THE EXPERIENCES OF PRIMARY CAREGIVERS PROVIDING PALLIATIVE CARE TO WOMEN LIVING WITH ADVANCED BREAST CANCER

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A mini-thesis submitted in partial fulfilment of the requirements for the degree of Master of Psychology in the Department of Psychology, Faculty of Community and Health Sciences, University of the Western Cape.

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December 2006

ABSTRACT

The aim of this explorative study is to understand the experiences and challenges of primary caregivers providing palliative care to women with advanced breast cancer. The recruited participants were primary caregivers providing palliative care to women with advanced breast cancer attending the Radiation Oncology Department at Groote Schuur Hospital. Participants were from the age of 18 years and have been providing palliative care to the women with advanced breast cancer for a minimum of two months. Eight English-speaking participants were selected, through purposive sampling, to participate in the study. This study was conducted within a qualitative research design framework underpinned by phenomenology. In-depth interviews with the aid of an interview guide, biographical questionnaires, as well as observations and note-taking during the interviews were utilized as tools for data collection. This study was theoretically located within a phenomenological framework. The significance of this study was to contribute to the knowledge that would help health care professionals understand the experiences and challenges that primary caregivers face whilst providing palliative care to women with advanced breast cancer. This understanding would help to motivate for primary caregivers being considered in the management process of the treatment of women with advanced breast cancer.

Keywords

Palliative care, primary caregiver, family, caregiving role, women with advanced breast cancer, phenomenology, qualitative, experiences, challenges of primary caregiving

DECLARATION

I hereby declare that this thesis, *The experiences of primary caregivers providing palliative care to women living with advanced breast cancer*, is my own work; that all sources have been acknowledged and that it has not been previously submitted for any degree or examination in any other university.

Jyoti Chauhan December 2006

Signed:

ACKNOWLEDGMENTS

I wish to extend a very special thank you to:

National Research Foundation (NRF), for their financial contribution towards my research. I acknowledge that this research does not in any way represent the views and opinions of the National Research Foundation (NRF).

Research Ethics Committee, Faculty of Health Sciences, University of Cape Town, for granting the approval to undertake this study at Groote Schuur Hospital.

Prof. Pamela Naidoo, my supervisor, for her expertise and guidance through the research process.

Ms Denise van Schalkwyk, for assisting with referrals of eligible participants for this study.

The participants, for so willingly participating in the study and for sharing their experiences with me.

My family and friends, for their encouragement and invaluable support.

My husband, for his endless support and patience.

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CHAPTER ONE

INTRODUCTION

1.1 Background to this study

Changing patterns of health and social care place greater emphasis on care in the community for patients with end-stage disease (Payne, Smith & Dean, 1999). With cancer rapidly developing into a continuous care problem because of increasing incidence rates, longer survival times, reduction of stays in acute care settings and shifting of treatment toward ambulatory care, increased responsibilities have been transferred to family members for both the physical and emotional care of patients with cancer (Given & Given, 1991 in Kurtz, Kurtz, Given & Given, 2004). Recent treatment, economic and policy changes have resulted in a shift from inpatient to outpatient care for many serious illnesses, including cancer, placing an increased caregiving responsibility on family and friends of the ill patients (Given, Given & Kozachik, 2001). As care has shifted from the hospital to the home, the role of the family caregiver has been transformed into a complex, multifaceted responsibility that many are ill prepared to assume (Glajchen, 2004).

Family members often assume the caregiver role under sudden and extreme circumstances, with minimal preparation and uneven guidance and support from the health care system, posing significant challenges and considerable psychological and physical consequences for the caregiver (Glajchen, 2004). As a result of health care services being restructured and more cancer patients dying outside of hospital, the reliance on family caregivers to support patients with terminal illness at home is growing (Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle, Willan, Viola, Coristine, Janz & Glossop, 2004).

In general, family caregivers represent a significant portion of the population of caregivers. In the United States, 1997 national surveys estimated that there were between 24 million to 27.6 million adults providing care to a family or friend with a chronic, disabling or terminal illness (Arno, Levine & Memmott, 1999). The National Caregiver Profile notes that 72% of all unpaid family caregivers in the United States are women. The most consistent finding in caregiving research is that the majority of family caregivers are women (Stone, Cafferata & Sangl, 1987).

1.2 Caregiving: Home based care of terminally ill individuals

Cameron, Franche, Cheung and Stewart (2002) asserted that end-of-life care for many patients with advanced disease is provided at home by a family member who assumes and /or coordinates the majority of care. Informal carers are generally unpaid and untrained, and provide care as the result of a pre-existing relationship with the cared person. Informal carers are also referred to as family caregivers, lay carers, home carers, and unpaid or untrained carers. ‘Being a carer’ represents a social relationship in respect of another person (Smith, 2001).

Cameron et al. (2002) defined family caregivers as the person who conducted or coordinated the majority of the patient’s home care needs without receiving reimbursement for the care they provided. Primary caregivers are essential supporters of cancer patients in the palliative phase who are staying at home, since they provide practical and emotional help and care (Grov, Fossa, Sorebo & Dahl, 2006). Northouse, Kershaw, Mood and Schafenacker (2005) defined family caregivers as the family member or significant other identified by the patient as her primary source of emotional and physical support during the recurrent phase of breast cancer and confirmed by the designated individual. The participants in this study are the family caregivers of women with advanced breast cancer.

According to Cameron, Shin, Williams and Stewart (2004), family caregivers most often assume responsibility for most care provided in the home including providing assistance with activities of daily living (e.g. bathing, eating), instrumental activities of daily living (e.g. finances) and home medical procedures (e.g. medications). Especially at the end of life, family caregivers are essential because they provide needed help with activities of daily living, medications, eating, transportation, and emotional support, as well as communicating with health care professionals about the patients' condition (Mc Millan, 2005).

The course of the patient's illness shapes the caregiver's experience (Wilkinson & Lynn, 2005). The caregiving experience is complex. It impacts on all aspects of the caregiver's life, including his or her physical, emotional, and psychological health (Deeken, Taylor, Mangan, Yabroff & Ingham, 2003). Caregiving responsibilities are physically and emotionally challenging, especially for the person who has not had any specialized training for this role (Payne et al., 1999; Toseland, Blanchard & McCallion, 1995).

While there is an abundance of literature on ‘carers’, there is very little that relates specifically to those in a palliative care setting. Although there may be many similarities between carers of different groups, a particular disease trajectory and the certain process of dying acknowledged within palliative care may have an impact on the situation that cannot be accounted for in the general literature (Smith, 2001).

For the purpose of this study ‘primary caregiver’ is defined as the family member or significant other identified by the woman with advanced breast cancer as her primary source of emotional and physical support. Furthermore, for the purpose of this study, the terms ‘primary caregiver’, carer, informal carer, family caregiver will be used interchangeably.

1.3 Defining palliative care

The World Health Organization (2006) defined palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. The World Health Organization asserted that the needs of the family also should be addressed and that families need support to sustain their caregiving (Ramirez, Addington-Hall & Richards, 1998). The emphasis of palliative care has been to support both the patient and his/her carer, and to maintain their involvement through the patient’s illness and death (Payne et al., 1999). With increasing number of terminally ill people remaining at home family caregiving is an important aspect of palliative care (Seale & Cartwright, 1994 in Smith, 2001)

1.4 Cancer

Cancer is a major illness which affects many people, directly or indirectly (Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt & Van Den Bos, 1998). Unlike many other illnesses with relatively predictable courses, cancer does not have a predictable course but proceeds with unpredictability and uncertainty. The chronicity of cancer with a variety of complications contributes to frequent health care visits, medications, treatment, and enormous life-style changes for the patient and the caregivers (Creamer, 2002). Advanced cancer was defined as having an estimated three to six month survival prognosis, as indicated by their health team (Cameron et al., 2004). Metastatic or advanced breast cancer is the presence of disease of distant sites such as bone, liver or lung. It is not treatable by primary surgery and is currently considered incurable (Hortobagyi, 2002). Symptoms may include pain from bone metastases, breathlessness from spread to the lungs, and nausea or abdominal discomfort from liver involvement (Stebbing, Crane & Gaya, 2006).

This study focuses on the experiences and challenges of primary caregivers providing palliative care particularly to women with advanced breast cancer.

1.5 Cancer as a family illness

Cancer is not a disease of one individual but impacts the entire family system. The family must confront and attempt to understand the meaning of cancer for the patient, for each family member individually and for the family system as a whole (Blanchard, Ruckdeschel & Albrecht, 1996). The stage of the illness is a major factor determining patient and family concerns. The physical and emotional demands on the family reach their peak if the illness progresses to the terminal stage. Family members must assume new caregiving tasks without feeling they lack the skills, information or assistance to perform them. Their own needs may be neglected leading to emotional isolation, exhaustion and alienation (Blanchard et al., 1996).

The biopsychosocial model has shown that individuals have psychological and spiritual dimensions that impact on their health states and all of this takes place within a social context (Curtis, 2000). We must enquire into the structure of illness meanings: the manner in which illness is made meaningful, the processes of creating meaning, and the social situations and psychological reactions that determine and are determined by meanings. The family consequences of illness have this in common: each family must make sense of their experience and come to terms with it. In so doing, all the things that distinguish a family as unique are replicated in that process of imparting meaning to experience. Understanding the influence of illness on the family necessitates understanding the family itself, not just the illness. When the family becomes the focus, it will be seen that illness influences relationships as profoundly as it does individuals (Kleinman, 1988).

Family caregivers must deal with many unfamiliar situations and unexpected demands, as cancer patients have multifaceted needs which include disease and treatment monitoring, symptom management, medication administration, assistance with personal care, and emotional support (Given et al., 2001).

The course of cancer is shifting from an acute disease with a prompt outcome, usually death, to a chronic disease with long-term treatment often implemented in the home settings with a continued need for care (Nijboer et al., 1998).

The life-threatening nature of breast cancer, along with the side effects of treatment, places great strain on patients and their families. Husbands may be especially vulnerable as the main source of support to patients (Wagner, Bigatti & Storniolo, 2006). Although family caregivers perform an important service for society and their relatives, they do so at considerable costs to themselves. Schulz and Beach (1999) in their study suggest that being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers. Studies support the observation that caregiving for a patient with advanced breast cancer becomes more demanding and difficult as the disease progresses (Nijboer et al., 1998).

1.6 Epidemiology of breast cancer

Breast cancer is the most common cancer in women, accounting for a total of 211,300 cases and 39,800 deaths per year in the United States (Lichter, 2004). This represents one third of all female cancer diagnoses and 15% of cancer deaths. Breast cancer is the second leading cause of cancer deaths in women today (after lung cancer) and is the most common cancer among women, excluding nonmelanoma skin cancers. According to the World Health Organization, more than 1.2 million people will be diagnosed with breast cancer this year worldwide. Though much less common, breast cancer also occurs in men (Imaginis, 2006).

According to Vorobiof, Sitas and Vorobiof (2001), cancer is an emerging health problem, especially in South Africa, with breast cancer being one of the leading cancers in women, following similar worldwide statistics. Statistics from the Cancer Association of South Africa show that one in every 36 women in South Africa has breast cancer, now the most common cancer among South African women.

1.7 Rationale for the study

Research into cancer caregiver experiences over time is rather scarce (Nijboer et al., 2000). Despite the recent research directed toward the role of family caregivers in cancer care, the role of caregivers in the end-of-life care has been described infrequently (Given, Wyatt, Given, Sherwood, Gift, DeVoss & Rahbar, 2004).
The family member who is the primary caregiver is referred to as the family caregiver.

Although a great deal of research has been performed on correlates of distress for caregivers who are at various points in the care trajectory, little work has been done to assess the impact of providing end-of-life care on the distress of family caregivers of patients with cancer. Given the manner that distress echoes throughout both the family and community in the setting of cancer, the caregiving experiences of the partner or significant other of women with breast cancer is of great interest. What is not fully understood is the emotional and psychological impact of taking on the role of family-based caregiver in the cancer setting (Lethborg, Kissane & Burns, 2003). Research on caregiving to cancer patients is sparse and there has been little research specifically addressing the experiences of caregivers who are caring for women with advanced breast cancer (Nijboer et al., 1998).

The study attempts to contribute to the gap that exists in the literature specifically on the experiences of primary caregivers who provide palliative care to women with advanced breast cancer. The study hopes to highlight the experiences and challenges faced by primary caregivers providing palliative care to women with advanced breast cancer. The study also attempts to understand the impact of the caregiving role on the primary caregiver. It is further hoped that through increased awareness and understanding, health care professionals will consider developing interventions that will support the caregiver with a view to reducing caregiver strain and distress.

The researcher has an interest in the field of caregiving, given her background in social work and her previous experience in providing an inpatient counselling service to women with advanced breast cancer and their families at the radiation oncology department at Groote Schuur hospital. The researcher became aware of the challenges primary caregivers experienced when caring for women with advanced breast cancer and realized the importance to recognize and highlight these experiences.

1.8 Aim and objectives

The aim of the study is to explore and understand the experiences and challenges family caregivers' face while providing palliative care to women with advanced breast cancer.

The study has the following objectives:

1. To explore the experiences of primary caregivers while providing palliative care to women with advanced breast cancer.
2. To explore the challenges that primary caregivers face while providing palliative care to women with advanced breast cancer.
3. To understand how the caregiving role impacts on the primary caregiver.
4. To explore the ways in which the primary caregivers give expression to their own feelings and needs.

Theoretically, the phenomenological approach offers the most appropriate means of making sense of the experiences of family caregivers providing palliative care to women with advanced breast cancer.

1.9 Concluding comments

This chapter has briefly outlined the context of the current study and has presented the rationale and motivation for undertaking this research. The aim and objectives of the study have been described. The study has been located within a phenomenological methodological framework. Chapter 2 provides the theoretical overview on phenomenology, some aspects related to caregiving and the review of the literature. Chapter 3 presents the research design, methodological framework, selection and description of the participants, procedure, data collection and data analysis. The chapter also includes credibility and dependability, reflexivity and ethical considerations that were taken into account during the study. Chapter 4 presents the findings and discussion of the analysis. Chapter 5 provides a conclusion on the study including contributions of the study as well as limitations and recommendations for future research.

CHAPTER TWO

THEORETICAL OVERVIEW AND REVIEW OF THE LITERATURE

2.1 Theoretical overview

2.1.1 Introduction

This study is located, theoretically, within a phenomenological framework. The study is intended to illuminate the lived experiences of primary caregivers providing palliative care to women with advanced breast cancer.

2.1.2 Phenomenology

The German philosopher, Edmund Husserl viewed phenomenology as a foundational science underlying all of the sciences and sought to clarify, through the use of critical reflection and description, the foundation and constitution of knowledge in consciousness (Hein & Austin, 2001). Husserl developed a systematic method of studying human consciousness and experience. He believed that experience of life events in the everyday world, with theoretical understandings suspended, was an invaluable source of knowledge (Becker, 1992). Seamon (2000) defined phenomenology as the exploration and description of phenomena, where phenomena referred to things or experiences as human beings experience them.

Husserl argued that the relation between perception and its objects is not passive. Rather, human consciousness actively constituted objects of experience. Consciousness, in other words, was always consciousness-of-something and existed always already-from the start-as a constitutive part of what was conscious of.

Husserl’s project was to investigate the structures of consciousness that made it possible to apprehend an empirical world (Gubruim & Holstein, 2003).

Phenomenologists focussed on how we put together the phenomena we experienced in such a way as to make sense of the world and in so doing, developed a worldview. There was no separate (or objective) reality for people. There was only what they knew their experience was and meant. The subjective experience incorporated the objective thing and became a person’s reality, thus the focus on meaning making as the essence of human experience (Patton, 2002).

Phenomenology thematized the phenomenon of consciousness and it referred to the totality of lived experiences that belonged to a single person. Consciousness was described as the medium of access to whatever was given to awareness, since nothing could be spoken about or referred to without implicitly including consciousness. By experience Husserl meant the intuition of “real objects’, that is, those objects that were in space and time and regulated by causality and thus were given in ordinary perception (Giorgi, 1997). Concerned with the experiential underpinnings of knowledge, Husserl argued that the relation between perception and its objects was not passive. Rather, human consciousness actively constituted objects of experience (Denzin & Lincoln, 2005). The analysis often required that the “phenomenal meaning” be related to the “objective meaning” in order to attain greater clarity, but it was always the meaning of the object precisely as given that was the focus (Giorgi, 1997).

Husserl demonstrated that every act of consciousness was necessarily "intentional", which was to say, it was always directed toward some "object". Thus the preeminent feature of human consciousness was its essential directionality (Jennings, 1986).

Husserl asserted that the phenomena that form our conscious experience manifested essences or structures. He viewed experience as consisting of both concrete particulars and the categories of meaning to which they belonged (Hein & Austin, 2001). Husserl believed that philosophy should be concerned with "essence", and its goal had to be the clear comprehension of the essential nature of reality. Essences were immanent, meaning that they were grasped in an act of reflective consciousness. For this reason, consciousness commanded the fundamental position as the special medium that constituted *all* forms of "being" in the world (Jennings, 1986).

Heidegger (1962) continued Husserl's phenomenological method of exploring consciousness and knowledge by undertaking a broader explication of being and time. Heidegger's work was cited as the first union of existentialism and phenomenology, resulting in the existential-phenomenology viewpoint. The phenomenological viewpoint was based on two premises. One premise was that experience was a valid and fruitful source of knowledge. Experience was the source of all knowing and the basis of behavior. A second premise of the phenomenological viewpoint was that our everyday worlds were valuable sources of knowledge. Important insights could be gained into the essential nature of an event by analyzing how it occurred in our daily lives (Becker, 1992).

This study used a phenomenological approach in an effort to understand the lived experiences of family caregivers providing palliative care to women with advanced breast cancer. Phenomenology could be thought of as a method of inquiry and a way of organizing information about people's lived experiences in such a way as to capture the essences of those experiences. Through a phenomenological method, the essence of caregiving as a lived experience in families could be unfolded.

2.1.3 Perspectives on caring for fellow human beings

People defined themselves in terms of their social relationships with others. Within these relationships people learnt reciprocity, the give and take of normal social life and learnt to be both cared for, and caring, to others. It was recognized that physical and psychological problems could not be separated out in a simple way, and for most people the experience of illness and of dying were a complex inter-play between physical, psychological, social, and existential issues (Payne & Ellis-Hill, 1996).

Various views on "care" were offered in the literature. Leininger (1984), in particular, hypothesized that care was an essential human need for birth, growth, survival, and for people who are dying. Human development and human fulfilment were achieved through the unfolding of the human capacity to care, through investment of the self in others, through commitment to something that matters (Roach, 1992). Caring was a feeling of dedication to another to the extent that it motivated and energized action to influence life constructively and positively by increasing intimacy and mutual self-actualization (Leininger, 1988).

Another theoretical position was that caring could be provided in different ways by both females and male caregivers through learned socialization processes. Traditionally, caregiving had been linked primarily to women in the home who were feeding, nurturing, caressing, and providing direct care to offspring, whereas males performed non-house and non-child caring activities. Social status and division of labor along sex role were evident. In general, caring was essentially a culturally learned and expressed behavior (Leininger, 1984).

Feminists have seen caring and nurturing as an integral part of women's identity and that women undertaking these roles, whether in private life or the public sphere, were not doing so simply because these roles have been assigned to them, but because they were meaningful and fulfilling for them (Miller, 1976; Gilligan, 1982 in Poole & Isaacs, 1997). They believed that caring had been devalued because it was seen, in a patriarchal society, as women's work. They would argue that women should continue to care, that caregiving be recognized and valued as a humanizing experience and that men should not only be encouraged to value the attributes of caring and nurturing but should adopt them, themselves.

The dominance of women and the tendency to describe the caregiver role in terms of personal care activities highlighted the societal image of caregiving as a largely female endeavor (Miller & Cafasso, 1992). According to Horowitz (1985 in Burack-Weiss, 1995) caregiving was primarily women's work, with men more likely to participate if the illness affects a spouse or mate or if no woman was available.

Mayeroff (1971 in Roach, 1992) dealt with two basic themes on caring: one, a generalized description of caring, and two, an account of how caring could give comprehensive meaning and order to one's life. Of particular relevance was the work of the philosopher Heidegger. According to Heidegger, man's essential relation to the world was one of care. "To be is to care," and the various ways of "being-in-the-world" were different ways of caring. Heidegger interpreted reality as care. Caring suggested being in place, providing meaning and order to one's life; qualifying relationships with the other; and subsuming the characteristic of devotion – a convergence between desire and thought (Roach, 1992). The values that governed our lives could endow our lives with meaning only if they were personal ones. Impersonal value alone could not give life meaning. Hence, the objects of deep-seated or serious caring were capable of endowing our lives with meaning (Blustein, 1991).

Especially with regard to those who were close to death, the difference that care made took on a special significance. It called upon the caregiver not to take further measures to cure individuals, but to focus on their personal well-being with sensitivity to the pain and discomfort they were experiencing, helping them to be as comfortable as possible. At that point, the task of care became not primarily treating the body but rather responding and listening to the personal needs of individuals whose biggest fear had become further suffering (Sabatino, 1999).

Kleinman (1988) asserted that in the terminal phase of life, looking backward constituted much of the present. The gaze back over life's difficult treks was fundamental to this ultimate stage of the life cycle. Illnesses, like other misfortunes, occupied an edifying place in this tale as exemplary difficulties and determinant forces, something that was formidable, now to be smiled over. For the caregiver what was important was to witness a life story, to validate its interpretation, and to affirm its value. Illness was not simply a personal experience; it was transactional, communicative, and profoundly social. The study of illness meanings was not only about one particular individual's experience; it was also very much about social networks, social situations, and different forms of social reality. Illness meanings were shared and negotiated. They were an integral dimension of lives lived together. Given these perspectives and the overall complex process involved in the caregiving experience, this study attempts to illuminate the experiences of primary caregivers providing palliative care to women with advanced breast cancer.

2.2 Review of the literature

2.2.1 Introduction

There are four areas of foci in the review of literature. Firstly, there is a discussion on family members as primary caregivers. Secondly, the discussion is on the emotional experiences of primary caregivers and thirdly, on the impact of the primary caregiver's health. Lastly, the literature review looks at the role of social support and communication as well as interventions to support caregivers. Since research on caregiving to cancer patients is sparse, the literature review entails a review on the caregiving of those suffering from cancer as well as other chronic illnesses.

2.2.2 Family members as primary caregivers

There is no dispute that a life threatening illness such as cancer echoes through the entire family; not least because the family is the primary unit for both social support and health care (Baider, Kaufman, Peretz, Manor, Ever-Hadani & Kaplan De-Nour, 1996). In a quantitative study by Cameron et al. (2004), it was mentioned that regardless of patient or family preferences, current health care trends, including shortened hospital length of stay, increased amounts of care being provided on an outpatient basis and limited availability of palliative care beds contributed to the shift of care to the home setting. To make this possible, usually a family member had to assume the role of primary care provider.

Often the role of caregiving fell to a family member (Houts, Nezu, Nezu, & Bucher, 1996; Weitzner, McMillan & Jacobsen, 1999). In their longitudinal study of breast cancer patients and their principal caregivers (Grunfeld et al., 2004), over half the caregivers were male (55%) and the patients' spouse or partner (52%). Spouses, in particular, occupied a central position during the cancer experience. They have been frequently identified as the key person who gave emotional support and provided physical assistance to the woman with breast cancer (Northouse, 1988). Furthermore, spouses often took on additional roles when their wives were ill in order to maintain the day-to-day functioning of family life. Spouses were important not only because of the tangible support that they provide for their wives, but also because their adjustment to the illness affected the adjustment of their wives (Northouse, Dorris & Charron-Moore, 1995).

The family was a major factor in the individual's health process and played a prime role in the course and management of an illness (Wright & Leahey, 2000; Weihs, Fisher & Baird, 2002 in Duhamel & Dupuis, 2003). Patients and their caregivers were now commonly based in their homes with complicated medical therapies to be administered. These changes placed great demands on caregivers' and patients' 'informal' support structure. The caregiver role could dramatically impact on a family member and a family (Deeken et al., 2003).

Coristine, Crooks, Grunfeld, Stonebridge and Christie (2003), in their focus groups on caregiving for women with advanced breast cancer, found that most married patients' husbands assumed the role of principal caregiver. Spouse caregivers viewed care giving as part of their marriage partnership. Working spouse caregivers had to juggle employment, family responsibilities (such as child care) and caregiving. Non -spousal caregivers took on the role of principal caregiver as an extension of an existing role as daughter, sister, niece and friend.

Weitzner et al. (1999), in a quantitative study on family caregiver quality of life, showed that the adult child, most often the daughter, usually was the caregiver if the spouse was not. The caregiving experience was very different depending on the caregiver's relationship to the patient. The adult child may have had to care for children and job responsibilities in addition to caring for an ill parent.

The role of family caregivers has shifted from one of custodial care to a complex, multifaceted role that included symptom management, monitoring for changes in hallmark symptoms, equipment care, patient transport and advocacy, and management of activities/responsibilities the patient has foregone because of illness. Due to advances in treatment, the cancer care trajectory has increased from days and weeks to months and years (Given et al., 2001).

2.2.3 Emotional experiences of primary caregivers

As cancer progressed, care tasks were generated, which could be perceived by the caregiver as either negative (i.e. burdensome) or positive. These caregiving experiences may have led to negative as well as positive effects on the caregiver's health (Nijboer et al., 1998).   It was well recognized that caregiving could adversely affect the psychological adjustment of the family caregiver as well as increase caregiver burden (Weitzner et al., 1999). 'Caregiver burden' was generally used to refer to the physical, psychological, social and /or financial reactions that could be experienced in giving care (Hinds, 1985).

There is an abundance of literature demonstrating the emotional, physical and financial distress experienced by primary home caregivers, as well as their frequent social isolation (Ferrario, Cardillo, Vicario, Balzarini & Zotti, 2004). Grunfeld et al. (2004) who conducted a longitudinal study found that caregivers experienced substantial psychological morbidity (anxiety and depression) at the onset of the patient's palliative illness and a substantial increase in caregiver burden and depression when the patient reached a terminal stage of the illness. Their finding that caregiver's psychological morbidity was equal to or greater than the patient's was consistent with other research in the field (Weitzner et al., 1999; Chappell & Penning, 1996).

Their findings also indicated that although patient's physical and emotional factors predict caregiver distress, perceived burden was the strongest predictor of caregiver anxiety and depression. Family caregivers reported distress from uncertainty about the course of the disease as well as feelings about their inability to provide care and also to manage the patient's symptoms such as depression and anxiety (Hinds, 1985).

Another study also found that carer's level of anxiety particularly in palliative care, were extremely high (Higginson, Wade & McCarthy, 1990). Coristine et al. (2003), reported that in their study caregivers found the anxiety of the patient a more difficult challenge to meet than some of the physical care requirements, and it heightened their own anxiety. Given et al. (2004) who conducted a prospective longitudinal study found that caregivers aged 45 to 54 reported the highest levels of depressive symptoms, and caregivers aged 35 to 44 reported the strongest sense of abandonment. Caregivers who were the adult children of patients with cancer and those who were employed reported high levels of depressive symptoms. Feeling abandoned was more prevalent in female, non spouse, and adult children caregivers.

Higginson et al. (1990) in their study of the views of patients and their families regarding palliative care, concluded that the needs of the carer may exceed those of the patient. The results of the study conducted by Baider, Kaufman, Peretz, Manor, Ever-Hadani and Kaplan De-Nour (1996) supported earlier work showing that spouses were as distressed as patients. The study provided additional evidence for cancer as a problem not of the individual but of the couple. In light of the significant emotional impact that cancer could have on spouses, some investigators have questioned who the real patient was during the cancer experience - the woman or her partner (Baider & Kaplan De-Nour, 1988 in Baider et al., 1996).

The findings of a study by Northouse, Mood, Kershaw, Schafenacker, Mellon, Walker, Galvin and Decker (2002) indicated that recurrent breast cancer seemed to take a sizeable emotional toll on family members. Family members were expected to be the primary providers of physical and emotional support to the patient, yet they perceived little support from others, either professional or personal, in carrying out this essential role. Often, the family caregiver was the one most responsible for managing the side effects of treatment and symptoms of disease at home as the patient's condition deteriorated. The distress that they experienced not only may have affected their ability to care for the patient, but also may have impacted their ability to provide emotional support, to support activities of daily living, and to assist with other physical aspects of care (Laizner, Yost, Barg & McCorckle, 1993 in Weitzner et al., 1999). In a quantitative study done by Cameron et al. (2002) on lifestyle interference and emotional distress in family caregivers of advanced cancer, patients found that caregivers experienced increased emotional distress, regardless of the amount of care provided, when limited in their ability to participate in valued activities and interests.

According to Coristine et al. (2003) caregiving for a loved one with advanced breast cancer was emotionally difficult. Personal variables such as anxiety and depression affected the caregiver's perception and reactions to caring. Husbands' and wives' coping styles, for example, facilitated coping for some couples, but for other couples caused emotional distress and an increased sense of burden. A study by Northouse (1996) indicated that husbands of women with recurrent breast cancer appeared to be especially vulnerable to the impact of the illness because of more role adjustment problems, higher levels of uncertainty and more hopelessness they experienced.

Kurtz, Given, Kurtz and Given (1994) found that as the illness progressed, caregivers experienced more depression, a greater adverse impact on their own health and daily lives and spent more time helping patients cope with daily living activities. Studies of family members caring for persons with advanced cancer have shown that most experienced stress in the caregiving role and significant stress in observing the patient suffering. Additional stress could be experienced by having to ‘stand by’ and observe the disease progress while being unable to alter or manage the illness (Stetz, 1987).

Pain was experienced by many cancer patients, either acutely or chronically. Knowing that a loved one was in pain, and trying to help were very difficult experiences for family members (Gotay, 1996). The findings in a qualitative study done by Lindholm, Rehnsfeldt, Arman and Hamrin (2002) showed that the significant others experienced deep often unrelieved suffering and considered themselves prisoners of a situation of uncertainty and powerlessness when standing by the woman. The significant others considered the suffering of the woman as the primary thing and their own suffering ‘at second place’.

Cameron et al. (2004) mentioned that caregivers experienced multiple challenges, including declining health of the patient and psychological distress over social and cultural issues surrounding death and dying. Caregivers to individuals with advanced cancer were often required to provide increasing amounts of care as the patient’s health deteriorated, and had to also prepare for their imminent death.

2.2.4 Positive aspects of caregiving

Grunfeld et al. (2004) reported the positive aspects of caregiving and stated that the caregiver’s commitment to the patient had primacy over his or her own occupational and health concerns. Firstly, recognition of positive experiences, in terms of love, affection, rewards, challenge, meaning, commitment, purpose in life or joyful events (Horowitz, 1985; Oberst, Thomas, Gass & Ward, 1989; Carey et al., 1991; Folkman, Chesney & Christopher-Richards, 1995 in Nijboer et al., 1998), may have increased the caregivers feelings of pride in their ability to meet challenges and improve their sense of self-worth (Motenko, 1989 in Nijboer, 1998).

Secondly, caregiving may have also defined identity and involvement to one's society and thereby maintain wellbeing. Kinney and Stephens (1989) argued that caregivers, who were most intensely involved in caregiving, may have had greater opportunity to derive satisfaction from caregiving (Nijboer et al, 1998). Folkman et al. (1995) reported that caregiving may have improved the quality of relationships between caregivers and care recipients, and this may have contributed to self esteem. However, research concerning positive aspects of cancer caregiving was in its infancy (Nijboer et al, 1998).

According to the literature, the role of caregiver was not always a completely negative experience. Acting as a caregiver could be very gratifying for family members (Barg, Pasacreta, Nuamah et al, 1998; Brown & Stetz, 1999 & Nolan, 2001 in Duhamel & Dupuis, 2003), and taking on the role could boost family members' morale and improve their well-being. Shifren and Hooker (1997 in Theis, Biordi, Coeling, Nalepka & Miller, 2003), found that caregivers who had high levels of optimism had low levels of negative affect, indicating that they may have been able to put negative feelings aside to focus on dealing with stressful situations.

A study of caregivers by Brown and Stetz (1999) indicated that the role could be associated with a number of positive emotions. Examples included the opportunity to express love to the patient and pride in having shown strength in the terminally ill person's presence. Coristine et al. (2003) in their study mentioned that caregivers admired the strength and courage of patients who were facing illness and death and had done their utmost to support the patient. In a qualitative study by Hudson (2004), it was asserted that sixty per cent of the caregivers acknowledged positive or beneficial aspects associated with their situation. These data disputed conceptions that caregiving in this context had only inherent negative consequences.

It was recognized for some time that carers who could find positive aspects to their role were likely to experience better morale and well-being (Gilhooly, 1984; Motenko, 1989 in Nolan, 2001) with Given and Given (1991 in Nolan, 2001) arguing that the presence of caregiving satisfactions provided a significant predictor of less stressful situations.

However, despite the extensive existing research in the field of family care and the recent emergence of more holistic approaches that have improved understanding of the reciprocities and satisfaction of carers, gaps in our knowledge remain, with very few studies having explicitly explored the perceptions of both carer and cared-for persons. Moreover, there was clearly a need to better understand the sources of satisfaction in differing chronic illnesses and in palliative care context if a genuinely holistic view of the dynamics of care was to emerge (Nolan, 2001).

Consistent with caring research in general, most studies into the satisfactions of care adopted a largely quantitative approach (Kramer, 1997) and there was a need to complement such studies with qualitative approaches that spoke to the caring process or subjective experiences of caregivers'(Brody, 1995 in Nolan, 2001). An important addition to the satisfaction literature would be the more widespread use of an existential dimension that addresses a broader life perspective concerning values, choices, responsibility, and consequences, in order to appreciate how to transform the caring experience into something meaningful and valued (Farran, 1997).

In a qualitative study by Milberg and Strang (2004) it was found that although the situation was stressful and burdening for the informal carer, the ability to achieve positive states of mind that facilitated comprehensibility and manageability was not totally hampered. Comprehensibility and manageability was facilitated by open information, previous knowledge, power, support, competence and accessibility.

2.2.5 Impact on primary caregiver's physical health

Since family members were often unprepared to provide care in the home, they commonly experienced stress and burden, which could negatively impact on their own health and well-being and could also compromise the quality of care provided Cameron et al. (2004). Weitzner et al. (1999) in their study comparing the impact of care giving in curative and palliative settings on family caregiver quality of life found that family caregivers of patients receiving palliative care had significantly lower quality of life scores and lower scores on physical health.

Family members of chronically ill patients experienced a variety of problems that arose from the various demands of their caregiving role. This role placed immense emotional, social, physical and financial stress on the family caregiver. Caregiver burden and caregiver strain have been the terms most often used to describe the persistent hardships or the physical, psychological, social, financial and emotional responses that could be experienced by family members providing continuing and supportive cancer care (Given & Given, 1996 in Chen & Hu, 2002).

Strain arising from prolonged caregiving was found to have negative consequences for the well being of both the caregiver and the patient. Sisk (2000) found that caregivers experiencing higher subjective burden paid less attention to their own health, compared to those with lower subjective burden scores. A study conducted by Northouse et al. (2002), indicated that there was little assessment, if any, of the extent to which caregivers' own health problems or their accumulating care giving burdens may have interfered with their caregiving abilities.

Carers' distress increased as patients experienced more physical symptoms like pain and as their functional status deteriorated (Northouse, Laten & Reddy, 1995; Kurtz, Kurtz, Given & Given, 1995; Miaskowski, Kragness, Dibble & Wallhagen 1997 in Pitceathly & Maguire, 2003). In a qualitative study by Hudson (2004) it was mentioned that one of the challenges associated with caring for a dying relative/friend was that some of the caregivers' own ill health made caregiving difficult. Some of the other challenges reported were that caregivers found it difficult to observe the patient's deterioration. Over one-third of caregivers in the same study expressed that they had very little time for themselves and that this made their role difficult. Caregivers could experience deterioration in their physical and psychological health due to their new role (McMillan & Mahon, 1994; Oberst et al., 1989 in Deeken et al., 2003).

2.2.6 Role of social support and communication

Studies have reported that caregivers had significant unmet needs related to their caregiving role despite the significant, yet often invisible, contribution that caregivers made to society and the economy. Although the negative impact of caregiving for a relative/friend with a life threatening illness was well documented, research demonstrated that caregivers providing support to individuals receiving palliative care reported unmet needs for information, communication, service provision and support from health and community services (Aoun, Kristjanson, Currow & Hudson, 2005).

Significant demands were being placed on the informal caregivers of chronically ill patients, including those suffering from cancer. Health care professionals needed to be aware of these demands and assess the impact these demands placed on the caregiver (Deeken et al, 2003). If family members were informed and supported while delivering care, they, in turn, would be less anxious, better able to integrate care into their lives, and would see the experiences of caring in a more positive light (Given et al., 2001).

Payne et al. (1999) in their combined qualitative and quantitative study reported that carers often felt reluctant to share their concerns with friends as they did not wish to be seen as complaining about the patient. Thus, they appeared to be relatively isolated in terms of emotional support. Health professionals needed to recognize that primary family caregivers often were gatekeepers themselves and may have been reluctant to seek assistance even when they felt inadequately prepared to provide care and reported both informational and skills deficits (Given et al., 2001).

Ramirez et al. (1998) indicated that caregivers were often reluctant to disclose their needs to health professionals. Reasons for non-disclosure included not wanting to put their needs for care before those of the patient, not wanting to be judged inadequate as a caregiver, and believing that concerns and distress were inevitable and could not be improved.

Payne et al. (1999) identified that there was a need to develop effective ways to offer emotional physical support for relatives, not only to sustain them in their role as informal carer but also to maintain their mental and physical health. Investigations showed that carers were more distressed when their needs for medical information were not met (Pitceathly & Maguire, 2003).

Coristine et al. (2003) in their study mentioned that caregivers to women with advanced breast cancer were faced with day-to-day demands of understanding symptoms experienced by patients and deciding when an intervention was needed. Accompanying patients to medical appointments was seen as an important way to support the patient and to stay informed. Caregivers sought out information and regretted the things they did not know. It was suggested that increasing patient and caregiver knowledge could reduce distress.

Cancer included multiple physical needs, intense psychological distress manifested by pain, anxiety and depression and restrictions in social and sexual functioning. Alterations in a patient's functional ability, bodily functions, appearance, employment status, sexual functioning, family and social role had a direct impact on the caregiver. Informal caregivers may have faced existential concerns that forced them to reevaluate their future, which may have led to changes in life goals (Nijboer et al., 1998). According to Duhamel and Dupuis (2003), as death drew closer, individuals and families readjusted their value system and turned to their spiritual beliefs, including religion. Rolland (1994 in Duhamel & Dupuis, 2003), mentioned that when transfer to palliative care became unavoidable, families gave new meaning to the disease and its consequences in light of their religious and spiritual beliefs and thus helped alleviate their suffering.

Interacting with terminally-ill patients was significantly stressful for caregiving families. Numerous investigators documented interactive difficulties and repeatedly noted that family caregivers and their patients seldom discussed the inevitability of death and the conclusion of their relationships. In fact, most caregivers never discussed the illness, prognosis, and life ending plans with the patient (Beach, 1995).

A study conducted by Payne et al. (1999), found family communication to be difficult for many of the carers although some found that the situation had brought them closer to the patient or other family members. It was further found that the support received was variable and could be divided into family, friends and health professionals. Participants in this study appeared to value self-reliance and independence and were hesitant about placing additional demands on family and friends who were often perceived to be busy with their own lives.

Support from health care professionals, family and friends could help family caregivers expand their capacities to respond to care demands. The goals of support should have been to enable family caregivers to maintain the patient's comfort and enhance the patient's quality of life, and to prevent or minimize unnecessary caregiver distress (Given et al., 2001). According to Hudson (2004) health professional support for the families of patients requiring palliative care was a core tenet of international palliative care philosophy.

2.2.7 Interventions /programs for family caregivers

The World Health Organization defined addressing the needs of family and family caregivers as one of the primary objectives of palliative care (World Health Organization, 1990 in Deeken et al., 2003). A sophisticated model for conceptualizing the experience of family caregiving within the domain of palliative care was not yet developed (Hudson, Aranda & Kristjanson, 2004).

Informal caregivers primarily needed to be recognized as equivalent members of the health care team (Nijboer et al., 1998). The health care system could facilitate positive outcomes by embracing the family caregiver as a partner in the health care team, providing instruction and guidance to the caregiver as he/she assumed this role, and evaluating the home care situation. Research has only scratched the surface of testing interventions that met the needs of the cancer caregiver (Given et al., 2001).

The findings of a recent study by Northouse et al.(2002) indicated that caregivers in particular may have benefitted from intervention programs because they were automatically assumed to be capable of providing complex care with little preparation and support.

Grunfeld et al. (2004) suggested that strategies to support caregivers would reduce caregiver burden, potentially prevent psychosocial distress and allow caregivers to focus on their most immediate concern, caring for the dying patient. After all care giving was an identified risk factor for mortality (Schulz & Beach, 1999). Actively taking proactive measures to support caregiver’s through the terminal stage of the patient’s illness and through the transition period following the death of the patient may have ultimately resulted in cost savings to the health –care system (Coristine et al., 2003).

In another study by Northouse et al. (2005), on the effects of family intervention on the quality of life of women with recurrent breast cancer and their family caregivers, it was reported that caregivers also reported less negative appraisal of caregiving.
Given the stressful effect that cancer had on the lives of patients with advanced breast cancer and their family caregivers, more family based intervention programs were

needed to assist patients as well as their family caregivers to manage the effects of the illness.

Maintaining the health and well-being of the caregivers also had to be considered in the health care design. Family caregivers had to be considered as an integral part of the advanced cancer care (Given et al., 2001). Interventions designed to produce psychological benefits had to target carers at high risk of high levels of distress or affective disorders and had to be tailored to their specific needs (Pitceathly & Maguire, 2003).

Given et al. (2001) mentioned that psychotherapeutic interventions for family caregivers were designed to enhance morale, self-esteem, coping, sense of control, and problem solving abilities, and to decrease caregiver emotional distress while caring for patients at home. These interventions were designed to focus on helping caregivers psychologically adjust to the demands of caring. Family caregivers had to be assessed periodically for psychological/emotional distress, and the specific sources of this distress had to be identified.

According to Herr (1997) problem- solving and stress management were important components of psychological support for caregivers and health professionals needed to recognize when family caregivers could benefit from such interventions. According to Cameron et al. (2002) the development and evaluation of interventions and programs aimed at assisting caregivers maintain participation in valued activities could have a positive impact on their emotional well-being.

Given et al. (2004) in their prospective longitudinal study indicated that practitioners needed to treat the patient and caregiver as a patient-caregiver dyad, be aware that the caregiver was at risk from negative outcomes from caregiver and patient characteristics, and be aware that concern for well-being needed to be given not only to the patient but also to the caregiver providing care at the end of life.

Northouse et al. (2005) in their study provided an initial test of a family- based intervention for patients with advanced breast cancer and their family caregivers. Patients who received the family intervention reported significantly less hopelessness and less negative appraisal of illness at three months follow-up than controls. Their family caregivers also reported less negative appraisal of caregiving. Given the stressful effect that cancer had on the lives of patients with advanced breast cancer and their family caregivers, more family-based intervention programs were needed to assist patients as well as their family caregivers to manage the effects of illness.

Nikoletti, Kristjanson, Tataryn, Mc Phee and Burt (2003) in their study found that needs that were ranked among the lowest in importance were related to caregivers' own needs for practical help and their own health. Health care professionals therefore had to be alert to the possibility that caregivers might have overlooked their own needs in their concern for their loved ones and could benefit from supportive interventions that explicitly addressed these needs.

The findings in the study by Cameron et al. (2004) suggested that even a brief problem-solving intervention could be beneficial for family caregivers to individuals with advanced cancer. Despite a large amount of research that identified consistent unmet caregiver needs, there was a dearth of intervention studies to improve this important area of palliative care practice (Hudson, 2004).

It is only through increasing our understanding of caregiver coping that programs could be tailored to be more supportive to caregivers who provided care to their dying loved ones (Strang & Koop, 2003). Clinicians had to recognize the emotional intensity of home-based palliative caregiving and be sensitive to the tremendous responsibility carried by family caregivers. They had to work with family caregivers, the dying persons, and with each other as true and equal partners in the caregiving process.

Few studies have specifically explored the key challenges of assisting with the care of a dying relative. Exploring these challenges was important so that family caregivers could be appropriately advised about the common issues associated with the role and to enhance intervention development (Hudson, 2004).

Until researchers and health care professionals developed and validated a model for family caregiving that was directly applicable to understanding the family caregiver experience, there would continue to be difficulties for practitioners in applying a suitable framework for guiding their care decisions (Hudson, Aranda & Kristjanson, 2004).

2.3 Concluding comments

This study attempts to build on and contribute to previous research through exploring the experiences of primary caregivers providing palliative care to women with advanced breast cancer. The research culminates in the development of recommendations aimed at assisting health care professionals become increasingly aware of the role played by primary caregivers and to continue to provide interventions that would support them.

The following chapter describes the methodological approach and framework of the current study and delineates the methodology used to explore the experiences of the participants.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The study is conducted within a qualitative research design framework. The chapter sets out the phenomenological research methodological framework that informs the study. This is followed by a description of the participants followed by the procedural aspects of the study. The method of data collection and analysis will follow thereafter. Finally, an overview of the researcher's self reflexivity as well as ethical issues will be presented.

3.2 Research design: A qualitative approach

Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape enquiry. Such researchers emphasize the value- laden nature of inquiry (Denzin & Lincoln, 2003). Qualitative researchers seek answers to questions that stress how social experience is created and given meaning. In contrast, quantitative studies emphasize the measurement and analysis of causal relationships between variables, not processes (Denzin & Lincoln, 2005). Proponents of such studies claim that their work is done from within a value-free framework (Denzin & Lincoln, 2003).

Critics of qualitative inquiry have charged that the approach is too subjective, in large part because the researcher is the instrument of both data collection and data interpretation and because a qualitative strategy includes having personal contact with and getting close to the people and situation under study (Patton, 2002). According to

Payne (2004) some research method textbooks present qualitative research as fundamentally different from quantitative research; others suggest that methodologies can be regarded as on a continuum. Qualitative and quantitative methods are tools, and their utility depends on their power to bear upon the research questions asked. As tools they require different competencies in carrying out quantitative computations or conducting linguistic or empathic analysis of qualitative data (Kvale, 1996). Qualitative inquiry is particularly oriented towards exploration, discovery, and inductive logic. Inductive analysis contrasts with the hypothetical-deductive approach of experimental designs that require the specification of main variables and the statement of specific research hypotheses before data collection begins (Patton, 2002).

Both qualitative and quantitative researchers are concerned with the individual's point of view. However, qualitative investigators think they can get closer to the actor's perspective through detailed interviewing and observation. They argue that quantitative researchers are seldom able to capture their subjects' perspectives because they have to rely on more remote, inferential empirical methods and materials. The empirical materials produced by interpretive methods are regarded by many quantitative researchers as unreliable, impressionistic, and not objective (Denzin & Lincoln, 2003). Qualitative researchers believe that rich descriptions of the social world are valuable, whereas quantitative researchers are less concerned with such detail.

Qualitative research is essentially a creative, subjective interpretation of subjective experience, which does not generate demonstrable facts and which relies heavily on the integrity of the researcher (Rose, Webb & Waters, 1997). Qualitative research is concerned with the meanings people attach to their experiences of the social world and how people make sense of that world. It therefore tries to interpret social phenomena in terms of the meanings people bring to them; because of this it is often referred to as interpretative research. Rather than simply accepting the concepts and explanations used in everyday life, qualitative researchers ask fundamental and searching questions about the nature of social phenomena. A distinguishing feature of qualitative research is that it studies people in their natural settings rather than in artificial or experimental ones (Pope & Mays, 2000).

Qualitative research certainly seems to hold out a number of possibilities in the area of palliative care (Clark, 2001). Qualitative research is undoubtedly the best research method for researching many aspects of palliative care. This methodology allows questions about the extent of the problem and the degree of an emotion or feeling to be answered. It is a sensitive method of research when sensitive topics are to be studied (Wilkie, 2001).

Qualitative research was considered to be the most appropriate method to access the subjective perspectives of the participants and therefore making it an ideal method for research into subjective meaning (Camic, Rhodes & Yardley, 2003). The unique strength of qualitative inquiry for research is that it is exploratory, assumed the value of context and setting and that it searched for the deeper understanding of the participants’ lived experiences of the phenomenon (Marshall & Rossman, 1995).

Qualitative research method using a phenomenological approach was employed in this study to better understand the phenomenon of caregiving by primary caregivers to women with advanced breast cancer. The qualitative method of inquiry allowed for the lived experiences of primary caregivers providing palliative care to women with advanced breast cancer to be captured. Therefore, interviews, which capture, in the participants' own words, their experiences, was the method of choice (Taylor, 2005). With the focus of the interview on the experienced meanings of the participants' life world, phenomenology appeared relevant for clarifying the mode of understanding in a qualitative research interview.

3.3 Phenomenological research method

The study is conducted within a phenomenological research methodological framework. A phenomenological methodology enabled the researcher to capture the rich descriptions of the caregivers' experiences in providing palliative care to women with advanced breast cancer.

Phenomenological psychological research aims to clarify situations lived through by persons in everyday life. Rather than attempting to reduce a phenomenon to a convenient number of identifiable variables and control the context in which the phenomenon will be studied, phenomenology aims to remain as faithful as possible to the phenomenon and to the context in which it appears in the world. This means that to study a particular phenomenon, a situation in which individuals have first-hand experiences that they can describe as they actually took place in their life. The aim is to capture as closely as possible the way in which the experience takes place, in this case of caregiving. Phenomenologists seek the psychological meanings that constitute the phenomenon through investigating and analyzing lived examples of the phenomenon within the context of the participants' lives (Giorgi & Giorgi, 2003).

According to Giorgi (1997) phenomenologists study people's experience of everyday life within a definite philosophical context that generates specific assumptions about human nature and human living. The human science approach recognizes that our privileged access to meanings is not by way of numbers but rather through perception, cognition and language. It indicates that the way for psychology to comprehend human behavior and experience as it is actually lived in everyday social settings is to begin by soliciting descriptive accounts of our actual experiences in such settings (von Eckartsberg, 1998).

The researcher searches for the essential, invariant structure (or essence) or the central underlying meaning of the experience. The researcher also sets aside all prejudgments, bracketing her experiences and relying on intuition, imagination, and universal structures to obtain a picture of the experience (Cresswell, 1998). The empirical phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience (Moustakas, 1994). The human scientist determines the underlying structures of an experience by interpreting the originally given descriptions of the situation in which the experience occurs.

The aim is to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it. From the individual descriptions general or universal meanings are derived, in other words the essences or structures of the experience (Moustakas, 1994). The ultimate aim of phenomenological research is to use these descriptions as a groundstone from which to discover underlying commonalities that mark the essential core of the phenomenon (Seamon, 2000).

The value of empathy is emphasized in the phenomenological doctrine of *Verstehen* that undergirds much qualitative inquiry. *Verstehen* means “understanding” and refers to the unique human capacity to make sense of the world (Patton, 2002). Moustakas (1994) described this non-judgmental empathic stance as “Being-In” another’s world by listening deeply and attentively so as to enter into the other person’s experience and perception (Patton, 2002).

The goal of phenomenological research is to illuminate the phenomenon’s essential, structural qualities. In other words, phenomenologists want to understand the common aspects of a phenomenon that permeate and also transcend diverse individual experiences. Phenomenologists assume that experience is a valid source of knowledge and that people’s everyday experiences contain rich insights into phenomena (Becker, 1992). Through a phenomenological method, the essence of caregiving as a lived experience in families could be unfolded.

3.4 Participants and research setting

3.4.1 Selection of participants

A technique known within qualitative research as ’purposive sampling’ was used (Field, Clark, Corner & Davis 2001). In descriptive phenomenological research the researcher wishes to sample expressions of life-world experiences relevant to the phenomenon of interest. ‘Sampling’ within this framework is not about size but about quality. The aim is to understand a phenomenon more deeply through adequate exposure to the qualities of the phenomena that are given by the living of the phenomenon. A purposive sampling strategy is designed to gather a depth and richness of the experience (Todres, 2005). Participants were the primary caregivers of women with advanced breast cancer attending the Radiation Oncology Department at Groote Schuur Hospital. Participants were the primary caregivers, 18 years and older, as recognized by the women with advanced breast cancer and have been providing palliative care for a minimum of two months. Eight primary caregivers providing palliative care to women with advanced breast cancer and living in the vicinity of Cape Town were selected with the assistance of the social worker at the Radiation Oncology Department at Groote Schuur Hospital.

Interviews were scheduled at a time and place that was convenient to both, the participant and the researcher. Six of the interviews were held in a private office at the hospital and two interviews were held in the homes of the participants in a private setting. The average length of the interview was approximately sixty minutes and the interviews were audio-taped and transcribed verbatim.

3.4.2 Description of participants

Table 3.1 gives an overview of the demographic profile of the participants. The participants in the study were residents of Cape Town. There were eight, English speaking participants, four of which were male and four were female. The ages of the participants ranged from 43 -68. Three of the participants were spouses of the patients, one was the sister, one was the daughter, one was the daughter-in-law, one participant regarded the patient as a ‘mother figure’ and one was a friend. Three of the non-spousal participants were married, one participant was separated from her husband and one participant was divorced.

Seven of the participants had children and the other participant had step-children. Three of the eight participants had dependants. Three of the participants had tertiary education, four had grade 8-11 level of education and one had a grade 1-7 level of education. Two participants were employed on a part-time basis, two were retired, one was a pensioner and three were unemployed.

Five of the participants were Christian and three were Muslim. All the participants except for one lived in the same household as the woman with advanced breast cancer. Seven of the participants had previous caregiving experience and cared for family members as well as other patients with cancer, tuberculosis, diabetes and psychiatric illnesses. Of these, two participants had experience of caring for family members who had cancer. One of the participants did not have any previous caregiving experience.

Participant	Age	Sex	Marital Status	Religion	Highest Educational Qualification	Previous care-giving experience	Monthly Income	Children	Other dependents	Living arrangements	Relationship to patient	Health condition of participant
1	60	M	Married	Muslim	Grade 8-11 National Certificate N2	Father had lung cancer & cared for him for 3 yrs	Retired	4		. In same household	Husband	Arthritis in his shoulder
2	56	F	Married	Muslim	Qualified as professional nurse	Cared for mother and sister-in-law, both of whom had cancer	R3500+	3	3	In same household	Patient is a ‘Mother figure’ to participant	Back injury and wears a brace
3	43	F	Married	Christian	Grade 9	Caring for husband for past 6 yrs	Unemployed	3	Grand-children	In same household	Sister	Hyper-tension
4	47	F	Married	Christian	Grade 8-11	Assisted with care of her father who was ill	Unemployed	3	Husband	Both, same and separate households periodically	Daughter-in-law	No health problems
5	68	M	Married	Muslim	Grade 1-7	Cared for late wife who had diabetes	R501-R1500			In same household	Husband	Diabetes, Heart problem
6	58	M	Married	Christian	Grade 8-11		Unemployed	3		In same household	Husband	Diabetes, Hyper-tension, Arthritis
7	59	F	Separated	Christian	Grade 8-11	Cared for father who had TB	R501-R1500	7		In same household	Daughter	Hyper-tension, Suffered a stroke
8	66	M	Divorced	Christian	Qualified as professional nurse	Professional nurse for 44 yrs	R3500+	4		In same household	Friend	Aneurysm

Table 3.1: Demographic variables

3.4.3 Procedure

Women with advanced breast cancer and their primary caregivers attending Groote Schuur Hospital were approached by a health care professional to enquire whether the women with advanced breast cancer was agreeable to their primary caregiver participating in the research study. Verbal consent was obtained from the women with advanced breast cancer and an information sheet, providing the relevant information about the study, was given to them (see Appendix A). Where women with advanced breast cancer were agreeable, their primary caregivers were approached to enquire whether they would be keen to participate in the research study.

The researcher made telephonic contact with the women with advanced breast cancer to inform them of the study and to enquire whether they were still interested in their primary caregiver participating in the study. The researcher explained, telephonically, the purpose and nature of the research to the willing primary caregivers. Interviews were arranged with willing participants and held at a time and place that was convenient to both the participant and the researcher. Six interviews were held at Groote Schuur Hospital and two interviews were held at the participants' homes.

Participants who were recognized by the women with advanced breast cancer as their primary caregivers were included in this study. Another inclusion criterion was that participants were 18 years and older and have been providing palliative care to the woman with advanced breast cancer for a minimum of two months. In view of the researcher's fluency in English, participants that were fluent in English were selected for the study.

Participants were informed that participation in the study was voluntary and that they were free to decline from participation or withdraw from the study at any time, without redress (see Appendix B). Signed informed consent was obtained from the participants and their confidentiality and anonymity was assured. Each participant completed a biographical questionnaire (see Appendix C) after signing the consent form.

Permission was obtained from the participants for the use of an audio-tape recorder, to ensure accuracy of the data captured. All the interviews were recorded and transcribed verbatim. Participants were assured that the tapes and transcripts would be erased after the completion of the study. In-depth interviews were conducted and the average length of the interviews was approximately sixty minutes. At the end of the interview, the researcher expressed her appreciation to the participants for their time and contribution.

Researchers have mentioned that conducting research in the field of palliative care is very challenging. Due to the severity of the illness, some of the prospective participants could not be relieved from their caregiving role to participate in the research.

Conducting this research study involved negotiating with different staff members, including the medical superintendent of Groote Schuur Hospital, the head of the ethics committee of the Health Sciences Faculty, University of Cape Town, doctors managing the radiation oncology department and the health care professional who assisted with the recruitment of participants. The researcher obtained permission and approval to conduct this research study from the ethics committee, the medical superintendent as well as the head of the Radiation Oncology Department and the consultant of the Breast Clinic at Groote Schuur Hospital. Having worked previously as a social worker at the Radiation Oncology Department at Groote Schuur Hospital, the researcher received good co-operation from the hospital personnel in gaining access to the setting.

3.4.4 Data collection

The researcher herself was the major instrument for collecting data (Patton, 2002). Participants signed the informed consent form at the beginning of the interview (see Appendix B). A biographical questionnaire to capture the details of the participants was administered after the signing of the consent form (see Appendix C). Qualitative interviews were used as the primary tool for data collection. The qualitative interview is a uniquely sensitive and powerful method for capturing the experiences and lived meanings of the participants' everyday world (Kvale, 1996). In-depth interviews were conducted with the participants. To gather data, one must undertake in-depth interviews with participants who have directly experienced the phenomenon of interest (Patton, 2002). The in-depth interviews were guided by a series of questions (see Appendix D). The opening question was open and unstructured allowing the participants to present their experience not only in their own words but also in their own style (Taylor, 2005).

The interview guide provided subject areas within which the researcher was free to explore, probe and ask questions that would elucidate and illuminate the particular subjects (Patton, 2002). The interview guide explored areas such as experiences through a day of caring for the patient, positive and negative experiences of providing care, the importance and meaning of the caregiving role, motivation to provide care, impact of caregiving on the participants' physical and mental health, taking care of own needs, ways of dealing with own emotional issues and social support. The interview ended after giving the participants the opportunity to add anything that they felt was important to mention that they may have forgotten or the researcher may have omitted to ask.

The researcher made notes during and after the interviews to capture data such as non-verbal cues, body language, tone of voice and facial expressions to gain a richer understanding of the data. Combined with observation, interviews allow the researcher to understand the meanings people hold for their everyday activities (Marshall & Rossman, 1995). The researcher liaised with health care staff on a regular basis to enquire about prospective participants as well as after the interviews to enquire about any feedback from the participants.

Given that the researcher is an intern clinical psychologist and has several years of experience in the field of social work, particularly in the area of cancer and palliative care, she was able to establish rapport quite easily with the participants. The researcher's experience also enabled her to have the insight into the challenges that caregivers experienced and felt empathic towards them.

3.4.5 Data analysis

The phenomenological approach to analysis taken by Moustakas (1994) was used. Moustakas' method of analysis has been chosen for this study because of its theoretical soundness and practical feasibility. There are four primary steps in the analysis as suggested by Moustakas. The first step in phenomenological analysis is called epoche. In taking on the perspective of epoche, the researcher looks inside to become aware of personal bias, to eliminate personal involvement with the subject material, that is, eliminate, or at least gain clarity about, preconceptions.

The second step is phenomenological reduction. The researcher "brackets out" the world and presuppositions to identify the data in pure form, uncontaminated by extraneous intrusions (Moustakas, 1994). Once the data are bracketed, all aspects of the data are treated with equal value, that is, the data are "horizonalized." The data are then organized into meaningful clusters. The researcher then identifies the invariant themes within the data in order to perform an "imaginative variation" on each theme.

The researcher moves to the textural portrayal of each theme. Phenomenological analysis then involves a "structural description" of how it was experienced. The final step requires "an integration of the composite textual and composite structural

descriptions, providing a synthesis of the meanings and essences of the experience" (Moustakas, 1994). The recorded interviews of the participants were transcribed verbatim and the data analyzed following these steps. The researcher immersed herself in the data and became very familiar with the interviews.
Epoche is seen as a preparation for deriving new knowledge but also as an experience in itself, a process of setting aside predilections, prejudices, predispositions and allowing things, events and people to enter anew into consciousness, and to look and see them again, as if for the first time. This requires that we allow a phenomenon or experience to be just what it is and to come to know it as it presents itself (Moustakas, 1994).

The process of epoche was difficult for the researcher given my previous work in counselling women with advanced breast cancer and their caregivers. The researcher consciously as far as possible set aside preconceived notions of the subject, everyday understandings and judgments of the phenomenon of caregiving and attempted to "see with new eyes in a naïve and completely open manner" as described by Moustakas (1994).

The second step of this method of research is the "bracketing" where the researcher "brackets" out any information he or she has about the research topic. In phenomenological reduction we return to the self; we experience things that exist in the world from the vantage point of self-awareness, self-reflection, and self-knowledge (Moustakas, 1994). This reduction prepares us for critical examination of what is given before our interpreting beliefs enter in. With the reduction, we are led back to the origins of phenomena (Morse, 1994). The researcher was self reflective and engaged as far as possible in a disciplined way and bracketed assumptions about the phenomenon of the experiences of family caregivers providing palliative care to women with advanced breast cancer. As far as possible the researcher was open and receptive to the participants' description of the phenomenon of caregiving.

The researcher read the transcripts several times and then proceeded to identify statements that appeared to hold meaning to the phenomenon of caregiving. These statements were listed and considered as having equal value, that is, horizonalization of the data in order to determine which meanings stood out as invariant qualities of the experience. Statements that were irrelevant or overlapping and repetitive were removed, leaving only those invariant constituents of the caregiving phenomenon that could be clustered into themes.

The researcher moved to the textural portrayal of each theme which was the textural description of "what" was experienced by the participants. The textural descriptions were supported by quotes chosen from the individual interviews representing the various meanings that formed the themes. Phenomenological analysis then involved a structural description of "how" it was experienced. The structural description of the caregiving experience was developed based on the textural descriptions and "imaginative variation" of each theme.

Perspectives of the phenomenon are considered from different vantage points and meanings in an effort to discern the structural elements that gave rise to the textural qualities. This includes “varying the frames of reference, employing polarities and reversals, and approaching the phenomenon from divergent perspectives, different positions, roles, or functions (Moustakas, 1994). “Imaginative variation” was performed by the researcher by inferring a range of possible meanings of the themes. In the final step the researcher integrated the textural and structural descriptions providing a synthesis of the meanings and essences of the caregiving experience reflecting the essences shared by the participants. The analysis process culminated in the emerging themes that would hopefully meet the aim and objectives of this study.

3.4.6 Credibility and dependability

Qualitative researchers maintain that some research is better than others, and they suggest that research can be evaluated according to its credibility. Credible research produces findings that are convincing and believable. The credibility of qualitative research is established while the research is being undertaken (Terre Blanche & Durrheim, 1999). The researcher attempted to demonstrate that the inquiry was done in a manner whereby the participants were accurately identified and described. The researcher aimed to be open and empathic so as to get a sense of the participants’ situation and experience. Steps were taken to assure validity and reliability often referred to as trustworthiness in the qualitative research literature (Guba, 1981 in Milberg & Strang, 2004). The interviews were conducted at a place that was suitable for the participants to ensure an environment that would be as private and confidential as possible for them, thereby strengthening the ‘internal validity’ or credibility.

To ensure methodological rigor and trustworthiness of the interview process, the researcher attempted to ensure that the voices of the participants were clearly heard and that the interview process was clearly articulated within the context of both the methodological and the researcher's perspectives and assumptions (Holloway, 2005). An assumption is that reality can be interpreted in various ways and the understanding is dependent on subjective interpretation (Graneheim & Lundman, 2003). An essential issue when discussing trustworthiness of findings in qualitative content analysis is that a text always involves multiple meanings and there is always some degree of interpretation. The researcher's interpretation may have been influenced by her experiential world which resonates with that of the participants.

According to Terre Blanche and Durrheim (1999) triangulation entails collecting material in as many different ways and from as many diverse sources as possible. This can help researchers to 'home in' on a correct understanding of a phenomenon by approaching it from several different angles. Triangulation involved comparing the different methods such as interviewing and observations made during the interviews. The researcher made observations during the interviews and additional data sources included field notes taken during and after the interviews. Weighing the evidence was done by reviewing the captured data as each interview was transcribed and studied. The researcher liaised with health care staff on a regular basis to enquire about prospective participants as well as after the interviews to enquire about any feedback from the participants.

For Moustakas (1994), “establishing the truth of things” begins with the researcher’s perception. One must reflect, first, on the meaning of the experience for oneself, then, one must turn outward, to those being interviewed, and establish “intersubjective validity,” the testing out of this understanding with other persons through a back and forth social interaction. Transcripts were read by the researcher and information that was unclear was clarified with the participants to overcome any bias.

Dependability is achieved through rich and detailed descriptions that show how certain actions and opinions are rooted in and develop out of contextual interaction (Terre Blanche & Durrheim, 1999). The researcher attempted to account for changing conditions in the phenomenon chosen for study as well as changes in the design created by increasingly refined understanding of the setting (Marshall & Rossman, 1995).

3.4.7 Reflexivity

Most of the interviews were held at the hospital where the women with advanced breast cancer received treatment and this may have influenced participants’ perception of the researcher as being part of the institution which could have impacted on the level of disclosure of any possible negative experiences in relation to the hospital.

The researcher has been aware of her role in the shaping and the interpretation of the phenomenon given her background in social work and psychology. The researcher has had previous experience in providing a counselling service to women with advanced breast cancer and their families. The researcher was aware that she felt more empathic to the participants and this could have impacted on the research process.

Participants were aware that I was an intern psychologist and this variable may have influenced the nature of the interviews and the information obtained. Participants may have seen the research interview as an opportunity to receive counselling. Participants viewing the researcher as a professional may have given them a sense of security when disclosing information about sensitive issues. The researcher's maturity may have made them feel comfortable to share details of their lives.

Since participants were the primary caregivers, the researcher was aware and sensitive to their availability to be interviewed. The researcher was flexible with the appointment times to allow for the participants to select a time that was convenient to them. Because of my previous experience in social work as well my training as a psychologist, the researcher had to be more mindful of the way in which the research interviews were conducted.   The researcher was aware of her inexperience in phenomenological research. Furthermore the quality of analysis of the interview transcripts could have been influenced by the lack of experience of the researcher in analyzing the data.

Reflexivity means an awareness of self within the process of data collection and analysis and is often regarded as an important element in demonstrating the rigor of qualitative analysis (Payne, 2004). All qualitative research methodologies recognize, at least to some degree, that the researcher is implicated in the research process. It is agreed that the researcher is a central figure who influences the collection of data and that our prior experience and understandings effect how we construct what we see. In order to develop self-awareness of these inter-subjective dynamics, qualitative researchers usually engage in reflexivity. This involves critical self-reflection, focusing on the ways a researcher's social background; assumptions, positioning and behavior affect the research process (Finlay, 2006).

Not only are people aware of themselves and the world, they are aware of their awareness; they are self-reflective. Being self-reflective, people can think about experience, about thinking, about themselves, about the object world, and about the interpersonal world. People are naturally reflective and self-reflective. Phenomenologists assert that the quality of life improves when people clarify their values and act in accord with them (Becker, 1992).

.3.4.8 Ethical considerations

The intersubjectivity of much qualitative work, especially where it occurs in relation to illness, disease and end-of-life issues, calls for the highest standards of ethical engagement when designing and conducting studies (Field et al., 2001). Approval to undertake this study was granted by the Research Ethics Committee, Faculty of Health Sciences, University of Cape Town as well as the Faculty of Community and Health Sciences of the University of the Western Cape. The purpose and nature of the study was explained to participants. Participation was voluntary, informed and confidential. Participants were assured that their identity will remain anonymous and all personal details will remain confidential. On completion of the study, audiotapes and transcripts of the interviews would be erased to ensure confidentiality.

Participants were aware that they had the right to withdraw from the study at any time if they so wished. It was made known to the participants that they were in charge of their own degree of disclosure. Due to the sensitive nature of the research, counselling by a health care professional at the hospital was made available to the participants in the event they required this. According to Banister, Burman, Parker, Taylor and Tindall, (1994), participants need to be protected from harm; their psychological well-being, health, values and dignity need to be preserved at all times.

3.5 Concluding comments

This chapter provided a systematic account of the methodological procedure utilized in this study. A description and a motivation for utilizing a qualitative research design framework were provided. The study was located within a phenomenological methodological framework. A description of the participants and research setting followed this. The procedure, method of data collection and data analysis was delineated. Finally, credibility and dependability of this study, reflexivity and ethical issues were discussed. The following chapter presents the findings and discussion of the analysis.

CHAPTER FOUR

FINDINGS AND DISCUSSION

4.1 Introduction

A phenomenological approach was used to gain a deeper understanding of the experience of caregiving by primary caregivers to women with advanced breast cancer. Seven themes emerged from the data analysis. Under the second theme, three sub-themes emerged. It should be borne in mind that English was not the first language for some of the participants and that the data may not be easily understandable in some instances.

The essence of the phenomenon of caregiving, experienced by the participants, is portrayed in the following themes:

1. Increased demands of the women with advanced breast cancer cared for by the participants
2. Emotional burden
    2.1 Feelings of frustration
    2.2 Feelings of anxiety and depression
    2.3 Feelings of helplessness
3. Meaningful relationship between the caregiver and the woman with advanced breast cancer
4. Religious beliefs and values as foundations for caregiving
5. A sense of commitment
6. Caregiving as a positive experience
7. Social support received by caregivers while providing care

4.2 Increased demands of the women with advanced breast cancer cared for by the participants

Participants related that the women with advanced breast cancer became physically weaker and less ambulant. This resulted in the participants becoming more involved in the physical care such as assisting with activities of daily living e.g. eating, dressing and bathing. The increased demands of the women with advanced breast cancer were experienced by the participants as their condition deteriorated. The progression of cancer affected the functioning of the arm of women with advanced breast cancer receiving care from participant (P3) who is a 43 year sister and participant (P6) who is 58 year old husband. This is illustrated by participant (P3) in the following quotation:

P3: *"…she didn't want anyone else to work with her. So I had to cut her hair and I had to go out and get her a wig and not only that I am doing everything physically, for her".*

The increased demands were also reflected by a 59 year old daughter, participant (P7):

"There are times that she needs, the sides sometimes feel completely very sore and then she can't do it herself and then I help her with everything…"

Consistent with research findings, participants experienced the increased dependence of the women with advanced breast cancer as their illness progressed and the main caregiving demand was managing their physical care. As the condition of women with advanced breast cancer deteriorated, caregivers also found that they spent an increasing amount of time with them. According to Cameron et al. (2004) caregivers to individuals with advanced cancer were often required to provide increasing amounts of care as the patient's health deteriorated. Pitceathly and Maguire (2003) in their review of the psychological impact of cancer on patients' partners and other key relatives asserted that a patient in the later stages of cancer was likely to need more physical care and provoke more concerns for the caregiver.

Participants related the symptoms suffered by the women with advanced breast cancer which included drowsiness from the medication, nausea, vomiting and shortness of breath as illustrated in the following quotation by a 56 year old female participant (P2) who was raised by the woman with advanced breast cancer and who regarded her as a maternal figure:

P2: *"Since a week ago when this belly started to swell and her abdomen is becoming bigger I have noticed that she is getting short of breath." For the past week I have become more involved."*

This increasing demand of caregiving concurs with the findings by Stetz (1987). In a descriptive study by Stetz (1987) on caregiving demands during advanced cancer, it was found that the most frequently reported demand for spouses was the physical care, treatment regimen, and imposed changes. It included such demands as assisting the ill spouse with activities of daily living and treatment regimens, as well as coping with alterations in the physical and /or emotional state of the ill spouse.

Participants maintained a close proximity to the women with advanced breast cancer in order to be available to meet their needs as required. Despite other responsibilities such as having a family of their own to care for, work responsibilities or caring for an ill spouse, participants described being readily available to the women with advanced breast cancer. This is reflected by participant (P8) a 66 year old retired male friend:

P8: *"I'm always there for her you know, if she calls I'm there."*

A 58 year old male participant (P6) experienced the increased demands of his wife despite her need to be independent. The inability to use one of her arms due to the cancer made her dependent on the participant to a certain extent. The increased demands are illustrated in the following quotation:

P6: *"…I do assist…making breakfast…we need to go somewhere...I would maybe assist with washing her back for her…things she cannot normally do that what she would have done with both her hands"*.

The physical disability of the women with advanced breast cancer placed greater demands on the participants as confirmed by Nijboer et al. (1998) who asserted that there was a direct impact on the caregiver by alterations in a patient's functional ability, bodily functions, appearance, employment status, sexual functioning, family and social role.

The 58 year old male participant (P6) became retrenched following the deterioration of his wife's condition and he felt that he needed to stay at home to care for her instead of finding employment. A 60 year old retired male participant (P1) felt that the prolonged caring for his wife affected his career opportunities. He explained that he had to refuse an offer to work in England as he had to take care of his wife. A 43 year old participant (P3) described having to juggle her roles between her ill husband, caring for her grandson and her sister who is the woman with advanced breast cancer. She left her work to be more available to her sister and took over her sister's household responsibilities as well as illustrated in the following quotation:

P3: *"Now I had to leave my work that I get and took over where she, you know, stand in her place and it was, it was very tiring…"*

The increased demands of the women with advanced breast cancer impacted on the participants' work situation, restricted their roles and activities such as reduction in social interactions as confirmed by Given and Given (1996 in Chen & Hu, 2002). They asserted that family members of chronically ill patients experienced a variety of problems that arose from the various demands of their caregiving role. This role placed immense emotional, social, physical and financial stress on the family caregiver. Caregiver burden and caregiver strain have been the terms most often used to describe the persistent hardships or the physical, psychological, social, financial and emotional responses that could be experienced by family members providing continuing and supportive cancer care. In a quantitative study done by Cameron et al. (2002) on lifestyle interference and emotional distress in family caregivers of advanced cancer, patients found that caregivers experienced increased emotional distress, regardless of the amount of care provided, when limited in their ability to participate in valued activities and interests.

According to Given et al. (2001) in their study on family support in advanced cancer, the role of family caregivers had shifted from one of custodial care to a complex, multifaceted role that includes symptom management, monitoring for changes in hallmark symptoms, equipment care, patient transport and advocacy, and management of activities/responsibilities the cancer patient had foregone because of illness.

In accordance with the literature, participants indicated that they needed to become more attentive and alert to the symptoms and needs of the women with advanced breast cancer. Participants related that the demands of the women with advanced breast cancer increased and that safety and monitoring became necessary in the past few weeks as reflected by participant (P1) a 60 year old husband and participant (P7) a 59 year old daughter:

P1: *"It just put a bit more demand on me. Now I have to watch her more all the time." "She gets up from the bed and stands up and just falls asleep like that. If I'm not there, she will just collapse. I have to wake her up and lead her back to the bed".*

P7*: "…I am very alert for her you see. There are sometimes that she gets me a little worried because when she inhales or so on and then it doesn't sound right to me".*

Participants also expressed their concerns and fears about the increased demands of caring for the women with advanced breast cancer as their condition deteriorated even further and they were worried about how they were going to manage. This is in accordance with the study by Cameron et al. (2004) on a brief problem-solving intervention for family caregivers to individuals with advanced cancer, in which they found that caregivers experienced multiple challenges, including declining health of the patient and psychological distress over social and cultural issues surrounding death and dying. Caregivers to individuals with advanced cancer were often required to provide increasing amounts of care as the patient's health deteriorated, and had to also prepare for their imminent death. This is illustrated in the following quotation by participant (P2) a 56 year old surrogate daughter:

P2: *"What I'm thinking now is that I will approach …and I will make the necessary arrangements with the hospice people…. When it comes to intense nursing I don't think my husband can do it and I don't want my children should get involved there"*.

As the condition of women with advanced breast cancer deteriorates, religious and cultural issues surrounding death come to the fore. The same participant (P2) was faced with issues of the difference in religion between herself and the woman with advanced breast cancer as reflected in the following quotation:

P2: *"We'll respect her religion and she respects our religion. I don't think I can and will not hand her over to anyone else"*.

Studies supported the observation that caregiving for a patient with advanced breast cancer became more demanding and difficult as the disease progressed (Nijboer et al., 1998). Caregiving responsibilities were physically and emotionally challenging, especially for the person who has not had any specialized training for this role (Payne et al., 1999; Toseland et al., 1995). According to Jansma, Schure and de Jong (2005), this became particularly relevant when the woman with advanced breast cancer had to be taken care of for an extended period of time. Participants were expected to provide palliative care to the woman with advanced breast cancer at home without preparation or training for the caregiving role. According to Northouse et al. (2002) caregivers were automatically assumed to be capable of providing complex care with little preparation and support. Although two of the participants, participant (P2) a 56 year old surrogate daughter and participant (P8) a retired male friend were qualified nurses, they themselves felt emotionally challenged whilst providing care to the woman with advanced breast cancer. Arno et al. (1999) in their study on the economic value of informal caregiving asserted that informal caregivers were seldom adequately trained and almost never offered appropriate follow-up services, reevaluation of care arrangements, or referrals to community services.

4.3 Emotional burden

4.3.1 Feelings of frustration

Caregiving was experienced as emotionally burdensome by the participants at times. Different feelings were experienced by the participants at various times such as frustration, irritability, anger and exhaustion. Participants commonly described the emotional impact of the caregiving role as illustrated by participant (P1) a 60 year old retired husband and participant (P6) a 58 year old unemployed husband in the following quotations:

P1 *"There are times when you feel you had enough but then you sit and think or take a walk and clear your mind and come back and everything is okay again"*.

P6: *"It's actually difficult to say, I don't know how to sort of express it, but there are times when you feel frustrated, there are times when you feel tired and there are times when you are not feeling well and you think all these things but somehow you just got to discard those thoughts"*.

Participant (1) felt that he tried to do everything for his wife and that she did not want to listen to him and perceived her as being resistant and this led to him feeling frustrated. Participant (6) described coping by changing his negative thoughts to positive thoughts when he felt frustrated. In accordance with the literature by Coristine et al. (2003), they found that caregiving for a loved one with advanced breast cancer was emotionally difficult. Personal variables such as anxiety and depression affected the caregiver's perception and reactions to caring.

A participant who is a 43 year old sister (P3) spoke about feeling irritated at times. Apart from her household chores, she has to leave what she was doing to attend to the woman with advanced breast cancer as reflected in:

P3: *"…sometimes I do get irritated…there's just a lot of boys that's living here and sometimes this house can be a mess…then I must pick up the pieces …then she want something and I am too busy…then I must leave that and I mean…that is really working on you…"*

The experience of feeling confined to their role of caregiving and at times feeling robbed of their individuality was felt by the participants. Participants experienced a lack of personal space and the need to leave the caregiving situation to take time out and to reflect on their thoughts and feelings. Walking away from the situation and speaking to someone helped some participants to cope with the situation as reflected in the following quotation:

P1: *"…if I am feeling frustrated, I will take a walk and come back after an hour or two". "Sometimes I'd take the car and visit my sister or brother and talk to them".*

4.3.2 Feelings of anxiety and depression

Feelings of anxiety and depression were experienced by the participants when they realized that the condition of the women with advanced breast cancer was deteriorating as reflected in the following quotations by a 56 year old female participant (P2) and a 68 year old retired husband (P5):

P2: *It probably put a bit of sadness into me if I fear her going down".*

P5: *“…the night time I’m not sleeping as well as I did before …I think of her illness and that makes it a little stressful”.*

Participants expressed feeling sad about the limited time that they have with the women with advanced breast cancer. Participants also felt depressed about facing the loss of the women with advanced breast cancer that they have been providing care to as illustrated in the following quotations:

P2: *“I’m really going to miss this woman. …the chair is going to be there and she is not going to be there”.*

P5: *“I’ll miss that very nice person”.*

This was consistent with research findings by Grunfeld et al. (2004) in their longitudinal study of family caregiver burden with regard to breast cancer patients and their principal caregivers. They found that caregivers experienced substantial psychological morbidity (anxiety and depression) at the onset of the patient’s palliative illness and a substantial increase in caregiver burden and depression when the patient reached a terminal stage of the illness. In their study on the interaction of age, symptoms, and survival status on physical and mental health of patients with cancer and their families; Kurtz et al. (1994) found that as the illness progressed, caregivers experienced more depression, a greater adverse impact on their own health and daily lives and spent more time helping patients cope with daily living activities.

Admitting to feelings of sadness by the participants about the illness was difficult as this was perceived by them as a sign of weakness. In addition, the participants felt that they could not feel sad in the presence of the women with advanced breast cancer as this would lead to them losing hope. Participants repressed their own grief to give the impression of being self-controlled as illustrated by a 56 year old surrogate daughter (P2), a 43 year old sister (P3) and a 59 year old daughter (P7) in the following quotations:

P2: *"…I will try and keep strong in front of her…"*

P3: *"Oh, I am crying a lot when she isn't watching"*.

P7: *"I'm not sad all the time. I can't be, can't be. I've got to be strong for her because if, if I am going to be sad all the time then how is she going to feel about it…"*

Giving the impression of being self controlled suggested hardiness as described by Ross and Deverell (2004) who thought that hardiness reduced the effects of stress, such as those caused by illness or disability. Family caregivers in one study who reported higher family hardiness were more likely to appraise the illness/caregiving as "challenging" or "beneficial" rather than as a negative experience (Carey et al., 1991 in Northouse et al., 2002).

Participants felt protective towards the women with advanced breast cancer by not letting them witness or know about the emotional strain they were facing whilst caring for them. Participants felt they did not want to burden them with their own suffering and tried to restrain themselves so as not to distress them further. Three participants, participant (P1) a 60 year old husband, participant (P5) a 68 year old retired husband and participant (P6) a 58 year old husband, suffered from severe physical pain themselves and hid their pain from the women with advanced breast cancer in order to protect them. This is illustrated by participant (P6) as reflected in the following quotation:

P6: *"I also have pain so try and, and hide things …I try to not tell cause I don't want to burden her still with, you know, my disability".*

In a study done by Lindholm et al. (2002) on the significant others' experience of suffering when living with women with breast cancer, the significant others considered the suffering of the woman as the primary thing and their own suffering 'at second place', protecting the women with breast cancer by not revealing what they felt and experienced.

Three participants, a 56 year old surrogate daughter (P2), a 43 year old female sister (P3) and a 47 year old daughter-in-law (P4) felt that they would not burden others with their feelings and would deal with them on their own. They tended to repress any negative thoughts or feelings that they experienced. Participants felt overwhelmed at times due to the additional stresses that they experienced. Participant

(P2), a 56 year old surrogate daughter, felt strained having to deal with the marital stresses as well as providing care. Participant (P4), a 47 year old daughter in law, felt torn between family members and the woman with advanced breast cancer as a result of conflict experienced within the family as reflected in:

P4: *“she’s very depressed and you know that type of thing. So she’ll phone me and lay that onto me and you know some day I do think, “Do I really need that?”*

This concurs with the study by Coristine et al. (2003) that the increased demands of caring and the emotional strain often left caregivers physically and emotionally depleted.

4.3.3 Feelings of helplessness

Witnessing the pain and suffering of women with advanced breast cancer made participants experience an ongoing struggle of not being able to do anything to relieve the suffering. For the participants, a 68 year old retired husband (P5), a 43 year old sister (P3) and a 58 year old husband (P6), the experience of being with suffering was difficult and they reacted with feelings of helplessness.

Participants expressed their inability to control the pain of the women with advanced breast cancer as this was out of their control and this contributed to their feelings of helplessness. This is illustrated by participant (P3) in the following quotation:

P3*: "…having to see that she's suffering, the way she's suffering. That actually hurt and I had to go out." "…I cannot relate to the kind of pain that she must be feeling". "She had a lot of pain …actually the pain is making her rock and that I had to watch and couldn't do anything for her. I cannot take away the pain and whatever I'm saying doesn't take away that pain".*

The feelings of helplessness experienced by the participants was described in the study by Lindholm et al. (2002) who showed that significant others experienced deep often unrelieved suffering and considered themselves prisoners of a situation of uncertainty and powerlessness when standing by the woman with breast cancer. Knowing that a loved one was in pain, and trying to help were very difficult experiences for family members (Gotay, 1996).

Participants found it very difficult to witness the suffering of women with advanced breast cancer with pain as described by a participant (P6) a 58 year husband:

P6 *"To me that is not something very nice because I can sometimes see in bed that she's got a lot of pain and what affects me most is that there is nothing that I can do about it, that's the problem".*

The same participant felt guilty about falling off to sleep while his wife sat up the whole night with pain as he felt that he had to stay awake with her.

Four participants, a 43 year old sister (P3), a 68 year old retired husband (P5), a 58 year old husband (P6) and a 66 year old retired male friend (P8), felt depressed from witnessing the pain and suffering of women with advanced breast cancer as illustrated in the following quotation:

P8: *"I become depressed myself, not that I become so depressed, but I do feel sad, because there is nothing really I can do to alleviate the pain but she definitely was in terrible pain…"*

Participants described feeling helpless as they watched the women with advanced breast cancer suffer with pain. The difficulty experienced by participants in witnessing the suffering is highlighted in the study by Lindholm et al. (2002). They asserted that the powerlessness and helplessness experienced by the significant others' of woman with breast cancer and who lived with her but were unable to influence the situation was the cruelest suffering. It was difficult to see another person depressed, anxiety-ridden and crying in agony because of her mortal illness, without being able to alleviate and help. Kotkamp-Mothes, Slawinsky, Hindermann and Strauss (2005) in their study on coping and psychological well-being in families of elderly cancer patients found that the emotional distress centered on helplessness, loss of control, insecurity about the course of illness, and the fear of losing family members.

4.3.4 Meaningful relationship between the caregiver and woman with advanced breast cancer

Participants and women with advanced breast cancer experienced a close union regardless of whether the participant was a husband, daughter, daughter-in-law, sister or friend. Two participants, a 60 year old retired husband (P1) and a 58 year old husband (P6) described the quality of the relationship between themselves and the women with advanced breast cancer as illustrated in the following quotations:

P1: *"It's natural for me." "We are together for 42 years and that is a long time"*.

P6: *"…we have been married now for almost 34 years and we love each other, we care for each other. Her pain is my pain and to me, it's only natural"*.

Because of the nature of their relationship with the woman with advanced breast cancer, becoming caregivers was a natural or expected role for the participants. A participant described his marital relationship as sacred and believed that caring for his wife was his duty. Although this suggests an obligation, participants felt an intrinsic need to care because of their love for the women with advanced breast cancer. Because of the close relationship participants could empathize more deeply with them. The history of their relationship determined the strength of the bond between them. This bond was positively influenced by the caregiving experience. Participants regarded their relationship with them as significant and the women with advanced breast cancer were their ultimate priority as highlighted by the following quotation by participant (P7), a 59 year old daughter:

P7: *"She's my mother, I will put everything, anything aside and I will look after her" "I feel blessed, I feel so blessed to do that, really"*.

Three female participants, a 56 year old surrogate daughter (P2), a 43 year old sister (P3) and a 47 year old daughter-in-law (P4) felt grateful to the women with advanced breast cancer for being a maternal figure to them. Two male participants, a 68 year old retired husband (P5) and a 58 year old husband (P6) felt grateful to the women with advanced breast cancer for standing by them when they were ill. Participants felt the need to reciprocate the care they received from these women. The past intimate relationship between the participants and the women with advanced breast cancer obliged the participant to be close at hand all the time.

Participants related that they would be there for the women with advanced breast cancer through good times and bad times as illustrated by a participant, a 68 year old retired husband in the following quotation:

P5: "*through thick and thin I will do it for her anytime with no complaints."*

Strong relationships even existed between participants and the women with advanced breast cancer who were not a family member. This was illustrated by a participant who is a 56 year old surrogate daughter in the following quotation:

P2: *"She's part of the family." "She means the world to me. She means the world to me besides myself I can also say raising me, she never stood aside for my children."*

The fact that participants gave priority to the needs of the women with advanced breast cancer over their own needs was indicative of the quality of their relationship as reflected in the following quotation by a 58 year old husband (P6):

P6: *"I might sometimes feel tired or …but to me she comes first and that is the way I see it and I would assist whatever with whatever is necessary".*
"…she's actually the priority so it comes to about making a decision about my needs and her needs, I would rather have her needs first..."

Spouses, in particular, played an important role during the cancer experience. They had been frequently identified as the key person who gave emotional support and provided physical assistance to the woman with breast cancer (Northouse, 1988). The family was a major factor in the individual's health process and played a prime role in the course and management of an illness (Wright & Leahey, 2000; Weihs, Fisher & Baird, 2002 in Duhamel & Dupuis, 2003). Understanding the influence of illness on the family necessitated understanding the family itself, not just the illness. When the family became the focus, it would be seen that illness influenced relationships as profoundly as it did individuals (Kleinman, 1988).

4.3.5 Religious beliefs and values as foundations for caregiving

Three participants, a 43 year old sister (P3), a 47 year old daughter-in-law (P4) and a 59 year old daughter (P7), described deriving sustenance from their own spirituality as illustrated by the following quotations:

P3: *"Maybe the Lord put me here in charge if I didn't have a positive attitude of what I'm dong and why I am doing it".*

P4: *"We always maintain God has a plan …recently I've become very involved with my spiritual life and I always say God has a plan for each of us and if that is set out for you it comes your way and you feel strongly that it is like that then so be it".*

P7: *"And being a born again Christian I should do just that and know that it is expected of me because the Lord says in his words…"*

These three participants, (P3, P4 and P7) mentioned a belief in a higher being and a power out of their control and would accept whatever is expected of them. This concurs with the view of Mullen (1994) that fatalistic thinking was not passive, but represented a belief that control lied outside the individual, which did not preclude religious activism.

These participants also described deriving their strength to face situations from their faith in a higher being. They often found religion and spirituality a valuable resource to help them cope with the demanding caregiving role. They drew on their religious and spiritual beliefs to help them cope. Five participants, (P3, P4 and P7) as well as a 60 year old retired husband (P1) and a 68 year old retired husband (P5) described having a trusting faith and turning to prayers for comfort and solace. Three participants (P3, P4 and P7) read the Bible when they felt depressed.

Spiritual beliefs and values profoundly affect how a person copes with illness, its treatment, and the suffering it can bring. Patients drew on their spiritual beliefs to manage the uncertainty of the illness, to instill hope, find comfort and support-and to bring resolution (part or whole) to existential fears. One's spirituality, in whatever manner it was formulated and actualized, assisted with meaning making (Gregory, 2005).

The spiritual needs for every situation were different. Participants coped in different ways by praying, reading the Bible, providing spiritual comfort to other ill people and attending church. Participant (P2), a 56 year old surrogate daughter, described the different religions followed by her and the woman with advanced breast cancer living in the same household and the experience of mutual respect between them. Participant (P1), a 60 year old retired husband described his experience of daily prayers and that he attended the mosque when there was someone to relieve him of the caregiving role. At times the participant and the woman with advanced breast cancer would pray together at home.

Participant (P3), a 43 year old sister, belief that God would not give you more than you can manage helped her to cope with caring for the woman with advanced breast cancer as well as her ill spouse. Participant (P7), a 59 year old daughter, expressed a belief in honoring her parents and believed that she has honored her mother by caring for her as illustrated by the following quotation:

P7: *"You've got to do everything that the Lord wants you to do. It's only right that you look after your mother and your father, your parents, you've got to honor them"*.

Two of the participants, a 43 year old sister (P3) and a 58 year old husband (P6) experienced internal conflict and questioned God in a search for meaning as reflected in the following quotations:

P3: *"…dear Lord what did I actually do to, I don't want to say do to deserve this…"*

P6: *"you would sometimes ask, you know, why does it got to happen like that or what has she done or what have you done…"*

These participants tried to make meaning of their situations and according to Kleinman (1988), illness was not simply a personal experience; it was transactional, communicative, and profoundly social. The study of illness meanings was not only about one particular individual's experience; it was also very much about social networks, social situations, and different forms of social reality. Illness meanings were shared and negotiated. They were an integral dimension of lives lived together.

According to Duhamel and Dupuis (2003) the facilitative belief that one would be repaid for the good one brought to the woman with advanced breast cancer brought great comfort. Two participants, a 60 year old retired husband (P1) and a 43 year old sister (P3) believed that they would be rewarded by God for the care they have provided to the women with advanced breast cancer as illustrated in the following quotations:

P1: *"Maybe its God's plans already…but maybe there will be a time when I will be rewarded for this or whatever, so I just carry on".*

P3: *"… and he will lift me up one day or maybe I should get my reward you know, when I am when after death…"*

According to the literature very little attention had been paid to religious faith and the role of informal carers of cancer patients (Leis, Kristjanson, Koop & Laizner, 1997 in Soothill, Morris, Harman, Thomas, Francis & McIllmurray, 2002). It had been suggested that the feeling that one was supported by one's religious faith correlated to emotional well-being amongst carers (Rabins, Fitting, Eastham & Fetting, 1990).

As death drew closer, individuals and families readjusted their value system and turned to their spiritual beliefs, including religion. According to Rolland (1994 in Duhamel & Dupuis, 2003), when transfer to palliative care became unavoidable, families gave new meaning to the disease and its consequences in light of their religious and spiritual beliefs and thus helped alleviate their suffering. People in distress often sought refuge in the peace that their religion or other form of spirituality provided (Duhamel & Dupuis, 2003).

4.3.6 A sense of commitment

All participants expressed a sense of commitment to caring for the women with advanced breast cancer. Participants felt morally committed which stemmed from a sense of obligation toward the women with advanced breast cancer. Their sense of commitment is illustrated in the following quotations by two participants, a 56 year old surrogate daughter (P2) and a 66 year old retired male friend (P8):

P2: *"It is a commitment that I have made to my inner self and it must be done".*

P8: *"...and I said to her I'll never walk out on you, I'll stick with you, if you die before me then I will fine , then I will move, but as long as you are alive I'll stick with you, I will not desert you".*

These participants described having a sense of duty and being persistently involved in their caregiving role. Pierce, Lydon and Yang (2001) in their study on enthusiasm and moral commitment and what sustained family caregivers of those with dementia, asserted that when individuals were morally committed as in the case of caregivers, they provided care because they felt they ought to. Morally committed caregivers would have said that they provided care to the patient because it was their duty and they felt personally obligated to do so.

Two participants, a 60 year old retired husband (P1) and a 58 year old husband (P6) made a commitment to care for the women with advanced breast cancer at the time of marriage and will adhere to the commitment made. Participants felt that once they took on a responsibility, they would see it through and they would always be there for the women with advanced breast cancer. One of the participants, a 56 year old surrogate daughter (P2) felt committed to care for the woman with advanced breast cancer because she had raised the participant. Participants had made a commitment to caring for the women with advanced breast cancer and they were determined to carry it through to the end as illustrated in the following quotations by participant (P1) who is a 60 year old retired husband and participant (P4) who is a 47 year old daughter-in-law:

P1: *"When I got married I said that this is a lifetime commitment…" "The promise I made to her mother is something that I must keep…"*

P4: *"…once I take on a responsibility, I will see it through"*.

4.3.7 Caregiving as a positive experience

Participants experienced some positive aspects associated with their role of caregiving as illustrated by participant (P2) a 56 year old surrogate daughter, in the following quotation:

P2: "It makes me feel exceptionally good".

Participant (P2) experienced caregiving as satisfying and expressed that she did not know what more she could do for the woman with advanced breast cancer. The opportunity to reciprocate caregiving was experienced as satisfying for some of the participants.

Participants described the enjoyment derived from caregiving. They found the care giving role enjoyable for different reasons such as having conversations with the woman with advanced cancer, confiding in each other, spending time together, laughing together, going for a drive together and accompanying her to hospital as illustrated in the following quotations by participant (P3), a 43 year old sister and participant (P5), a 68 year old retired husband:

P3: *"…I'm taking her along with me and then the two of us can sit somewhere and have something nice to eat and have a chat about…its goodness that I get out of it…"*

P5: *"Sometimes I talk to her and she can make you laugh a lot"*.

It was the simple things in life that gave participants the fulfilment derived from caregiving. Participant (P4) described experiencing spiritual growth in the time of caring for the woman with advanced breast cancer and has gained fulfilment in discovering that through her influence, the woman with advanced breast cancer became more involved spiritually. In a study on spirituality in caregiving and care receiving, Forbes (1994) found that there might be a spiritual bonding that took place between caregiver and care receiver, which possibly led to better caregiving outcomes. Some participants experienced an improvement in the quality of their relationship with the woman with advanced breast cancer and this made them feel good about themselves as illustrated by the following quotation by participant (P4), a 47 year old daughter-in-law:

P4: *"…she said to me is 'I'm her pillar of strength" "It will only be me that I think that she's now chosen to"*. *"It makes me feel good"*. *"We actually become very close"*.

The improvement in the relationship was also confirmed by Folkman et al. (1995) who reported that caregiving could improve the quality of relationships between caregivers and care recipients, and this could contribute to the caregivers' self esteem. Participant (P8), a 66 year old retired male friend, believed that caring for others is an inherent part of his personality and described his experience of caregiving as very rewarding. Feelings of compassion caused the participant's altruistic behavior as reflected in:

P8: *"no money can pay me for the reward I'm getting for helping other people." The reward is that I feel great that I've done something good". "I love what I'm doing and I enjoy it".*

The fulfilment experienced by the participant is supported by the literature that the role of the caregiver is not always a completely negative experience. Acting as a caregiver could be very gratifying for family members (Barg et al., 1998; Brown & Stetz, 1999 & Nolan, 2001 in Duhamel & Dupuis, 2003), and taking on the role could boost family members' morale and improve their well-being. Studies have confirmed the high percentage of carers experiencing satisfactions and have reinforced the importance of satisfactions, both to a more complete understanding of the reciprocal and dynamic nature of family care, and to the development of services to support family carers (Nolan, 2001).

4.3.8 Social support received by caregivers while providing care

Support from health care professionals, family and friends could help family caregivers expand their capacities to respond to care demands. The goals of support should be to enable family caregivers to maintain the patient's comfort and enhance the patient's quality of life, and to prevent or minimize unnecessary caregiver distress (Given et al., 2001).

Participants identified receiving support mainly from informal sources such as their family, friends or church. Families were relied on most often by the participants for emotional support and assistance with the caregiving tasks.

Participant (P6), a 58 year old husband described receiving emotional support from his youngest daughter with whom he shares a close relationship as reflected in:

P6: *"My youngest daughter. We have a very, very good understanding…she would really give me all the support"*

Participant (P2), a 56 year old surrogate daughter described having sufficient support from family members with relieving her of her caregiving role and felt that she could request their assistance at anytime as reflected in:

P2: *"I can stick my arms out anytime". "I can phone my sister or brother…"*

Participant (P7), a 59 year old daughter described receiving assistance with the household chores from her daughter which enables her to cope with her caregiving role as reflected in:

P7: *"I got my daughter with me and she helps me a lot…"*

For one participant, a 43 year old sister (P3) the support from family was limited as illustrated in the following quotation:

P3: *"my sister…she's actually taking the load off … when she is standing in a little bit for me but she cannot be here all the time"*.

The little support the caregiver received from a family member provided her with relief and gave her time to attend to her own needs. One participant, a 66 year old retired friend (P8), felt depressed because of the lack of support from the family of the woman with advanced breast cancer as reflected in:

P8: *"…they sort of withdrew from her; they don't want to know her…makes one depressed to know that your family is not interested in you when you are sick"*.

The support received by the participants was mainly from family members as confirmed by Northouse et al. (2002) in their study on the quality of life of women with recurrent breast cancer and their family members. According to Northouse et al. (2002) family members were expected to be the primary providers of physical and emotional support to the patient, yet they perceived little support from others, either professional or personal, in carrying out this essential role.

Two male participants, a 60 year old retired husband (P1) and a 58 year old husband (P6) experienced reduced socializing with male friends resulting in social isolation as illustrated in the following quotations:

P1: *"They come to the house and we can sit and talk and at the same time I can watch her. I really don't go and visit friends". "Do need some male attention, someone you can talk to".*

P6: *"…the going out …with the guys…I set all those aside now I mean even up to now I do not even have anymore friends …I am more at home than I would".*

Two participants, a 43 year old sister (P3) and a 59 year old daughter (P7) identified the church and people from the church as significant supports for them as reflected in:

P7: *"…like now our church going people, I talk a lot to them and they give me that comfort …"*

Participant (1) who is a 60 year old retired husband felt that he personally did not receive support from hospice even though they visited the woman with advanced breast cancer as reflected in:

P1: *“The sister from hospice only comes to her. The hospice sister comes to visit her and to check on her”.*

Participant (4) a 47 year old daughter-in-law felt uncertain, anxious and isolated and did not know whom she could turn to for assistance when the condition of the woman with advanced breast cancer deteriorated. She considered approaching the hospice for assistance when she felt that it would become necessary as illustrated in the following quotation:

P4: *“…as time goes on you know, I would probably turn to hospice if need be because I don’t know anybody else to turn to…”*

Kinsella, Cooper, Picton and Murtagh (1998) in their review of the measurement of caregiver and family burden in palliative care identified a variety of psychological sequale among caregivers including depression reduced self-esteem, feelings of isolation, fatigue and anxiety.

Family members often assumed the caregiving role under sudden and extreme circumstances, with minimal preparation and uneven guidance and support from the health care system, posing significant challenges and considerable psychological and physical consequences for the caregiver (Glajchen, 2004). If family members were informed and supported while delivering care, they, in turn, would be less anxious, better able to integrate care into their lives, and would see the experiences of caring in a more positive light (Given et al., 2001).

The findings of this study suggest that providing palliative care to women with advanced breast cancer seem to take a toll on the family caregivers. They are expected to be the primary caregiver with little perceived formal support; no training for their role as caregivers and with no financial remuneration. It was noted that despite the relatively low income of the participants, none of the participants complained about financial difficulties and it appeared that the limited income did not affect the quality of the care they provided. Little mention was made of formal support received by the participants. This could be due to them not being aware of the limited community resources that are available or their reluctance to utilize these services. An interesting aspect of these findings was that participants in general, could rely on their families for emotional support and assistance in their role as caregivers.

Interesting points which emerged from this study was the involvement of the husbands in caring for their wives', the changes in family roles and the significant length of their relationship. It is important that family caregivers are offered emotional and physical support by health care professionals which are tailored to their needs and in this way contribute to the maintenance of their physical and mental health.

4.4 Concluding comments

The findings of the study have been explained and presented as seven themes. Direct quotations from the participants were taken to provide qualitative descriptions of their experiences as primary caregivers providing palliative care to women with advanced breast cancer. The findings confirm previous research that caregivers experience psychological distress and strain whilst providing palliative care at home to individuals with cancer. The following chapter presents an integration of the findings, contributions of the study, considers the limitations and recommendations of the study and provides suggestions for future research.

CHAPTER FIVE

CONCLUSION

5.1 Integration of findings

The study aimed to explore and understand the experiences and challenges family caregivers faced while providing palliative care to women with advanced breast cancer. Seven themes emerged from the data analysis which are:
increased demands of the women with advanced breast cancer cared for by the participants, emotional burden with three sub-themes of feelings of frustration, feelings of anxiety and depression and feelings of helplessness, nature and quality of the relationship between caregiver and patient, religious beliefs and values as foundations for caregiving, a sense of commitment, caregiving as a positive experience and social support received by caregivers while providing care.

The findings from this study demonstrated that there are a variety of challenges that family caregivers are faced with when caring for women with advanced breast cancer. The findings indicated that as the condition of the women with advanced breast cancer deteriorated they became physically more dependent on the participants. Participants found that they spent more time with them as the cancer progressed. The increasing demands of the women with advanced breast cancer impacted on the caregivers' work situation, restricted their roles and activities such as a reduction in social interaction. This is supported by Cameron et al. (2004) who indicated that caregivers to individuals with advanced cancer were often required to provide increasing amounts of care as the patient's health deteriorated.

Participants became more alert to the symptoms and that safety and monitoring of the women with advanced breast cancer by them at home became necessary. Three participants became worried about the management of the women with breast cancer as their condition deteriorated. According to Northouse et al. (2002) often the family caregiver was the one most responsible for managing the side effects of treatment and symptoms of disease at home as the patient's condition deteriorates. Pitceathly and Maguire (2003) in their review of the psychological impact of cancer on patients' partners and other key relatives asserted that a patient in the later stages of cancer was likely to need more physical care and provoke more concerns for the caregiver.

Participants felt emotionally burdened at times and experienced feelings of frustration, anger and exhaustion. According to Coristine et al. (2003) caregiving for a loved one with advanced breast cancer was emotionally difficult. Some participants denied that caring for the women with advanced breast cancer was challenging and felt they were in control of the situation. The contradictions expressed by the participants may be suggestive of the internal conflict experienced by them. Participants displayed stoicism and hardiness in their role as caregivers.

Participants felt that their pain was less important than the illness of the women with advanced breast cancer and protected them by not disclosing what they were going through. Suppression of affect was a way of coping for some of the participants. According to Lindholm et al. (2002) the significant others considered the suffering of the woman as the primary thing and their own suffering ‘at second place’, protecting the women with breast cancer by not revealing what they felt and experienced.

The experience of witnessing the suffering of the women with advanced breast cancer was difficult for the participants and they reacted with feelings of helplessness. Some of the participants felt depressed as a result. The feelings of helplessness experienced by the participants is described in the study by Lindholm et al. (2002) who showed that significant others experienced deep often unrelieved suffering and considered themselves prisoners of a situation of uncertainty and powerlessness when standing by the woman with breast cancer. Knowing that a loved one was in pain, and trying to help were very difficult experiences for family members (Gotay, 1996).

Participants experienced a close relationship with the women with advanced breast cancer regardless of the nature of their relationship. They shared a lengthy relationship and the history of their relationship determined the strength of the bond between them. Participants gave priority to the needs of the women with breast cancer which was indicative of the close relationship between them. The participants’ relationship with them was a motivating factor in providing care.

Participants found that being religious and spiritual enabled them to cope with the challenges of the caregiving role. They described having a trusting faith and turned to prayers for comfort and solace. According to Duhamel and Dupuis (2003) people in distress often sought refuge in the peace that their religion or other form of spirituality provided. Two participants searched for meaning about their situation by questioning

God. Two other participants believed they would be rewarded for the care they have provided and this belief motivated them to continue. The religious beliefs and values of the participants made them feel obligated to provide care. Duhamel and Dupuis (2003) suggested that the facilitative belief that one would be repaid for the good one brought to the woman with advanced breast cancer brought great comfort.

All participants expressed a sense of commitment to caring for the women with advanced breast cancer. Participants felt morally committed which stemmed from a sense of obligation toward the women with advanced breast cancer. Pierce et al. (2001) asserted that when individuals were morally committed as in the case of caregivers, they provided care because they felt they ought to.

Participants described experiencing some positive aspects related to their role as caregivers. Some participants felt that it was an opportunity to reciprocate and were positive in their attitude towards providing care. Participants derived enjoyment from sharing simple moments together which they found meaningful. The fulfilment experienced by the participants is supported by the literature that the role of the caregiver is not always a completely negative experience. Studies have confirmed the high percentage of carers experiencing satisfactions and have reinforced the importance of satisfactions, both to a more complete understanding of the reciprocal and dynamic nature of family care, and to the development of services to support family carers (Nolan, 2001). One participant experienced spiritual growth in the time of providing care and felt that this has influenced the interest of the woman with advanced breast cancer in spirituality and this experience lifted her self- esteem. One participant felt that caring for others were an inherent part of his personality and found the caregiving experience rewarding.

Participants identified receiving support mainly from informal sources such as their family, friends or church. Families were the main source of support for the participants' except for one participant who was disappointed by the lack of support from the family of the woman with advanced breast cancer. An interesting aspect of these findings was that participants in general, could rely on their families for emotional support and assistance in their role as caregivers. Little mention was made of formal support received by the participants. The findings of a study by Northouse et al. (2002) indicated that family members were expected to be the primary providers of physical and emotional support to the patient, yet they perceived little support from others, either professional or personal, in carrying out this essential role.

5.2 Contributions of the study

This study contributes to previous research aimed at exploring the experiences and challenges experienced by primary caregivers providing palliative care to women with advanced breast cancer. This study further contributes to the field of women's health issues and as a woman researcher the well-being of women is of particular interest to me.

While previous research has highlighted the experiences of caregivers caring for people with other chronic illnesses, this study contributes to further understand the primary caregivers' experiences particularly caring for women with advanced breast cancer. This study also contributes to understand the challenges faced by primary caregivers such as role changes, especially with regard to husband caregivers, no training for their role as primary caregivers and little perceived formal support. Another contribution by this study is the understanding of the important role played by the family as a support system for the primary caregiver, as well as the importance of the close relationship between the caregiver and the woman with advanced breast cancer.

This study was conducted with participants caring for women with advanced breast cancer attending Groote Schuur Hospital, a tertiary hospital providing services to the larger community. The study therefore contributes to the public health sector and could be considered to be socially relevant.

The qualitative methodology contributed towards an in-depth exploration of the subjective experiences of the caregivers and thus providing a deeper understanding of the lived experience of the phenomenon.

5.3 Limitations of the study

This study aimed to illuminate the essences of the caregiving phenomenon as it was understood by the eight participants. Although the small sample size and qualitative design of this study was an effective way to understand the experiences of primary caregivers providing palliative care to women with advanced breast cancer, the small sample size may limit the generalizations that can be made from this study.

A specific limitation is that the interviews were conducted in English and the participants needed to be fluent in English. As a result this study excluded those not able to speak English. Although all the participants were fluent in English, for some of the participants English was not their first language.

Conducting research in the field of palliative care is challenging as experienced in this study as a few of the prospective participants were excluded because of the death of the women with advanced breast cancer.

5.4 Recommendations

Since primary caregivers are not prepared for their caregiving role, it is suggested that they receive guidance and support from health care professionals. The health care system should acknowledge the valuable role played by primary caregivers and should nurture this resource. The findings of a study by Northouse et al. (2002) indicated that caregivers in particular may benefit from intervention programs because they are automatically assumed to be capable of providing complex care with little preparation and support.

Health care professionals in the hospital setting should take cognizance of the difficulties primary caregivers' experience in dealing with their emotions and the need for psychological support. The emotional needs of primary caregivers could be identified with the help of health care professionals and appropriate interventions could be put in place with a view to reducing the psychological distress. It is suggested that psychological services be made available to caregivers to enable them to cope more effectively with their emotional difficulties. It is further suggested that primary caregivers be offered a training program to enable them to cope with the demands of caregiving. Primary caregivers could benefit from additional support to provide care while maintaining their own health and well-being. Grunfeld et al. (2004) suggest that strategies to support caregivers would reduce caregiver burden, potentially prevent psychosocial distress and allow caregivers to focus on their most immediate concern, caring for the dying patient.

5.5 Recommendations for future research

With advances in treatment and longer survival times of women with breast cancer, primary caregivers are likely to be providing care for a longer period of time. In light of this, more research needs to be done on the experiences and challenges faced by primary caregivers providing palliative care over an extended period to women with advanced breast cancer.

In this study husbands were identified as the primary caregiver providing palliative care to women with advanced breast cancer who were married. The impact of the role changes on husbands providing palliative care to women with advanced breast cancer could be explored further.

The sample of participants in this study did not represent the diversity of the South African population. Future research with primary caregivers providing palliative care to women with advanced breast cancer from culturally diverse populations is needed.

5.6 Conclusion

It is hoped that this study contributed to the knowledge that would help health care professionals understand the experiences and challenges that primary caregivers face whilst providing palliative care to women with advanced breast cancer. Primary caregivers are an important resource and play a crucial role in providing palliative care to women with advanced breast cancer. It is imperative that primary caregivers are considered as part of the health care team and their well-being is taken into consideration.

An increased awareness and understanding of the experiences and challenges faced by primary caregivers would give direction to the implementation of appropriate interventions to support them. This understanding would also help to motivate for primary caregivers being considered in the management process of the treatment of women with advanced breast cancer.

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Appendix A

Information Sheet for Patient

Participation by caregivers in a research study

I am conducting a research study for my Masters Degree in Psychology at the University of the Western Cape. The study is entitled *“Exploring the experiences of primary caregivers providing palliative care to women with advanced breast cancer”*. For the study, I will need caregivers to volunteer to participate.

The caregiver willing to participate should be a primary caregiver who is 18 or older and has been providing palliative care to you for at least two months. If your caregiver is eligible, I will need your verbal permission to contact him or her.

Participation by caregivers will involve an interview to explore their experiences whilst providing palliative care to you. The identity of patients and caregivers will be kept anonymous and personal details will remain confidential.

The outcome of this research can be used to increase the awareness of health care professionals of the challenges faced by primary caregivers. It is hoped that through this increased awareness and understanding, health care professionals will actively take steps to provide support to the primary caregiver. In this light, participation by the primary caregiver will be greatly valued.

Your assistance in getting me in touch with your caregiver is greatly appreciated.

Researcher: Ms Jyoti Chauhan

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Appendix B

Consent Form

I, …………………………………………………………......hereby give consent to voluntarily participate in the research study entitled:

Exploring the experiences of primary caregivers providing palliative care to women with advanced breast cancer.

It has been explained to me that the minithesis is in partial fulfilment of a Masters of Psychology Degree in the Department of Psychology at the University of the Western Cape.

The purpose of this research has been explained to me and I understand that I have the right to withdraw from participating in the research study at any time, without redress.

I understand that my identity will be kept anonymous at all times. I understand that after the minithesis has been written; all tapes and transcripts of the interview will be erased to ensure confidentiality at all times.

I am aware that the researcher can assist by referring me to an appropriate counselor if sensitive information spoken about during the interview causes me to feel emotionally distressed.

Signature: Participant ……………………… Date: …………………

Signature: Researcher ……………………… Date: …………………

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Appendix C

Confidential Biographical Questionnaire of Participant

Name	

Age	

Gender	Male	Female

Marital Status	Single	Married	Separated	Divorced	Widowed

Religion	Atheist	Buddhist	Christian	Hindu	Jewish	Muslim	If other please specify

Highest Educational Qualification	Primary School Grade 1 – 7	Secondary School Grade 8 - 11	Matriculation	Diploma/Degree	Other (Specify)

Previous care-giving experience

Monthly Income	Unemployed	R501 – R1500	R1501 – R2500	R2501 – R3500	R3501 +

Children	
Other Dependents	

Living situation	In same household	Separate household

Area in which participant lives	
Area in which patient lives	

Relationship to patient	Spouse/partner	Child	Sibling	Parent	Other (specify)

Caring assistance received	Hospice	Other family members	None	Other

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Appendix D

Interview Guide

1. Describe your experience through a day of caring for the patient?
2. What are some of the good experiences of providing care?
3. What are some of the negative experiences you have faced?
4. What are the difficulties you face whilst providing care?
5. Describe your caregiving role.
6. What does the caregiving role mean to you and why is it important to you?
7. What motivates you to provide care?
8. How does this role affect your life?
9. How has this role affected your physical and mental health?
10. How do you take care of your own needs while taking care of the patient?
11. How do you deal with your own emotional issues?
12. What social support do you receive?
13. What other support do you think would be beneficial to you?
14. Is there anything else you feel is important to mention?