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An investigation into the emotional experience of caregiving

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Research Report for Masters in Community-Based Counselling

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A Research Report submitted in partial fulfilment of the requirements for the degree of Master of Arts in Community-Based Counselling Psychology in the Humanities Faculty, University of Witwatersrand, Johannesburg.

Declaration

I declare that this research project is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university.

Sign: _____

Date: _____

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ABSTRACT

The study investigated the experiences of formal caregivers within a community setting, and the emotional experiences of the individual caregiver. There is insufficient research into the subjective experiences and perceived role of the formal caregiver, as previous studies have concentrated on quantifying the role of the family or informal caregiver. Eleven interviews were conducted with participants from a community-based palliative care institution. The interviews explored areas of interest that surround caregiving, considering both the positive and negative factors that caregivers consider influential within the emotional experience, as well as the role of a formal caregiver. The study investigated the emotional challenges, motivations, support mechanisms and the perceived effectiveness of the coping strategies employed. The data was analysed through thematic content analysis, allowing for the selection of the most salient themes and subthemes, which converged around notions of caregiving and the positive and the negative elements within the caregiving experience of formal caregivers. The data was considered in relation to an interpretative phenomenological perspective, which allowed for the contextualisation and interpretation of the knowledge obtained through the study, and the augmentation of this knowledge with the knowledge already existing in the field of caregiving. The themes were able to provide an understanding of how caregivers construct their role as a formal caregiver, in comparison to the informal caregiver, and their perception of the importance of formal knowledge within caregiving. The themes also provided an understanding of the coping mechanisms and the contextual factors that interrelate with a caregiver's ability to manage the difficulties within caregiving and their emotional reactions. These findings illustrated that community-based caregiving, although subject to significantly more stressors, also has significant positive aspects that could be fostered to operate as protective mechanisms.

KEYWORDS: Caregiving, formal caregivers, emotional experience, community-based palliative care, interpretive phenomenology, South Africa.

CHAPTER ONE

Introduction

This chapter provides an introduction into the nature of caregiving and formal caregivers. The chapter also provides an understanding of the formal caregiver, and discusses the role of the context within the research. It also provides the rationale for the research, the aims of the research conducted, definitions of several terms utilised in the research, and, lastly, the synopsis of the chapters that follow.

Caregiving

Caregiving represents an area in which individuals, trained in various professions provide diverse services, from medical treatment to support. This primarily involves the holistic care of an ill individual. Caregiving is a fundamental occupation that plays a significant role in mental and physical healthcare. This is especially the case with regard to palliative care, which is pertinent within a society where medical technology is advancing rapidly, while the available resources wane. As a result of these technological advances, the average longevity has increased. However, simultaneously, the periods of disability have also increased and created a greater need for caregiving – in both the familial and formal caregiving contexts (Hoyert & Seltzer, 1992). The relevance of community mental health centres has increased substantially, especially in relation to the movement away from psychiatric institutions and their role in palliative care (Stengard, 2002). In this regard it is important to reiterate that caregiving operates within larger systems, and the influences within these systems are reciprocal in nature. The social ecological model provides the study with the opportunity to incorporate the interrelations and interdependence between the different factors within caregiving.

Li, Lee, Lin and Amidon (2004) indicate a distinction in relation to familial and formal relationships with the patient. Formal caregivers are considered individuals from several professions that provide care usually within nursing homes or palliative care institutions, but are not restricted to these settings (Clarke, 2001). “The caregiver’s role is defined as a set of

expected behaviours associated with being a caregiver" (Clarke, 2001, p. 29). Thus, research into formal caregivers may highlight elements, or certain expected behaviours that may not have been of concern within the context of informal familial relationships. The most prominent distinction between formal and informal familial caregivers is the relationship and the principles surrounding that relationship – especially those relating to the professional sphere. Formal caregivers are meant to abide by ethical principles which dictate the prevention of emotional attachment between themselves and the patient concerned – however this is very often inevitable as a result of the context in which the relationship is fostered (Clark, 2001). Furthermore, the origins of the stressors, as well as the stressors themselves will differ considerably between the professionals, facing these stressors within a work context, and those the familial caregivers may present as more personal concerns and stressors (Keith, 1995; Machac-Burleson, Henderson, Nelson, Hayslip, King, & Harman, 2008; Williams, 1993). In community-based palliative care institutions, caregiving operates as a resource to the community (Miller & McFall, 1991). It is important to maintain the resources available to ensure their continuation and succession. This is an important consideration in relation to the social ecological model, as the distribution of resources is highly significant in South Africa and succession provides a means to utilise the resources available and ensure progression.

Research aims

The study investigates formal caregivers' perceptions of the emotional experiences of caregiving. The study also explores both the positive and negative factors that the caregiver's perceive as influencing their emotional experience and caregiver's conceptualisation of the role of a formal caregiver. Through the exploration of these factors, the study seeks to contribute to current understandings of caregiving from the perspective of caregivers and provides insight into the specific elements that influence the emotional experience of individuals within caring professions. The study also explores the factors that contribute to both positive and negative emotional experiences. As such, the study investigates the emotional challenges and motivations, the presence of support mechanisms and the effectiveness of coping strategies. This also enables the study to examine any potential intersection between these elements.

Another aim of the research is to discover whether the perception of emotional experiences of caregiving, from the perspective of formal caregivers, differs to that of the family caregiver. The majority of previous research relates to the emotional experiences of informal caregivers. However, understanding how such a difference manifests may be significant to the caregiving field as a whole, but particularly the formal caregiving sector. Through this investigation, the complexity of the caregiving relationship is examined, with particular attention paid to the aspects specifically related to the professional realm of caregiving. The phenomenological nature of the study allows for the exploration of the rudiments within caregiver coping, burden, stress and burnout, compassion fatigue, compassion satisfaction and motivation within the specific context of formal caregivers in a community-based setting in South Africa. As the qualitative component is located within the phenomenological interpretive paradigm it allows the in-depth analysis of the subjective experiences of formal caregivers and allows the considerations of emotional aspects relevant to their subjective experience as a caregiver within a South African context. This is highly significant to being able to understand the different aspects within the systemic means of functioning, thus understanding the interplay between the individual and the other spheres of influence that have reciprocal effects upon one another.

Rationale

There are several factors that motivate for the current research. Dilworth-Anderson, Williams and Cooper, (1999), state that there is still a substantial need for research into the effects of caregiving. This is particularly important given the priority of palliative care in relation to the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic. Through the consideration of the emotional experience of caregiving, in relation to formal caregiving, knowledge can be generated, which furthers the understanding of the experiences of the caregivers (Pinquart & Sorensen, 2007). This research provides an opportunity to create and augment training programs for formal caregivers within, but not confined to, community-based institutions. Understanding the operation of the emotional experiences of caregivers may be useful in fostering greater capacity within these individuals, which would mobilise personal resources as well as the caregiver's health (Tugade, Fredrickson & Barrett, 2004). It could also provide a foundation for further research

especially in relation to skills that may be beneficial to these caregivers, and could potentially infiltrate into both the current, and the development of further training programs (Harding & Leam, 2005; Rowe, 2003; Scherck, 1999). The ability of the caregivers is intertwined with the emotional stability and well-being of the care recipient, in this manner the individual caregiver's well-being is intrinsically linked to promoting the well-being of the patients within their care (Decker & Young, 1991; Liebhaber, 2008; McCorkle & Pasacreta, 2001; Pinquart & Sorensen, 2007). Thus, the importance of the well-being of the caregiver, simultaneously allows for the well-being of the care recipient. This reiterates the importance of understanding the caregiver's experience and emotional factors that may influence the experiences of caregiving as a profession.

The majority of previous research into caregivers' emotional and physical well-being has simply quantified the understanding of caregiving, especially the consequences of the negative emotional components (Butcher & Buckwalter, 2002; Faison, Faria, & Frank, 1999; Kramer, 1993), that arise out of the complex relationship that is forged between the caregiver's well-being and that of the patient's (Keith, 1995). The inclusion of positive elements allows the research to consider a positive focus (Linley & Joseph, 2007), thus providing a balanced and holistic understanding of the caregiver's emotional experience. It also provides the ability to understand how positive factors may operate as protective factors, enhancing caregiver well-being. The process of understanding and awareness in relation to both negative and positive elements provides the knowledge needed to effectively counteract the negative elements, while fostering the positive elements to increase the well-being of the caregivers (Ngai & Cheung, 2009). This is often an area that the caregivers want to be able to discuss (Cohen, Colantonio, & Vernich, 2002). It also allows for the consideration of the maintenance of the well-being of caregivers and the implications of how to possibly initiate such maintenance in other caregivers (Yamamoto-Mitani & Wallhagen, 2002). In addition, this knowledge has the ability to influence theory and utilise the knowledge to inform preventative interventions within the caregiving field (Cohen *et al.*, 2002; Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt, & Van Den Bos, 1998; Pierce, Steiner, Govoni, Thompson, & Friedeman, 2007). This is especially relevant as previous studies in the United Kingdom and Australia have illustrated the high prevalence of stress and burden in palliative care nurses (Keidel, 2002), and few studies have considered the additional influence of contextual influences in relation to community-based palliative care caregivers. This is particularly important in relation to the South African context, as there are limited studies

into the formal caregivers within a community context, and the contextual factors in South Africa differ substantially from those in high-income countries, where the majority of previous research has been conducted.

South Africa's unemployment rates are at approximately 25.5 per cent (South African Business Guide Book, 2007/8). This provides an indication of the nature of the South African workplace and begins to illustrate the difficulties that may arise in relation to volunteer caregivers that receive some form of compensation for their work. This is further aggravated by high poverty rates. Poverty rates in 2001 were considered to be "approximately 57% per cent of individuals" all of whom were living below the line of poverty (HSRC in, Asmah-Andoh, 2009). These high rates of poverty and deprivation reiterate that the limited resources available need to be utilised in the best possible manner. Although palliative care is comprehensive in certain areas within South Africa, within the rural and disadvantaged community contexts it is still underrepresented, or nonexistent (Clark, Wright, Hunt, & Lynch, 2007). Thus, research into the advancement and promotion of human capital within these institutions is of primary concern both to the institutions involved, and to the community as a whole.

Conducting qualitative research into the experiences and personal understandings of formal caregivers allows for a more in-depth investigation into both the negative and positive aspects associated with the emotional experiences of caregiving. Such an exploration into the experiences of the caregivers allows for the acknowledgement of the complexity of caregiving and the opportunity to instigate change within the caregiving field. The results of this exploration can also operate as a fundamental component in future interventions and research within the field, particularly in relation to the South African context. The subjective understanding from the perspective of the individual caregiver, allows the research to gain a unique in-depth perspective of such a complex role within society. This is especially distinctive as the majority of research has quantified both the effects of emotional experience and the repercussions, without being able to explore the fundamental elements involved in the processes and the social context in which these emotional states arise. The proposed study also provides insight into positive elements that may be beneficial to reducing elements such as, burden and stress commonly associated with caregiving (Parks & Novielli, 2000).

This study considers burden and stress, burnout, and compassion fatigue, as the negative elements, while considering compassion satisfaction and altruistic motivation, as the positive

elements. These elements are frequently the foremost elements of concern in relation to previous caregiving research. Considering the role of coping with these caregiving experiences enables future studies and interventions which will help caregivers effectively cope with or manage the difficulties inherent in the caregiving process (Stengard, 2002). The emotional experiences and the caregiving relationship are intertwined (Cousineau, McDowell, Hotz & Hebert, 2003), with each element being particularly significant in the overall understanding of caregiving.

In palliative care institutions in particular, emotional management is often one of the most vital aspects necessary to maintain work requirements and satisfaction (Karabanow, 1999). This relationship is complicated further by the limited resources and the limited understanding of caregiving, especially in the context of formal caregivers. Hence, South Africa has a greater need to explore the emotional well-being and potential risks inherent within the caregiving role (Clarke, 2001), especially if such risks can be prevented through enhanced understanding of the caregiver experience. Greater knowledge in this area would aid in the efficient use of the limited available resources. Consideration of the contextual implications should be included in the palliative care programme, for the patients, the caregivers, and the organisation as a whole (Keidel, 2002).

Since the proposed study considers the caregivers emotional experiences intertwined with the role of a formal caregiver, it allows for the understanding of the perceptions that surround the role of a caregiver and the potential to alter and transform the current perspective. Previous studies have not considered the connection between the emotional issues and the notion of emotional labour (Karabanow, 1999). Insight generated may stand to be beneficial for further research and create understandings that may prove valuable to the educational process as well. It could also serve as a source of knowledge on how to approach and progress with the issues of importance within this sphere. The results could also encourage further debates and awareness, creating a foundation that could have vast effects for caring and caregiving as a whole – especially in relation to the sphere of formal caregiving.

Definitions

The terminology outlined below is utilised in the current study and provides an understanding of the meanings of these concepts in relation to their application in the current research.

i. **Caregiving** refers to the process of providing care to individuals suffering from an illness, terminal disease or physiological or psychological disorders. In the conceptualisation of caregiving as work, it is considered "something that requires skills that have to be acquired or learned" (Leira, 1994, p. 189).

ii. **Formal caregiver** refers to an individual that has been trained to provide care and carries out such care on an occupational basis.

iii. **Informal/familial caregiver** refers to an individual that provides care to a family member and has not received any training in caregiving.

iv. **Emotional experience** refers to the internal emotional and affective processes by which the individual is able to make sense of the caregiving process and influencing factors. It includes the positive and negative elements that influence their experience as a caregiver.

v. **Palliative care** refers to medical approach aimed at increasing quality of life, prevention of unnecessary suffering and holistic care in relation to patients that often have terminal illnesses but also illnesses that do not possess curative treatment (Birch & Draper, 2008).

Synopsis of the chapters

Chapter one provides the introduction to the emotional experience of caregivers as well as a broad understanding of the research and the rationale for the research conducted. It also provides the aims underlying the research conducted and definitions of some of the terminology utilised in the research. In this manner, chapter one provides an understanding of the foundational aspects upon which the research was built. Chapter two consists of the literature review, which considers the role of formal caregivers, and the nature of the

caregiving relationship. This chapter differentiates the formal caregiver from the informal or familial caregiver, and discusses the importance of the formal caregiver. It also considers the understanding of emotional experiences and the positive and negative elements that influence those experiences. Moreover, it provides an understanding of the interaction between these factors and the individual caregivers coping strategies. This understanding considers several positive and negative elements that may operate within the caregiving process, and how these factors influence the experiences of the caregiving process. The chapter also provides an account of the context of community-based palliative care in South Africa. This is particularly important as the context in many respects shapes the research and provides a new element that has not been significantly explored in previous literature. The chapter also provides an overview of the literature and notes the gaps in the literature. Lastly, the chapter provides a discussion of the theoretical framework and the rationale underlying the choice of framework.

Chapter three presents the method section which considers the research questions the study undertook and the manner in which both analysis and interpretation were conducted. It provides an overview of the importance and relevance of the approach taken. It explores the nature of the qualitative investigation and the specific method by which the research is analysed. By implication the section also considers the practical components of the research procedure, providing information regarding the contextual components and the specific details relating to the research participants. It also provides a discussion of the researcher's self-reflexivity. This is an important component within understanding the subjective nature of qualitative research and provides a sense of transparency and understanding of the researcher's contextual position. This chapter also provides an overview of the ethical considerations for the research conducted, the participants' rights and the ethical considerations specific to the research and the organisation.

Chapter four presents the results and discussion, which provides an overview regarding the emergence of the themes, as well as a discussion of the individual themes. These themes represent an understanding of the caregivers that participated in the study and their perceptions of their emotional experiences. The themes illustrate a variety of different perceptions in relation to formal caregiving within a community context in South Africa. The themes differentiate the role of formal caregivers, in addition to providing an understanding of the coping mechanisms the caregivers rely upon. The contextual factors and the underlying

motivations for caregiving are also considered in the results section. It also provides understanding of caregivers' experiences of loss; the occupational environment and the meaning-making processes relied on. Overall, it provides a cohesive interpretation of the themes in relation to the theoretical framework employed in the research.

Chapter five provides an overview of the research findings, drawing from the themes that arose in the results and discussion, in the prior chapter. It also provides the strengths and weaknesses within the study, as well as recommendations for future research in relation to the implications within community-based palliative care institutions in a South African context. The knowledge generated from the research fosters practical considerations in relation to interventions and means to increase caregiver well-being in formal caregiving settings.

Conclusion

This chapter provided the introduction into understanding the caregiver's emotional experiences within a community-based palliative care institution. It also illustrated the importance of the study, the relevance of the South African context with regard to the research conducted and the importance in terms of the social ecological model. Finally, it provides definitions of certain terminology within the research and a synopsis of the chapters that follow. The chapter to follow provides the literature review.

CHAPTER TWO

LITERATURE REVIEW

Introduction

The literature review considers the role of a formal caregiver and the nature of the caregiving relationship within the context of palliative care in South Africa. It considers the role of the context and the environment in relation to the understanding of the individual's role as a caregiver. The predominant focus is upon the emotional experiences of the formal caregiver and locating these experiences relating to the contextual sphere within a community based palliative care institution in South Africa. The emotional experience can be differentiated into the negative and positive emotional impacts, specifically stress and burden, burnout, compassion fatigue, and altruistic motivations and compassion satisfaction, respectively. The notion of motivation is considered in relation to both forms of emotional experiences, in the sense that both the negative and the positive aspects of the caregivers' emotional experience operate as motivation, thus the positive aspect focuses predominantly on the altruistic motivations of the caregiver. The coping skills and strategies are important in understanding the emotional experiences and the manners in which impacts on those experiences are managed and the interaction between the emotional experiences and coping skills. The literature review also provides an overview of the literature and the gaps within the literature relating to formal caregivers. Finally, it provides the theoretical framework relating to the current research.

The nature of caring, caregiving and formal caregivers

The term 'caring' is defined as "an enduring dyadic emotion that continues over the term and that serves as an autonomous motivation to see that the needs of a specific partner are met" (Bell & Richard, 2000, p. 75). This places caring as a distinct continuous emotion and in this sense fundamentally conceptualises it as functioning to fulfil a need rather than representing a pleasure; however, in the same token this does not imply that the need fulfilment is not a form of motivation (Bell & Richard, 2000). Although there is a broad conceptualisation of caring – there is no agreed definition and limited definitions are often not assessed in relation

to the formal and informal caregiver (Davies, 1995). The way in which caring is understood is dependent upon the society and context in which different rudiments of the definition are emphasised over others (Leira, 1994). Caring should not only be conceptualised as specific to the familial sphere, but also in relation to the formal caregiver (Leira, 1994). Caring work could be considered "as attending, physically, mentally and emotionally to the needs of another and giving a commitment to the nurturance, growth and healing of that other" (Davies, 1995, p. 18-19). The conceptualisation of caregiving as work is often problematic as these two understandings of caring, and work, are unable to merge (Leira, 1994). The central tenets, by which work is usually defined, are related to production and capitalism, are not applicable to the understanding and context of caregiving (Leira, 1994). Thus, caregiving as a form of 'work' often has inherent contradictions. It should also be considered that caring within the definition of work, is conceived as obligatory, in that the responsibilities have to be carried out as work commitments. At the same time, however, it could be argued that the formal caregiver chooses to pursue this career and in that sense takes on a different motive and ultimately a different conceptualisation of caring and the process of caregiving. Leira (1994) highlights caring as the attainment of skills through informal means. However, when caregiving is conceptualised as work, it no longer relies on the simplistic and innate characteristics of caring alone, but includes the formal skills required.

Navaie-Waliser, Spriggs and Feldman (2002) define formal caregivers as, "paid health care professionals or paraprofessionals" (p. 1249). Formal caregivers within palliative care organisations usually represent multidisciplinary occupations and have diverse roles within the specific context of palliative care (Clarke, 2001). Caregivers needs and means of relating are multiple and diverse in nature (Stengard, 2002), and also depend upon the nature of the relationship established between the patient and caregiver (Baronet, 2003; Clair, Fitzpatrick & La Gory, 1995; Faison *et al.*, 1999). This creates a sharp distinction between informal family caregivers and formal caregivers. Often formal caregivers remain in the caregiving role, thus being confined to the notion of helping others and not being able to be in need of help themselves. There is a plethora of research into the effect of caregiving on well-being within the sphere of family caregivers, yet little research into the formal caregiver (Herbert, Arnold & Schulz, 2007).

Faison *et al.*, (1999) considered specific elements of the caregiving relationship, such as mutuality and length of time as a caregiver, and found that both of these had an impact upon

the perception of burden. However, a formal caregiver would possess a different sense of mutuality to that of an intimate family member, and length of time would be substantially different to that of an informal caregiver, as formal caregivers usually provide care for a continuous period of time. Caregiving is often considered in relation to attachment, which fosters the notion of reciprocity and often aids in motivation (Solomon & George, 1996). Clair *et al.*, (1995) considered the amount of time as a significant factor negatively influencing the personal resources of the caregiver. This is important as it relates to the need for further research and understanding within the domain of the formal caregiver.

The role of a caregiver

According to Pearlin and Aneshensel (1994), "the proliferation and accumulation of stressors is another feature that differentiates caregiving from most other careers" (p. 377). Primarily, caregivers are family members and thus constitute informal caregivers. Palliative caregivers, however, are usually not confined to operating as inpatient caregivers and thus, are represented as formal caregivers. Research into the role of formal caregivers is limited as two factors hinder further exploration of this area. Firstly, the majority of tests that measure elements such as burden conceptualise the caregiver in a role distinct from that of their everyday vocation, relating burden only to familial dilemmas that surround the patient/family member. Secondly, the terminology relied upon is interconnected with the context from which it emerged, namely the family context, and considers a role distinct from a formal caregiver within palliative care. It is important to differentiate between the tasks performed by the caregivers and their subjective experiences as a caregiver (Nijboer *et al.,* 1998), as this highlights the distinction drawn between formal and informal caregivers. In addition, caregiving has been considered to more appropriately relate to the responsibilities than living with the patient (Reinhard & Horwitz, 1995).

As a caregiver a vast amount of stress is placed onto the individual, creating a position whereby their health, both physical and psychological may be compromised (Rowe, 2003). Pratt, Schmall, Wright and Cleland (1985) describe caregiving as both "extremely taxing and exhausting", with a multitude of contributing factors affecting the caregiver's well-being – such as coping, burden, stress, burnout, and compassion fatigue (p. 27). Having effective coping strategies is paramount given the elevated number of contributing factors and in

relation to what Rowe (2003) explains as society's "unrealistic expectations" of caregivers (p. 17). These unrealistic expectations then get placed on the individual and can create situations whereby the caregiver has a substantial amount of stress and burden relating to the caregiving process. These negative experiences are not isolated from the other skills and responsibilities each caregiver carries on a daily basis and consequently, have a continuous and accumulative effect.

As a healer and caregiver, empathy is seen as one of the necessary skills (Rowe, 2003) and this, at times, comes with a substantial expense to a caregiver's emotional and physical well-being, while at other times provides the motivating factor to continue caregiving. The individual caregiver identifies with the role of a caregiver, which creates a certain image of the caregiver and implicitly that of a patient. By implication the caregiver is usually unable to take on the role of a patient themselves as the two roles are unable to co-exist and are often contradictory in nature, usually resulting in the employment of certain coping strategies by caregivers rather than the adoption of the patient role (Harding & Leam, 2005). Often this role conflict is considered to be the motivation associated with caregivers creating active coping strategies (Clarke, 2001). These strategies can be beneficial provided that these coping strategies adopted are effective. The manner in which caregivers themselves perceive their role will influence the amount and type of support offered to them – thus, reiterating that the role of the formal caregiver is distinct to that of the familial caregiver (Payne, Smith & Dean, 1999).

Leira (1994) considers the connection between caregiving and work to be related to the need for the kind of satisfaction gained from the involvement with others. Often such work is conceived as labour because the caregiver engages in laborious tasks often within the confines of some form of attachment (Davies, 1995). The most difficult aspect of understanding work and caring is the unpredictable and varying nature of caregiving itself (Davies, 1995). Caregivers often have a fundamental responsibility of emotional management, regarding any emotional responses they may have in relation to the patient and the circumstances that surround the patient's well-being (Karabanow, 1999). Ultimately by taking on the role of the caregiver, the individual locates themselves in a role in which their needs are secondary to those of their patients' (Leira, 1994), but their role also needs to be located within the greater context (Davies, 1995). This is particularly important in

consideration of the interaction between different factors within the environment and the reciprocal effects they have on each other.

The caring relationship

The formal caring relationship presents fundamental differences when compared with informal caregiving relationships. The formal relationship presents a multidimensional consideration; the relationship between the caregiver and their position in the workplace, the relationship fostered between the caregiver and the patient; and the relationship with the community and the caregivers as a whole. The individual caregivers also have multiple roles within the caregiving sphere. This multiplicity may result in increased negative emotional experiences and consequently have implications for the manner in which the caring relationship is perceived and understood (Kim, Baker, Spillers, & Wellisch, 2006), as well as present several different ways in which to get into caregiving. This is particularly pertinent as the subjective construction of the interaction between the caregiver and the patient has an integral role in caregiver strain and motivation – these operate as factors which enable better caregiver and patient outcomes (Zweibel & Lydens, 1990).

Reciprocity is a component that often informs relationships. “It is relatively easy to adopt this self-giving attitude when we are in reciprocal relationships with like-minded people, or when our giving is acknowledged by an appropriate response” (Hudson, 2007, p. 25-26). However, in formal caregiving, the reciprocity that is experienced is often the individual’s attainment of some form of financial support. Self-interest is considered a prominent aspect in both the attachment fostered between the patient and the caregiver, and caregiving often presents within interactions between the caregiver and the patient (Finkenauer & Meeus, 2000). This is particularly emphasised in situations where there is insufficient acknowledgement from the community and the institution.

A significant component in the caregiving relationship is the impact of the involvement of the community within palliative care institutions. The nature and the dynamics within caregiving are constantly evolving and thus constantly present both demands and difficulties (Pearlin & Aneshensel, 1994). Building and forming relationships within community contexts often influences this process as the caregivers are frequently aware of or know the patients

within the palliative care institution (Luker, Austin, Caress, & Hallett, 2000). This often presents the caregivers with additional difficulties and burdens in relation to confidentiality regulations and simultaneously operating as part of the community. It is also important to reiterate that family burden changes over the course of the illness; however, with formal caregivers this differs, as several causes and different burdens are constantly present throughout the process (Chadda, Singh, & Ganguly, 2007). Formal caregivers are also exposed to continuous caregiving burdens, usually in several patients and work shifts of eight to twelve hours illustrating the increased exposure and time with patients (Evans, Bibeau, & Conley, 2001).

Emotional experience of caregiving

Intrinsic to the role of caring is the interpersonal connection and emotional processes which accompany it (Leira, 1994). In some sense the emotional experience of caregiving eludes to a similar concept of emotional labour (Karabanow, 1999), whereby the idea of caring as a 'labour' seems to indicate the negative impact of working with specific emotions and the responses towards such emotions. The key characteristic of emotional work is the dedication of the individual themselves, more directly than other types of work, which illustrates the potential costs and benefits that could follow from the individual experience of providing care within the caregiving setting (Wharton, 1999). The concept of emotional labour also implies the problematic element of emotions that arise out of the interactions with patients and their families (Wharton, 1999). In certain situations the caregiver may believe they are obliged to respond with certain emotions, thus adding another dimension of burden and responsibility to the caregiver (Wharton, 1999). In addition, emotional labour is considered the management of feelings in relation to circumstances that involve daily occurrences (Skilbeck & Payne, 2005). Labour is usually performed on the premise of some extrinsic reward (Himmelweit, 1999), thus in this sense caregiving can be considered as a process able to extract both positive and negative elements. Pavalko and Woodbury (2000) provide evidence that the process of caregiving has a consistent emotional impact on the caregivers' emotional management. The caregiver's emotional experience is concerned with both, the negative impact, which would manifest in the stressors, and the positive impact, these being the resources and satisfaction an individual may foster as a result of the caregiving process

(Clair *et al.*, 1995; Kramer, 1993). Often emotional impact is conceptualised as entirely negative, which is usually not the case (Pierce *et al.*, 2007)**.**

Caregiving should not be conceptualised as a situation that is devoid of elements of positive impact in relation to elements of negative impact. It is important to consider that the experiences will be multifaceted, presenting a combination of positive and negative elements (Pierce *et al.*, 2007). The best manner in which to conceptualise negative and positive experiences is in a ratio. Radley and Figley (2007) consider the positivity-negativity ratio – the former representing the positive effect, experiences and impacts, in relation to the latter – representing the negative effects, experiences and impacts that arise from caregiving. This conceptualisation is important as it allows for the consideration of negative and positive elements in relation to one another, which enables the depiction of an overall emotional impact that incorporates the interrelation between these elements. This study focuses on specifically two elements of positive impact – compassion satisfaction and altruistic motivation – and three elements of negative impact – stress and burden, burnout and compassion fatigue. These are the elements that are typically of concern in research into the cost of caring (Linley & Joseph, 2007). The cost of caring is often researched in an objective and quantitative manner. However, being able to consider the subjective importance caregivers attribute to the different positive and negative experiences provides the ability to gain an understanding of caregiving and the influences upon caregivers' experiences from a phenomenological perspective. This provides the ability to ascertain the caregivers' emotional experiences and the interaction between the contextual and personal factors within the other spheres of influence. These different facets within caregiving interact and alter one another (Pearlin & Aneshensel, 1994), thus understanding the factors operating within the emotional experience, in addition to those outside of the subjective experience but impact upon this experience, directly or indirectly.

Negative emotional experience

The negative emotional experience arises due to the stressful and demanding role a caregiver is confronted with on a daily basis (Pavalko & Woodbury, 2000). Steiner, Pierce, Drahuschak, Nofziger, Buchman and Szirony (2008) illustrate the negative impact caring has on the well-being of the caregiver. Caregivers' negative emotional experience is often related

to the continuous process of stress production and the creation of negative patterns. Thus, the time period as a caregiver would have a considerable impact upon the degree and severity of the emotional consequences (Kramer, 1993; Pavalko & Woodbury, 2000). This theory of 'stress proliferation' is in contrast to the 'adaptation' theories, which claim that increased contact with stress may have a stabilising effect after a certain period of time (Pavalko & Woodbury, 2000, p. 94). Nijboer *et al.* (1998), however, support the stress proliferation theory describing a steady increase in health problems in parallel to the time spent as a caregiver – the greater the exposure to certain experiences; the greater the chances of the individual being far more susceptible to health degeneration (Nijboer *et al.*, 1998). These negative impacts are usually associated with "stress, strain, burden, depression and overall decrements in well-being" (Clair *et al.*, 1995, p. 195). Stress is important as it can operate as a precipitator to burden. Situational stress is commonly associated with the concept of burden. Primary stressors are those that arise from having to care directly for the patient, while secondary stressors are indirectly related to caregiving (Pearlin & Aneshensel, 1994). Within the context of the study; situational stress is considered the stress that arises as a result of the process of interaction inherent in the caregiving relationship (Dilworth-Anderson *et al.*, 1999; Goldberg-Arnold, Fristad, & Gavazzi, 1999). Often the nature of the caregiving relationship, as over-involved and overinvested, increases the caregiver's vulnerability to burnout, burden and compassion fatigue (Keidel, 2002). This is further exacerbated by the constant exposure to loss and the constant reminder of one's own mortality (Keidel, 2002). In addition, the role, and thus the lifestyle, of the caregiver is altered and this may create feelings of isolation, and the accumulation of such factors can have ruinous effects on the individual themselves (Payne *et al.*, 1999). Furthermore, the negative aspects, such as compassion fatigue and burnout, often lead to decreased occupational performance, and this makes caring for patients significantly more difficult (Keidel, 2002). Such difficulties can manifest in strained interpersonal relationships between colleagues and within the institution as a whole (Keidel, 2002), in addition to strains within familial relationships.

Stress and burden

Caregiver distress and stress, often functions as caregiver burden (Given *et al.*, 2005). It is important to illustrate that there can be healthy levels of stress that may allow the caregiver to operate more efficiently and provide motivation for their work. But excessively high levels of

stress can be damaging and this form of caregiver stress has been related to several physiological symptoms and disorders, with depression being the most predominant (Tsai & Jirovec, 2005). Caregiver burden can also be considered as strain, which can be referred to as "physical, psychological, social and/or financial reactions that can be experienced in giving care" (Nijboer *et al.*, 1998, p. 4). Burden and distress are usually manifested in physiological means, often presenting with depressive symptoms or depression (Given *et al.*, 2005). Tsai and Jirovec (2005) consider stress as one of the emotional aspects of coping strategies, as stress is usually the perception of experience rather than the objective reality. This should also be considered in relation to the specific types of tasks which may present in a distinct manner when comparing a formal caregiver's role to that of the familial or informal caregiver (Nijboer *et al.*, 1998). However, it is important to reiterate that burden and distress are usually the result of experiencing a sense of responsibility which is not negated within the formal caregiving role (Given *et al.*, 2005). This notion of responsibility may relate to a sense of or lack of reciprocity, alternatively manifesting as a relinquishment of responsibilities often within the individual's personal life (Given *et al.*, 2005). Stress and burden are inherently related to coping and the coping strategies of the caregiver, because the manner in which the caregiver perceives the experiences within the caregiving field reflects the resolution of the stress or, alternatively, the augmentation of the stress. Coping strategies enacted in reaction to stress are usually temporary in nature and thus will not operate to protect the caregiver in the future, having a profound effect upon their well-being (Tugade, *et al.*, 2004). The relation between caregiver stress and depression is considerably high, with several factors such as the environment and gender influencing and mediating the relationship (Tsai & Jirovec, 2005).

Dumont, Fillion, Gagnon and Bernier (2008) define burden as a "psychological and emotional experience related to the perception of different demands that are specifically associated with accompanying and providing care for a dying person" (p. 153). This definition allows the concept of burden to relate to the palliative care context, while also including the psychological and emotional dimensions of burden and not limiting the caregiver role to simply a family or informal caregiver. Moreover, burden is linked to the responsibilities relating to caregiving substantially more than the element of living with the patient (Chadda, *et al.*, 2007; Reinhard & Horwitz, 1995). This is important, as formal caregivers carry a substantial amount of responsibility, not simply to the patient, but also the context surrounding that patient, which often includes elements such as the well-being of the

family. Burden is comprised of several components, either negative or positive depending on its ability to negatively or positively influence the caregiver's experience. It can have a positive effect, such as prevention against burden for example support, or a negative effect, which are usually those components precipitating the negative consequences of burden (Reinhard & Horwitz, 1995).

The conceptualisation of burden is not necessarily simplistic, as it is heavily dependent on the context in which it arises. Dumont *et al.* (2008) highlight the importance of the distinction between objective and subjective burden. Objective burden relates to the observable changes and demands, while subjective burden is the aspects of burden referring to the emotional experiences involved (Dumont *et al.*, 2008). This study conceptualises burden as having two aspects; the first being the cognitive aspect relating to the needs of the patient, and the second being the individual experience of burden. This study focuses predominantly on the latter component, exploring subjective perception of burden and its role in the emotional experiences of caregiving.

The dimensions of subjective burden are considered to be dependent upon other factors such as, the resources available, the interpersonal relationships with patients and the support systems obtainable (Dumont *et al.*, 2008). Resources, interpersonal relationships and support structures, all play a significant role in coping and the strategies people adopt. These two variables – coping and subjective burden – clearly illustrate a mutual interaction between the following three facets: coping, coping strategies and burden. By assessing the levels of burden, there is an indirect assessment of the coping strategies available to the individual, which also enables the identification of those individuals that are at risk for potential physical and emotional deficits as a result (Baronet, 2003; Parks & Novielli, 2000).

Increased burden may have an immense effect upon the physical and psychological health of caregivers (Faison *et al.*, 1999). Caregiver burden is considered the cost of the well-being of the individual as a result of providing care to others in need. Parks and Novielli (2000) emphasise the importance of assessing an individual's perceived sense of burden in the process of maintaining well-being. In attempting to deal with burden, caregivers employ certain coping strategies (Chadda *et al.*, 2007). These coping strategies provide the caregiver with the means to deal with the challenges of constant care, both as a formal caregiver in a palliative institution, or as an informal family caregiver. However, the understanding that formal caregivers also experience burden with patients, even though they do not pertain to the

direct familial environment is often left unnoticed (Pratt *et al.*, 1985). This is particularly relevant as the rural or community-based organisations often present with substantially fewer resources and an overburdened workload which increases the stress and burden levels of the caregivers (Dwyer & Miller, 1990). Environmental influences often have a much more severe effect and these stresses usually implicitly influence the caregiver's burden. Consequently, the interaction between the environmental elements should be a primary concern. This is particularly important in acknowledging the interaction and the reciprocal influences they may have on each other.

Burnout

The term burnout is conceptualised as a state of being that is "associated with feelings of hopelessness and difficulties in dealing with work or in doing your job effectively" (Stamm, 2005, p. 5) and these feelings generally arise over a period of time. Initially, burnout was considered an occupational stress that arose from the demands and intense emotionality among healthcare workers (Maslach & Schaufeli, in Ngai & Cheung, 2009). However, these considerations of burnout seem to be indicative of only the occupational environment and often could not be extended to other influencing factors. Thus, burnout can more appropriately be considered to relate to enduring minor stressors over an extended period of time (Kulik, 2006), allowing the definition to simultaneously account for factors outside of the occupational environment. However, there is some discrepancy between the different understandings of the term burnout, and there is no single definition for what amounts to burnout (Maslach, Schaufeli, & Leiter, 2001). Burnout can be conceptualised as the relationship individuals foster with their occupation, often referring to the overextension, physically, emotionally (Kahn, 1993; Maslach *et al.*, 2001) and mentally (Keidel, 2002).

The most prominent underlying aspect of burnout is exhaustion (Maslach *et al.*, 2001). Exhaustion is often, incorrectly, considered to be only a physical aspect without the implications of emotional demands, such as depersonalisation (Maslach *et al.*, 2001). The duration of time an individual is exposed to caregiving, influences the burnout they may experience (Linley & Joseph, 2007), and caregiving over a longer duration is often associated with fluctuating feelings of care (Meagher, 2006). This highlights the significance of the continuous nature of formal caregiving, as opposed to the shorter defined period to which

informal caregivers are exposed, reiterating the significant impacts upon the formal caregiver's well-being. Burnout has been considered the element within caregiving that hinders compassion satisfaction and elements of personal growth by preventing the individual from being able to obtain positive affect and experience within the caregiving sphere (Linley & Joseph, 2007). In particular, the caregiver often has a reduced sense of competence and becomes detached from the work related processes (Maslach *et al.*, 2001). Burnout is usually associated with an environment in which a caregiver's work is unaccommodating, or an extremely heavy workload (Stamm, 2005). Both of these are factors that are continuously present in community institutions, especially within the South African context and in communities with limited available resources. Burnout is of great concern as it is considered as the initial indication of emotional exhaustion manifesting as compassion fatigue (Ngai & Cheung, 2009). It can also result in negative self-concept, attitude, or loss of concern or feeling (Keidel, 2002). Burnout leads to negativity and the prolonged exposure to burnout increases the risk of compassion fatigue (Radley & Figley, 2007). Both burnout and compassion fatigue have similar risk factors or stressors, however burnout manifests as a gradual and increasing response to these stressors, whereas compassion fatigue is often more severe and sudden in nature (Collin & Long, 2003). As a result burnout may undermine the connection between the patients and the caregiver (Kahn, 1993), particularly in situations where the effects of burnout, such as negativity, are continuous and in many respects pervasive in nature.

Compassion fatigue

Compassion fatigue is defined as "the secondary exposure to extremely stressful events", while in burnout, the symptoms associated with compassion fatigue usually arise immediately and relate to a specific event (Stamm, 2005, p. 5). It can be considered the cost that is associated with caring (Figley, 2002). The term secondary trauma is synonymous with the term compassion fatigue, in that the exposure to the traumatic event is not primary experience but rather through a secondary experience, and it is through this secondary experience that the symptoms arise (Stamm, 2005). Professional caregiving may result in a cost as the effects of exposure to emotionally taxing experiences and the administering of care within situations that are highly distressing can compromise the psychological and physiological well-being of a caregiver (Munch, 2007). Compassion fatigue is also considered a natural process (Adams,

Figley, & Boscarino, 2008), and is commonly associated with caring professions, because the caregivers have an inherent compassion for humanity. While this is usually the motivation to enter into these professions, often it is this very same factor that can deplete a caregiver's emotional resources and damage the well-being of the caregiver in the process. This is particularly the case in the public sector, such as formal caregivers and nurses (Wright, 2004). Usually the caregiver will take on the emotional difficulty presented not only by the patient but the family of the patient as well (Radley & Figley, 2007**).** This leads to the depletion of personal resources and manifests in compassion fatigue. Compassion fatigue often presents as both "sudden and acute" (Collin & Long, 2003, p. 19).

There are several risk factors that make the individual more vulnerable to compassion fatigue, such as high workload, previous traumatic experiences, the working environment, the support available and the caregiver's worldview and self-awareness (Killian, 2008). Although there is no consistent evidence, a substantial amount of research indicates that caregivers from disadvantaged groups are more susceptible to compassion fatigue (Adams *et al.*, 2008). Compassion fatigue embodies a sense of disempowerment, although it could also be argued that compassion fatigue, in many respects, operates as a coping mechanism by allowing the carer to defend against further difficulty (Wright, 2004). However, often it is this defence that prevents the carer from obtaining "care and insights we might receive from one another" (Wright, 2004, p. 3). It also creates a sense of depersonalisation, whereby the individual withdraws or adopts a sense of cynicism (Maslach *et al.*, 2001). This means that within a caregiving context the caregiver would withdraw, resulting in potentially damaging effects upon the caregiver relationship fostered with the patients. Burnout creates a cycle which seems to reiterate the sense of despair experienced by caregivers, and further isolate the caregiver, often simultaneously disempowering the caregiver.

Positive emotional experience

Unfortunately the environment of caregiving often operates as a precipitating factor to several negative aspects within the caregivers experiences. However, positive identification with the caregiver role has the potential to prompt several positive outcomes within caregiving (Karabanow, 1999). Often this is significantly difficult for the caregiver, as most caregivers experience great difficulty labelling such emotions and experiences, and this ability to label

the experiences and emotions is connected to significantly more functional coping strategies (Tugade *et al.,* 2004). Pavalko and Woodbury's (2000) study illustrated that although negative consequences are present, the rewards, motivation and satisfaction play a significant role in the positive impact of caregiving. In a study conducted by Pierce *et al.* (2008), caregivers reported higher successes overall within the first year of caregiving (Pierce *et al.,* 2008). Positive emotions play a significant role in overcoming and coping with difficult situations that may arise within a caregiving context (Tugade *et al.,* 2004). Radley and Figley (2007) place emphasis on the consideration of the positive elements that have a considerable effect on the manifestation of negative elements and the outcome of an individual's well-being. These positive emotions serve to protect the caregiver from negative health outcomes (Tugade *et al.,* 2004).

The connection between caregiving and work, conceptualised by Leira (1994), considers it to be the motivation of some people to derive fulfilment from the emotional involvement specific to the caregiving relationship. Karabanow (1999) considered the ideal role of an individual in a caregiving profession to be one that is present and invested in the individuals' or patient's well-being. Both emphasise emotional investment and in some way pertain to the inherent potential of that investment. Caregiver positive well-being can be considered to be linked to compassion satisfaction and the motivation of personal growth and positive psychological changes (Linley & Joseph, 2007). This is usually demonstrated within the caregiving process in relation to recognition, meaning, purpose and positive experiences (Nijboer *et al.,* 1998).

Compassion satisfaction

Compassion satisfaction is one of the positive emotional experiences associated with caregiving. Compassion satisfaction can be defined as, "the pleasure you derive from being able to do your work well" (Stamm, 2005, p. 5). Radley and Figley (2007), consider compassion satisfaction as, "feelings of fulfilment" (p. 207). It can be more simplistically understood at the reverse of compassion fatigue (Killian, 2008). Compassion satisfaction is important as the caregivers are placed in a distinct role in which they provide an empathetic connection (Radley & Figley, 2007) and caregivers that attain compassion satisfaction are considered to be more able to provide the necessary care (Killian, 2008). Through this

connection a great sense of compassion usually arises (Radley & Figley, 2007). There is a definite link between compassion and the altruistic motivations that guide the caregiver into the field of care work (Radley & Figley, 2007). Furthermore, compassion satisfaction has also been associated with greater levels of social support and "internal locus of control at the workplace" (Killian, 2008, p. 41).

Through establishing enjoyment in the caregiving process the caregiver is provided with the opportunity to find satisfaction, which ultimately manifests in compassion satisfaction (Radley & Figley, 2007), while simultaneously having a positive effect upon the patient. Caregivers that possess compassion satisfaction present a more competent and motivated approach to caregiving (Radley & Figley, 2007). This results in vast implications for the other facets within the caregiving process. Often compassion satisfaction is facilitated through a sense of pride that is fostered within the caregiver and the sense of identity that ensues from their experience as a caregiver (Nijboer *et al.,* 1998). It's important to understand that compassion satisfaction is not easily attained. The realities of the experiences and situations that caregivers endure are not easily translated into this sense of fulfilment (Radley & Figley, 2007). However, compassion satisfaction should be considered a vital construct to detract or minimise the effects of compassion fatigue (Radley & Figley, 2007). The coping strategies employed and the affect present, if positive, contribute to the level of compassion satisfaction experienced (Radley & Figley, 2007). This is especially the case in relation to satisfaction operating as a 'coping resource or therapeutic intervention' which means the focus on the positive often wards off the presence of the negative aspects (Cohen, *et al.,* 2002).

Altruistic motivations

Altruistic motivations, like compassion satisfaction, are also an element of positive emotional experiences and can be distinguished from other forms of motivation. Caregivers often rely on the intrinsic reward that accompanies the role of a caregiver as a means to sustain them through any negative experiences and to build on their motivation (England & Folbre, 1999). A distinction should be drawn between the motivation and the actual activity of caregiving (Himmelweit, 1999). The experience of positive emotions can have a direct effect upon all the different resources available to the caregiver, which implicitly gives rise to a greater sense

of well-being (Radley & Figley, 2007). Motivation is considered a key component to understanding the role of the caregiver – especially with regard to the coping strategies. The altruistic motivations that many caregivers possess are the same factors that influence the caregiver's conceptualisation of negative and positive experiences, which are integral to the coping strategies an individual adopts. Altruism is the "enduring tendency to think about the welfare of other people, to feel concern and empathy for them, and to act in a way that benefits them" (Penner & Finkelstein, in Ngai & Cheung, 2009, p. 108). This element of altruism enables the individual to have adaptive coping strategies in relation to the stresses involved in caring work (Ngai & Cheung, 2009). These altruistic motivations also include the notion of fulfilment as a motivating desire (Cohen *et al.,* 2002).

Within this sense of professionalism certain motivations are often enveloped in idealistic notions, and these notions are often the aspect that leads to emotional exhaustion and even compassion fatigue (Ngai & Cheung, 2009). Thus, motivations that are more grounded in realistic understandings of the profession, and the demands related to the profession, would provide a healthy and protective element against emotional exhaustion and compassion fatigue. When the caregiving process is considered a profession that has motivated individuals deriving enjoyment from their work within the caregiving sphere, these individuals are less likely to be compromised by the stresses, potential burnout and elements of burden that are inherent to the process (Ngai & Cheung, 2009). The positive effects of caring are often obtained through the vicarious experience with patients (Linley & Joseph, 2007). These effects then infiltrate into the motivations of the caregiver and promote a positive approach, and conceptualisation, of the caregiving role.

Coping and coping strategies

The term 'coping' refers to the employment of certain behaviours and internal processes in response to difficult situations (Scherck, 1999). The utilisation of and access to particular coping mechanisms differs depending on the individual and the context in which the coping is sought (Raina *et al.,* 2004). Coping strategies are viewed in two distinct categories; emotion-focused and problem-focused (Parks & Novielli, 2000). Emotion-focused coping is concerned with the emotional strain surrounding a situation; while alternatively; problem-focused coping considers a structured approach towards strain, as if seeking a solution to the

presenting problems (Scherck, 1999). A secondary distinction can also be made between internal and external coping strategies, thus providing a multifaceted understanding of coping structures an individual may employ (Pratt *et al.*, 1985). Although coping is considered a stable variable that occurs over a given period of time, often the strategies employed differ amongst people and over time (Scherck, 1999). Coping strategies should not be considered simply as reactions but rather as actively employed strategies which create a resource that has the potential to influence the caregiver's well-being (Tugade *et al.*, 2004). Coping strategies are often considered as vital mediators within the caregiving experience (Cohen *et al.*, 2002).

Even though coping is a stable construct, strategies that caregivers could potentially benefit from, should be implemented initially and the maintenance of such strategies should be a priority (Rowe, 2003). Wittenberg-Lyles, Oliver, Demiris, Petty and Day (2008) relate the burden of caring for patients to the inadequacy of available support; however this is not always the case. This reiterates the importance of research into understanding the coping strategies in caregivers, especially since coping strategies are considered vital in assisting caregivers in managing burden and as a preventative measure against affective disorders commonly associated with caregiving (Parks & Novielli, 2000). Coping strategies are often implicated in positive emotions forming the basis for coping strategies (Tugade *et al.*, 2004). Often this is referred to in relation to the undoing hypothesis – that the positive emotions are able to 'undo' the difficulties that negative emotions may manifest or create (Tugade *et al.*, 2004). Thus, the connection between the positive and negative emotions highlights the importance of the relationship between the two within the caregiver's emotional experience.

Spirituality as a means of coping

Coping and coping strategies can take on various forms, and one of the most prominent forms is spirituality or religiosity as a means of coping. Such a form of coping is often invoked due to the nature of the work and the existential questions that arise from caregiving. Defining spirituality is immensely difficult; there are several different constructions of spirituality (Gebhardt, 2008), and little agreement amongst these constructions (Chiu, Emblen, van Hofwegen, Sawatzky, & Meyershoff, 2004). Spirituality is a multidimensional construct, and in this manner there are various dimensions that both manifest and relate in various different ways (Stefanek, McDonald, & Hess, 2005). The term spirituality is often considered to be

interchangeable with that of religiosity (Baldwin, McDougall, & Evans, 2008), however it can be considered to be more involved in the role of meaning within life than simply restricted to religious beliefs (Doherty, 2006). It is more encompassing to consider religion as an element within a broad understanding of spirituality (Baldwin *et al.,* 2008). In many respects each individual represents a spiritual being seeking connectedness, fulfilment and belonging, however, not all individuals ascribe to religious beliefs (Doherty, 2006). Spirituality is related to the notion of human connectedness and operates as a means to enhance quality of life (Baldwin *et al.,* 2008). Spirituality often conveys meaning to the individual and in this manner, through spirituality, the caregiver is able to alleviate negative emotional influences within the caregiving experience. These beliefs, inform coping strategies which are considered to be connected to "adaptive health outcomes" (Pendleton *et al.,* in Baldwin *et al.,* 2008, p. 254). Doherty (2006) claims that spirituality and this manner of seeking meaning and connectedness, is the element that provides individuals with the coping skills that allow for adaptation to difficult circumstances. It has also been considered to have mediating effects on issues relating to stress (Chiu *et al.,* 2004).

Often it is these beliefs that provide the individual with a sense of hope and means of support (Baldwin *et al.,* 2008; Scherer, 1996). This is particularly important as palliative care institutions are founded upon the importance of holistic processes and providing the patient with spiritual support. Thus, in many ways having spiritual beliefs operates as a source of support for themselves. Spiritual beliefs, consequently, play a significant role in the caregivers' perception of caregiving, the role of their emotional experiences, and in palliative care institutions as a whole. It should also be noted that although several individuals may be religious or spiritual, it doesn't necessitate that religion is their source of support (Sato, Ricks, & Watkins, 1996). Spirituality is, however, a prominent component within palliative care institutions (Paley, 2008). Caregivers are often placed in the role, whereby they are the source of spiritual direction for the patients (Doherty, 2006). Spirituality has also been implicated in patients' recovery processes and in this manner it is not only fundamental to the caregivers' well-being but also implicated in the patients' well-being (Gebhardt, 2008). Spirituality also considers the implications in association with loss and existential crises (Paley, 2008), providing a means for caregivers to make sense of their experiences as a caregiver, in particular, the constant exposure to situations of death and dying within the palliative care institutions.

The relationship between coping and emotional impact

The relationship between coping and a caregiver's emotional experience is intricate (Chadda *et al.*, 2007). The effect of both negative and positive factors upon the individual, as well as the interrelation of coping and coping strategies presents a complex connected understanding of these facets within the context of caregiving. "Assessing caregivers' distress and helping them manage their problems, along with identifying and building on their successes, are critical to long-term adaptation" (Pierce *et al.*, 2007, p. 7). Both positive and negative elements are significant factors in the well-being of the caregiver, especially in relation to coping. Positive emotional impacts may have an alleviatory effect upon the negative emotional impacts (Tugade *et al.*, 2004). The role of coping strategies presents the link between these two factors. The role and process of caregiving is dependent upon the coping strategies adopted and these are used to regulate the caregivers' emotional experiences which are inherently related to the caregivers' well-being (Tugade *et al.*, 2004). For example, the experience of burden is much higher when accompanied by minimal coping and ineffective coping strategies, while lower levels of burden are usually associated with active, effective coping strategies (Chadda *et al.*, 2007; Parks & Novielli, 2000). The coping strategies available and those employed by the individual have an effect on the outcome and the perception of the emotions experienced. Ineffective coping strategies may increase the number and degree of emotional impact upon the individual, while effective coping can operate as a protective element in this regard. The protective factor can be seen in coping strategies that sustain positive emotions, which can be relied upon as a resource against any negative influences and can replenish coping mechanisms (Tugade *et al.*, 2004). Thus, positive emotions aid positive coping strategies by providing the individual with enhanced resources and protection. In Decker and Young's (1991) study the success of hospice home care was dependent upon the caregivers coping and their ability to manage their own well-being, which included both the negative and the positive elements.

Considering the concepts introduced above, the social exchange theory can account for both the positive and negative experiences related to caregiving. Social exchange theory assumes that people innately seek out the maximum rewards, while ensuring the smallest costs within interpersonal contact (Wright & Aquilino, 1998). Social exchange theory in congruence with equity assumptions, allows for the correlation of discontent or negative emotional impact with a disproportionate interpersonal exchange (Wright & Aquilino, 1998).

Thus, the theory considers relations of power and equity to be evident within caregiver interactions (Sinunu, Yount, & El Afify, 2009). It also considers that often individuals engage in the act of caregiving in order to make reparation for any particular damage done, or for the repayment after having personally received or having a family member receive such care (Sinunu *et al.*, 2009). By implication, through assessing the positive and negative outcomes, there can be the consideration of the balance or imbalance within the interpersonal relationship created through caregiving. The manner in which the caregivers conceptualise these emotional experiences is indicative of the emotions that play a significant role in the coping strategies employed (Tugade *et al*., 2004).

The social exchange theory can also be considered in relation to the behavioural patterns that are utilised in order to maintain a balance or sense of homeostasis. The exchanges that do occur within the system function in order to maintain a sense of homeostasis and maintain a balance or ratio. This could also be connected to the positivity-negativity ratio conceived by Radley and Figley (2007) as the system needs to provide a balance between the positive and negative elements within the caregiving process. Pierce *et al.* (2008) consider four dimensions of importance within the homeostasis of the system. These four elements are system maintenance, coherence, individuation and system change. Maintenance thus considers the practical aspects as well as the self-care aspects (Pierce *et al.*, 2008). Coherence relates to the process of self-identification and sense of peace, while individuation is the process through experience and learning that one develops (Pierce *et al.*, 2008). These processes lead to system change, which relies upon the awareness of the change which then instigates new behavioural patterns (Pierce *et al.*, 2008). Through this process the system is changed and advanced to maintain a homeostasis, without which impingement may occur. However, often this theory presents a mechanistic account of caregiving. Thus, the current research locates caregiving within the social ecological framework, providing an understanding of how caregiving may operate within the larger spheres, and emphasises the interactions between the spheres. The caregivers' subjective experiences provide a significant element to understanding the interactions and the behavioural patterns that occur within the microsphere and how the microsphere is influenced by other systems in turn.

Caregiving in the South African context

Understanding the interaction from the multiple different spheres of influence is important in conceptualising caregiving in a holistic manner and understanding the elements unique to the South African context. The South African context encompasses an understanding of the contextual influences, and how the caregiver may in turn influence the environment. South Africa has been faced with endemic proportions of palliative care cases, which are increasing exponentially as a result of the burgeoning AIDS epidemic (Demmer, 2007). This has had an increased effect upon the rural and disadvantaged communities (White & Morton, 2005), but is not restricted to such. The AIDS epidemic is often further exacerbated by the limited financial and material assets, within other spheres of the environment (White & Morton, 2005).

Although HIV/AIDS is often the predominant focus there is a significant need for palliative care for other terminal illnesses, such as cancer. Cancer is considered the third highest cause of death amongst Black South Africans and the second highest amongst White and Coloured South Africans (Beck, 1999). In addition to these high rates of prevalence, the incidence rates in the years 1990-1991 was approximately 152 new cases every day (Beck, 1999). The pain that accompanies cancer is recognised as a significant health concern globally, and this particularly significant to palliative care, as a substantial amount of cancer patients in South Africa are not provided the necessary pain relief (Beck & Falkson, 2001).

In South Africa palliative care should be considered a much higher priority and have an integral role within the response to the AIDS epidemic (Singer & Bowman in Skilbeck & Payne, 2005) and the management of pain associated with cancer. Previous research has illustrated disparities in relation to regional differences, especially in relation to the distinction between rural and urban areas (Schneider, Luckmann, Behmann, & Bisson, 2009). In South Africa, a substantial amount of the individuals live in rural areas, approximately slightly fewer than fifty percent of the population residing in rural areas and the majority of those individuals are considered ‘poor’ (Asmah-Andoh, 2009). Underlying these factors are those relating to poverty and powerlessness, which can be considered a fundamental component of previous regimes during the apartheid era in South Africa. The inequities from the apartheid legacy have greatly influenced the health services in South Africa and in particular the availability of resources (Beck, 1999; Beck & Falkson, 2001). In a consideration of the contextual understanding it is important to acknowledge the nature of

health in South Africa, as well as palliative health care and the constant challenges within these systems. The poor presence of palliative care is also largely related to the specific training required and the stigma associated with palliative care, and diseases such as HIV/AIDS (Uys, 2003). This stigma is linked to social rejection, which often results in individuals avoid gaining assistance in fear of the stigma attached (Uys, 2003). This stigma is considered one of the most significant challenges to the health care system's response to the epidemic (Desmond, Gowa, Loening-Voysey, Wilsond, & Stirlinge, 2002). Furthermore, there is a division in relation to the presence of palliative care institutions in the rural versus the urban contexts (Clark *et al.,* 2007). In many disadvantaged areas in South Africa health care services are limited, under resourced and often overburdened. It is these factors that have a secondary effect upon the need for palliative care institutions, especially community-based palliative care institutions. This is further exacerbated by the poverty in which terminal patients are often treated, creating a vicious cycle (Uys, 2003).

Although there are a significant amount of institutions, it is important to realise that the population is large, the need is great and that South Africa has one of the highest HIV/AIDS prevalence rates in the world (Demmer, 2007). As a result, South Africa possesses a substantial demand for such services. Especially as the majority of funding is allocated to preventative public health measures and thus attention is not directed towards palliative care initiatives (Akinsola & Mulaudzi, 2009). Often the community palliative care institutions that are available either operate as non-profit organisations (NPO's) or non-governmental organisations (NGO's), both dependent either upon minimal governmental support and additional independent funders or are solely based on independent funding. Palliative care institutions also require specific training (Uys, 2003). However, this specialised treatment is often unavailable, and most formal healthcare services in South Africa were considered to have poor palliative care services (Uys, 2003), further burdening the organisations providing palliative care. Thus, the implications of the above are that the caregivers, although trained, receive trivial payments which usually operate as stipends rather than salaries. However, given the economic and the unemployment status within South Africa, these positions as caregivers, are often the only plausible opportunity for employment for many individuals. This means that caregivers may occupy the position of "volunteers", while treating the position as a full time job.

Community volunteerism has significant implications, especially in a field such as palliative care, as the effects of the job are often difficult and in many situations unmanageable. Although the effects of caregiving are often unmanageable they are considered, in many cases, the only alternative available. Implicit in volunteerism are altruistic concerns, however, the opportunities provided to caregivers also provide secondary gains in the form of palliative care training and work experience (Swart, Seedat, & Sader, 2004). In studies conducted by Swart *et al.,* (2004) in low-income communities and in neighbourhoods where poverty is prevalent the sources of reimbursement, either through food or transportation costs, were a significant contributing factor to participation. Although there are initial altruistic values that may spur the individual to be involved in palliative care institutions there are also substantial factors, such as the individual's livelihood, that need to be taken into consideration (Swart *et al.,* 2004). This is particularly important in South Africa, which has such high poverty and deprivation rates (Clark *et al.*, 2007).

This has significant implications in relation to the individual's motivation to become a caregiver and it is important to acknowledge that there are a significant number of motivations to be a caregiver other than the altruistic motivation considered above. In community contexts, especially in disadvantaged areas with under-resourced or under-funded institutions, caregiving is often the individual's livelihood. This means that in many aspects caregiving is not necessarily self-selected in such situations and as a result these caregivers are placed at a substantially greater risk in terms of a sense of obligation and distress associated with the experience (Pearlin & Aneshensel, 1994). Thus, the contextual factors pervade the emotional impact within the understanding of the caregiving experience. In this manner, these factors alter the consideration of the caregiver and the nature of the caregiving experience. Previous research into informal caregiving, considers the influence of contextual factors. However, the contextual circumstances surrounding formal caregiving are often neglected.

Palliative care environment

The understanding of palliative care enshrines the philosophy of enhanced quality of life to patients with life-threatening illnesses (Latimer & Dawson, 1993; Seale, in Decker & Young, 1991). Palliative care is conceptualised as "person-centred care that focuses on optimising

function and comfort in the setting of life-limiting illness" (Aberbethy, Currow, Fazekas, Luszcz, Wheeler & Kuchibhatla, 2008, p. 586). Palliative care should provide the patient and their family with compassionate care that considers physiological, emotional, psychosocial and spiritual needs (Latimer & Dawson, 1993). Palliative care relies upon a holistic approach, which demands that the institution go beyond simply providing medical treatment and address issues of support and bereavement, especially in relation to the family members involved (McCorkle & Pasacreta, 2001). Palliative medicine has an extremely significant role to play within caring and the caregiving processes. Each year approximately 300 million individuals are considered to need palliative care (Singer & Bowman in Skilbeck & Payne, 2005). Within palliative care institutions several goals are considered paramount and operate within stringent ethical principles. The goals consider providing a comfortable space and supporting the patient as well as the family and that quality service is rendered in the above mentioned spheres (Latimer & Dawson, 1993). It also changes the role of the formal caregivers compared to those operating outside of palliative care institutions.

The plethora of the research concerning caregivers' well-being focuses primarily upon informal family caregivers, rather than formal caregivers working within a palliative institution (Chadda *et al.*, 2007; Faison *et al.*, 1999; Harding & Leam, 2005; McCorkle & Pasacreta, 2001). This once again reiterates the impermeable nature of the caregiver role being combined with the role of being a recipient of care. Formal caregivers are often confined to the role of giving care rather than the focus of much needed care themselves. The majority of the assistance given to patients within a palliative care facility is provided by the nurses and caregivers who usually have differing levels of support and are often overburdened with cases (Payne *et al.* 1999). It is also important to acknowledge that studies have been primarily based upon contexts vastly different from the South African context. In particular, institutions within the community often face vastly different contextual considerations and engage with different dynamics, depending on the community in which they are located.

Overview of the literature

The literature review initially provides an understanding of the contextual and environmental implications particular to the South African context and the palliative care environment.

These sections illustrated the high prevalence and increasing incidence of terminal illnesses, such as HIV/AIDS and cancer within South Africa. Factors, such as financial means, human capital and high levels of poverty and unemployment were indicated as factors that further exacerbate the difficulties, particularly in disadvantaged communities (White & Morton, 2005). The high rates of unemployment may result in volunteerism providing some means of secondary gain (Swart *et al.*, 2004). The literature review also provided a brief indication of the influence of apartheid upon the services within South Africa and the high levels of poverty and deprivation (Clark *et al.*, 2007). While the palliative care environment illustrated the importance and necessity for palliative care. As well as the abundance of literature in relation to family caregivers as opposed to formal caregivers, especially those based in community-based palliative care institutions.

The concept of caring, and the nature of the caring relationship, or dyad was briefly considered, providing an understanding of the role of a formal caregiver and the implications of the occupational role. Caring and caregiving in relation to formal caregivers is a continuous process (Bell & Richard, 2000) and context dependent, and its relation to the occupational sphere, as emotional labour (Leira, 1994). The caregiver role was investigated, and the literature indicated caregiving as having significant responsibilities and multiple contributing factors to physical and psychological complications (Rowe, 2003). The role of the caregiver also encompassed an understanding of the attributes of caregiving and the interaction between these and others factors. The caring relationship was included in the literature review providing an understanding of the multidimensional nature of interactions and the implications of the interaction between the relationship and both the positive and negative elements of the caregivers' emotional experiences.

The emotional experience of caregiving within the literature review provided an opportunity to consider the notion of emotional labour and distinguish the positive and negative elements of the emotional experience and the importance of both aspects within a holistic understanding. This section in the literature review indicated the importance of the subjective understanding attributed to both the negative and the positive elements of the emotional experience. Based on previous literature, several positive and negative elements were focused on in the literature review and the study as a whole. Altruistic motivations and compassion satisfaction were the positive elements discussed, and stress and burden, burnout and compassion fatigue were the negative elements discussed. The positive elements were

considered significant in coping and protecting the caregiver from the negative elements of the emotional experience of caregiving. This provided the understanding of the influence the negative emotional elements have upon the caregivers' well-being and the implications of increased and often continuous exposure to these elements (Steiner *et al.,* 2008). This allowed for the literature to consider two contrasting theories, the first stress proliferation and the second, stress adaptation theory. The first highlighted greater exposure leading to greater vulnerability, while the second describes the greater exposure as linked to decreased reactions or resilience (Nijboer *et al.,* 1998).

The importance of coping and the coping strategies employed by the caregivers are illustrated. This section distinguishes the different strategies of coping and the potential of coping as a central resource for caregivers (Cohen *et al.,* 2002). This highlighted the importance of coping and different coping strategies in the caregivers' emotional experiences of caregiving. Spirituality was considered as a specific means of coping. The literature review highlighted the connection of spirituality to positive outcomes and ability to alleviate negative elements (Chui *et al.,* 2004). Often it is the implications of the spiritual beliefs held that are influential. This form of coping was considered significant in relation to palliative care and the relation between spiritual means of coping and existential crises (Paley, 2008).

Gaps in the literature

Research in relation to caregiving predominantly focuses upon the patient and their families. This research into caregiving has been conducted from several different perspectives, with a myriad of motivating factors. However, psychological research into the caregivers is limited and most commonly restricted to familial or informal caregivers. The limited research available on formal caregiving quantifies negative aspects within experiences as caregivers (Butcher & Buckwater, 2002; Faison *et al.,* 1999); however there is limited knowledge and research regarding the subjective conceptualisation of the caregiving experience. This study provides a phenomenological perspective which enables the consideration of the social interactions, and the manner in which caregivers perceive and create meaning of their experiences as formal caregivers (Bailey, 2007). Research into the subjective accounts of caregivers emotional experiences are significantly less common, and nearly absent in South African community contexts. The negative and positive elements associated with caregiving

are often investigated separately, with positive elements only more recently being considered. However, the current research considers both the positive and the negative elements, in addition provides a consideration of the interaction of these factors with coping strategies. This is beneficial as it provides the opportunity for interventions to utilise the knowledge, but also considering the interacting factors and the interacting environmental factors (Nijboer *et al.*, 1998).

The focus upon the family caregiver results in the formal sector of caregiving being neglected and the research often confined to individualistic accounts of caregiving, predominantly in quantitative manners. Thus, the contextual influences and their role within the emotional experience of caregiving often remain unacknowledged. However, the role of the caregiving in the formal sector is increasingly important and relevance given the epidemic of HIV/AIDS and the stigma associated with the illness. Stigma plays a significant role in willingness to access health care services and often results in families, or individuals, relying upon palliative care institutions to care for family members that are often neglected or abandoned. In addition to concerns of stigma, formal caregiving has been conceptualised as emotional labour (Karabanow, 1999). However, research into the effects of caregiving has maintained an individualistic account of the implications of caregiving, thereby negating the factors, such as stigma and poverty, operating within the spheres surrounding the individual. "If, therefore, we seek to understand fully why caregivers are at risk for such disorders as depression or anxiety, we have to examine their experiences not only as caregivers but also incumbents of other roles and as people whose cherished self-concepts may be threatened" (Pearlin & Aneshensel, 1994, p. 378). Therefore, these contextual factors are highly significant in presenting a holistic account of the caregiving experience (Keidel, 2002) and allow for the opportunity to understand the intersection between the interacting spheres of influence.

Furthermore, the majority of research into caregiving has been conducted in developed countries, specifically the United Kingdom and Australia (Keidel, 2002), with notably less focus upon community-based organisations. This is particularly important as the influencing factors within a developed country, versus those within a developing country, have substantial implications for the contextual environment. Developing or low income countries are often faced with significant difficulties unique to the country, such as access to resources, health care and housing; in addition significantly smaller budget and opportunities for

research (Pastrana *et al.*, 2009). This is especially relevant in South Africa, profoundly affected by apartheid and the effects of the apartheid legacy with a significant, and growing, division between poor and the wealthy within the country (Beck & Falkson, 2001) and the increasing HIV/AIDS epidemic and other highly prevalent terminal illnesses, such as cancer in South Africa. Understanding the link between the different spheres of influence in relation to caregiving may provide new areas for research and hopefully prompt further research to account for caregiving within the formal sector and located within the contextual understandings.

Theoretical framework

To obtain a comprehensive understanding of caregiving and the interaction with South African contextual factors, the theoretical model utilised within the study comprises of an integration of the following two models. The first model is the social ecological model, which is not specific to caregiving but rather provides a holistic account integral to understanding the caregiver's emotional experiences. This model predominantly focuses upon the environment and the interactions between the environment and the person (Trickett, 2002). The second model is the multidimensional model proposed by Raina *et al.* (2004). This model is based upon research specific to the area of caregiving, in particular caregiving of individuals with developmental disabilities. The integration of these two models allow for the incorporation of the specifics within the caregiving sphere, while simultaneously providing a broader more contextualised understanding of caregiving. In this manner the multidimensional model operates within the social ecological framework. By utilising these two models together provides the opportunity to account for the individualistic factors without negating the contextual understanding, and considering the interaction between the two. These models were utilised within the context of the current study as they provide the ability to negotiate both the individual caregivers experience and the contextual factors that inform that experience, in a coherent and encompassing manner.

The social ecological framework is particularly relevant as palliative care institutions are considered to have a myriad of influencing factors and thus the model is able to account for all such factors (Blevins & Deason-Howell, 2002). The model also provides the opportunity to consider the nature of the context, and thus, provide a contextual understanding of the

lived experiences of the caregivers (Trickett, 2002). In trying to gain an understanding of the caregivers experience it is important to acknowledge the other spheres of influence that impact and alter those experiences. The social ecological model allows for the consideration of multiple interactions operating within a larger system (Visser, 2007). In this manner, the formal caregivers interactions within and outside of the palliative care institution are taken into consideration. This enables the model to also consider the reciprocal effects that each sphere may have on another. In particular, the social ecological model places significant emphasis upon creating a holistic account, and the contextual factors which are integral in understanding the system in a holistic manner. In much the same manner, the mechanisms and demands within caregiving are dynamic and interact with other facets within the caregiving process (Pearlin & Aneshensel, 1994).

The social ecological model has two propositions the first is that development occurs through reciprocal interactions (Bronfenbrenner, 1994). The second proposition relates to the "form, power, content, and direction of the proximal processes effecting development", relating to both the environment and the nature of the outcomes (Bronfenbrenner, 1995, p. 621). These two propositions together refer to the "process-person-context-time model" (Bronfenbrenner, 1995, p. 621). Through this conceptualisation the focus is not restricted to the caregiver's interaction with the environment.

The social ecological model is also composed of four principles: (i) interdependence, (ii) distribution of resources, (iii) adaptation and (iv) succession (Visser, 2007). Interdependence denotes the interrelation between the multiple components – altering the environment (Visser, 2007). In understanding the caregiver's experience it is particularly important to recognise the magnitude of influencing factors, as formal caregiving cannot be isolated from the environment in which it is conducted. The element of interdependence implicates the multitude of settings and life domains within the caregivers' occupational and personal lives (Woods, 2009). The second principle relates to conceptualisation of the resources and the distribution of the resources within the community (Visser, 2007). In South Africa, palliative care institutions are predominantly placed in urban areas, whereas rural and disadvantaged communities are often overlooked. Thus, it is particularly important to understand the means of operation of the community-based palliative care institutions to enable further institutions and the best possible utilisation of the existing resources. It is also important to explore the stigma associated with palliative care resources and the implications of the stigma on other

spheres of influence. Adaptation enables multiple levels to be analysed and facilitation of these different levels (Visser, 2007). Lastly, succession considers the goal of seeking community change, through empowering caregivers and providing the opportunity for progression within the institution and the caregiving field as a whole (Visser, 2007). Palliative care and formal caregiving intersect with several different elements, thus, several levels of analysis are necessary to understand the experiences in a holistic manner.

The multidimensional model provides the inclusion of both direct and indirect effects on the different constructs within caregiving (Raina *et al.,* 2004). In this manner the model is able to consider multiple different factors and also considers the role of coping (Raina *et al.,* 2004). This allows for particular concepts within caregiving to be considered within the theoretical framework, providing a focused explanation of the initial spheres within the social ecological model. The multidimensional model is also able to consider both informal and formal caregiving, and the role of the caregiver (Raina *et al.,* 2004). Thus, in this manner provides substantially greater specificity in relation to the micro-system within Bronfenbrenner's theory of ecological development.

Bronfenbrenner's theory of ecological systems places emphasis upon the operation of different systems within the larger systems. There are five interacting systems. These systems both interrelate and impact upon one another (Bronfenbrenner, 1994; Visser, 2007). The micro-system relates to the individual interactions (Visser, 2007) and to the immediate environment (Bronfenbrenner, 1994). Whereas the multidimensional model provides opportunity to understand caregiver strain and the effects of the caregiver responsibilities and role demands within the micro-system (Raina *et al.,* 2004). Furthermore, the coping strategies employed by the caregiver are considered, and social support and the accessibility to such is important aspect of caregiving, linking these to the other ecological systems. In this manner the micro-system considers the caregiver and their interactions with others; this is illustrative of the caregivers and their individual attributes. The micro-system consists of the patients and their families at the institution and the caregivers, nurses, doctors and other members of staff at the palliative care institution (Blevin *et al.,* 2002). The meso-system considers the links between the micro-systems (Bronfenbrenner, 1994). Thus, the meso-system considers the relation between the caregivers and their work or home systems, as well the individuals within the micro-system, such as patients, and the effects of these interactions. This includes all the interactions between the micro-system, in addition to the demands and tensions that

arise between these micro-systems (Blevin *et al.,* 2002). The third system is the exo-system which consists of the connections between at least two settings and allows for the indirect influence of the individual (Bronfenbrenner, 1994). In caregiving this system represents the relation between the individual and the institution or the community. This system also encompasses the local geographic components (Blevin *et al.*, 2002).

The fourth system is the macro-system, which considers the integration of the first three systems, in particular considering systems of belief, customs and knowledge, to mention a few (Bronfenbrenner, 1994). This is particularly important in the current study in relation to the social norms regarding death and dying, and the influence of stigma within caregiving experience. It also considers the ethical rights of the patients and the regulations that oversee the institution (Blevin *et al.,* 2002). The macro-system also considers the political, physical and social influences within the systems. The fifth system is the chrono-system which considers the parameters of time, in particular considering stability and change within the system (Blevins *et al.,* 2002). The chrono-system places significant emphasis upon the historical nature of interactions and changes, and changes in the influences at different levels over period of time (Blevin *et al.,* 2002). Thus, the chrono-system considers the influence of the apartheid upon the contextual factors, such as resource distribution and access to health care, in addition to the other factors, such as poverty and the historical events that have influenced palliative care in South Africa. It also includes understanding the time the caregiver has with the patient and the amount of time spent at the palliative care institution. This is a particularly important concept as the stress proliferation theory considers the greater the exposure to stressful situations, the higher the caregiver's vulnerability to negative emotional impacts (Pavalko & Woodbury, 2000).

The social ecological model and the multidimensional model place significant emphasis on the influence of the context. The multidimensional model claims that caregiving cannot be considered without the social and experiential aspects within the context, and thus, factors relating to the social and economic elements are deemed highly significant in both models (Raina *et al.,* 2004). Utilising the social ecological model, several different spheres of influence are able to be considered, while with the multidimensional model, several different facets particular to caregiving can be considered. The addition of the multidimensional model provides an additional element in which caregiving can be understood within the social

ecological model. The integration of these two models provides a holistic account, but does not sacrifice on specificity.

Thus, the consideration of emotional experience with regard to the role of formal caregivers is significant in understanding how the caregiver is able to manage their emotions and sense of subjective burden, because this forms the basis for negative and positive outcomes (Wharton, 1999). This is particularly important for succession, which is relevant given the nature of the South African context. Attaining knowledge of the experiences of caregiving, not only allows for the understanding of both positive and negative emotional experiences, but also enables a greater ability to create an understanding of the management and improvement in well-being amongst caregivers (Wharton, 1999). These positive and negative elements of the caregiving experience provide an understanding of the influence of coping and different coping strategies which provide means to increase the protective factors within caregiving and decrease the factors that precipitate and perpetuate the negative emotional impacts within the caregiving experience.

Formal caregiving presents with significant differences to familial caregiving and alters the nature of caregiving and the dyad between the caregiver and the patient. Palliative care institutions further illustrate the differential components of formal caregiving, with caregiving as emotional labour and the practical differences such as multiple patients to attend to and the responsibility associated with the caregiving role. It is important to understand that the caregiver is not experiencing caregiving in isolation, but that it operates within a context which influences the process and outcomes (Given *et al.*, 2005). This reiterates the importance of the contextual understandings and the theoretical framework providing a consideration of the interacting and reciprocal influences throughout the caregiving process. It is the combination and interaction of the above elements that provides an understanding of the caregiver's emotional experience of caregiving.

Conclusion

The literature review encompassed the nature of the caring relationship and the role of the formal caregiver within community-based palliative care in South Africa. It also provided the understanding of the emotional experiences of caregiving and the influence of the context in

which these are located, while distinguishing the positive and negative elements of the emotional experience and the interplay between these factors and coping strategies. The chapter also considers the gaps in the literature and provides a brief overview of the literature review and provides a discussion of the theoretical framework utilised in the research. The chapter to follow provides the method section, indicating the interpretative phenomenological paradigm and the specifics regarding the participants and the means of analysis.

CHAPTER THREE

METHOD

Introduction

The research conducted sought to explore the emotional experience of caregivers within a community-based palliative care institution in relation to several positive and negative emotional factors that are implicated in the caregiving experience. The methods section presents the research questions, as well as a framework in which the interpretation and analysis was conducted. The section also considers the practical components of the research procedure, such as the participants and the method of analysis to be utilised in the study. It also provides information regarding the data collection tools utilised in the research. The section also includes an understanding of the researcher's self-reflexivity as an important component of the research process.

The interpretative phenomenological paradigm

The interpretative phenomenological paradigm, having theoretical foundation in phenomenology and hermeneutics, is concerned with an individual's "lived experience and how individuals make sense of that experience" (Eatough & Smith, 2008, p. 179). Experience is subjective and thus represents an understanding of one individual's particular reality, however it enables diversity and variability in the realities presented through different experiences, in this sense it is idiographic in nature (Eatough & Smith, 2008). This is immensely pertinent to this research, as the individual's experience of the emotional impact of caregiving is dependent upon the conception of caregiving relative to their specific worldview and experiences that have influenced such a worldview. The interpretative phenomenological paradigm strives to gain an enhanced understanding of a particular phenomenon (Eatough & Smith, 2008), which in this case would be the emotional experience of formal caregiving. Through focusing on the social interactions and the manner in which individuals create their social world, through multiple different manners, such as meaning making, feelings and experiences (Bailey, 2007). The phenomenological paradigm also enables the consideration of contextual implications. This means that the data collected is

understood within the context from which it has arisen (Terre Blanche & Kelly, 1999). This is important as the contextual implications within the research influence the understanding of both the caregivers and their experiences as caregivers. The context is inherent within the experience of each caregiver and attempting to separate the understanding from 'the understanding within the context' prevents the subjective nature of the experience from being acknowledged, and gaining meaning of the experience in a holistic manner (Patton, 2002; Terre Blanche & Kelly, 1999). As such the paradigm utilised is appropriately furthered through the qualitative design of the research. It is this design that provides both an in-depth analysis, as well as the ability to integrate contextual components that play a fundamentally integral role in the understanding of the process.

Previous research has maintained a predominantly quantitative focus with regard to the emotional experience of caregiving on caregivers; however a qualitative study allows an in-depth understanding of the phenomena and enables studies to consider the subjective accounts and experiences in promotion of a specific understanding and most importantly within that particular context (Whitley, 2002). This is highly pertinent to the proposed study as the investigation seeks to elicit the experiences and relative emotional impact of each individual in order to gain insight into the role of formal caregivers in a South African context. The social issues that exist within the system have a profound impact on all the systems both within and beyond the caregivers' existence.

Faison *et al.,* (1999) consider qualitative designs advantageous in exploring the role of the caregiver, as well as in assessing any potential impact upon the individual. Nijboer *et al.*, (1998) present the difficulty in trying to assess the different dimensions of caregiving through quantitative means, as often having to rely upon several different measurements; however, qualitative designs provide the opportunity to consider multiple dimensions within a given context. Qualitative studies also allow active involvement, which furthers the interpretation of these subjective accounts to create a progressive means of interpretation, which creates more dimensions and complexity within our understanding. This is achieved through the participants being able to draw upon personal experiences in relation to their role, particularly within a community setting and create meaning and understanding through such a process. This is especially relevant since the study allows for the consideration of the positive aspects of caregiving – which makes the research "innovative" (Butcher & Buckwalter, 2002, p. 116).

Research questions

The research questions guiding the current study are indicated below.

(i) What are the negative emotional experiences of caregiving in community-based palliative care institutions?
    - How do factors such as, burnout, compassion fatigue, stress and burden, influence the emotional experiences of caregiving?

(ii) What are the positive emotional experiences of caregiving in community-based palliative care institutions?
    - What are the roles, if any, of both compassion satisfaction and motivation, within the emotional experience of caregiving?

(iii) How do the caregiver's coping and coping strategies influence their emotional experience of caregiving?

(iv) How is the conceptualisation of the role of a formal caregiver influenced by their relative emotional experiences?

(v) How are caregiver's experiences interrelated with contextual factors?

Participants

Participants were caregivers, providing in-patient care, at a community-based palliative caregiving institution in Gauteng, South Africa. Palliative care institutions rely upon a holistic approach, the "unit of care" is not restricted to the patient, but goes beyond to include the family members and informal caregivers (Aberbethy *et al.*, 2008, p. 586).

Eleven participants were obtained for the study – these included trained carers and professional nurses that work within the community-based palliative care institution, which provided an in-depth understanding of the individual caregiver's experiences of emotional impact as a formal caregiver. Of the eleven participants, three were male and eight were female, and all participants were Black. The study focused on formal caregivers, as they represented the population that is not usually researched in regard to the effects of caregiving. The study provided a means to identify the emotional components that foster growth, and

those that deplete the individual caregiver. This is not simply beneficial to the training of individuals within the caring professions, but also to the promotion of the patient's well-being, which as stated earlier, is intrinsically linked to the well-being of the caregivers (Liebhaber, 2008). The caregivers within palliative care institutions encompass a fundamental element within the organisation and are often the individuals that are provided constant care to the patients within the institution.

The researcher had approached several organisations across Gauteng to participate in the research. One organisation had indicated an interest in participation. Prior to ascertaining access to the participants, the researcher set up a meeting with the head of the community-based palliative care institution and was granted the opportunity to meet several of the caregivers and gain a sense of the environment. Permission to approach and invite caregivers to interviews was then obtained from the institution and specific days were scheduled for data collection. Those interested in participating were able to select an available time slot. The strategy employed to ascertain participants is a non-probability strategy and it operates as a purposive sample since the individuals have to meet several criteria in order to be included in the study. These include presently occupying a position as a formal caregiver in a palliative institution, for a period of at least six months. The restriction on the time having worked as a formal caregiver is important as it will have a marked influence on their experiences and the influence of both the positive and the negative aspects of caregiving. The research was conducted through convenience sampling as the initial interaction and access to the participants was through the head of the community-based palliative care institution. This individual then provided the means to approach the formal caregivers within the institution and enquire whether caregivers were willing to participate in the research.

Data collection

The data was obtained through semi-structured interviews with each participant. One of the most important aspects of qualitative research is the assumption that the perspective of the participant being interviewed is meaningful and allows the participant to openly express their experiences as a caregiver (Patton, 2002). This in-depth information can be obtained through semi-structured interviews because these permit the interviewer to probe into the participant's response (Terre Blanche & Kelly, 1999). This allows for clarification and does not require

any specific level of literacy (Terre Blanche & Kelly, 1999). Semi-structured interviews are also flexible in nature and allow for a continuous process of engagement (Bailey, 2007), further aiding the data collection process while also obtaining a sense of naturalism (van Vuuren & Maree, 1999). In this manner the data collection method chosen is best suited to the context and the participants within the research, providing conditions that fostered a positive process and allowed for an in-depth enquiry. Utilising semi-structured interviews allowed for the integration of the interpretative paradigm (Bailey, 2007). The semi-structured interview allows the researcher to investigate certain aspects or areas within the research scope, but also enables the participants to elaborate based on their own experiences as a formal caregiver. Semi-structured interviews are also advantageous as they allow for an informal setting (Devlin, 2006), which is conducive to the subjective exploration into the participants experiences, allowing them to elaborate on elements they consider important thus, not restricting the understanding to predetermined questions that do not allow for extrapolation. In this sense it allows for the consideration of novel perceptions and understandings (Smith & Osborn, 2003). It also enables the establishment of rapport (Smith & Osborn, 2003), which is a central element when trying to ascertain an individual's emotional experiences, as these experiences may be of a very personal nature.

The interview schedule (See Appendix A) initially focused upon the general role of the formal caregiver, which provided the participants with the opportunity to engage with their understanding of the differentiation between formal and informal caregivers. The second part of the interview schedule relates to each participant's experience and their perception of the different negative and positive elements of emotional impact within their experience. This entailed more specific enquiries into certain experiences, as well as questions that allowed the participants to elaborate on experiences that may have been fundamental to their experience as a caregiver. In particular, the aspects that motivate and enhance the caregiving process, compared to those factors that deplete the caregiving process were investigated, as well as the different means of coping utilised by each individual. The questions within the interview schedule were open-ended allowing for the exploration of each participants experiences as a formal caregiver.

Procedure

The participants were invited to participate in the study on a voluntary basis, through an informant within the palliative care institution. Those who were willing to participate in the interview were welcomed and thanked. The participants were all provided with information regarding the focus of the research, and procedures, as well as an explanation of their ethical rights in relation to the research. The ethical considerations included informing the participants that participating in the interview was voluntary in nature and explaining that should they not wish to participate or decided that they would no longer like to be part of the research at any stage, they would be able to withdraw from the study. They were also informed that they were able to leave at any stage, and were also able to refuse to answer any of the questions within the interview. The participants were informed of the confidentiality and the protection of their identity within the research report, as well as the procedures taken to ensure the safety of the data. The issues surrounding confidentiality were reiterated and it was explained that the research report would include direct quotes from the interviews. The necessary consent forms were provided and the participants were provided with opportunity to read through the forms and ask any questions, and then sign the forms. (See Appendix E and F).

The interviews were held at the palliative care institution, as this proved both convenient and comfortable for the participants. It also meant that the participants were able to set aside a specific time within their schedule. The interviews lasted between 30 minutes to just over an hour in duration. The researcher then presented the questions from the interview schedule (See Appendix A). However, the semi-structured nature of enquiry allowed the participants to generate spontaneous responses and allowed the researcher to gain clarification on any elements during the interview. At the closing of the interview the participants were debriefed and thanked for their participation.

Data analysis

The data obtained from the interviews was analysed using thematic content analysis. Thematic content analysis operates within the interpretative framework, allowing for the in-depth exploration into the subjective experience of a phenomenon (Whitley, 2002). Thematic

content analysis considers the relation between themes within a given context (Du Plooy, 2002). The qualitative design enables active involvement, furthering the interpretations of caregiving and the understanding of emotional impact within the context. This created an opportunity for progressive dialogue and the opportunity for more dimensions and complexities to arise from the data.

The research operates within the theoretical framework of interpretative phenomenological analysis. Thus, emphasis is placed upon the contextualisation and the meaning created can be considered from a psychological perspective, allowing for the in-depth understanding that is crucial to the qualitative design (Larkin, Watts, & Clifton, 2006). This framework reiterates the understanding that there is no single interpretation of complex phenomena (Denzin & Lincoln, 1998), but rather the existence of an array of themes that present within the data which create a detailed understanding of the caregiving experience. This aspect is important as it enables the acknowledgment of subjective constructions of caregiving and emphasises the emotional impact from the perspective of each individual caregiver. Within the analysis, the researcher becomes one of the key interpretive instruments (Terre Blanche & Kelly, 1999), thus making the researcher a vital part of the interpretation process (Smith & Osborn, 2003). This aspect of self-reflectivity reiterates the experiential manner in which the individual's construction of the world can be understood and described (Fook, 1996). The semi-structured interview allows for sufficient structure to provide a broad framework to explore specific constructs, while still remaining flexible enough to incorporate the individual constructions. This is especially significant as flexibility is paramount to the procedure of interpretation, since it allowed for multifaceted accounts to emerge from the data, presenting a more in-depth understanding of the data in relation to the context and reflexivity (Braun & Clarke, 2006). Thematic content analysis follows certain steps; however these steps are not considered rigid in nature but rather create a structure, or basis from which to operate. The analysis is not considered a simplistic linear process, but rather one that involves the constant reflection of the researcher, not only with the data and interpretation, but the self-reflexivity surrounding the issue as well.

Thematic content analysis relies upon the processes of identifying, analysing and interpreting the recurring themes within the data (Braun & Clarke, 2006). Themes were understood as units that embraced a unique or significant element of the data in consideration of the research questions proposed (Braun & Clarke, 2006). All the material obtained from

the interview was included in the analysis as well as the information that arose from the researcher's self-reflexivity. The initial step was the engagement with the data, which involved repeated interaction with the data, creating a holistic understanding of the data (Terre Blanche & Kelly, 1999). The second step was the consideration of the initial codes, and then the process of organisation of the data in relation to the initial themes followed (Braun & Clarke, 2006). The number and degree to which the themes encompassed the data was dependent upon the complexity of the data obtained from the interviews (Terre Blanche & Kelly, 1999). An important aspect in deriving themes was the approach taken to the data. This research makes reference to the literature; however, the primary method was inductive in nature, as the themes were linked to the data while remaining within the framework of the literature. This places emphasis, not simply upon the contextualisation of the data but also on understanding the perspective and experiences of the caregivers as meaningful (Babbie, Mouton, & Prozesky, 1998). The initial coding provided for as many themes as possible, however the research did not limit certain extracts to having one exclusive theme, but rather a broad range of relevant themes (Braun & Clarke, 2006). These themes considered content to be the underlying meaning as well as the apparent meanings being conveyed.

In the third step the codes and coding from the previous steps, were considered in relation to overarching themes (Braun & Clarke, 2006). It was also important to consider the different levels at which these themes operated and consider the relevance of the themes to one another in developing the subthemes (Braun & Clarke, 2006). In the process this coding created meaning within each individual theme. This allowed for the process of critical engagement with the themes derived and the coded data (Terre Blanche & Kelly, 1999). The process of deriving themes was complex, which emphasised the importance of maintaining a link between the research questions, the themes and the relevant data (Kelly, 1999). The fourth step dealt with the refinement of the themes, as well as the consistency between the data and the representing themes (Braun & Clarke, 2006). Initially the focus was on the coding and then shifted to the data set in its entirety (Braun & Clarke, 2006). The fifth step signalled the end of the conceptualisation of themes, and allowed for the designation of names that were able to capture the quintessence of the theme, and thus the data within it (Braun & Clarke, 2006). By the end of the fifth step the data presented a succinct understanding of the themes which allowed for further defining of these themes (Braun & Clarke, 2006) and the creation of several sub-themes in relation to the broader themes that operate within the data analysis. The final step was the process of collation (Terre Blanche &

Kelly, 1999), which considered the explanations and understandings created and then combined these with the researcher's reflexivity to create a holistic logical illustration. This illustration provided an account of the data that embodied the research questions. The extracts selected highlighted the essence of each particular theme and substantiated the interpretation of the themes, in relation to the relevant literature (Braun & Clarke, 2006).

Self-reflexivity

Self-reflexivity was a crucial element within a qualitative study, especially in relation to its operation within the interpretative phenomenological paradigm. It considers the process of research as both dynamic and two-pronged (Smith & Osborn, 2003). Firstly, as the participants created meaning, and developed an understanding of their own subjective account of their emotional impact in relation to caregiving (Smith & Osborn, 2003). Secondly, the researcher simultaneously tried to understand the participant's conceptualisation and the meaning construction within it (Smith & Osborn, 2003). The implications of such were that the researcher had to ascertain the participant's perspective relative to the study, and how any potential factors may have influenced the perception and interpretation of the research.

Self-reflexivity denotes the importance of self-awareness within the research process; this often requires the researcher to be conscious of the, often inherent, discourses and ideologies that are perpetuated during the course of the research (Patton, 2002). This is a fundamental process as it enables the researcher to engage with and reflect upon the experiences that occurred within the role as a researcher and within a different context (Gibson, Sandenbergh, & Swartz, 2001). This self-reflexivity allows the researcher to utilise their own voice in understanding their interaction within the process, and provides the researcher with an opportunity to express their authentic experiences encountered during the research process (Patton, 2002), and in relation to the interpretation this arises through the data analysis (Potter, 1999). This is particularly crucial to the current research as the contextual considerations are not only a fundamental component of the research, being fundamental to the meaning the caregivers' construct from their experiences (Potter, 1999), but also a crucial element in understanding the interactions that occurred during the interviews. It should also be acknowledged that although self-reflexivity became the most

salient during the data collection it is an ongoing process, and was not confined to the collection of the data but rather beyond, into different aspects within the research process.

Self-reflexivity became an important aspect of the research for me, as the researcher, because the majority of the research previously conducted had simply quantified the experience, reporting on general patterns or trends. This seemed to represent, in some senses, what I came to understand as an idealistic representation of caregiving. The importance of the contextualisation and the embedded nature became substantially more apparent in relation to the South African context. Initially, I had found it difficult to fully grasp the understanding of the contextual influence and the embedded nature of caregiving within the other systems that were currently in operation. However, it was this factor that became the primary consideration within the research process. The factors influencing caregiving within a community-based context in South Africa differed vastly from those high-income countries where the majority of research on caregiving had been conducted.

From the initial contact with the institution where participants were sourced the discrepancies between the contextual factors were apparent. I had entered an informal settlement situated on the periphery of the urban centre that differed vastly from my own environment. In many respects this led to the participants having constructed me in a manner that presented me as an outsider. This was beneficial in some senses, as the participants felt more at ease discussing their difficulties and the influence of the contextual factors within their personal and work environment. However, it simultaneously set up a power dynamic that became difficult to shift. This power dynamic seemed to place me in the position of an 'expert' and treated me as someone who could alter the current status within their work environment. Although the nature of the research and myself, as the researcher, tried to foster the importance of local knowledge these power dynamics were still indicative within the interaction. This also included the social constructions of 'race' as a dividing factor. My status as a 'white' women represented an apparent discrepancy to the predominantly black informal settlement, which seemed to instantly identify me as an outsider to the area. This was even more salient in consideration of the distinction that I reflected upon earlier – the contextual differentiation, which is particularly important, as there are still significant trends illustrated within research, that access to the vast majority of resources is still racially-based (Duncan, Bowman, Stevens, & Mdikana, 2007). This is particularly important when integrating the contextual understanding of the historical impact of the constructions of 'race'

within South Africa. This self-reflexivity also fosters the process of flexibility, being aware of my own influence, biases and perceptions that were being perpetuated allowed me to reassess several components within the research. Through these experiences and the awareness of the process, self-reflexivity enabled me to integrate my understanding of the research within the context from which the research arose.

Ethical considerations

Often ethical considerations are considered simply as one component within research. However, ethical considerations are the most crucial aspect within research, and usually legitimatise the research conducted (Payne & Payne, 2004). Ethical considerations are consistently applicable throughout the process, and not restricted to the planning and implementation phase of the research (McLeod, 2003). Research has implications for the production of knowledge, and may have additional influences upon the implementation of interventions and other means to improve caregiver well-being. Thus, factors such as dishonesty or unethical practice may have profound negative impacts beyond the study (Payne & Payne, 2004), reiterating that ethical considerations are indispensable.

One of the fundamental components of ethical research is informed consent. This is based upon three aspects: the first is voluntariness of the research, the second is the competence of the researcher, and the third is that sufficient information is provided to the participants (Homan, 1991; McLeod, 2003). It was also important that the participants were made aware of their rights within the research, such as their right to withdraw from the research at any given stage (Payne & Payne, 2004). Informed consent was necessary in relation to both accessing the organisation, as well as the individuals within the organisation (Israel & Hay, 2006). (See Appendix B and C) Those interested in participating in the research were given a participant information sheet (See Appendix D), entailing information regarding the nature and purpose of the study, as well as an explanation of what participation required. The participants were invited to participate in the research, however the choice to participate was completely voluntary and there was no advantage or disadvantage whether they decided to participate in the study or whether they chose to forgo the opportunity. The voluntary nature of participation should be emphasised and so the research should not be

connected to an external reward that may be an influencing factor to the participants or the organisation (Babbie *et al.*, 1998).

Participants received two forms, the first being the consent to participate in the interview, (See, Appendix E) and the second, being the consent to the recording of the interview. (See, Appendix F). Both forms were explained to each participant, and each participant was granted the opportunity to ask any questions regarding the forms or research as a whole. Supplementing the written informed consent with verbal informed consent was beneficial (Israel & Hay, 2006) because, although the participants were literate, several of the participants were not first language English speakers, and so verbal discussions allowed for terms to be explained and better understood by the participants.

It is important to acknowledge the difference between anonymity and confidentiality. In research where confidentiality has been maintained the researcher still has knowledge of the identities of the participants, whereas with anonymity, the researcher does not possess this privy (Bailey, 2007). In supporting the ethical considerations of confidentiality, the participants were randomly assigned a number and only the researcher has access to the number-participant correlation (Babbie *et al.*, 1998). However, the participants were made aware that the researcher would be privy to their identity, as well as the potential limitations of confidentiality in relation to the direct quotes within the research report. The participants were made aware of the removal of all identifying information from the data – not just within the research, but in the data files as well (McLeod, 2003). Thus, all records of the participants' identities are not available and the participants are only identifiable by the researcher through their randomly assigned number. The direct quotes utilised within the research have been supplemented with [name of institution] where the participants named the institution, and [name] where the participants made reference to another person within the institution, or person associated with them, in an increased effort to protect the participant's identity.

Ensuring confidentiality is an important aspect in research (McLeod, 2003) and especially within the current research, as the participants provided information relating to their personal experiences, and means of coping, within their work environment. This also means that the name and details of the institution at which the research was conducted are not included in the research (Payne & Payne, 2004) in order to ensure the safety of the institution and the participants within the institution. The participation of both the organisation and the

individual participants in the research should not place the participants in positions that have the potential to harm their lives, working careers, or endanger them in any manner (Babbie *et al.*, 1998). This was initially a particular concern in the research conducted. The participants were assured that the transcriptions and mp3 files were only accessible to the researcher, thus confidentiality would be maintained throughout the research process. All data is stored in a safe location and will be stored until the obtainment of the degree, unless published, and then the data will only be destroyed two years after publication. The nature of the exploration into the participants' emotional experience, required sensitivity around the experiences shared. It was also vital to reiterate that the participants were not expected to answer any questions that they felt uncomfortable with. This also had to rely upon the researcher's reflexivity regarding the interaction, as in certain situations the participants may have felt unable to refuse to answer a question and felt somewhat compelled to answer (Kelly, 1999).

Transparency in relation to the participants' rights and what participation may amount to is particularly important as providing the participant with sufficient evidence means that the participant is aware of any potential harms, although all harms, if any, should also be minimised by the researcher (McLeod, 2003). The direct quotes within the research may communicate a problem within the organisation, amongst the caregivers or exposure in the means of coping, emphasising the importance of initially having provided information in relation to the nature and purpose of the research (Homan, 1991). The researcher should be aware of the limitations of the research, which reiterates the researcher's role in accountability, not simply to the participants, but also the community (Babbie *et al.*, 1998). This also relates to transparency regarding the researcher's aims and competencies in research (Babbie *et al.*, 1998). Ethical considerations also relate to providing feedback to the participants and the organisation involved, the participants were made aware of their right to attain feedback. A one page summary was made available as feedback to all participants upon request and the participant information sheet reiterates this process to obtain feedback. In addition, general feedback was provided to all participants and the organisation. See Appendix G for ethical clearance certificate.

Conclusion

This chapter on methods provided the research questions and the practical components of the research, such as the participants involved in the research, and the procedure involved in obtaining both the data and the participants. It also explained the manner in which data was obtained and the reasons supporting the choice of methods. It provided an understanding of the framework in which the research was conducted, as well as the self-reflexivity of the researcher. It also provides an overview of the ethical implications and the safeguards in relation to the participants within the research. The chapter to follow provides the results from the thematic content analysis discussed above.

CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

This chapter presents the results of the present study. In accordance with the thematic content analysis, several themes and subthemes were identified as salient within the data. These themes where formed on the basis of the information and knowledge obtained through the participants. The results present these themes in relation to current theoretical understandings of caregiving and emotional experiences in relation to caregiving.

The emergence of the themes

Caregiving is commonly constructed in the literature in relation to the satisfaction and altruistic components available within the caregiving process. Although this research found similar patterns of wanting to make a difference, and providing satisfaction through caring for terminally ill patients, a substantial proportion of the carers found caregiving to provide a means of financial income. This was also considered one of the spheres which provided additional stress within the individual's personal life and thus, on their abilities at work. This is particularly important given the context and the implications of social issues, such as high rates of unemployment, and the prevalence of poverty within South Africa, and their relationship to caregiving.

The first theme provides an understanding of the how the participants perceive their role as a formal caregiver. This perception often relied upon other dominant roles the individual held as a member of society and the operation of these roles within the micro-sphere. The distinction between the formal and informal caregiver seemed to differ across participants with several different variables being considered as points of either divergence or convergence. This theme also considers the construction of the caregiver as fulfilling a specific role, as a unique talent versus the construction of caregiving as a job. The caregivers' abilities to manage stressful situations are influenced by the manner in which the caregivers perceive their role, in addition to negotiating the contextual factors within their working environment. This alludes to the second theme of coping which considers the role of different

support mechanisms available to the individual caregiver and the implications of such coping mechanisms. In many respects coping is indicative of the experiential aspects that are illustrated within the multidimensional model. The third theme considers the coping mechanism of meaning making. It considers how meaning making is utilised by the caregivers to cope better with the difficulties within caregiving. Through meaning making the caregivers are able to gain an awareness of the influencing factors and the interaction with the different spheres. The fourth theme considers the processes of loss and the aspects of hope within caregiving and the function of these in relation to the individual caregiver. In this manner the interrelations between the caregiver and the patient are brought in consideration.

The fifth theme incorporates the meaning within the experience of caregiving, and the contextual understanding as well as the difficulties, in relation to the context, that influence the individual caregiver the patient and their interaction with the community. Thus, the theme draws upon the notion of stigma and the implications of this in relation to the role of the formal caregiver. When considering the contextual understanding, the immediate environment plays a substantial role in relation to the experiences of caregiving, but also the spheres that interact with the immediate environment. Throughout the interviews it was evident that many caregivers had initially been informal caregivers, in this manner their previous experiences provide a significant means of knowledge. This previous experience provides the sixth theme in that the individuals constructed caregiving as a means to make reparation, as well as a means of motivation.

The themes revolve around two broad notions. The first considers the elements in relation to the emotional experience and the coping that is fostered in relation to these experiences. The second considers the factors that may aggravate or alleviate stressors in relation to the work environment and the greater context into which the institution falls. Together the themes provide a holistic understanding of the experience as a caregiver – both the negative and the positive elements situated within a community context.

Theme one: The canvas of caregiving

Caregiving is often emphasised as the process by which family members provide care for another family member that is suffering from an illness. However, caregiving represents a

broad category, and relates to the contextual and environmental factors that influence the conception of caregiving (Leira, 1994). The subjective nature of the caregiver dyad often provides a more encompassing perspective of caregiving (Zweibel & Lydens, 1990), as it considers contextual and environmental stressors, enabling the construction of caregiving in a formal capacity. The conceptualisation of a caregiver within a formal care context often has differing presentations depending upon the relationship that is established between the caregiver dyad (Baronet, 2003). The nature of formal caregiving within the study was considered to be the interaction between innate personal characteristics, such as empathy, and some degree of knowledge or skills. This provided a basis upon which further notions relating to the caregiver were considered and which formed an understanding of the identity of a formal caregiver. This interconnection between aspects of knowledge and personal attributes allows for the creation of an intimate yet professional atmosphere within a palliative care institution (Richardson, 2002); however, it is these principles that provide an understanding of how the individual caregiver may obtain a perception of themselves within the caregiving role. The perspective was influenced by several, and often diverse, principle aspects, which all informed the picture or canvas of caregiving.

The role of the caregiver

The first subtheme considers the participants construction of the role of the caregiver. The role of the caregiver is often presented as having a position of responsibility. With this responsibility is the distinction between the informal and formal caregiver. There are several variables that may influence the construction of their caregiver role or perception of caregiving. Usually the activities a caregiver may perform forms a part of their role, but this fails to define the subjective component within their identity as a caregiver, as well as the distinction between the formal and the informal caregiver. The activities a caregiver engages in are often conceptualised as their role, as illustrated in the following exemplars.

> My role as a caregiver especially to the patient I think I'm ... eh I don't know how I can put it in English, but to be eh eh to take care or at least encourage a patient like if, ... my job description I have to bath a patient, bath the patient with love um um to make sure that the patient is getting food and eh at least even to talk with the patient to support the patient emotionally and even eh physically whether it is bathing, feed him or do everything for him or her. So I don't know if I can use this with word of advocacy – to be

> a representative of a patient, a patient's needs. That is my understanding of my role as a caregiver.
>
> (Participant 10)

> I understand that I have to make somebody who is... um… not happy to be happy, even though it is not easy, um to take care of somebody who cannot take care of themselves. So … Basically it is to take care of somebody who cannot take care of themselves because they are, they are sick, they are patients.
>
> (Participant 9)

> Um, my role is that the most important thing as a caregiver is completely confidentiality, the most important thing and then to give them love again and to support the patients and the family, eh.
>
> (Participant 7)

> Bathing them, feeding them sometimes if we got time, quality time just talking to them.
>
> (Participant 11)

> But otherwise if we got patients who are lying down, and then they wake up, you you help them out to a shower, feed them, make them snacks, give them this, they ask this, you go, they ask you this, you go, watch TV – there is no stress.
>
> (Participant 4)

Participant ten relates to caregiving as a *'job description'*. The emphasis is placed upon the activities, or duties performed as a caregiver. However, this may represent the difficulty caregivers often experience, "to put into words what it is that they do and how they feel about caring responsibilities" (Davies, 1995, p. 18). Participant ten's conception of caregiving places significant distance between the caregiver and the recipient of care – through explaining the process with regards to activities performed rather than subjective experience and consideration of the caregiving role. There is a significant distinction between the actual tasks performed by a formal caregiver and their subjective experiences of caregiving (Nijboer *et al.*, 1998). In relation to the multidimensional model this operates as an indirect effect influencing the construction of caregiving. It also highlights the distinction between the informal and the formal caregivers because caring within this concept is a job and thus portrayed as significantly more focussed upon the activities conducted, than the emotional connection. While participant nine also provides the consideration of their role as the process by which the caregivers '*take care of somebody who cannot take care of themselves'*. This in a similar manner highlights the practical duties and reasoning in relation to caregiving. Whereas several of the participants highlighted the importance of the emotional aspect, of

being able to provide care and love. Participant seven and eleven indicate practical duties; however consider the importance of the emotional elements. This is indicated in the statements: *'give them love again'* and *'quality time just talking to them'*. These participants seem to consider their role as a caregiver to provide both the practical and the emotional components, while to other participants this is merely secondary to the duties within their occupation.

Although some participants considered the emotional component as separate, and often secondary to the role of a caregiver, the component of emotional care and supportiveness was often considered important outside of their caregiving role, as indicated by the exemplars below.

> … myself, I see the patient for the first time and then I don't know where she comes from. I'm doing my work, I want to see her up and about and then she the one who cares at home, she feels eish I'm going to lose this person. Its… that that love, so she can't care and love at the same time you see, she's anxious, I wonder when I come back from home will I ever find her – it stresses her too much, unlike me seeing a patient for the first time – I'm not related to the patient but I give that patient love and care. She's related and she's she's afraid, she's got that fear of seeing my, seeing seeing my brother like this breaks my heart – you see, and then I can't I can't do more than this – I can't, can't can't bear to see my brother like this, you see.

(Participant 4)

> It is different because a family won't just be there every time. Like now we are on 7 in the morning I'll be off in 7 in the evening, so we spend a lot, a lot of time with them. At home, at home it will be more difficult because you are staying with them, sleeping with them, again the other they are staying with the patients and it's very difficult

(Participant 11)

While other participants emphasise the importance of the emotional and supportive connection they provide as a caregiver, the emotional relationship that develops between a caregiver and a patient, within the meso-system, seems inherently different when the caregiver possesses a previous relationship with the patient. Participant four seems to indicate that as formal caregivers they often spend more time with patients than family, indicating that in some senses they may foster closer relationships than the patient's family. This is illustrated by the statement that *'a family won't just be there every time'*. The dyad that fosters is often weighted, placing significant emphasis on the caregiver having to provide support and comfort, without expectations of such in return. This is indicated by participant

four stating that, *'I give that patient love and care'*, however participant four discusses the difficulties families face in trying to love and care for the patient while having personal concerns of losing their loved one, making it incredibly more difficult for families to engage in caring for the patient. This may be the element that makes family caregivers differ from formal caregivers, as often the pre-existing relationship within a given family had been premised on the notion of reciprocity. Since interactions are based on interrelations, and in the absence of such the caregiver creates interactions with their institution providing reciprocal feedback, rather than the patient. A formal caregiver's role often involves the consideration of the systems well-being and not simply the individual. It is also important to consider that the caregiver has no previous relationship or attachment with the patient, therefore is only connected with the patient when they are already ill.

> Ahhhh, (pause) when there is for example when we witness a death, maybe there is a death you can see like a family where they were seeing you taking proper care and sometimes they get used to talk with you, ask you how is their patient and all those things. So when that person died you know, they still come to you and need comfort from you, so I think that one that is the one that make me a caregiver.
>
> (Participant 10)

> We give back dignity because eh… if eh… maybe let's say it's somebody who takes care of the family now is sick, he or she cannot take care anymore, so the responsibility is no more there and those who are, who are looking after that person, they see that now things are changing and they don't respect that person any more. Now things that that person was able to do, he can or she cannot longer do that, so you know they feel that they are nothing now. But when they come here, my role is to make sure that … um…. respect is there. I I make sure that he or she can feel that she's a mother or sister, I don't make them feel like they are unable to do anything just to make them understand that it's the situation they are in and being strong again can make things better, they can go back to working and supporting their families.
>
> (Participant 9)

Participant ten constructed the formal caregiver as an important component in supporting the family; the individuals *need* support from them. In many ways this forms an important part of the closure and maintaining the distance between the caregiver and the patient. This often provides the caregiver with the ability to continue providing care, thus allowing for succession within caregiving. Whereas, participant nine emphasises the distinction between the formal caregiver and the informal caregiver, as the element relating to the emotional connection, as well as the knowledge that trained caregivers possess. From this account the caregiving is perceived as having the ability to provide respect, and that the patient's family

'don't respect that person anymore'. This seems to indicate the caregiver almost takes on the roles previously available within the family, fulfilling certain roles to maintain the patients role as a *'mother or a sister'*. This provides the system with a sense of homeostasis, which greatly influences the patient's ability to cope with the crises they are often faced with.

The importance of knowledge

The knowledge is perceived as the element providing the caregiver with the ability not only to manage the patient but also to manage the emotional component as well. In this manner it seems to provide the means for the caregiver to understand and deal with the situation without being engulfed in the process itself. The knowledge the caregiver possesses operates as a personal resource that they are able to rely upon for support and at times a sense of relief (Kramer, 1993) and also as a defence against the difficulties within caregiving, allowing for the succession of the individual's resources. Botes (in Baumann, 2008) considers knowledge to be of a much greater significance in countries such as South Africa, were reliance upon formal knowledge operates as a protective factor against elements such as exploitation, as indicated in the exemplars below.

> I'm I'm telling you correctly what you want because my role is defined according to the the know-how, the pro- the knowledge that what I have passed educationally, professionally, what did I pass and the experiences.
>
> (Participant 6)

> Someone who is a carer at the [Name of institution] he can have all the materials that he needed to work with the patient, and even if he knows nothing he has the sister in charge to his disposal if there ever is something he does not understand, he can go to the sister in charge or the sister will go to the doctor until they find out what's going on about the patient. But at home it will be different; it will be a procedure like, eh if he needs something there is no-one around him even though he will take time and unaware the patient is suffering. So it's just like a risk but I do not know, it depend but for me It's, it's something that will take a long time to and the other thing is that eh here we can, we work as a group and at home you find that you are alone and then you'll use some of the things and you can't do them properly because of you are alone. But here if ever I can see that this patient I can't manage it alone, I'll call somebody and then I have got help and then we can make sure that the patient is comfortable all the time. The other thing, is that … is that sometimes it might be possible that the patient need to be referred to somewhere, but at home, here we can like we have an ambulance we can just refer the patient immediately, but at home it

> will be like you call the ambulance it will take time and all kinds of things, so I think that is the different.
>
> (Participant 8)

> You must have patience, you must have love, you must have compassion, you must must have the knowledge of what what… how you are doing things and what you are doing and if you don't have the knowledge, um it was … go for like trainings, ja because people sometimes people think that being a caregiver is just to take care of somebody and you don't need to study for that. But you must have training … so that you must know that you are doing the correct thing and it's really hard because not everybody can just come and say I would like to be a caregiver.
>
> (Participant 5)

> Yes, because we are trained. At home those who take care of their families who are who are sick, they are not trained so they are so many mistakes sometimes they they lack care, I can say that because they get tired easily. Now we are trained and we know what we are supposed to do and not to do.
>
> (Participant 9)

> You know, if something happening and you eh you expecting that you you can't call it as a big challenge. So it is all about training. If you went for training and eh um I don't think it will be a big problem to you, but it will be difficult to the person who never trained.
>
> (Participant 10)

Participant six highlighted the importance of knowledge and having the skills, '*the know-how'*, that informal caregivers are not privy to. In this manner, the belief in their abilities and the expectations associated with their formal knowledge provide a sense of security. Participant eight alludes to formal caregiving as a constant in the patient's treatment or recovery process; it also highlights the reliance on the other caregivers within the organisation and the interrelation between the caregivers. This highlights the importance of interdependence and both the indirect and direct effects on it. This multidisciplinary approach may provide further understanding of the distinction between the formal and informal caregiver. This 'superior' ability to be omnipresent and the notion of 'privileged' knowledge form a crucial component of how the caregivers construct their identity and in most circumstances their status attached to that identity. Reputation within palliative care institutions is based upon expertise and competency, therefore knowledge is a significant resource for the caregiver (Arber, 2007). Important within the perception of their identity as formal caregivers is their competence as caregivers. However, there seems to be an interaction of prestige attached to the knowledge they possess – as participant five highlights

that: *'not everybody can just come and say I would like to be a caregiver'*. This notion informs their abilities and professional identity, and that along with this professional identity, participant five describes their ability as being able to discern *'what we are supposed to do and not to do'*. This perception of caregiving, as well as the application and emphasis of knowledge within caregiving, provides a dichotomous understanding, with the creation of definite 'rights' and definite 'wrongs' emphasising a sense of reliance upon formal means of knowledge. This creates the perception that caregiving, in the arena of work, is not restricted to a natural process, but rather that inherent within the system the caregiver acquires knowledge throughout the process, which is deemed vital and necessary as a formal caregiver (Leira, 1994). The utilisation of these resources and reliance upon this knowledge operates a problem-focused method of coping, attempting to "take action to change a threatening or damaging relationship between themselves and their environment" (Kramer, 1993, p. 384), indicating the interchange between the individual and the environment rather than coping mechanisms that would interplay with the caregiving dyad, and the emotional distress that may be fostered.

Knowledge is illustrated as a vital component within their identity, and without such their identity and role as a caregiver is depleted. This reiterates the interplay between the caregiver's knowledge and their competence. The majority of the participants considered the most important aspect as a *formal* caregiver, as the knowledge that they possess. This knowledge is often constructed as the source that enables them to cope with and adequately care for their patients. Thus, knowledge forms an important theme which reiterates the importance of information and the necessity for this information as a prerequisite for caregiving (Davies, 1995). However, throughout the interviews formal knowledge was constructed as the most important form of acquisition, while experiential knowledge was considered as an adjunct, contradictory to the results from Davies (1995) study which felt that formal knowledge was considered to operate "alongside" alternative forms of knowledge (p. 22), which is also emphasised by the multidimensional model. Through the augmentation of different forms of knowledge there is substantially more ability to adjust the understanding and make the circumstances more specific and relevant (Davies, 1995). This distancing from their own experience reiterates the reliance upon factual and knowledge based understandings and may operate as a means to shield themselves from the reality of their experience or distance themselves from the responsibility associated with their role as a caregiver.

When knowledge fails

The caregivers rely upon their knowledge, not only as a defining factor but as an element necessary within the caregiving relationship. Knowledge often provides confidence within their position and within their identity as a caregiver (Richardson, 2002) as well as competence in their abilities (Scott & Brown, 2004). However, this interplay may create a sense of helplessness within the caregivers. When knowledge failed to provide the answers the caregivers were often consumed by feelings of helplessness. Unfortunately, it is also the reliance on formal knowledge that often leads the caregivers to circumstances where a sense of helplessness is evoked. When formal knowledge fails or in circumstances where formal knowledge has fulfilled its purpose, but the situation remains the same, the caregivers often described an overwhelming sense of hopelessness, as illustrated in the exemplars below.

> You see, you, it's only it's just that there is nothing you can do but feelings are there, you feel eish….. I wish I could do this or that, so that they can feel comfortable, but you can't it's it's its beyond you your your ... care you see
>
> (Participant 4)

> As a caregiver. On the day is like not giving the total care you were supposed to give during the day that's most disturbing thing especially when things are like when you can't provide money and all from your pocket but you do say other things, but you can provide information of how can a person live or get income, but you can't, you can't give out money on your own and give it to some person because of you will give one, but what about the others? So the problem is eh is that you can help, but there is certain barrier that is there that you can't go beyond helping but there are things that you eh can do to help like giving information on how to access maybe grants and all, so … that is the one that's stressful and then the stressful part of the day or maybe not actually not seeing not seeing the person know that she is not achieving not seeing not seeing the person not achieving what you have given information to him about, that is the most stressful thing and not finding help anywhere else.
>
> (Participant 1)

> …. like if the patient is um, you know you tried everything. I remember having this patient with severe diarrhea and I tried everything and the doctor, I phoned the doctor, we tried everything and nothing could help and this poor lady she was only I think 22 years old, she was very very young and she was still healthy, but her main problem was only diarrhea, we couldn't do anything about diarrhea and I thought I knew everything, the doctor say ag, he tried everything and she end up dying. We couldn't do anything for this poor lady… (pause)
>
> (Participant 5)

> Eh, (pause) some of the things, ne some of the things that happen on a daily basis, the burdens and all the stress and problems, some of the things get you up to go to work and then some of the things where they bring you down emotionally that eish, I don't feel like going to work I don't feel like doing 1, 2, 3 because of uh the person is not getting well or the the condition is not improving
>
> (Participant 1)

The caregivers often felt confined to their knowledge systems in which they operate. Participant one describes the competency and ability to help as reaching a *'barrier'*, indicating the positions caregivers often found themselves in when they are unable to help. Participant four states that at times circumstances are *'beyond'* the care they are able to provide within the given situation. While participant five highlights the helplessness attached to having *'tried everything'* and a sense of failure when they, as a team, were unable to help the patient. Participant five even discusses relying on the doctor and even the knowledge available to the doctor was unable to change the outcome. Although the loss of a patient is often a difficult experience for the caregivers, caregivers often seek a means to alter the outcome and evade the feelings of both them, as caregivers, and their knowledge being obsolete. Participant five emphasises the difficulty of not being able to do anything, – '*and nothing could help'*.

Teram (in Karabanow, 1999) indicated two responses to such situations, that the caregiver would engage in self-blame or alternatively place faith in their abilities and provide a rationalisation for the events that occurred. For participant five, navigating the reliance and importance of knowledge, and simultaneously acknowledging the failure of such knowledge is difficult. These two concepts contradict and often lead the caregiver to blame themselves rather than the failure of knowledge. Participant five's statement *'I thought I knew everything'*, illustrates that knowledge did not fail but rather that the caregiver felt that their knowledge had in some way been insufficient. These situations often place caregivers in vulnerable positions. Caregivers rely upon their emotional resources to continue to meet work requirements, and the stressors inherent to the working environment. Often these difficulties are further exacerbated by the caregivers taking on the identity pressed and promoted by the organisation – as both professional and capable (Karabanow, 1999). In this manner the organisation often possesses the ability to alter the emotional responses of the caregivers (Karabanow, 1999). A significant amount of their identity incorporates their ability to care for and help others, and often the help and care required goes beyond what they are able to provide, usually generating a residual sense of failure to embrace or fulfil their role as a

caregiver. This has significant impacts upon how the caregiver perceives themselves and their abilities as caregivers, which indirectly influences their ability to manage both patients and their own emotional difficulties.

Confining and nurturing nature of caregivers

Once within the caregiving role, the individual is confined to being a source of aid on which others can rely without themselves being acknowledged as a source requiring help. This is particularly indicative of the caregiving role; participant two provided examples of the neighbours, family and friends relying upon them for information, or their knowledge and care, or their abilities.

> Um… I think this influence as a caregiver um… I experience many things cause now there are some other people who can come to that place and say to me, [participant's name] here I am and I don't know which procedure I am going to take, I am very ill I am sick, as a person as I know that you are working with people who are sick, please I don't know what procedure that am I going to take, please, will you help me? I'll just give that person the experience, the experience that I'm having, go do this and that and that and then we will take it from there. I think again at home it does help me cause I find out that my mother is sick, and then or maybe my mother is sugar diabetic and then I will just give him a certain food, just help him to do certain foods, to make his sugar level not going high or normal, just to stay as normal this, that's has helped me a lot.
>
> (Participant 2)

Davies (1995) considered caregiver to "be highly rewarding at a personal level; it can also be draining and exhausting" (p.19), which seems to echo participant two's statement. For many of the caregivers, this was a compliment or testament to their training and ability and in some senses emphasised their status within the community. This is an element consistently overlooked because caregiving as skilled work is not usually accepted as a form of work that requires formal skills (Leira, 1994). However, for others it provided circumstances in which they were unable to escape from their work environment and felt constrained to their role as a caregiver. Their construction of their identity seemed to hinge on alternative or additional roles that the caregivers occupy beyond the work environment. Thus, the interaction between the different spheres of influence occupies an important position within their caregiver identity, suggesting the importance of the interacting spheres on the caregivers' microsphere. Although the majority of the participants felt that there was a substantial difference between a

familial caregiver and a formal caregiver, especially in relation to the aspects of knowledge and emotional connection, several participants referred to their abilities that were related to their own familial roles, as important to their role as a caregiver. The following statements illustrate the intertwining of other identities with their identity as a caregiver, in most instances it was their identity as a mother.

> Eh the other word is to be a counsellor again and work as a counsellor, as a mother, as a family you know, and not as a caregiver only.

(Participant 7)

> Because I'm a mother and I ..... I think if it was my son who's admitted in [name of institution] – will I be happy if a caregiver comes and says I'm enjoying myself at work and knowing that my son is admitted there – those will be wonderful words I'll be hearing if my son was here and somebody say I'm a caregiver at [name of institution], oh I'm looking forward to seeing my patients today – like I do – I'm always looking forward to see them and I enjoy myself being with them a lot.

(Participant 4)

This conceptualisation emphasises the feminine role of caring and nurturing. This role is usually based upon a strong underlying emotional connection between the infant and the mother and in this instance the connection manifests in relation to the patient. In much the same manner as an infant is reliant on its mother, so too is the patient reliant upon the caregiver and requires, in many circumstances, that the caregiver both nurture and comfort the patient, as a primary caregiver/mother. Through the fulfilment of a pre-existing role, the caregivers possess the abilities to engage with that role and have a sense of surety within such a role. In this manner the exemplars above illustrate an attempt at merging different identities. The role of mother allows them to maintain boundaries in relation to their professional role, while simultaneously fulfil their caregiving duties. This may be indicative of difficulties of the caregiver merging their professional identity represented in the duties they perform and emotional closeness fostered. Thus, taking on an additional, often pre-existing identity illustrates the struggle caregivers have in trying to reconcile the two contradictory roles within caregiving. It also may operate as a means to maintain those identities, concerned that their identity as a caregiver will overwhelm the other identities within their lives, in this manner it is the process by which the caregiver maintains a sense of self (Yamamoto-Mitani & Wallhagen, 2002). It is the alternative roles that often diminish at the cost of the identity of a 'carer', as the compromise is often too difficult to maintain throughout the process (Yamamoto-Mitani & Wallhagen, 2002).

Theme two: Managing the unmanageable

Coping is a significant factor in palliative care as caregivers are constantly exposed to death and dying, and this is often further complicated by the need to manage the emotional needs of patients and the patients' families (Hawkins, Howard, & Oyebode, 2007). This magnitude of sustained caregiving often makes caregivers vulnerable to long-term stressors (Pearlin, Aneshensel, & Leblanc, 1997). This is further exacerbated by the difficulties in relation to limited resources, insufficient support and elevated workloads (Hawkins *et al.,* 2007). The initial stressors and the persistence of these stressors, result in stress proliferation to other spheres within the caregiver's life (Pearlin *et al.,* 1997). This reiterates the causal implications of stressors and the significance of the increased and prolonged nature of stress.

Although there are significant stressors and overwhelming circumstances that caregivers have to engage with, there are also several means that operate to ameliorate the influences of such stressors. Coping can be divided into emotional and problem-focused coping. The former is indicative of the process of trying to alter the underlying problem, and the latter relates to the process by which the individual decreases the stress experienced (Kramer, 1993). Religious beliefs and practices are often indicated to operate as a protective factor enhancing the caregiver's ability to tolerate the stressors (Stepfanek, *et al.*, 2005). It is also considered an important aspect for most caregivers and often associated with decreased depression (Hebert, Dang, & Schulz, 2007).

Managing the unmanageable provides insight into how the caregivers perceive the role of coping and the different support mechanisms available to them as formal caregivers. The coping mechanisms relied upon were diverse, having provided the understanding of how the individual caregiver is able to manage, or unable to manage, their workload and the daily challenges encountered. Ultimately the caregivers' coping is often intricately intertwined in their emotional capacity and their ability to feel adequately prepared to manage the difficulties (Hawkins *et al.,* 2007). There are various aspects within managing difficult situations. Individuals provided information regarding how they perceived certain techniques or manners of decreasing the negative effects and promoting the positive effects. The application of certain techniques endorsed further difficulties. In addition, certain circumstances, such as high workload, were considered noticeably more difficult to manage.

Having someone to share with

Participants often discussed their need to have someone to confide in. This process of sharing was acknowledged as vital to the caregiver and their abilities. These exemplars below indicate the manner in which the participants perceived having someone to share with as a positive means of coping.

> I think the best way is to talk with somebody, ja. If ever I talk with my friend or my colleague especially because of some of the people that I am working with them and some are my friends, so if I can talk with them then I still feel that thing, then I go … I can go to one of the sisters and talk to her about it and if ever I can't be alright then I go to some else, the matron or the directors then I will finally be alright.
>
> (Participant 8)

> I think that people, if you are stressed, you must talk about it. In the morning before we start uh… with um our work we have this small gathering think where we pray and somebody who is doing the prayer will ask everybody how they are today. So if you feel that you are stressed I think you must find somebody to to talk to and you must look for help because you will end up eh eh eh … not doing your work and you'll end up hurting other people…mmmm…
>
> (Participant 5)

> You know you just take things the way they are. That's why the most important thing if you have got something that hurts you, don't keep quiet, don't take those things all if you, it's hurting, but be free to tell anyone who you trust, Ja, …You know everyone will trust you and you know that this one always when I have got problems is the one who hears me. For sometime eish, I open the window, I'm singing the whole day, I'm singing, I'm singing, I'm singing or I sleep for my stress, if I sleep I forget about these things, but the thing is I still - if I got stress I sleep for a long time. I can sleep now until tomorrow, hey, not waking up, um….
>
> (Participant 7)

The extracts above demonstrate how several participants felt that the idea of talking to someone is equated with significant positive implications and that it allows them to *'finally be alright'*. Participants considered seeking someone to confide in as an aspect within their occupation and without such the individuals are denied the opportunity to alleviate the stress. Having someone supportive, especially within the institution has been considered a significantly important coping strategy, especially for the caregivers (Keidel, 2002). The participants placed significant emphasis on the individual seeking the support themselves *'you must find somebody', 'you must look for help',* indicating that support is not perceived as readily available but rather something that has to be discovered by the individual. In some

senses this seems to allocate further responsibility to the caregiver. Although participants indicated that being able to confide in one another was a positive means of coping, they often tended to additionally engage in more individualistic coping strategies, as illustrated by the exemplars above. Participants engaged in coping strategies, ineffective and effective, such as sleeping and singing respectively. This may be indicative of the concerns centring on trust and the consequences attached to confiding in another, as well as not having immediacy of someone to confide in. Social support plays an intricate role in the caregiver's ability to provide care to patients and to utilise such support to prevent these difficulties from having significant negative influence on others facets of their personal life.

The complexity in confessing

The majority of the caregivers felt that having external support to share their experiences with was beneficial. However, several participants felt that, although being able to confide in another about the experience was beneficial, it was significantly more complicated. Individuals feared that their difficulties would become public knowledge or would have some form of repercussion for their careers or current employment.

> It's it's not nice because sometimes you need somebody to talk to you know, just to talk to but it's not safe because everybody will know what you've been going through, everybody around you
>
> (Participant 3)

> I find spirituality – I talk to God, because it's not easy to trust somebody you'll talk to somebody and you'll hear it from another one – so the only refuge is God hmmmm…
>
> (Participant 3)

> I think sometimes it's that, sometimes when you've got a stress you must talk so that you must resting because if I talk about something that maybe is stressing me, I must talk to one of my my colleague maybe he is healing me with some other words. But here you can't because if I talk to you as a colleague will say eh, I am having this, you are going to take this thing to to to the seniors. They will make you sit and then you'll struggle with with with the stress the whole day, not knowing where to … take it to
>
> (Participant 7)

> Ya, like talking cause, here here at this place I cannot talk to my colleagues cause he's the very … we are in a very same situation, so how is he going to help me. Maybe

> somewhere, somehow meeting a different person, who doesn't know him, I don't know me, maybe sometimes it does help, it helps a lot.
>
> (Participant 2)

These exemplars above illustrate that participants clearly found a need to have someone to talk to but at the same time recognised that it was *'not safe'*. In many instances the idea of confiding in someone or being able to share your difficulties is linked to the feelings of being ashamed of those experiences, which is furthered by the potential embarrassment or punishment that accompanies sharing any difficulties. This is indicated by the statement that individuals would *'take this thing to to to the seniors'*. These statements seem to also indicate a fear of being placed in the 'patient' role or attaining a label denoting them being 'sick'. Thus, by not approaching others within the institution they are able to maintain their role of 'capable'. It also illustrates the stigma associated with the sick role that often caregivers themselves go to lengths to avoid being connected with such. While others felt that their colleagues were unable to help them through the experience given that they were going through the same process. This may also allude to their concerns of placing additional burdens upon others.

> Focusing helps a lot, I remember one night I started focusing I had a problem I couldn't share with anyone. But since, I'm still in the focusing course – after focusing, change just came, I didn't prepare myself to say today I'm going to talk to focus on this, the problem of mine just came, I wanted to make space in myself for happiness, want to take everything that hurts me out, but I can't find anything that hurts – but there is something that hurts me, but I can't I can't I can't see, get a space for it, you see so that problem just came and then I gave it to her and then I focus on it, then it was gone.
>
> (Participant 4)

> If then maybe I discuss it with my colleagues what happened and then I won't just speak for myself, just say such and such a sister in charge or whom then it's over, because sometimes it's not easy to hold the other person you know, they give you stress when you say this and that and that sometimes they just piling a lot of work on you
>
> (Participant 11)

The act of confession seems to have repercussions on the individual caregiver as well. Often it is considered an additional burden and in this sense the individuals are considered to be "*piling a lot of work on you"*. One participant discussed a technique known as focussing, where talking about it allowed the caregiver to focus on the problem and attain a sense of control and perspective by placing the difficulties outside of themselves. The caregivers feel isolated from help in many respects and feel that certain experiences they *'couldn't share*

with anyone'. This isolation is the result of failure to have the difficult experiences acknowledged and their responses validated, which consequently places the caregiver in a position in which they could experience significant negative effects such as disenfranchised grief (Frank, 2008). Social support provides one of the most important elements of effective coping and has significant mitigating effects on negative impacts such as burden and depression (Kramer, 1993). This is particularly relevant to caregiving given the interpersonal nature of the stressors within the profession (Kramer, 1993). This sense of isolation is considered to be indicative of the difficulty of not having someone to confide in, as indicated in the exemplars below.

> Ya, it does, ya it does, but it is part of life, you know it's part of life I think. It is hard you know, it's hard, but if you do not have someone to talk to, you find yourself in a lonely place, lonely place if you don't have someone to talk to but then I think time goes on, maybe if … you'll just find a person who will be there for us, talk to us like you are doing now, asking me about the challenges and the stressful parts, I think it, it will be better.
>
> (Participant 2)

> If there is no support inside sometimes it's difficult, so support is very very important and as a person you have to create that support. Don't create support while we have problems. You have to create the support around you to cooperate with people to help them with their trouble and you are creating, you have to have a way how to create um the support so that when we are having problems sort of these people can in.
>
> (Participant 10)

> Eish, sometimes I just think I can cope, I can cope with stress. The thing is that when I'm stressed, I share it somebody else. I will… won't just keep it in. And no especially here at work, at home I like to share it with somebody
>
> (Participant 11)

The participants felt that being able to have the opportunity to engage with an 'uninvolved' individual, such as the researcher was beneficial. This was referred to in statements such as *'talk to us like you are doing now'* and in an earlier statement *'meeting a different person, who doesn't know'*. Beyond simply the neutrality of the researcher, participant two refers to the ability of the individual to *'be there for us'*. Reiterating that it is not the opportunity to talk with someone alone, but also the support they would provide and the stability in being a constant and devoted source of support that was deemed trustworthy. This seems to suggest their expression for a dedicated caregiver – much the same as a mother role. In many respects this notion expresses a previous concern of the caregivers need for support and care, and their

want to simultaneously maintain their professional identity and uphold boundaries between the two. In particular, this highlights the distance between their professional role and their personal difficulties that arise in relation to caregiving. Managing and confiding in individuals cannot be reduced to the availability of these resources but also the capability of the listener. Caregivers' ability to cope with stressors is highly dependent on the resources the caregivers have or perceive to be available (Kramer, 1993), in addition to the quality of resources available.

The high workload

Several factors are considered to interplay with the caregiver's ability to manage the inherent stressors within palliative care institutions. An increased or high workload, in particular, often has ripple effects on the caregiver's well-being. High workload or overload operates as a primary stressor, placing the individual in a vulnerable position for the expansion of stressors due to stress proliferation (Pearlin, *et al.*, 1997). High workload often incites high stress (Hawkins *et al.*, 2007). Underlying this stress are often perceptions of inadequacy related to the difficulties in trying to manage during periods of high workload (Keidel, 2002). Situations of high workload are often aggravated further by the limited resources and caregivers available, as illustrated in the exemplars below.

> Sometimes you find that you've got a lot of patients but staff we are few. Like you find that I am working at the male ward alone and will have eh 8 patients and then it's not easy to work with the patients when you are alone. And to find that, that you have too much work and then you can't just complete them within that time. I think for me it is only the difficult time that we have.
>
> (Participant 8)

> Yoh, the most stressful part of my day is when we help many many patients here it becomes so stressful. And you find out now, you don't know what to do or where you can run to, especially when we have patients, cancer patients because they are in pain, so some of them you cannot control them. Those things they give me stress, those things they give me stress. But as a person that I told myself that I am going to work, so I will just maintain it until the end of the day.
>
> (Participant 2)

> There's a lot of stress, a lot of challenges, especially challenges that you can't even you know, solve and trying to do many things at the same time. Like sometimes myself I feel

> burnout because I do so many things at the same time. Somebody will call me to to, for a meeting, somebody will call me for this and somebody will call me for that ooh five people, at the end say ooh burnout and I need to run away from this place.
>
> (Participant 5)

> Ultimately you are going to burst – either you are going to lose control and shout at the patients you know, hmmm… because I think we we react differently … when we have stress. Then we leave everybody one way or the other we experience this – but it's how you deal with them when it does matter
>
> (Participant 3)

Participants described instances of high workload as the most stressful of the daily challenges in the palliative care institution. The caregiver's ability to cater to multiple patients often results in the caregiver feeling a sense of loss of control and a sense of uncertainty. This is illustrated by, *'you don't know what to do or where you can run to'* and *'challenges that you can't even know'*. It is as though caregivers reach a point where it seems impossible to continue, hoping to avoid the stressors, as illustrated by their *'need to run away from this place'* or the feeling that they will ultimately lose control by *'bursting'* or reacting to the stress. The stressors seem to place significant pressure on the caregivers, participant three describes that *'you are going to lose control and shout at the patients'*. This seems to indicate the severity associated with the stress that caregivers often go to extremes, in that, their caring is often reversed into shouting at the patients. This statement illustrates the fragile nature of participant two's emotional reactions and that such stressors illuminate the difficulties caregivers experience in trying to maintain emotional stability. The implications for high workload are severe and participants alluded to notions of burnout and an inability to manage, both the situations and also their own well-being and reactions to these stressors.

Seeking alternative means of support

Alternative support beyond the institution often results in individuals obtaining successful and differentiated coping strategies, but also ineffective and damaging coping strategies. The exemplars below illustrate the different support caregivers may seek during difficult times.

> That's when I can go and talk to the professionals. I can go and ask where I can get eh … professional somebody who can counsel me so that I will be alright.
>
> (Participant 8)

> I don't know the problem is that I have been here a long time so I found out I need to be motivated.
>
> (Participant 11)

> You know to be honest with you, sometimes I say let it go but then sometimes it really comes and then I'll end up drinking a lot, to be honest, I'll end up drinking a lot but it's not helping, it's not helping really but then sometimes I just take my money and buy drinks and drink a lot.
>
> (Participant 2)

> So my family always counsels me because if I I I get home and then [name] asks me how was the the the job, I am telling him hey, this and this happened this and this and even my children and then [name] says ah this world, these things, these things are happening all over, there is nowhere you can find that this is not there and you are not the same and then ….. he just goes as long as they don't chase you away, just take it and then don't take in a high level, you know.
>
> (Participant 7)

Participants discussed their ability to utilise services outside of the institution, as well as their own internal resources, such as motivation. These illustrate positive coping strategies that endow the individual with the ability to continue. Participant two discussed their reliance on alcohol, but stated that *'it's not helping'*. Often ineffective coping strategies make the individual more vulnerable to the negative implications of caregiving and stress, and allow for secondary effects that arise from relying upon a coping strategy such as alcohol usage or abuse. Jones (2005) considers exaggeration of addictive behaviours to be one of the aspects relating to the emotional experience of caregiving. Such dependency may indicate emotional dependency needs. This often gives rise to a vicious cycle as it operates as a temporary coping mechanism, but ultimately making the caregiver more vulnerable to the next stressor. Other participants utilise their family as a means to attain relief; however, given the contextual implications families often illustrate the importance of the job as opposed to the individual caregiver's well-being. This is indicated by participant four being told, *'as long as they don't chase you away, just take it'*. This has the potential to create a vicious cycle as participants are both unacknowledged and still suffering the influencing factors of caregiving, while having additional responsibility, or burden, to provide for their families. In many respects the division between their family role and their role as a caregiver is viewed as insignificant, placing them in a vicious cycle. This vicious cycle reiterates how the caregiver is unable to maintain the patient role themselves while simultaneously having to continue their role as a caregiver in multiple spheres within their lives.

Two participants discussed utilising music as a coping mechanism, as indicated by the exemplars below.

> So after work sometimes yes there are things that are stressing sometimes it depends what kind of stress. I am not a person that will keep grudges, to keep issues in my heart, and sometimes I… if it is a patient I just talk with somebody like just to keep in my heart and uh um … when I am off going home, even if that thing is in my my my mind or in my heart I listen to music and I just keep the music in my mind. I don't think anything I don't want to see anything and I don't want to talk with anyone, I just want to listen to the music and that's it.
>
> Yes, so far it is working for me, ja.

(Participant 10)

> Ah … the way I cope is, what do I do um the things that I do for a day like during the day I I do do my caregiver work, I give care to people, to patients, eh maybe during the night I sit eh play some music or I just think, really think, recap of what I have done for the day,

(Participant 1)

Participant ten discussed using music to, in a sense, pre-occupy thoughts and concerns. In this manner the music operates as a means to provide a distraction and the statement *'just keep music in my mind'* seems to indicate its ability to fill their mind and in this manner remove any opportunities to ruminate over stressors or difficulties. Through this engagement with the music the participant seeks to *'just want to listen to the music and that's it'*. In this manner the participant utilises music as a means to both distance and disengage from the challenges and stressors associated with caregiving. Music could also operate as a means to symbolically represent and work through difficult emotions that the caregivers feels unsure or has difficulty sharing. Upon further enquiry participant ten stated that this technique seemed to be working for them. While participant one seemed to regard music as a tool to reflect upon the challenges and as a means of relaxation rather than a means of supplementing their engagement with the challenges.

Spirituality and religion operated as a significant means of support to the caregivers. It is important to acknowledge that religious or spiritual beliefs often fluctuate over time and are greatly influenced by the circumstances in which they operate (Hebert *et al.,* 2007). This is particularly important as often palliative care institutions themselves enshrine a sense of spirituality and the situations lay the foundations for existential and religious interactions (Blinderman & Cherny, 2005). Religiosity and spirituality are considered coping strategies

associated with positive outcomes (Mytko & Knight, 1999; Stepfanek *et al.*, 2005). Religion and spiritual beliefs are multidimensional (Stefanek *et al.*, 2005). Thus, it is important to acknowledge that religious or spiritual means of coping can also operate in a negative manner (Mytko & Knight, 1999).

> Ah because at some, you you get you'll meet the situation like you have to go back and see and … play that whole thing in your mind you know … it's not effective at all but the only hope I have is from Jesus
>
> (Participant 3)

> … but now myself the only hope is from my lord and savior – because I've been disappointed so many times even by my family that I have I have no hope from anyone – I don't trust nobody except for him …
>
> (Participant 3)

> You know I think the other medicine when you when you... come across such things, pray. Because I understand that what I say, like I'm talking to you now – that's the way I should communicate with God. Whatever problems, I must name my problems to him, I must tell him, I must not just say our father who art in heaven – I must tell him what I need and
>
> (Participant 4)

> That is when you are one on one with God, God I feel like I don't have strength, help me. And then he will be here, the next thing you did feel like you are not well in your body and then you can feel it when you enter the, you know we are working with very ill patients, if you do not feel like working, if you feel like you are sick, you have to stay away because maybe you'll be worse you know because people are sick here and they need somebody who can take care of them you know 100%. So with God, you know you just find the strength from nowhere and then at the end of the day you, you you realise that God there really and God is really working.
>
> (Participant 9)

> Well I am a spiritual person, so I have realised that by receiving God and being able to be a born again Christian helps a lot. If I feel very stressful, I have realised that we differ and sometimes you'll tell somebody how we feel, they'll change their information, like if you feel tired, maybe they will take it that you don't want to work anymore, but if you – God knows us so well, if you feel like you are tired you just ask the strength from God and then I feel strong so...
>
> (Participant 9)

Spiritual and religious means of coping provide means to utilise several different coping mechanisms (Mytko & Knight, 1999). Often religion or spirituality allows the individual to attain a sense of meaning and hope, as well as being a supportive element – providing

strength and reassurance to the caregiver (Bussing, Fischer, Ostermann, & Matthiessen, 2008). This is indicated in the above statements as participants ascertain strength from their relationship with God. In this manner God and the religious or spiritual beliefs a person holds, operate as a support system (Blinderman & Cherny, 2005). One of the participants equated prayer to medication – as communication with God is believed to have healing effects in the same manner as medication. There is a significant amount of trust in their beliefs and the capabilities of God, as exemplified by, *'I trust nobody except for him'*. Trusting in the higher guidance provided by religious or spiritual beliefs and practices is referred to as 'intrinsic religiosity" (Bussing *et al.,* 2008, p. 358). Such beliefs are also able to operate as motivation and a source of hope: *'the only hope I have is from Jesus'*. Religious support allows the caregiver to ascertain a sense of control through making meaning from interactions (Fillion *et al.*, 2009).

Coping with the mixing of home and work difficulties

Caregivers work for long hours, over extended periods of time. In addition to this emotionally and physically exhausting work, their home situations are, at times, often as difficult to manage. Caregivers' ability to balance their personal lives and their professional roles is often considered one of the most challenging barriers to coping (Frank, 2008). The different roles the caregiver occupies often result in stress proliferation and these stressors impede the other roles within the caregiver's life. Several participants found it difficult to negotiate the opposing roles and the struggles associated with such, as illustrated by the exemplars below.

> Ya… Sometimes it does help, to talk with some other people because here I am facing these difficult things and then at home again maybe I am facing with difficult things again, so it becomes a problem, becomes a problem, because you are now mixing with a work situation problem and then family matters sometimes become a problem, ya
>
> (Participant 2)

> It really affects them in a bad way … ne? I saw saying and meaning we have problems of our own ne, sometimes we don't handle them the same way you find that people harassing patients, they will just say eh you are sick – that is why you got this disease because you got one two three, and you it might not be that the person is just saying it – but it's it's something he –she or he might be having problems of her own, you see, mmmm so it there is the stress is really a negative is making a negative
>
> (Participant 3)

> Ja, something you feel that especially when you are at home sitting and just relaxing, you you think back to to the [name of institution], you can't even sleep at night
>
> (Participant 5)

Stressors experienced at the palliative care institution are considered to exacerbate difficulties the caregivers may be experiencing in their personal lives. Difficulties in their personal lives also begin to manifest in their caregiving, illustrated by participant three stating that *'there is the stress is really a negative is making a negative'*. The merging of difficulties experienced at work and those experienced at home, result in the increased vulnerability for the caregiver. Participants explained the merging of work related and personal difficulties as creating a continuous problem. Having to perform in several competing roles requires the individual to engage with their own limited personal resources, which increases levels of stress and decreases their ability to cope with this stress (Kim, *et al.*, 2006). A balance between their personal and their professional lives is important, especially as caregiving is an ongoing process and such a balance has significant mitigating effects upon negative impacts, such as burnout (Jones, 2005). Other participants mentioned that work related difficulties in combination with personal difficulties can have substantial effects upon their abilities as caregivers. One participant indicated that *'sometimes we don't handle them the same way you find that people harassing patients'*. This statement put the importance of their coping within context and provided an indication of the outcome of the enduring challenges. Burnout is linked with the continuous exposure to daily stressors that are enduring, rather than significant stressors that are restricted to a critical aspect (Kulik, 2006).

Other participants utilised their personal environment as a means to dissociate from the challenges they face. The distance between their personal and professional lives was considered an important coping strategy for several participants, while others found that the distance provided only a temporary solution.

> It is like being at home; maybe when I am at home I'm just like I just do whatever around the home. I can't, I can't remember, I can't just think about there whatever I am doing at work. It is like when I am at work, I don't think about whatever I am doing at home. I'm just doing whatever I'm supposed to do, so for me it is all about doing something at the right time, at the right place. I don't have any problem, if I have a problem at home I make sure that I solve it at home and when I come to work I find that I do not even think about it. Like if I can have a problem here, I can't just take it and go and solve it at home. I just solve it here and then I'll finally be alright.
>
> (Participant 8)

> Ya, that might help me. But then tomorrow again is another day and I am going to face that same particular situation. So I find it hard again, but then I don't know, but then I don't know, it's hard to take it away.
>
> Ya and when we come back the next day … it comes again to your head again.
>
> (Participant 2)

Participant eight stated *'I don't have any problem, if I have a problem at home I make sure that I solve it at home and when I come to work I find that I do not even think about it'*. Participants eight's description depicts the disassociation of the two experiences in relation to the difficulties in trying to combine personal and work difficulties. For participant two, there is a predominant focus upon the enduring nature of their caregiving difficulties. This is illustrated by the caregiver's perception that the difficulties experienced each day may only be temporarily erased as they *'come again to your head'*. This seems to indicate that the difficulties are not limited to the presence of both personal and occupational difficulties, but rather the enduring nature and often the accumulation of such difficulties. This is usually exaggerated further by the long working hours over an extended period of time. It is aspects such as high work load and elevated responsibilities, as well as the persistent nature of these aspects that initiates burnout and compassion fatigue (Maslach *et al.,* 2001).

The outcomes of (not) coping

Caregiving have significant effects upon the individual caregiver emotionally, psychologically and physically. This is further exacerbated by the constant exposure to death and dying within palliative care institutions, making the implications of those processes on the caregivers important throughout the caregiving process (Hawkins *et al.,* 2007). In addition there are certain factors that may place the individual in a more vulnerable position. These factors include, but are not restricted to, the differential effects of stress and coping strategies in men and women (Marks, Lambert, Jun, & Song, 2008). This is further influenced by contextual factors, with male rural caregivers considered to be at a substantially higher risk for physiological and psychological difficulties (Sato, *et al.,* 1996). These stressors often have an accumulative effect upon the caregiver and their working abilities, as depicted in the exemplar below.

> Yes it does because when you're stressed you can't, you can't deal with the challenges because sometimes as I was saying eh there are so many challenges with the [name of institution] so when you're stressed you end up dropping in the families and dropping the patients um…. you end up not doing your work correctly.
>
> (Participant 5)

For participant five the *'many challenges'* faced as a caregiver are conceived as having significant implications for the caregiver's abilities. However, it seems to indicate the creation of a vicious cycle. The influence of multiple stressors results in the individual having difficulty fulfilling their vocational obligations which in turn presents the caregiver with additional stressors which further compound the caregiving process. Participant five's description also provides an implicit distinction between the formal caregiver and the informal caregiver. This distinction highlights the vocational aspects within caregiving and their contribution to the process. It is this distinction that often results in caregivers feeling a need to provide a constant means of support for each patient. The extract below demonstrates the inherent difficulties in trying to ascertain this sense of 'perfectionism' in their vocational work.

> Ya …You you shoulder everything; you think ah! I want to – I feel like I should take all their sufferings and carry myself for them and you can't, cause they leave there. And you've got – you don't only concentrate on one patient you've got maybe three, four six patients to care and they come with the same problem
>
> (Participant 4)

The caregiving process has the potential to evoke further stressors that arise due to the sense of burden and obligation caregivers feel to attend to everything. In participant four's description there is a sense of compulsion in that the caregivers are almost expected to *'shoulder everything'* as well as the implicit expectations associated with being a caregiver – such as indicated by participant four: *'I feel like I **should** take all their sufferings'*. There are substantial expectations on caregivers, and the reassurance of their competence is often needed to counter these expectations experienced by the caregivers (Moody, Webb, Cheung, & Lowell, 2004).

These experiences can escalate to a point whereby the caregivers are unable to envisage an alternative. Furthermore, these experiences are often accompanied by feelings of hopelessness and a sense of helplessness in light of their coping abilities and the

circumstances that surround their difficulties. This is indicated in both participant six and seven's statements below.

> Eish, it's difficult. Sometimes you think that's what about eish, you feel not to come back here.
>
> (Participant 7)

> With this, you feel, ja, it it it throws some burden on one because you feel that you you you won't achieve what you want. So that is the effect.
>
> (Participant 6)

However, participant eleven attributes her ability to manage such stressors to the extended duration and the familiarity of the experience, while participant ten feels that acknowledging the presence of stress and managing that process as highly beneficial in coping.

> Sometimes I just go, nowadays, I've been here for 5 days, I've already what can I say, I don't know how to explain it. I'm just I will just take it like, I'm used to
>
> (Participant 11)

> Ya even stress, but the main thing is uh how can you tell to come with techniques that can makes you at least coping on the stress, but the stress is always there. Every job or in life the stress is there and you can't avoid it, but it will depend how you deal with that stress.
>
> (Participant 10)

Participant eleven conveys a sense of acceptance of the difficulties and reiterates that the process is one that they consider themselves to be *'used to'*. Adaptation theory considers caregivers as able to adapt to the stressors as a result of being exposed to the stressors over that period of time (Miller & McFall, 1991). This exposure is deemed to decrease their sensitivity to the stressors through familiarity with the stressors. But in the same token there is the notion that the caregiver has no choice. Perhaps the familiarity with the situation operates as a means to emphasise their helplessness and inability to control certain aspects of the caregiving process and their reactions to the process. Being able to acknowledge or accept the consequences of the stressors provides the caregiver with a means to ascertain a sense of control over the caregiving process and thus ultimately the outcome of caregiving. This aspect of control is often indicative in caregivers' attempts to adjust the environment (Davies, 1995) and in this manner ascertain a sense of control and thus remove the helplessness that is often present within caregiver's role, particularly in palliative care.

The majority of participants emphasised some degree of difficulty or circumstances involving the management of stressors, such as burden and stress. However, there were participants, such as participant four, that felt that they were able to manage circumstances and emotional experiences in an effective manner, as indicated in the exemplar below.

> that makes me happy – I don't know if there is anything that is going to weaken my caregiving, nothing no – and I won't allow that to happen, because if I can allow that thing to happen to be weak in caring then I won't supposed to be here. My always been I want this done – nothing must be bad bad bad or better, must be good and caring
>
> (Participant 4)

Participant four prevents a dogmatic representation of his/her role as a caregiver. Participant four's statement: *'I won't allow that to happen, because if I can allow that thing to happen to be weak in caring then I won't supposed to be here'*, in many respects indicates narrow conceptualisation that prevents caregivers from being able to be conceived of as weak. Weakness is associated with people that are not caregivers, those in the patient role, and it places a significant amount of pressure on the caregiver, in that they can't let that happen. In this manner the caregiver is not provided the opportunity to engage with weakness and difficulties, often placing them at a higher risk for burnout and stress.

Although motivation and commitment to caregiving often places the individual in a position where they are able to motivate themselves and their experiences within the institution. Motivation has been considered one of the most prominent elements in performing well in palliative care institutions and has been connected to the ability to acknowledge and accept the positive aspects within a given experience (Jones, 2005). Competency and self-esteem operate as a means to allay negative perceptions and thus, operate as an effective coping strategy. However, it is important that these aspects do not prevent the caregiving from being able to have a genuine emotional experience, as well as the ability to experience vulnerability.

Theme Three: Meaning making

Jones (2005) describes caring as a "fulfilling, enriching, and meaningful experience" (p. 125). Being able to make meaning from caregiving provides a means to ascertain a sense of fulfilment and simultaneously decrease the negative implications of stressors (Jones, 2005).

Meaning making allows the caregiver to engage in a process through which understanding and development is fostered, in addition to having vast effects upon the caregivers' self-care (Jones, 2005). Self-care in caregiving is a fundamental component of the caregiver's ability to provide the necessary care. Making meaning from work also operates as an opportunity to enhance growth and connection with oneself and others (Mirvis, 1997).

Meaning also intersects with spirituality (Dyson, Cobb, & Forman, 1997), usually providing a foundation from which individuals try to ascertain meaning regarding difficulties, such as loss. Meaning can initiate the process of healing (Butcher & Buckwalter, 2002). This is considered particularly important in understanding experiences of loss and utilising the process of meaning making to further personal development and mitigate the negative consequences associated with caregiving. The concept of meaning is often implicated in human suffering and providing a means to understand the experience of this anguish and loss (Baldwin, *et al.*, 2008). As human beings, we seek "connectedness, continuity, security, belonging, purpose, fulfilment, significance and hope" (Doherty, 2006, p. 204).

Interpretation constitutes a significant component of understanding experiences and allows the caregiver to attribute a sense of meaning to the caregiving process (Butcher & Buckwalter, 2002). Being able to engage in meaning making processes strengthens the caregiver's sense of control and allows for the integration of both positive and negative aspects (Fillion *et al.,* 2009). Aspects of the caregivers' experiences are currently present in their engagement with caregiving but also implicated in their past and "*thrown* into the future" (Butcher & Buckwalter, 2002, p. 118). Butcher and Buckwalter (2002) describe this *'thrownness'* as the aspect that is able to negatively influence or precipitate psychological distress, such as depression and burden, as well as physiological difficulties.

Fulfilment

The ability to utilise meaning to connect with something greater than oneself allows the caregiver to make sense of their experiences (Breitbart, 2002). Being able to connect a caregiver's vocation with a greater sense of fulfilment or purpose has vast implications for the community and social meaning (Mirvis, 1997). In this manner meaning operates as both a coping mechanism and an outcome (Breitbart, 2002). It can be considered an active coping

strategy (Fillion *et al.*, 2009) and as a coping strategy it allows individuals to ascertain the opportunity for growth and understanding (Breitbart, 2002).

> Eh, the most satisfying eh, (pause) ah the satisfying factor is that … (pause) the satisfying factor is that umm… eh most people are not where I am now you know to see the beauty in the care that we give, that's the most satisfaction one because that but they need to see it either way so but that's why I'm satisfied about that, that most people they are not where I am now to see the love, the care that we give. So I am very proud of what I am doing.
>
> (Participant 1)

> Sometimes I say oh! But I say my blessing not my doom this is my work
>
> (Participant 4)

Participant one discusses the most satisfying factor as being able to *'see the beauty in the care that we give'*. There is a sense of pride attached to being able to see the beauty in caregiving and it makes the meaning of the experience as a privilege in many respects. While participant four also discusses the search for positive meaning within the process of understanding the experience, the participant chooses to engage with the components that are deemed meaningful within their life (Butcher & Buckwalter, 2002). Through focussing upon the positives or *'blessing*[s]*'*, the participant is able to create meaning through the difficulties within the palliative care process (Butcher & Buckwalter, 2002; McFarland & Sanders, 1999). Although participant four was able to identify blessings amongst the challenges not all caregivers are privy to such abilities (Butcher & Buckwalter, 2002). While some participants made meaning of the change that caregiving initiated in their lives, and the ability to understand the implications of such, as illustrated in the exemplars below.

> And then as a caregiver ne, we know, you know since I have been a caregiver ne, I have changed. Ja, I've learned more about people, different kinds of people and then they have changed my life that thing, because really someday somethings I'm going to confront them whatever you like or what you are going to get there in life and then you won't run away from them.
>
> (Participant 7)

> Uh .. each… In life we are different and how much we value life. There are people who have no purpose in life there are those that have a purpose in life, so it has taught me that.
>
> (Participant 6)

Caregiving has the ability to greatly influence the caregiver's world view, especially when confronted with repeated losses (White, 2004) and their perception of their ability to handle these losses and difficulties. Participant seven's description indicates a sense of determination that resulted from the exposure to different people. The participant highlights the process of vicarious learning and states that caregiving has provided them with the opportunity to acquire a sense of determination and a process of seeking purpose in life and the importance of such.

The ability to make a difference is connected to the notion of fulfilment. Making a difference is often related to altruistic desires and connectedness to others. These desires and connections provide the caregiver with the ability to foster a sense of fulfilment, as indicated by the exemplars below.

> Oh, you know the difference I'm doing to the people who cannot do for themselves
>
> (Participant 9)

> So that's the way I see it, that's, that's the role I see I play in the community it is very important to me and then to the community also.
>
> (Participant 1)

> Um… the difference that I make in other peoples life – because everyone is special, I know I am special my task is special everything when I talk to them I can see I'm making an impact in their lives
>
> I would say it's that that impact – that that difference that I make to other people's lives
>
> (Participant 3)

> Here I am working with different people, we have different people here, I'm working with different people, so ya I think I'm playing a big role for people here.
>
> (Participant 2)

From the above statements it is evident that the participants emphasise their ability to make a difference to the people within the palliative care institution and the community at large. Participant nine indicates being able to cater to the needs of *'people who cannot do for themselves'* and in this manner the caregiver is able to make sense of their role and the help they are able to provide, inherently indicating their importance to the patients and community. Being able to contribute to the community is considered an important role for them as caregivers and the ability to understand the implications of their work.

Seeing themselves in their patients

In palliative care, the caregivers are always confronted with death and dying. Attached to these constant confrontations is the caregiver's concern for their own mortality and this instigates the caregivers persistently exploring meaning within their lives (Wasner, Longaker, & Borasio, 2005). Caregivers are also confronted with the suffering the patient endures, and often the caregivers themselves gain an understanding of such suffering (Wasner *et al.*, 2005).

> Sometimes it's difficult … you put yourself in, in in their position at that time, you… eish sometimes it's difficult.
>
> (Participant 4)

> It also stresses me you know, I feel so sorry for them because that can also happen to me.
>
> (Participant 11)

Participant four provides an example of empathy for the patients and how this usually involves being able to understand their experiences. The experience of human suffering often results in the caregivers fearing that they too would endure such suffering and caregivers often place themselves in the position of their patients and fear their future, as illustrated in the exemplars above. Participant four describes the difficulty of trying to place oneself in the patient's position. Thus, being able to understand the difficulties that individual may face and the fragile nature of that identification. While participant eleven feels sympathetic to the patient's suffering, feeling that the experience could just as easily be them. In this manner the experiences caregivers are exposed to through caregiving alter their own perceptions and sense of reality, in particular their inability to escape their own mortality. Caregivers have an awareness of their position on the continuum of death anxiety and death awareness – thus caregivers begin to recognise their own position on the continuum more clearly when confronted with the processes of trying to make meaning of their patient's struggles (Manis & Bodenhorn, 2006). The meaning created by individuals in relation to their experiences is crucial in providing a sense of understanding (White, 2004).

Participant two's description of identifying themselves in the patient indicates the fear associated with this identification.

> I just told myself that I don't want to see myself like this people and I just told myself that I am going to stay negative until until until I'm dead, so I told myself. I do not want to end up looking like these people cause really it's so painful if you can just take your time and try to spend your time with some of our patients and you will see that these people are going in a rough patch, and then it's like you can't, can't change things, well you can feel like just turn the clock, but then you can't what's done is done and you have to focus on the future, can't I don't think it's, we live to regret and then if, if you don't you don't regret, it seems like you are not living, I'm not saying in the way of regretting in this way, but then there are some other things that you can do at the end of the day you'll regret, ya, but then we live to regret sometimes, ya but then for me, it's a great it's an honour to work with these people cause like as as young as young person, some other young person like me they don't know what's going on out there they just see see or hearing that this disease is taking us or killing us but they don't know how a person who has been in a situation because some of our people they told us I was like thinking I was dying, but here I am I'm still living.
>
> (Participant 2)

> Sometimes it makes me feel that … ah.. that I have to be aware that in this life I just live once. Ah… You can see that you you are perfect but you are not, you'll see that particular person is suffering, you'll ask yourself what is going to happen to me? Am I going to suffer like this particular person? You never know; only God knows. But then …. It feels so so so so so difficult, feels so difficult and I just wish ah… like we can just be be faithful to one another because this thing is killing us really, this HIV thing is killing us I just think like we can just be faithful to one another and then … because most of the people they don't know how those people they are feeling.
>
> (Participant 2)

The statement, '*can't change things, well you can feel like just turn the clock, but then you can't what's done is done'* indicates the finality associated with having certain illnesses. In some senses it challenges the notion of a just world and that one mistake or *'regret'* can have vast influences on the patient's life. This definite nature provides an unforgiving perspective of life and inert reality of consequences. Participant two finds identification with the process of suffering to be easily compatible with their life experiences and it seems to reiterate the fragile nature of life and mortality. Seeing patients suffer has led participant two to challenge how the world relates to HIV positive individuals without having knowledge of their experience. At the same time it illustrates the need for the caregivers to be able to understand *'how those people are feeling'*, suggesting something particular to the caregiver and their caregiving abilities.

Theme Four: Negotiating hope and loss

Hope is an important aspect within caregiver well-being (Clayton *et al.*, 2008). It is also considered a commonality, as it is a spiritual need that everyone possesses (Nowotny, 1989, Herth, 1989, 1990 in Dyson, *et al.*, 1997). It is important to acknowledge that in some aspects hope can operate as a means to avoid the difficulties, or may create significantly more difficult situations through the creation of false expectations or hopes (Clayton *et al.*, 2007). Thus, it may be important to distinguish the different manners in which hope may operate and the implications of such (Dyson *et al.*, 1997).

The inherent processes within palliative caregiving often create a cycle of attachment, through the caregiver-patient relationship, and then the severing of that attachment through loss of the patient (Hawkins *et al.*, 2007). The caregiver's role within this cycle has vast implications for how the individual caregiver seeks support in the future and in relation to their future attachments both within the institution and relationships fostered outside (Hawkins *et al.*, 2007). This attachment style that is fostered within the process may influence the vulnerability of caregivers.

The fantasy of rehabilitation

Fantasy is considered to operate as a symbol of hope (Yamamoto-Mitani & Wallhagen, 2002). Engaging in aspects of fantasy such as wishful thinking often operates as a means to escape or avoid the situation (Evans *et al.*, 2001). This means of coping is often ineffective as the caregivers have to continuously face the same situations on a daily basis (Evans *et al.*, 2001). Several of the participants discussed their motivating experience as having patients that were terminal and were able to get better, and get discharged. The exemplars below illustrate how the caregivers hold onto hope and how hope operates as a motivating factor to continue caregiving.

> I can tell you that when I go to [place] to collect a patient, maybe she comes with CD4 count of 1. I going to look after and care for her, I become anxious that this person must stand up on her feet, she must, I must give her that help she needs. Then maybe I go off for two days when I come back the first thing that excites me, I say ohh that patient I wonder, what happened to her. Then when I come I go there and start again, I want to push I want to help her to that she can go bounce back to the community. And it does happen here, we… you, know you nurse a patient to the extent that you want to see the patient up and about and it happens here, it does happen here.
>
> (Participant 4)

> Um… I have um many patient that I'm still remember them, I'm still ya I can remember them and I can mention their names and I can remember even the day when they came here. And … Uh, those people like they came here they were bedridden, so in fact they were terminal and at the end they came well and discharged. So that made me happy, then every time you admit a patient then the patient die, but those who are still alive even now so it make me very happy because of I can see what I am doing and ya, even then they can thank saying, you are doing well, they are spreading a good message to the community that that place is a lovely place where you can go

(Participant 10)

Participant four describes the perception that being able to rehabilitate terminal patients as being reliant on their care. The sense of determination that accompanies participant four's description of the caregiving process, '*that this person must stand up on her feet, she must, I must give her that help she needs'*. This sense of determination for the patient also highlights the caregiver's desire for validation of their role as a caregiver from the community, by being able to rehabilitate community members. Although this sense of determination may also operate to motivate the caregiver, it may also place the caregiver in a position where they are not only susceptible to disappointment but also in a position significantly more vulnerable to compassion fatigue and burnout from the sense of 'obligation' to the patient's well-being. Investing in the patient's well-being decreases the emotional distance within the caregiving dyad, which may place the caregiver at the increased risk. This is particularly important as caregivers are considered to cope significantly better with the difficulties, associated with caregiving, in situations whereby some emotional distance has been maintained (Keidel, 2002). This is evident with participant ten who considers a caregiver's ability to be intertwined with both the caregiving and the patient's outcome. It provides the caregivers with the opportunity for them to observe the change they are having or '*to see what I am doing'* for these individuals within the community. Thus, in these rare occasions the caregivers are able to create a tangible measurement or outcome of their caregiving. However, as caregivers they are continuously confronted with repetitive patterns of loss and thus unable to maintain this tangible expression of their efforts.

Participants also experience great difficulty in trying to maintain their hope for recovery, as illustrated in the exemplars below.

> um very very ill patients, they they especially for somebody very young, mmm…. I think, uh especially these young ones we always say eish, I hope this one will recover, eh she will go back home and go back to school and that's when I start to check condition and it go down, it really stress me a lot and dies.

(Participant 5)

> Even though I met challenges but I always have hope

(Participant 3)

> Having to deal with too much corpses you tell yourself I have experience but yoh it's not nice you know you get used to a person you become close and the next thing you know that when you you are meet the patient they might make it or they might not you know but at times you still have hope that maybe that person will get better, be discharged and be able to do everything for himself or herself you know and then the next thing the person is dead – it's really not a nice experience. But somehow we find strength to come back here again

(Participant 3)

Participant five and three both find the experience of trying to hold onto hope during difficult times a very difficult and stressful endeavour. For participant three there is hope, *'at times you still have hope'*, but often that hope is destroyed and that experience makes it difficult for the caregivers to continue to return to the institution without the hope they previously held. Research conducted by Clayton *et al.* (2007) illustrates that patient's desired hope even in situations where they had accepted the outcome of terminal illnesses. In much the same token the caregivers may benefit from being able to hold onto hope even in circumstances in which they are both aware of, and have accepted, the potential outcome of the illness. Hope usually manifests in different forms within the caregivers (Clayton *et al.*, 2007). Caregivers often possess hope for the patient and in relation to aspects within their lives, rather than simply related to the illness. For example, caregivers often displayed hope that patients would be able to resolve relationship difficulties and find meaning in life (Clayton *et al.*, 2007).

> You know sometimes people get sick because they don't know and they don't experience anything about it, but we you know when you get sick and you know there was something that you were supposed to do and you never did it, you feel stupid though and you become closer to God because you realise sometimes a person was supposed to die and then because you know we live by experience and we think we know a lot and then we will think that this person is very sick for a long time and you can see the signs that this person is going down. And then the next thing the person is awake, he's laughing, he's going home, then you can see that is, is God's work. And then you don't take anything for granted anymore.

(Participant 9)

> Ja, like …. Ummm I think one experience that I had is when the patient is admitted as bedridden and after that becomes well. Ja. I think that is a good experience to me because of we know that if a patient says not this one, it's terminal care patient, so we already lost

> the hope, so this person we can just take care of that person and just wait for the day only to find that that patient has become well.
>
> (Participant 10)

While participant nine acknowledges the reality inherent within the palliative care process also considers that experiences that do allow for rehabilitation are opportunities that provide sense of inspiration in that *'you don't take anything for granted anymore'*. This is perhaps a more positive manner to be able to benefit from the hope that is displayed but not hold onto the hope and create false expectation of such. Experiences are considered less stressful and usually far more rewarding in circumstances whereby the individual had a sense of awareness and was not naïve to the reality of the circumstances (Luker, *et al.*, 2000). Participant ten also discloses the relative ease with which caregivers are able to lose hope and the normalcy associated with losing hope.

The reality of disappointment and loss

Disappointment and loss are often considered a reality within palliative care, rather than the exception to the rule. The caregiver's previous experiences with death and dying are often re-experienced through being repeatedly exposed to circumstances of loss (Keidel, 2002). The exemplars below illustrate the difficulties that accompany caregivers experiencing repeated loss and their competence in relation to their caregiving abilities.

> That was really encouraging (pause) and that was something that discouraged. When you does the, those who are discharged here and they go back to the community and they start to bring to their studies and they not take their treatment, and again you are back to square one then die. It means all those efforts were useless…
>
> (Participant 6)

> … when a patient becomes well and while they are saying this patient is very fine and you will get discharged and that patient suddenly just die …. (pause)
>
> (Participant 10)

Participant six relates the experience of disappointment from a different perspective. Disappointment is not perceived solely as losing a patient but rather losing a patient after having worked so hard. The statement, *'It means all those efforts were useless'*, seems to

indicate the difficulty caregivers experience in having to constantly reinvest in new patients, and even in the rare cases where patients are able to return to the community – the possibility for loss or disappointment still remains. Participant ten also relays the nature of loss as unpredictable and distressing, in that the patient has gotten better and then the *'patient suddenly just die'*. Davies (1995) considers the unpredictability to operate as one of the most difficult aspects of caregiving, making it difficult for the caregivers to adjust to its constantly altering nature.

> Ja …. It's not nice to…. to care for the patient and then must go on passing, passing, dying, dying, dying, eih… You must fight and encourage the patient so that they are going to be better if you can do this when I gave you this you take it and then do this and then listen to me and then you're going to be alright and they take it and then you know you feel proud …. so that I already … I have done it.
>
> (Participant 7)

> I believe I am a hard worker and I still .. I have hope every morning when I wake up and come to this place, I have hope. Because I know wherever I go I make sure, I make everything, I'm a perfectionist I try to make everything perfect hmmm… So I know, starting from bathing our patients everything is done properly until the last minute I could go home
>
> (Participant 3)

Participant seven highlights the difficulty associated with patients *'passing, passing, dying dying, dying'*, but also with the motivation associated with these experiences. However, they also place emphasis upon the caregiver's role in supporting, encouraging and getting the patient better. This again places significant amount of responsibility and burden on their role as a caregiver. Participant three reiterates the importance of hope in motivating the caregivers, as well as being able to provide and care for the patients in order to avoid the guilt; *'to make sure'*.

Caregivers also utilise the rehabilitation of patients as a positive factor to motivate and further their caregiving, as illustrated by the exemplars below.

> The … the thing that keeps me going is seeing patients getting well
>
> (Participant 1)

> It's when I see somebody who who came in eh the unit not walking very ill and walking out here by himself. That makes me very proud always and again if somebody came here

> with like pain, severe pain and when I come back and she tell me that that pain is gone, I feel so motivated it give you strength to come back to work.
>
> (Participant 5)

Motivation often influences the manner in which caregivers make sense of their role. However, if these elements of motivation are too far removed from reality then burnout and compassion fatigue are likely outcomes. Participant one indicates that patients' improving is the aspect that enables caregivers to continue trying to succeed, even in situations where it may not be plausible. The ability to 'heal' patients is indicated in both the exemplars above and it is important to reiterate that this plays a fundamental role in the caregiver's competency and being able to consider the task as possible.

The difficulty in establishing a connection

In Richardson's (2002) study, patients felt that the interaction between the nurses within the palliative care and themselves was highly significant. This connection was considered to provide the patient with friendship and pleasure (Richardson, 2002). The participants highlighted their opportunities to enjoy the company of their patients as a significant element within the caregiving experience. However, the loss of a patient, in addition to an attachment, is difficult for caregivers to manage. "When patients die, residential hospice staff members must cope with the death of the person with whom they have associated for eight hours a day for many days, weeks, months, or even years" (Evans, *et al.*, p. 102). With participants having spent twelve hours each day at the palliative care institution, the propensity to initiate and engage in friendships is high. This meant that in circumstances where individuals had ascertained a connection or friendship with the patient it was much more difficult to cope with the loss. This may also influence the caregiver's ability to form friendships beyond the work environment, which may compound their loss further. The exemplars below illustrate the difficulties associated with losing the patient and their attachment or friendship with their patient.

> And you don't choose to to to to feel like you feel like when you meet somebody, eh … you connect, you you you become friends and then you don't choose to become friends and then you don't choose to become friends with that person and he or she is a patient. And then when they go down, you feel like you have done something wrong, like you are doing nothing that was supposed to be done. You feel guilty, feel like you are responsible for there going down, so that is the stressful part about ….

(Participant 9)

> The most stressful part is that, eh you know as you work with the patients, some of the patients they stay here for a long time and then you'll find that now you you become friendly with the patient, you know, he knows you and he also I also know the patient and we make something like brotherhood or something like that. So by that time you know then the patient and the patient just change condition and died then for me its gives me a stress you know, like when you see the patient is recovering and then the next day when you come back to find that the patient is dead, for me, it hurt, it's stressful but at least I know that I can go to my colleague, one of my colleague and tell them about it so that it will clear out.

(Participant 8)

> yeah, because you you feel that she needs help she needs love and she needs care and she needs everything and the bonding starts – you bond with the patient, when you go off, off duty, you thinking eish… I wonder when I come back will I ever find her there, or will god have done his will.

(Participant 4)

Participant nine describes the process of connection, not as something that is directly sought out but rather as a process that occurs as a result of interacting with the patients on a daily basis. The connection or friendship that is fostered often has difficulties, such as the guilt that ensues when the patient becomes ill. This may be indicative of the interaction also being considered a crucial aspect of caregivers' competence (Richardson, 2002), in that when the patient's condition worsens the caregiver feels a sense of responsibility to reverse those conditions. Caregivers may feel guilty that they sacrificed their role as caregiver when their patient became their friend. It is also important to acknowledge the potential effect 'bonding' and 'brotherhood' may have upon the caregiver. "He or she also needs to be cautious about blurring the boundary between being a professional and being a friend, another source of burnout" (Keidel, 2002, p. 201). This is particularly important as the caregivers often experience greater stress when they possess a connection with their patients, in which case the caregivers experience the loss of their patient in both their professional capacity and in their personal capacity. This loss of this, often newly formed attachment is further exacerbated by rapid successions of death in palliative care institutions (Hawkins et al., 2007). Such successive losses can have significant effects upon future relationships and increase the caregiver's vulnerability to burnout and compassion fatigue (Hawkins et al., 2007).

Theme Five: The context of caring

Understanding human beings as situated within a contextual environment involves being able to understand their existence in relation to the world and more specifically their engagement with the context in which they experience the world (Butcher & Buckwalter, 2002). In this sense, the caregiver is not a passive entity existing in the world, but intrinsically involved in the nature of experiences they endure. Burnout, compassion fatigue and compassion satisfaction are considered to be more appropriately connected to contextual factors than individual coping factors (Killian, 2008)

Caregiving comprises of the caregivers' personal environment, their work environment and the intersection of the two. The palliative care institution was based in an informal settlement in South Africa and thus, has significant impacts upon the implications of the surrounding environment that may not have been such a substantial factor in research conducted in developed countries. The environmental milieu considers a myriad of aspects that allow for an understanding of the contextual temperament in addition to considering certain elements that are unique to the implications of a community-based institution in South Africa.

Community-based palliative care

Participants differentiated palliative care from care provided at hospitals. The community context alters the nature of care and the perception of the institution, as illustrated by the exemplars below.

> Or in the hospitals you find that if the patient is dying, they just put the the patient put the patient at the corner and just leave the patient there to die. So here we stay with the patient, you hold the patient's hand and you're there until the patient passes away.
>
> (Participant 5)

> Um…. Anything as all the uh … grassroots level, let me put it like that, in the grassroots level anything that you feel this needs the authority and you forward to authorities it is attended to, it makes the conditions favourable, for the role player. And maintenance of interpersonal relationship within the workers themselves is important. If you are and you are eh happy you are able to give out that happiness, in the interaction of any kind there must be that, specially I'm speaking on the palliative care there must be that love – to

> anybody interacting who is doing the palliative care. Be a patient, be a family, be your co-worker, be it a psychologist, be a social worker, there must be that.
>
> (Participant 6)

> And the way I see uh, 3 things that that makes is it, it's in the community, it's within the community and then another thing we are caring only we are not caring for only specific people or specific diseases or illnesses, so we are treating as so we are treating it, as like treating people as the same, like friends, family and other people that they are not known to you or they not known to, to me. So it's um might be the third –the second friends of the family friends uh … (pause) and like I said they are 2 for me, I think there are two.
>
> (Participant 1)

> Sometimes if you care for people who here in the community, people are talking about this place, they look for people, they care for people much better than other hospitals than other like hospital hospital people are not okay, that they may you know we must look after sick people.
>
> (Participant 11)

Participants identify the palliative care institution as able to provide something additional that the hospitals do not provide. Hospitals were not perceived as providing for the patient, but rather neglecting a terminally ill patient. Participant five explains that *'in hospital you find that if the patient is dying, they just put the the patient, put the patient at the corner and leave them there to die'*. This reiterates the differentiating factors that may influence the caregivers' emotional experiences, as the caregivers are more involved in the death of patients and this 'humane' approach may increase their vulnerability to compassion fatigue and burnout. There is an emphasis on treating people as people, implying the humane and invested means of interaction with the patients. This may highlight a greater level of intimacy, but may also simultaneously highlight the possibility of a less professional space, contradictory to their constructions of the professionalism and distance within their caregiving role. Participant eleven identifies that caregivers, unlike those working in the hospitals, desire to be involved with the community, help the community and look after individuals. Unfortunately this to may result in the caregiver having to bear the suffering of another and this may eventually result in compassion fatigue (Figley, 2002).

Participant one identified some barriers that prevent them from being able to provide the care necessary within the community context, in addition to the implications for them as caregivers.

like let me say um (pause) destruction, like so yes. So eish some of the things are painful for the family and are painful for you as a caregiver you know because you have the information but you can't just say it, the information like it is.

(Participant 1)

Oh… Like I said, the most challenging is these barriers these laws and legal and ethical issues, so they're the ones that give challenges to some certain information giving or certain information that you have to give to patients so it gives them about their sickness so that is the most challenging parts.

(Participant 1)

Participant one discusses the difficulties in relation to confidentiality and explains that having the information, but being unable to utilise the information makes the circumstances surrounding the caregiving much more difficult. In circumstances where the caregivers are unable to engage with the knowledge available to them they may perceive themselves as helpless and obsolete.

Stigma within the community

Another obstacle within caregiving system is the stigma associated with palliative care. Stigma is often one of the major factors preventing HIV patients from accessing resources (Demmer, 2007; George & Quinlan, 2009; Mills, 2006). This often results in patients only accessing services when their condition is significantly poor, or when others are no longer able to manage caring for the patient. Thus, the caregivers are constantly faced with difficult situations and circumstances that may have been better had the patient been willing to access services earlier.

they they when when a child says momma I'm sick I'm HIV positive, then they get angry the neglect the children – they say that's not my business you go where you got it and get done with it.

(Participant 4)

Because if you go into these shacks we neglect our children, we leave them, we we we we are, how can I say it, we are shy to tell people that I have a child that is HIV positive we always lock them in the house, it's difficult to disclose sometimes, but .. you see your child now getting worse, but you keep on hiding her so this place lovely place

(Participant 4)

For participant four, the stigma associated with illnesses such as HIV/AIDS illustrates the increasing difficulties the caregivers have to consider in relation to the community well-being. Neglect and secrecy regarding terminal illnesses such as HIV/AIDS are not uncommon in South Africa (Demmer, 2007). This often places significant burden upon the caregivers and the institution to incorporate the reduction of stigmatisation into their efforts within the community (Demmer, 2007).

> Experiences that I have come across that defines me as a caregiver (pause) ahhh, there was this certain stigmatisation that most people in our community used to say that caregivers care for people living with HIV and all and all, but they didn't know that caregivers care for all people in patients old, old old males and females like and then women and children and men who are not able, so there's some of the information they really didn't know so most of my experiences were that lots of people didn't have the information - the correct information they did have information, but not the correct information about us as caregivers and then the experiences I had is that caregivers, we as caregivers we are not taken as important like in our community or maybe like in other departments.
>
> (Participant 1)

Participant one describes how the stigma associated with palliative care creates a false perception of the institution and the caregivers that work at the institution. This is known as secondary stigmatisation: institutions and individuals associated with HIV/AIDS patients are subject to stigmatisation as a result of the association (Demmer, 2007). This misconception and failure to recognise the caregiver's role has significant effects on how the caregivers perceive themselves and their role within the community.

These factors, such as ethical dilemmas and stigma, are often overlooked, but play an integral role in challenging the caregivers' coping abilities and therefore their ability to continue providing care. The understanding of caregiving and the caregiver's experiences operate within a holistic manner. Such factors have implications for the other spheres of influence and contribute to their ability to either manage or struggle through their caregiving experiences.

Understanding the environment

The caregiver's well-being is not restricted to the effects of the work environment. Caregivers often confront difficulties at home which exacerbate and are exacerbated by their personal difficulties. It is important to recognise that the work environment more commonly provides a source of conflict for the caregivers (Scott & Brown, 2004). This is also further complicated by the role conflict that emerges, with significant demands being placed on the individual as a caregiver, in addition to the other spheres of their lives (Kulik, 2006). The exemplars below illustrate some of the difficulties the participants meet on a daily basis.

> You know going back home it's like it was like going back to a hell-hole you know and then always I would feel like I wish I was working all through
>
> (Participant 9)

> Because I know I'm here for them, and then I know what I eat, what I wear, whatever I do – it's because they're here, if they were not here I wouldn't get the stipend, I wouldn't even have money to buy food, I'd be staying home jobless. So … That's why I say it must always be good, not to – you mustn't have weak, mustn't have weakening – too weak for the patients.
>
> (Participant 4)

> It's not easy …. (pause) umm… you know some times ne? You find that can't help yourself but you have to help the next person
>
> (Participant 3)

From the above accounts it is evident that the personal environments and crises that caregivers are constantly confronted with, often create a vicious cycle, as their support and personal environment has significant problems as well. Research by Keidel (2002) indicates that the environmental influences have a greater impact upon the caregiver's levels of burnout. This is coupled by the unavoidable personal difficulties outside of the institution, creating a vicious cycle (Keidel, 2002). This makes it more difficult for participants to be able to gain support from their personal environment and means that stressors confronted during work are further exacerbated by their personal conditions, and often neglected. Participant nine likens going home to returning to *'a hell-hole'* and perceives being able to continuously be at work and never return home as a desire. In this manner there is a desire to be emotionally disconnected from their home environment, suggesting significant emotional investment in their work, to the detriment of their personal lives. This description provides perspective on the extreme difficulties that these caregivers are facing within their own lives. For participant three it is difficult to endure helping others on a daily basis and not being able

to gain help themselves. This is often difficult as the caregivers are reliant upon their own capacities to manage their work environment and often these capacities are easily depleted. The caregiver has to manage both their personal difficulties and work related stressors, while having insufficient resources to adequately manage either.

Recognition within the work environment

Recognition plays a significant role in reinforcing the caregiver's sense of competence and often operates to motivate the caregivers through the perception of appreciation. The lack of professional communication often results in further burden and stressors being placed upon the caregivers (Street & Blackford, 2001). This is easily perpetuated through the hierarchical nature that emerges in the palliative care institutions among the different professionals. Participants found the lack of recognition to be one of the most difficult aspects of their work environment, as indicated in the exemplars below.

> Why the patients they are appreciating but our seniors they don't appreciate what we are doing, especially here we carers they don't recognise us as people.
>
> (Participant 7)

> again maybe there, when you come to here eh ah you are working very hard but there is no reward, there is no recognition so that maybe can make you and be one of eh eh ah you can eh eh I can say disadvantage.
>
> (Participant 10)

> there are some other people they don't appreciate what you are doing people they say that you are doing a a proper job, but the some they'll just look at him, he's just trying to be nice, but then he's not – that is killing my morale, really it's killing me morale, whereby people don't love each other.
>
> (Participant 2)

> Some might take us seriously that caregivers do a good eh eh a well good work job, but some of them they say ag, they are just voluntary workers, so why do we have to take notice about them or so... Sometimes we feel less important, sometimes ah we we we we pat ourselves on the shoulder that uh even then though they might not see the good that we do, but we are doing a good job.
>
> (Participant 1)

> Uhhh, um I mean … uh number one is you know when we check uh other people they can be the person who's working here or the person outside or who ever, they don't take

> me as a caregiver seriously. So um even respect, there is no respect, so it's like I am working, I'm doing the job that maybe eh the the people that are not educated they can do. So if you are not educated that is the job that you can do.
>
> (Participant 10)

Participants feel strongly about the lack of respect they receive within the institution and the difficulty in attaining recognition. Participant seven goes as far as to indicate that their senior employees at the institution *'don't recognise us as people'*. Participants felt that, irrespective of the hard work they had done, their seniors were not able to provide them with recognition or appreciation. This is particularly important as burnout has been associated with unsupportive working environments (Killian, 2008). The difficulty in not being able to attain this recognition has implications on the caregiver's behaviour, as participant two indicates *'it's killing my morale'*. Even outside of the institution caregivers are not granted status or recognition for their role within the community. The connection between volunteerism and lack of recognition is significant – often the individuals feel that their status as a 'volunteer' negates their knowledge and competence (Swart *et al.,* 2004). Participant ten explains that people assume that volunteering is equated with *'people that are not educated'* and in this sense negate the difficulties relating to caregiving. Lack of recognition of the skills and the demands associated with caregiving are consistently cited difficulties that often instigate burnout and compassion fatigue (Meagher, 2006). One of the most substantial difficulties in "volunteer" work is that financial rewards are often a prominent means to engage the community; however, in such community-based organisations financial rewards are often not possible (Swart *et al.,* 2004).

However, participant eight indicates the aspects of the working environment that foster motivation, as illustrated in the exemplars below.

> Okay it's like when, when when our supervisors come and they say they go through our work and they say here you have improved and here and here you see, they show you the right and wrong that you do. Then for me like most of the time when they come find that I have done my work correctly and then I think it is motivating for me.
>
> (Participant 8)

For participant eight being able to gain recognition from supervisors regarding caregiving provides a sense of competence. Being able to benefit from the supervision – *'they show you the right and wrong that you do'* – and feeling supported operate as motivating factors. This communication of such concerns with the interviewer may suggest an inability to express

such dissatisfaction within the institution and reiterates the role the institution has in disempowering the caregivers.

Theme Six: Underlying the caregiving choice

Caregiving is most commonly associated with altruistic motives (Kulik, 2006). In the same manner volunteering is often also considered to relate to altruistic concerns; however, there are several additional reasons and desires for caregivers, which are especially significant given the contextual factors (Kulik, 2006; Swart *et al.,* 2004). Understanding the underlying motivations of caregivers is beneficial to understanding what initially inspires individuals to become caregivers and what factors may be considered important for them to persist in a caregiving career (Davis, Hall, & Meyer, 2003).

Caregiver motivation

Caregivers' motivations can increase over time, usually coinciding with an ability to appreciate the broader perspective and provide an additional means to make meaning of loss (Jones, 2005). Those unable to broaden their sense of motivation are often discouraged and situate themselves in a position that makes them more vulnerable to factors that initiate burnout and compassion fatigue (Jones, 2005). The exemplars below illustrate the motivations of the participants.

> Uh… My motivation why I, is the objective why I came to the palliative care from the beginning. Um… I'm sure you are aware of my age, so I said okay, I have been in the curative care, I'm going to do, let me do the palliative. I'm doing this, the main principle reason is to be grateful for all that has happened into my life. This is a way of showing gratitude to my whole life that I have had in nursing. Yes, it is not more, money talks but not that much, the aim was gratitude for all the life I have spent. I must do directly something to the people, they very very needy people. Every patient is needy but these are the very very needy … above all. That's the point that's the factor that motivates me to say, I said I'm going to be here for these people and I must be here for them.
>
> (Participant 6)

> Ah say thank you – you been not here, maybe you been off and then when you come back they are happy and all that. You are here, cause we don't work the same, because

> sometimes that one who does that yesterday, not doing doing the same work with the patient the other day, I like that that gave me courage.
>
> (Participant 11)

> Ya… it motivates me in a way that I can be able to to to talk to people, listen to other people, what is listening to this particular person and then im there for him and it really motivates me because I'm young dealing with an elderly person telling me about his family problems and things and that and that it does motivate me because that particular person when he looks at me, he doesn't look at me as a caregiver, he looks at me as a person that, eh, he can talk to, share his problems, do you get me point? Because some other people, we dar- blacks we don't like to share problems actually, as an elderly person, I'm a young adult person it's not easy sometimes because you think this person he is young, how is it going to to motivate me but sometimes it, it comes again to me, that this particular person is talking to me as an adult and then it does help me, it motivates me that this, this particular person whose recommended me as a person in his life. It motivates me a lot.
>
> (Participant 2)

> … those people that you are taking care of them, those small people, those people that maybe community or people they can take them down, while you are doing the good things for them you are doing it for me. So that is motivating me that sometimes I don't, I don't even some patients just do things, you'll just prepare yourself to be out of order, but to me I'm I'm telling myself that no, I'm not doing it for somebody, I don't do for [name of institution], I don't do for somebody or a family, or I don't make a favour to anyone, but I am doing this for, for God and that's it.
>
> (Participant 10)

The participants find motivations both within the institution and outside of the institution. Participant six considers motivation to be the ability to show *'gratitude for all the life I have spent'* and feels that being provided with the opportunity to provide for the *'very needy'* is a means to help those in need. Participant two also describes the opportunities of being able to support those in need and being considered *'a person that eh he can talk to, share his problems'*. In many respects, the participants were able to gain motivation from feeling appreciated and they were able to contribute to something greater than themselves. For participant ten, however, motivation relates to spiritual beliefs and being a caregiver *'for God and that's it'*. These initial motivations are considered to be related to the perception of later rewards or a sense of fulfilment (Davis *et al.*, 2003).

Several participants also indicated aspirations to be caregivers as their motivating factors, as illustrated in the exemplars below.

> In fact it was my dream when I was still young, but for me it is about you see these days many people are suffering, especially can't cope, they can't

(Participant 8)

> You know what ne, eh, when you have got an experience, you are you enjoying your work even if the money's not there.

(Participant 7)

For participant eight, caregiving was a dream, they always wanted to be able to help those that cannot cope and are in pain. Participant seven concedes being able to attain enjoyment from being able to be a caregiver and gain experience, even though there is limited financial support. This is illustrative of being able to attain satisfaction from caregiving work. This has significant positive effects upon the caregivers' sense of fulfilment and their ability to manage difficulties associated with caregiving (Radley & Figley, 2007). Being able to gain a sense of enjoyment, irrespective of the inherent difficulties operates as an effective coping mechanism.

"Deciding to take on the role of caregiver may be motivated by the desire to reciprocate past assistance" (Carruth, 1996, p. 409). Several participants described having had a relative attend a palliative care institution or having had the need to rely upon a palliative care institution but were unable to for various reasons. Often previous experiences with someone else's death draw the individual to work in palliative care (Planalp, 2009). Thus, caregiving may operate as a means to make reparation for past personal experiences. It seems to indicate the notion of seeking to repay a psychic debt that can never be fully repaid, as illustrated in the exemplars below.

> Eh, um, what motivated me as a factor, (pause) …. there was once there was twice a case of some sort in my family that I lost my aunt and my uncle because of a certain disease, so at the end they did not get the care that most people have. So ja, I noticed that I could do something about about it, I must I must give him up, so I just, I just suggested that let me take this road and maybe, maybe I'm passionate about this work or maybe this work my future lies, I don't know, in the health side. So, so it motivated me very well, I have know get know information about diseases, eh different kinds because of some of the diseases were a shock to us as a family, so it motivated me to know more so about things. So that is why I had to learn as a caregiver so … so I think that's what motivated me in the whole thing, the emotional background of my family so it motivated me to become a caregiver.

(Participant 1)

> …as I said, I … I … my father, I had my father, he was a diabetic and when I started working here I used to leave him alone at home, then I said eish… I can't enjoy, I don't enjoy my work, I was a cleaner back then, said hey but I can't enjoy my work, my heart is seer – my other part of heart is at home with my dad, I don't know what's happening to him. So he came here, and then he was admitted here and I saw how they cared for him, they didn't do it the way I did it at home.
>
> (Participant 4)

> He's my father but sometime I failed him that way there and there, but the way it happened here – that's what made me think I must give back the love and care to patient to other people because I saw how they cared for my father.
>
> (Participant 4)

> Well… I didn't like it to be a caregiver, but then when time goes on I have, my my uncle … during that time I was not a caregiver, and I just it was on the weekend that I went to my uncle's place and saw that my uncle he was very very ill, unable to walk. I just told him uncle I came to visit you, seeing you what are you doing. He just said to me I'm fine my son, and then please be strong, I'll be fine, look after yourself and then during the night I slept, he was sleeping at his bed, I was like slept down down down and then at the night I just saw her touching the wall and then I ask myself is it my uncle who is walking like this?
>
> (Participant 2)

> I think there are many… I don't know because like myself, my father died at home, my sisters didn't want to care for or wash, I'd be off at work but I have to do that at when I get home, that was really difficult for me.
>
> (Participant 11)

Participant one discusses how, on two occasions within their family, they *'did not get the care that most people have'* and motivation had come from participant one feeling able to *'do something about about it'*. Whereas participant four states that *'I saw the way they cared for him, they didn't do it the way I did it at home'*, implying that 'they' cared for their father better than participant four had been able to. Participant four felt that the care that he/she had initially provided had been considered a 'failure' and that caregiving provided a means to rectify this sense of failure by providing for other patients. Participant eleven also found it difficult to care for a family member and this served as motivation to help others in that position. Thus, caregiving can be considered a means for a caregiver to alleviate concerns arising from past experiences, and in certain situations, the guilt attached to such (Clary & Snyder, 1991 in Kulik, 2006).

Caregiving as a calling or gift

The conception of caregiving as a calling or gift presents a means to provide some control and power over situations of crisis and helps to allay feelings of helplessness, often associated with palliative caregiving (Polzer Casarez & Miles, 2008).

> Because always when I talk to the other caregivers, I say, my co-workers, I think its caring is not a thing of going to school and learning how to care for a person, it must come within you, because if you are not the person, eh… for this job, caregiver, you won't be here, because there are somethings that you are going to throw away – it will show that this person doesn't care, it needs to come from within you – even at home you care for the other people. Maybe its … it's a calling. Let me say it's, it's a gift from God, and it's not just a simple kind of work. Like, like nursing, nursing the patient – it's it's a call. If a person is there for, maybe she is working in the hospital as a nurse and she the attitude doesn't go hand in hand with a person who cares. You can see if the person is here for money, financial, but if she has got that love you'll see by the way the things she is doing and how she talks to the patients. I think care, care comes from within you and it's a gift.
>
> (Participant 4)

> Ummm ya, but I think ya even them I can take them the one that influenced me, even me as me as individual it started for me like as I said that you know to be a caregiver is sometimes I call it as a calling. So it comes from you, you inside so even those things can make you more, they can encourage you to be more when you want to be a caregiver.
>
> (Participant 10)

> I think, ja, I think it can be the same reason that I give you that I think I have a special gift that other people, a special gift where I can take care of, where I can take care of a person, where I can listen the person who maybe people don't want to listen to them.
>
> (Participant 10)

> So um at the end yes, we have to work as you choose, as like we are understanding what is to be a caregiver. I don't think to be a caregiver you can call it as a, as a work or as a, I don't know. To me I think, I think it is a calling, uh to be patient to such an extent is a calling, it's not everybody that can do that.
>
> (Participant 10)

The participants' conceptualised caregiving as a 'calling' and in this manner constructed caregiving as an identity that is not available to everyone: *'it's not everybody that can do that'*. Being able to care is considered to '*come from within you'*, implying the nature of the desire to engage in caregiving as inherently within the individual and *'not a thing of going to*

school'. Participants also consider the ability to be a caregiver as a *'gift from God'*, which is further indicated in the exemplars below.

> I believe that by working as a caregiver it's a calling from God because it's not easy dealing with a person who is sick. And they are demanding, and sometimes they will say I'm hungry and when you prepare something for them they don't eat you know. It is so stressful you know thinking and then you take that food away and then they want it again you know it's like you know that's why it's not easy comparing what we do here and what the families are doing at home. Because when they're patients that don't eat, they just leave them like that and they turn away. So we don't do that here and we check, we always check that maybe because breakfast was not something they wanted then, but maybe if I keep on checking then they will feel like eating something and thank God I will be there to do something about it you know. Unlike if they at home see that this person is not eating, they just feel like they have to leave them alone. So.. the stressful part is when they come from home, you know they feel like nobody caring, you know that chance we give them sometimes they are taking it it is not easy for them to accept that you are here for them 24/7 you know. Because they think it's how they should live their lives, if they cannot do something they cannot depend on somebody they know already that at home, you know …
>
> (Participant 9)

> So that is what is motivating me that no, there is a special, special gift that God gave me because I can cope and I'm still coping.
>
> (Participant 10)

> Umm…. I'll tell you I believe it's something that God has chosen for me because we not getting paid we are only getting stipend – the money doesn't cover all our needs you know but I know if it wasn't if it wasn't uh uh the mission from god or the vision I don't think I'll still be here – I believe it's my time I have to serve these people make a difference in their lives
>
> (Participant 3)

> I'm enjoying to work with the people and then having you give them love, you know, you just say God knows I love them and I will do whatever. It is a call, it's a call and then sometimes you can't work in a job like this even if you don't have the love and even sometimes you forget about the money as long as you are working alright there is no disturbance or something hurting you. You do not think about the money and say ah, it is okay, the money's not there, it's not there but as long as you got love your work.
>
> (Participant 7)

Participant nine describes caregiving as a calling '*because it's not easy dealing with a person who is sick'*. From this perception, participant nine considers caregiving to be calling which

allows for the ability to cope with the demanding role. Thus, spirituality is utilised as a means to create meaning within their role as a caregiver (Chiu *et al.*, 2004) and operates as a coping mechanism through fostering a sense of connectedness (Stepfanek *et al.*, 2005). Participant three considers caregiving to have been chosen for them, and that there are no additional benefits other than that it provides the ability to *'serve these people make a difference in their lives'*. Even though participants had described significant difficulties, they truly felt comforted by the notion that being a caregiver was associated with a greater meaning – often a spiritual calling.

Economic sustenance

Caregiver burden can also be extended to social and financial problems (Frank, 2008). Monetary desires are often necessary for survival, especially within the community context and acknowledging the implications of the current South African climate.

> Ya and then … Another thing again the the the salary that we are getting is too small and we cannot maintain it, but then we say that we want to do it for, for for the patients and so on and on and on so we just try, trying to maintain the standard, but if there was something to do, I would just leave and if I do that thing just because I'm thinking about my family and [name] and then that's why I'm here. Cause if I just leave this job, [name] won't be able to eat, I can't be able to buy him clothes, winter clothes, summer clothes, no but then just because I want to make her happy and I don't want to punish her, so that is why I'm trying my best to, to work in this situation. It's hard, it's hard but then...
>
> (Participant 2)

> It is in a way, because you know like I said the financial part of it is the burden. We are not getting enough and then the patient will be losing their money, so it is a fact that we don't have the money to to take us maybe until the end of the month. So we are stealing, you know, it's only looking at the facts but it's not like that.
>
> (Participant 9)

> And again… Again being here, the thing that is stressing us is we are carers here, the nurses, but what about the salary? The gardeners and the cleaner they are above you with the salary you see, they are stressing, you know.
>
> (Participant 7)

> But now you know I'm feeling like …. somebody out there is in trouble, I know, I know that there everything is a start there is a start for everything. Maybe back where they come from there is trouble or maybe in this place because sometimes even when we tell them about the money issue, they say there is nothing we can do you know we are

> government, they are stealing that and that. I only understand one thing; that this is for the community and by the community and you know we are the community and if we expect more money here, you know our people are not working.
>
> (Participant 9)

For participant two, caregiving is considered the only viable option and had there been alternatives available the participant would have considered these instead of caregiving. From this account caregiving is a career that is undertaken for financial reasons and the need to support their family. "To become a caregiver by the force of external circumstances that run against the grain of one's own strong desires can be quite destructive" (Pearlin & Aneshensel, 1994, p. 389). From this perspective caregiving is considered an opportunity for survival rather than a voluntary altruistic endeavour. However, this is not generalisable to all other caregivers within a similar context. Participant nine's description indicates the impact of the difficulties people are facing within the community at large and on an individual scale. Participant nine discusses how people are forced to steal as a means of survival, but also the existence of this double bind as the caregivers cannot expect more money when the community is facing significant difficulties of their own, with the majority of people having no jobs.

Caregiving within the current context often has implications for 'volunteer' work that provides a financial reward, such as a stipend. With South Africa's high unemployment levels, coupled with the extent of poverty (Kanyane, 2008), this stipend often operates as an extremely influential motivating factor.

> Ya… they will always calling me, you know ma come why are you, are you early today – you don't want to talk to us, I said no I always want to be with you, and they say you don't rest you can't today you are here, tomorrow, tomorrow… I say ya. And I tell them you know why I am here, it's because of you, you know why I am wearing these shoes – it's because of you, because the stipend I receive from here, I wouldn't get it if I wasn't looking after you.
>
> (Participant 4)

> Well, ah … Caring for patients, working here in the [name of institution] sometimes is difficult, but then when, when I look at my background I can't be able to feed myself, I can't be able to feed [name]. If maybe …. I have some some other things to do for a living, I won't, I can't work here. But then just because I don't have anything for a living, so I will just work here and then try try to cope with, just to make a living cause if if I would just sit down at my place and say to myself no I can't take it anymore, [name] won't be able to eat, my family won't be able to to get something from me, so I

> think… towards my family. It is hard, but then, it's hard but then, I just take it with the flow and then I'll see on the way
>
> (Participant 2)

For participant four one of the major motivating reasons for being at work as a caregiver is that it provides the stipend that enables financial support that would not be possible *'if I wasn't looking after you'*. Whereas participant four describes the stipend as an addition to caregiving, participant two describes the financial assistance as the only motivating factor and reason for continuing such care work. Caregiving is considered the only opportunity through which participant two is able to provide for their family. For caregivers, such as participant two, the harshness of caregiving is endured for the ability to gain sustenance for their families. It is important to acknowledge that the contextual implications are present throughout the process of understanding caregiving in community-based palliative care institutions in South Africa.

Often family, or informal caregiving, is conceptualised as obligatory and in many ways formal caregiving, within a given context, is often compelling due to the impact of the environment upon the individual and may become a matter of survival rather than choice. Informal caregiving is not always an elective role; in much the same sense formal caregiving as a career is not always an elective role (Pearlin & Aneshensel, 1994). The contextual circumstances effect the motivation underlying the career choice a caregiver may employ. This in return has effects on their levels of motivation and perceptions of their own competence. The work environment has significant implications for the emotional well-being of caregivers. Work situations that have severe demands contribute towards the exhaustion element of burnout and may deplete an individual's sense of competence (Maslach, *et al.*, 2001). It is important to understand the implications of the under resourced and overburdened healthcare system, and that caregivers in community-based institutions are often exposed to "less support, longer working hours, have limited opportunities for debriefing", which all contribute to to the creation of this vicious cycle of impacting factors (Freeman, Ramanathan, Aitken, Dunn, & Aird, 1998, p. 150).

Conclusion

This chapter provided the results of the research and the discussion in relation to the integrated understanding of ecological and multidimensional models. The chapter considered six themes in which to locate the research findings and theoretical understandings of such themes and the relation to the theoretical framework. The chapter to follow presents an overview of the research findings and the strengths and limitations of the research. This chapter also provides an overview of the results, recommendations for future research, as well as the implications of this research.

CHAPTER FIVE

Introduction

This chapter presents an overview of the research findings of the current study. Secondly, the chapter provides the strengths and limitations for the research and the future directions for further research within the caregiving field. The chapter also provides the implications of the research in relation to interventions relating to the caregiving field as a whole, however in particular the formal caregiving sphere within the community context.

Overview of research findings

The results and discussion provided themes that assemble around two broad notions. The first notion relates to the emotional experience. In particular experiences that allow for positive and negative elements to increase and alter the experience, and the interplay between coping and coping strategies employed. This allows for the consideration of micro-system and ultimately its interactions and effects on the other systems. The second focuses upon the factors within the environment and the contextual influences that alter or affect the caregivers' emotional experiences. This provides the consideration of the impacting factors of the other systems and their ability to alter the micro-system and thus, also the outcomes of the micro-system.

The participants perceived their role as a formal caregiver in relation to the duties and activities performed. Participants often considered the emotional component as either a secondary component to the practical duties to be performed, or as one of the components inherent in being a caregiver. This focus upon the practical abilities intersected with the caregivers importance of knowledge, this being the factor distinguishing them from informal caregivers. This knowledge provided an integral component of the caregivers' competence and informed their perception of their professional identity as a formal caregiver. Their 'ownership' of this knowledge created the perception of caregiving as a privileged or restricted profession, in this manner attaching prestige to the professional identity. This provides the individual with sense of importance and increases the significance of his/her role. This constant reiteration of the professional aspects may provide the caregivers with the

ability to distance themselves from their sense of reality and emotional difficulties entrenched in caregiving. The use of knowledge as a means to maintain control and manage emotional difficulties becomes evident in situations whereby knowledge is deemed insufficient or fails to provide them with control and distance from their experiences. In this manner, the participants perceived themselves as helpless, and in several cases as having failed the patient by not having the ability to alter the outcome. Knowledge provides surety and competence to intervene and provides some sense of control over the outcome and in this manner pre-empts or prepares the caregiver for the outcome. These means of engaging with the caregiver role also provide a frame of reference which enables the caregiver to interpret their experiences.

As an informal caregiver reciprocity is sought from the patient, whereas the participants, as formal caregivers, indicated the sense of reciprocity in relation to the institution. This was particularly important for the caregivers in relation to their need for recognition from the institution, and the community as a whole. This reiterates the importance of a systemic understanding in relation to caregiving, and that caregiving cannot be restricted to the caregiving dyad alone. The caregivers' identity and how they perceived their role as a caregiver was often constructed in relation to others, or other spheres within the system. For example caregivers perceived their role in relation to the role they play within the community and their ability to make a difference.

In many ways, their perception and the creation of their role as a caregiver provides a means to manage difficulties. Participants seemed to illustrate a complex relationship in relation to managing the stressors. Participants were aware and often had knowledge regarding the importance of support mechanisms but often failed to rely on such support. This highlighted two main concerns, the first relating to trust and the implications of being 'in need' of help within their occupational role. While the second related to the difficulty of the caregiver within a patient role, or the avoidance of being placed within such a role. The stigma, and often shame, attached to confiding in someone exacerbated current difficulties even further. This was coupled with the concern of the confidante being competent and trustworthy. Such findings have significant implications for the creation of support mechanisms and the social norms that inform managing caregivers' negative experiences and the perception of seeking help.

Several participants had sought alternative means of managing. These resources relied on both personal, internal resources and external neutral resources. The reliance on these

different coping mechanisms seemed to highlight the effective and ineffective means of managing the difficulties within caregiving. For example, spiritual beliefs often provided the participants with support, especially through prayer, while coping mechanisms, such as alcohol usage, had exacerbated the difficulties even further. For several participants, work as a caregiver is vital to their survival and thus, often managing is not negotiable. In this sense participants found the reminders of the necessity of their job, as factors that would keep them coming back, but operated as temporary solutions and often means to evade the difficulties. For example, several participants continue, irrespective of the personal difficulties caregiving elicits, as they are the only source of income within their families. Unfortunately such temporary solutions, and ineffective coping mechanisms, often result in much more severe consequences. The accumulation of difficulties that the caregiver unsuccessfully tried to evade initiates a vicious cycle in which the caregiver continually finds it more difficult to manage the stressors that continue to arise thereafter. However, participants had also created effective means of coping, such as using music as a means of reflection and relaxation. Other participants provided mixed accounts of spirituality, religiosity, as a means of support. Their religious relationship provided a means of support that was considered trustworthy and a source of motivation. Through their spiritual beliefs some participants had felt a sense of control and ability to make meaning of their experiences and the experiences of the patients.

Difficulties in managing emotional problems seem to arise in situations of increased stress, in particular, high workloads and the combination of work and personal difficulties. This is further complicated by the difficulties relating to contextual factors, such as high rates of poverty and unemployment, which intersect both their personal and professional lives. The work environment, presents with long hours, limited support and little recognition or remuneration. This is then further exacerbated by the difficulties between the caregivers. Often these difficulties coincide with their own personal difficulties. Participants discussed caregivers harassing patients, instances of theft and difficulties in relation to the power hierarchy within the organisation.

It is particularly important to understand the reasoning underlying caregiving for many of the caregivers. Several caregivers described a previous personal experience of losing someone close to them and in many respects caregiving for them represented an opportunity to make reparation and to allay guilt associated with those experiences. While several participants perceived caregiving as a gift or calling, others considered it the only option

available. These reasons often serve to motivate the caregivers or place them in a position of great vulnerability. This illustrates the importance of understanding the underlying motivations and being able to facilitate and provide additional support to those at greater risk.

Coping or not coping, more often the latter, are common outcomes to the emotional experiences of caregiving. The caregivers often described an obligation to be able to handle the myriad of challenges faced on a daily basis and regularly contemplate not returning. Other participants felt the challenges, although stressful, were manageable and had the ability to motivate them further. This seems to illustrate the effects of positive elements such as motivation in their overall perception of their emotional experience. In the same manner, being able to make meaning from their experiences often provides participants with sense of fulfilment and can accompany active, positive coping strategies. Participants also highlighted their ability to make a difference in their patients' lives and the community as a whole. However, the difficulty with making meaning was that several participants often (over)identified with their patients, which often led to insecurities regarding their health and future. Yet for some participants this identification provided the means to motivate themselves further.

Throughout the process themes of loss and hope ensue, being instrumental in the coping strategies adopted. Both hope and loss were elements that influenced the vulnerability of the caregivers, as well as their previous personal and caregiving experiences. Participants seemed to highlight experiences of rehabilitation and held onto the hope of rehabilitation, in most circumstances. This investment in the patient's recovery often resulted in loss and disappointment when rehabilitation was not possible. Often loss of a patient was coupled with a loss of their sense of competence and overwhelming sense of failure. This was often made significantly more difficult in circumstances where a noteworthy connection between the caregiver and the patient had been established. This meant that, in many respects, the caregiver was made vulnerable to repeated losses; some also described an accompanied sense of guilt.

As mentioned earlier the contextual factors play an instrumental role in the perception of their emotional experiences and usually operate as both precipitating and perpetuating factors. Community-based institutions were perceived as significantly more intimate and caring than hospitals, however simultaneously acknowledged to have similar barriers, such as stigma and insufficient resources. Within the community-based institution recognition was

considered an important component within the caregiver's competence and thus, their increased ability to manage stressors, which was often neglected. The participants seemed to seek a means to convey the difficulties experienced with senior staff members through the research, as the hierarchy within the institution often prevented any communication between the caregivers and the senior staff members.

Both the positive and negative elements of their emotional experience are highly influential in promoting protective factors or alternatively increasing vulnerability. Through the awareness of the potentially negative aspects, and providing means to enhance and harness positive factors, caregivers have the potential to have significantly more positive and balanced emotional experiences.

Strengths and limitations of the study

Previous studies have concentrated upon the informal, either voluntary or familial caregivers (Goldberg-Arnold *et al.*, 1999; Hoyert & Seltzer, 1992; McPherson, Wilson, Lobchuk, & Brajtman, 2007; Parks & Novielli, 2000; Reinhard & Horwitz, 1995). Although there is significant support for the research into informal caregivers, often formal caregivers are overlooked. This research provides a means to adapt or augment the conceptualisation of the role of caregiving to better understand formal caregivers. It also provided a qualitative analysis providing an in-depth enquiry into the caregiving experience, as previous studies attempt to quantify the effects of negative aspects. In addition, this research considers both positive and negative factors within the emotional experience, creating a holistic understanding of how these factors may interact with coping strategies in formal caregivers. Further qualitative enquiries in combination with quantitative studies could provide a more holistic and in-depth account of caregiving within South Africa.

Although the research conducted was innovative within the caregiving field there were several components that may be beneficial for future research to be aware of. It could be beneficial to supplement research into formal caregivers through a longitudinal study – thus, having the ability to pursue the variables over a period of time and thus obtain additional information and understanding of formal caregivers' emotional experience over a period of time (Chadda *et al.*, 2007). This is significant since the majority of research into the effects of

caregiving, are cross-sectional in design and thus unable to account for the element of time (Pinquart & Sorensen, 2007). This study is unable to concentrate on all the emotional elements that have some relation to the impact upon the caregiver, but concentrates on the elements that emerge in the research surrounding caregiving.

The participants within the current research were competent in English, however it is important to acknowledge that English was not their first language and several of the participants had encountered difficulties at times to adequately communicate their emotional experiences. 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. All participants within the study were volunteers and thus the influence of their volunteer status and potential biases as a result may have operated within the study. Future research could pursue alternative organisations within South Africa and explore constructs such as gender and geographical location further.

Future directions

Caregiving as a whole could be benefitted through increased interaction and recognition of the caregivers and their role. The negative factors are often blatant which makes the effects and manifestations much more prevalent within the caregiving process, however being able to assist and acknowledge the positive aspects fostered within the caregiving dyad may indirectly benefit the caregiver by providing an alternative focus from the negative aspects. In this manner further research into the positive aspects and the potential means of fostering and facilitating the presence of these factors within caregiving would be highly beneficial.

There are several different themes or areas that became salient within the research. The first is the influence of the organisational environment – specific to palliative care institutions, where emotional and psychological impacts are often experienced without sufficient containment. Research considering the manner in which the working environment may be able to further cater and facilitate caregiver well-being would be highly beneficial. Being able to recognise the interrelationships between the different facets within caregiving and establish the interactions between the cross relationships, providing a more systemic perspective. Thus, there is substantial value in recognising and understanding the emotional experience in caregivers, and being able to attend to the needs of palliative care within a

community-based context. This research supports the need for further research into the formal caregiving sphere, in particular community-based settings that are often under resourced, and perhaps considers the implementation of interventions that may serve to enhance positive or protective factors and decrease negative factors.

The caregivers may also benefit from the opportunity to access emotional and psychological resources, not limited to the effects of their work environment but also in relation to the contextual difficulties these caregivers experience. This research can be considered in conjunction with previous research that considered the implications of emotional impact on families. In this manner literature could begin to contribute to the creation or adaptation of a model that is able to incorporate a contextual understanding and allow for the utilisation of this model within the caregiving process. The findings of this research indicated the importance of the contextual understanding and reiterate the distinction between the 'rural' South African context and predominantly high-income countries. Future research into different contextual spheres may provide a more detailed perspective of formal caregiving as a whole. This research could be beneficial in creating interventions that are able to account for contextual factors. The research would be able to locate the community resources and provide a practical approach to caregivers' emotional experiences and perhaps a platform from which further research and interventions could arise (McFarland & Saunders, 1999).

Implications in relation to caregiving and potential interventions

Caregiving interventions consider two primary approaches, the first is peer-peer support which presents the opportunity for the formal caregivers to obtain understanding of their experiences and enhance protective elements through casual interaction (Frank, 2008). The second approach to caregivers' interventions is instruction-based support, this relates to initiatives that are predominantly located in "discussion around an instrumental or psycho-educational topic or theme" (Frank, 2008, p. 526). Interventions should be systemic in nature and thus consider the different levels of interaction and interrelationships that are fostered between each sphere.

Several of the participants had found disclosing to co-workers a difficulty and often the process implicated the dynamics inherent in the working environment, thus, utilising the

second approach would be able to initiate a sense of recognition with the caregivers and would provide as a means to supplement their training while simultaneously fostering positive factors within the caregiving process. These approaches may enable the caregivers to gain support as well as a sense of recognition for their jobs. Psycho-educational interventions may also allow for the process of burden, compassion fatigue and stress to be understood and normalised, which may reduce the influence of these factors on the caregivers' emotional experiences (Frank, 2008). Awareness of the caregiving processes, and in particular the emotional processes occurring and likely to occur within caregiving, may be beneficial means to foster coping mechanisms and coping strategies that are able to counteract the negative experiences and enhance the positive experiences. Providing an interactive skills development may help the caregivers competence and may provide a sense of recognition of caregivers (Murray, Wilson, Kryworuchko, Stacey, & O'Connor, 2009). In studies conducted by McFarland and Saunders (1999), caregivers were considered to cope significantly better when the positive aspects within the caregiving experience took precedence. Thus, enhancing awareness and acknowledging the role of the positive factors may in itself be a coping mechanism to reduce the effects of the negative factors.

The community also provides opportunities to intervene with the underlying causes, such as unemployment, poverty and HIV/AIDS. Training the community in relation to issues regarding stigma, not restricted to the medical illnesses, but also in relation to the stigma attached to palliative care institutions. The community has substantial potential to operate as a resource for the community-based palliative care institutions, as well as within the broader contextual difficulties. It provides the opportunity to redefine the resources available in the community. The caregiving/organisational environment could also be benefited by sensitivity and awareness of the hierarchy that operates within the community-based palliative care institution and in this manner foster an organisational environment that facilitates the caregivers' growth. Caregiving, within community contexts in South Africa have significant potential for interventions in relation to caregiving and could operate as a great resource for the community.

Conclusion

This chapter provided an overview of the research findings. The chapter also provides the strengths and limitations of the study. The chapter also considered the implications of the

research, and the recommendations for future research, as well as implications of caregiving interventions, particularly in community-based institutions.

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APPENDICES

Appendix A

Semi-structured interview schedule

(i) How do you understand your role as a formal caregiver?

(ii) How do you distinguish your role from an informal familial caregiver?

- What, in your opinion, are the key distinguishing characteristics?

(iii) What are the most stressful and least stressful aspects of your day as a caregiver?

- Do you cope efficiently with those aspects just mentioned?
- If **yes,** what do you do to ensure this effective coping?
- And if **no**, what makes it difficult for you to cope efficiently?

(iv) How do you understand your strategies for coping with the different situations that manifest in a palliative care institution? (Caring for the patient, the family and the burden of it as a job?)

(v) What is your greatest motivating factor in being a caregiver?

(vi) What is your most satisfying factor in being a caregiver, you can explain by giving an experience that defines the factor?

(vii) What is the most challenging aspect of being a caregiver?

(viii) What role, if any, do you think stress and burden have in the challenges of being a caregiver?

- *(If they think they play a role):* How do you think these factors impact on, or influence, the coping strategies you adopt?
- Secondly, do you think these factors impact on, or influence whether you are able to cope/not cope?

(ix) What do you think leads to factors such as, burnout and compassion fatigue, in caregivers? (Explain what is meant by compassion fatigue if necessary: *having a reaction to the indirect exposure of emotionally taxing experiences; although you or your family may not be going through the illness, you may be inherently involved in these processes with patients*).

(x) What experiences have defined you as a formal caregiver? (depending on whether the answer provided focused on a discouraging or encouraging

experience, the alternative **one** of the two questions below will then be put forward)

- Can you describe an experience that was discouraging?
- Can you describe an experience that was encouraging?

Appendix B

Letter of permission for research site

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development

Private Bag 3, Wits 2050,

Johannesburg,

South Africa

Tel: (011) 717-4500 Fax: (011) 717-4559

Dear Madam/Sir,

I am conducting research for the purposes of obtaining Masters in Community-Based Counselling Psychology at the University of the Witwatersrand. My research area looks into caregivers experiences of emotional impact. Individuals willing to participate will be invited to an interview exploring the issues surrounding the topic under investigation.

I wish to obtain my sample from within a palliative care institution. I would like to request your permission to approach the formal caregivers and discuss my research and invite them to participate in the study.

Attached is the participant information sheet. If you would like to find out more any further information about the study, feel free to contact me on 083 291 9580 or via email at sarahuren@gmail.com, or alternatively, contact my supervisor Tanya Swart on (011) 717-4586 or alternatively via email at tanya.swart@wits.ac.za.

Kind Regards,

Sarah Anne Uren

Telephone: 083 291 9580 Email: sarahuren@gmail.com

UNIVERSITY
OF THE
WITWATERSRAND,
JOHANNESBURG

School of Human and Community Development

Private Bag 3, Wits 2050,

Johannesburg,

South Africa

Tel: (011) 717-4500 Fax: (011) 717-4559

Dear [Name of Institution],

I am currently a student at the University of Witwatersrand, busy completing my Masters in Community-Based Counselling Psychology. As part of the course requirements we have to complete a research thesis. I have already put forward my proposal and have gained ethical clearance from the University.

My research is into the emotional experiences of caregivers at palliative care facilities. It aims to explore the individual caregiver's experiences as a caregiver – considering both the positive and the negative elements that impact upon their emotional functioning and experience. It considers the coping mechanisms relied upon and the protective factor that may promote a positive experience as a professional in the caregiving field. I am focusing on paraprofessionals and professionals, as I hope that the findings may inform the training of caregivers in the field to enhance the positive emotional experiences and provide an understanding of how to prevent against the negative aspects of their personal experiences.

I would like to know if it is possible to conduct research at [Name of Institution] and the opportunity to approach the caregivers at your facility and find out if any of the caregivers would be interested in volunteering to participate in my research. Participation would mean taking part in an interview – which would last approximately one hour, at a venue most convenient for the caregiver. I will explain all their rights in relation to participation in research and it is completely voluntary. Unfortunately the volunteers must have received some form of training in caregiving, as my research focuses upon caregivers that have received some form of training. The interviews are most likely to be conducted at any time during June and July 2009.

If you have any questions regarding the study or the process, please feel free to email me at sarahuren@gmail.com or contact me on 083 291 9580. Alternatively you can contact my supervisor, Tanya Swart on (011) 717-4586. I am able to email through my proposal that indicates more about the research and the research procedure.

Yours Faithfully,

Sarah Uren

Appendix C

Letter of consent to conduct research



UNIVERSITY
OF THE
WITWATERSRAND,
JOHANNESBURG

School of Human and Community
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Private Bag 3, Wits 2050,
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Tel: (011) 717-4500 Fax: (011) 717-4559

Consent to conduct research

I _____ grant Sarah Anne Uren permission to conduct research at _____(name of institution) subject to her following the ethical and moral guidelines which guide the research process.

Date _____

Signature _____

Appendix D

Participant information sheet

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development

Private Bag 3, Wits 2050,

Johannesburg,

South Africa

Tel: (011) 717-4500 Fax: (011) 717-4559

Hello, my name is Sarah Anne Uren, and I am conducting research for the purposes of obtaining a Masters in Community-Based Counselling Psychology at the University of the Witwatersrand. My research area looks into the experiences of emotional impact, both negative and positive within the role of formal caregivers. Individuals willing to participate are invited to participate in an interview exploring the issues surrounding the topic under investigation. Since previous studies have focused on family caregivers, this research allows for the exploration of formal caregivers experiences into emotional impact intertwined with caregiving, in an attempt to consider whether further studies into these areas will be beneficial for training programs and the personal well-being of formal caregivers.

Participation in this research will involve the opportunity to participate in an interview. The interview will last for approximately an hour, at a time most convenient for you as the participant, either at a venue on the campus of University of Witwatersrand or at your place of work. With your permission, the interview will be recorded in order to ensure accuracy and with your permission, to include parts of the discussion within the study itself – however there will be no identifying information. Participation is voluntary, participating or refraining from participating will not be advantageous or disadvantageous to you in any way. This means that the research conducted will also have no advantages or disadvantages in regard to your position held at the organisation as well.

The transcripts and audio files from the interviews will be kept strictly confidential and only the supervisor and researcher will have access to these materials. No information that could identify you would be included in the research report as each participant will be referred to by a generic alias – thereby protecting your identity within the research. The transcripts and audio files will be kept in a safe and secure location, within the psychology department and access to the material will be limited to my supervisor and me. Once the research report is finalised, and upon the attainment of the degree, or alternatively if research is published, the data will be kept for a period of two years after publication, then all the audio files and transcripts from the interviews will be destroyed. As a participant, you may refuse to answer any questions you would prefer not to, and you may choose to withdraw from the study at any point. The researcher will make a one-page summary available to the participants upon request, explaining the results of the study, once research has been finalised.

If you choose to participate in the study please let me know either directly, by completing the slip attached, or by contacting me either telephonically at 083 291 9580 or via e-mail at sarahuren@gmail.com. If you leave your details on the slip attached, I will get back to you and provide all necessary details for the interview, arranging a time most suitable for you. If you would like to find out more about the study, you are welcome to contact me at any stage. Alternatively, contact my supervisor Tanya Swart on (011) 717- 4586 or via email at tanya.swart@wits.ac.za.

Your participation in this study would be greatly appreciated as this research will contribute both to a larger body of knowledge in caregiving, as well as the understanding of the experiences of the formal caregivers within a South Africa context.

Kind Regards

Sarah Anne Uren

Additional contact details:

Lifeline

Johannesburg Crisis Centre (011) 728 1347

South African National counselling line: 0861 322 322

Emthonjeni Centre

East Campus, University of Witwatersrand, Johannesburg

(011) 717-4513 or (011) 717-4567.

SADAG

South African Depression & Anxiety Group

(011) 262 – 6369 (8am – 8pm)

Appendix E

Permission for interview

I _____ consent to being a participant in an interview conducted by Sarah Anne Uren for her study into the experiences of the emotional impact as a formal caregiver.

I understand that:

- Participation in this interview is voluntary.
- That I may refuse to answer any questions I would prefer not to.
- I may withdraw from the interview at any time.
- No information that may identify me will be included in the research report.
- The study has no direct benefit, nor any foreseeable negative consequences in participating.
- Should unforeseeable negative consequences arise there are contact details available and assistance, to contact these institutions will be given if needed.
- I consent to the researcher using direct quotes in her research report, with reference to a generic alias – so my identity will not be included in the research, and that I understand that the researcher will keep responses as anonymous as possible.

Signed _____

Date _____

Appendix F

Permission to record interview

I _____ consent to the recording of the interview, as part of the study, of experiences of the emotional impact on formal caregivers.

I understand that:

- The audio files and transcripts will not be seen or heard by any, other than the researcher and the supervisor, and the information will only be processed by them.
- The audio files and transcripts will be kept in a safe and secure location, with only the researcher and the supervisor having access to these materials.
- All audio files and transcripts will be destroyed upon the obtainment of the degree; if the research is published the audio files and transcripts will be destroyed two years after publication.
- No identifying information will be used in the transcripts or the research report; where direct quotes are used within the research report there will be no identification attributed to the quote. References to all participants within the research report will be conducted with a generic alias.

Signed _____

Date _____

Appendix G

Ethical clearance certificate