int2	86.	You can't just go for five minutes and quickly quiet yourself	
	87.	Down?	
PAR	88.	I go maybe outside, because maybe if I'm inside the house	
	89.	The other one will shout mama come and see he do this to	
	90.	Me, ai wola, wola, wola you see	

Appendix E: Research journal

<u>**Research Journal**</u>

<u>**03 September 2010: Focus Group Discussion**</u>

Present: Dr K. Mohangi, Andreas, Chereen, Lolo

We arrived at the site to conduct our focus group discussion. I was prepared, questions in hand my role as researcher had begun. The chairs were positioned in a circle allow everyone to see each other. We sat down, I was very nervous. Dr Kesh explained to the participants the reason for our visit. She then went through ethical considerations of confidentiality, and that we would be recording the session. Lolo explained to the participants that she would be engaging in the role of translator as well where needed.

As the focus group began I became aware that this was going to be challenging. The language barrier between the participants and myself was certainly going to create a problem. I posed my first question for discussion and all I got was blank stares. I thought to myself this is going to be more difficult than I thought, first question and I've lost them already. Dr Kesh jumped in but before she could say anything one of the participants answered. I thought to myself thank goodness. From there more participants seemed to engage in the discussion. At times it appeared that three or four participants were carrying the group and I began to wonder if the other participants were interested in the process at all, in that they felt comfortable in sharing opinions or if language was indeed a bigger barrier than I had initially thought. At times I felt as if we were pulling teeth. I found myself rethinking and rephrasing my questions in an attempt to get the others to participate.

What I observed was that in the beginning of the discussion the participants painted the picture of loving their jobs and the kids. They came to work because of their love for the children. However as the discussion progressed their dissatisfaction with management materialised in terms of lack of support, poor wages as well as the difficulties they experience with the children such as discipline problems, the attitude of the children towards the caregivers. Towards the end of the discussion it became clear that they do not derive much joy from their work environment. It became apparent that the caregivers needed someone who was listening to where they were coming from and hear their frustration thereby co-constructing meaning from their experiences. Perhaps this discussion had allowed just that.

Once the discussion had been completed we offered the participants something to eat and drink that we had brought with in order to thank them for their time. We also then went around to the participants gathering further biographical information from them.

Research Journal

<u>**16 May 2011: Individual interviews**</u>

Present: Chereen, Andreas

Andreas and I decided on the participants for the individual interviews based on the focus group discussion. We noted that four of the participants were relatively well versed in English and openly discussed their opinions during the discussion. The reason these participants were selected was due to the fact that we would not have a translator at our disposal during the interviews as our fellow colleague fell pregnant.

I contacted the four participants telephonically asking them if they would mind if we came to see them for follow-up individual interviews. All four participants agreed and a day and time was set.

I prepared open ended questions that I wanted to pose to these participants in order to gain more information for my study. I would soon discover during our interviews that these questions merely served as a rough guideline and that language and educational barriers would cause me to have to rephrase questions as the interview progressed. Participants seemed to answer questions more easily if they were accompanied by concrete examples and elaboration of what was meant by the question posed. This may have an impact on my data analysis as a lot of the information provided was very basic and concrete.

I found myself frustrated by the process because the answers that they provided were not the same as the answers I would have expected. I found myself continuously having to bring participants back to the topic at hand as I found that their train of thought would digress from the question posed. Hence the interviews took significantly longer and were more draining than expected.

It appeared as though the participants were a lot more at ease with us today than they were during the focus group discussion. Could it be due to the fact that we were now familiar to them by now or perhaps because speaking to us on an individual basis may be less daunting than expressing their opinion in a group of colleagues? Trust may also have played a factor here seeing as how none of the content of the focus group discussion had been divulged to management.

It became apparent as it did during the focus group discussion that the caregivers began the interview by sketching a picture of a satisfactory working environment but by the end of the interview this picture turned to grey.

As researcher this process was useful as a method of data collection for my study however could not help but feel that these caregivers are working under such strenuous conditions that they inadvertently saw this as an opportunity to air grievances to someone willing to listen. These caregivers need support and possibly counselling? The information gathered I feel will be meaningful to my study.

Appendix F: Thematic analysis

Themes Identified	Sub-themes	Focus Group	Interview 1	Interview 2	Interview 3	Interview 4
Theme 1: Contextualising caregivng as working milieu	1.1 Caregivers' motivation for involvement in caregiving 1.2 Caregivers' view of their formal role in institutions	• L 60-62 • L 66 • L70 • L142-145 • L145-149 • L513-515 • L614-617 • L680-683 • L688-690 • L792-793 • 898-901 • L908 -912 • L1275-1281 • L1342-1346 • L1517-1519 • L1523-1525 • L1535-1537 • L1606-1609	• L. 12 • L16-20 • L 53-54 • L 56 – 57 • L85 - 87 • L 270-271 • L280-287 • L289-307 • L495-497 • 502 - 506 • L939-945	• L.4-9 • L.11 • L 210 • L290-293	• L. 19 • L. 22-35 • L42-46 • 1.2 L.77-83	• L. 3 • L. 5-7 • L14 • L20 • L25-27 • L34-35 • L39-40 • L44
Theme 2: Stress viewed through the eyes of caregivers	2.1 Manifestations of stress 2.2 Challenges faced by caregivers	• L1028-1033 • L1046-1054 • L1060-1063 • L1070-1072 • L1157-1163 • L1450-1452 • L1456-1468 • L161-171 • L181-183 • L186-198 • L120-211 • L218-221 • L389-391	• L546 – 548 • L560 – 565 • L568-569 • L571 – 575 • L901 - 902 • L61-65 • L66-70 • L94 - 101 • L129-133 • L186193 • L194-208	• L.. 104-106 • L110 • L. 15 -17 • L. 22-24 • L. 30-34 • L. 41-44 • L47 • L54 – 58 • L74 - 76 • L. 100-102 • L.179 – 181	• L222-223 • L236-243 • L250-254 • L351-355 • L. 89-94 • L.94-95 • L97-99 • L103-105 • L128133 • L256-263 • L314-317	• L134-137 • L157-160 • L.65-69 • L77-79 • L111-114 • L231-238 • L305-306 • L310-311 • L315-317
		• L412-419 • L483-486 • L520-529 • L575-576 • L654-663 • L694-704 • L727-733 • L784-790 • L826-832 • L845-848 • L856-860 • L864-871 • L875-879 • L956-965 • L1081-1084 • L1086-1091 • L1132-1133 • L1143-1148 • L1157-1163 • L1184-1191 • L1252-1258 • L1295-1300 • L1573-1581 • L1640-1648	• L209-221 • L308 - 326 • L398-399, 401 • L404-410 • L417 – 419 • L426 - 43 • L448 - 453 • L513-516 • L524 – 543 • L634 - 638 • L642 – 656 • L673-679 • L 679-698 • L710 – L713 • L715 – L740 • L816 – 825 • L880-888 • L933-938	• L. 186-187 • L.195-203 • L.212-216 • L. 219-222 • L. 226- 228 • L250-252 • L254-257 • L313-315 • L. 319-322	• L398 • L401-408 • L429-434 • L437-441	

Themes Identified	Sub-themes	Focus Group	Interview 1	Interview 2	Interview 3	Interview 4
Theme 3: Coping with stress	3.1 Religious beliefs 3.2 Lean on me 3.1 Internal	• L211-213 • L216-217 • L223-230 • L255-256 • L264-266 • L280-282	• L88 – 93 • L134 - 136 • L140-148 • L160-164 • L222-224	• L. 50-51 • L. 61-62 • L71 – 72 • L. 92-95 • L.110	• L168 - 176 • L188-194 • L205-208 • L303-310 • L332-338	• L. 94-95 • L100 • 104-106 • L108 • L144-145

	coping	• L289-293 • L320-324 • L994-995 • L1003-1004 • L1006-1011 • L1098-1105 • L1106 • L1107-1109 • L1124-1132 • L1319-1322 • L1443-1445	• L265-266 • L422-424 • L616-618 • L624 - 626 • L630 • L701 • L705 • L785 - 786 • L897-900	• L112 • L. 115-117 • L158-160 • L164-166 • L. 175 • L209 • L.276-277	• L.361-364 • L388-396	• L150-151 • L170-173 • L187-189 • L215-216 • L303-305

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