CHAPTER 1:
INTRODUCTION TO THE JOURNEY

1.1   WHERE IT ALL BEGAN

My personal journey as caregiver to my husband, who died of cancer, motivated me to undertake this study. The story which I am about to tell is my way of giving the experience of anticipatory mourning a voice and of relating the meaning I found in the journey as caregiver of my terminally ill husband. In this study, I committed myself to exploring the meaning-making processes of loss during anticipatory mourning – to saying the unsaid (Anderson & Goolishian 1988:371) and seeing the unseen – the gifts (Doka 2003:46). This is my story.

1.2   MY STORY

Louis, my husband of 22 years, died on 22 April 2005. We buried him three days later. Life went on, but a gaping hole was left where once a strong, vibrant man had occupied a space in my life. I found that incomprehensible – I still do.

Cancer entered our lives on 8 October 2003. It had made its insidious presence felt months before – a threatening and painful presence that we could not ignore, but that we could not yet name. On this day, however, Cancer was given a name, a voice and agency. With the diagnosis, it was given permission to claim my husband's healthy body and to proceed with a voracious appetite – leaving destruction and finally death in its wake. Helplessness and Fear were Cancer's companions and this threesome proved to be devastating in their onslaught.

Although we talked about cancer and its anticipated effects, a measure of dissociation ensued for both Louis and me, which proved to be a blessing and a sanity preserver. In her own cancer narrative, Kaethe Weingarten (1997:11) also says that detachment was the only way for her to deal with the shock of her diagnosis. A part of me looked on interestedly – it observed the thoughts when fear and panic spoke to me and it observed the indomitable human spirit which, in the face of the utmost despair, shoulders its burden, smiles, hopes, laughs, loves and does what needs to be done to survive.

I vividly recall the day Louis was diagnosed with cancer. He had been complaining of abdominal pain for a while, which we ascribed to a hernia that had been plaguing him. Although I had begged him to see a doctor, he procrastinated. By the time he submitted to diagnostic testing, the cancer had already spread to the liver. Over the next 16 months, he was operated on three times.

With each round of surgery, we hoped fervently that the cancer would be removed, but each time the cancer returned – more virulent than before. Each time, dismay and fear were followed by hope.

In June 2004, the doctor delivered the verdict we dreaded – Louis's cancer was terminal. That moment is marked in my memory as the point at which my *first grieving* began. This first grieving period was followed by a second grieving when Louis became unable to communicate or recognise me. In my story, I refer to the period from death onward (also called post-death mourning) as the 'final grieving' (see Section 1.2.3 below). In a sense, the final grieving presents an ongoing process of mourning and meaning-making. The focus of this study, however, is the pre-death or anticipatory mourning period. Kehl (2005:206) refers to the experience of grief prior to the death of a loved one as 'anticipatory mourning'. For the purposes of this research project, I use the term 'anticipatory mourning' to refer to the period commencing with the terminal diagnosis of a loved one and concluding at the moment of death.

1.2.1   The first grieving

Sampson (1989:8) cites Derrida, a French philosopher, who seeks to discover and unpack the meanings – visible and hidden – of concepts such as 'grief'. Derrida (cited in Sampson 1989:8) argues that when one meaning of a concept becomes visible, for instance, 'darkness', the opposite is invariably present as well, for instance, 'light'. Within the trauma of Louis's illness, the opposite of grief emerged as 'gifts' – moments of normality and respite of which I gratefully became aware. In contrast to the devastation of the *first grieving,* the first gifts became visible, namely the realization of the depth of Louis's love for me. He would painstakingly explain step-by-step actions to be followed after his death – from dealing with finances to finding potential life partners. He drew up a list of what I had to do from the moment of his death. We spoke about these matters calmly and matter-of-factly, as I knew he preferred to do.

I recall a specific incident, so profound in its care that I still marvel at it. Louis insisted that I perform a 'practice run' of his death, by phoning the funeral home. I obediently telephoned the company, introduced myself to the manager by name and informed him that my husband was dying and that I would soon require his services. As macabre as this activity seemed to me at the time, it proved strangely comforting during the following months. I clung to that 'to-do list' and the – now familiar – name of the funeral manager as the only 'predictables' in a world of 'incomprehensibilities'.

A second gift during the first grieving period turned out to be a profound time of discovering each other anew. We grew closer than we had ever been, an experience also reported by Sharp

(1996:181). We spent every waking moment together, talking at length about our relationship and the future. Many issues of past hurts and irritation were aired and dealt with. At night Louis would snuggle into the crook of my arm and we would repeatedly and desperately declare our love for one another.

I was acutely aware of the paradox of meanings embedded in a concept to which Derrida (in Sampson 1989:8) refers. Feelings of utter grief and desolation were juxtaposed to a new-found love, profound and devoid of petty complications. Loving a man, I discovered, was simple, provided one offered unconditional care. Loving a dying man was profound in both its simplicity and fear – there was no projection of future hopes, no holding on to past affronts – just an intense appreciation of the moment and the gifts it brings.

Christmas and New Year came and went in a blur of calm, alternating with trauma. Perhaps the biggest source of stress was the unexpected way in which Cancer attacks – silently and viciously. We too discovered that '[h]aving to wait passively for the development and onslaught of distressing events may be intolerable' (Zuidgeest 2001:51). Periods of seeming calm and wellness would be followed by severe attacks of pain and illness. I found myself in a permanent state of nervous anticipation – nothing in my frame of reference could have prepared me for that emotional rollercoaster. Louis refused to take morphine, because it made him bilious. When the pain gripped him, he would scream in agony so intense it seemed to herald straight from hell. That was more traumatic to me than anything else – I could not help him. I could not make it better.

Sometimes I would rush him to hospital for an intravenous drip and some relief. At other times, I remained a desperate and impotent onlooker. I could not enter his world, and despite the availability of friends, hospice and medical personnel, I knew that ultimately we were alone, at sea – barely afloat – directed by a rudder called Cancer.

Despite fear and helplessness, we talked endlessly during the periods of calm. We also spoke at length about hospitalization, especially closer to his time of death. The doctor suggested that Louis remained in a ward on a permanent basis. Louis could not bear the thought and I resolved to care for him at home. He was greatly comforted by this decision and I somehow found solace in the fact that he would be in a loving and nurturing environment. My experience confirms the findings of Carol Komaromy (2005:32), who cites a study which supports the claim that personalized palliative care affords the bereaved greater consolation in the aftermath of death. I also resolved that I would be there to hold him at the moment of death. Until that moment, however, many unexpected gifts would become visible. I looked at Cancer, simultaneously dreading its destruction and marvelling at the gifts it brought.

1.2.1.1 A gift of revival

In January 2005, I fell ill and was admitted to the intensive care unit at our local hospital with an apparent heart condition. I was stunned – my health had always been extraordinarily good. I was to discover that a number of studies have found evidence of an increased incidence of heart disease, impaired immune response and emotional distress in grieving and/or caregiving people (Ferrario et al 2004:129; Greenberg 2003:1; Williams 2005:90). I was desperate to get back to Louis. At the same time, I felt strangely apathetic. Utter exhaustion and death ideation fed my apathy. If death came to my rescue, I argued, I might avoid the pain of losing Louis. Indeed, Moskowitz, Folkman and Acree (2003:476) found that bereaved caregivers experience a higher incidence of depression due to physical, psychological and social depletion. However, over a seven-month post-bereavement period, those who find positive meaning in caregiving tend to display less depression.

My illness proved to be a blessing in disguise. Louis was painfully thin by this time, but he was granted a miraculous, albeit brief, two weeks of renewed energy and painlessness. I will never forget his gaunt face at visiting hours, greeting me with a huge grin and a cool drink. In the absence of my – sometimes over-zealous – caregiving efforts, he was freed to have fun, which included felling a tree and eating large quantities of biltong! This respite turned out to be the last time he would ever consume anything by mouth.

The day before my discharge, Louis became violently ill. He was rushed to hospital and into surgery in an attempt to remove the fetid mass of semi-digested food that was stuck in his intestines. From that day on, he received saline solution intravenously – we knew time was getting short. I would rush off to the pharmacy or grocery store accompanied by a wild and overwhelming fear that he would die alone in my absence. At night, during fitful periods of sleep, I would wake up in a panic in case he had died while I had been asleep. The warmth of his body was profoundly comforting – we had been given another day.

1.2.2 The second grieving

By February 2005, the pain had become unbearable and I was instructed to administer large doses of morphine. Louis would become disoriented and lost and, during moments of clarity, became distressed – he was losing his mind, he would lament. And Louis, in 'losing his mind' was lost to me as well. That moment is marked in my memory as the *second grieving* – more devastating than the first. I lost him two months before his death – a desolation I was quite unprepared for. Now I was alone on the raft, taunted by Cancer and accompanied by the wild ramblings of a stranger, a madman, my husband.

We were in a 'twilight zone' – a timeless and measureless limbo where every waking moment was consumed by caregiving; and 'every moment charged with the unspeakable and the unknowable' (Weingarten 1997:8). Becker and Knudson (2003:702) refer to this period as the 'twilight between living and dying'. I experienced the 'twilight' in an intense way – I imagined feeling what Louis felt and at times I identified so strongly with him that I had to remind myself that it was not *I* who was ill or dying. Fulton (2003:346) asserts that identification is a possible occurrence in survivor spouses.

1.2.2.1 Gifts

Humour and hope sustained me during those terrible months after Louis's presence had left. Once, in a moment of lucidity – or so I thought – he looked directly at me and in a flirtatious voice wanted to know whether I was a nurse and who was paying me for my services. I giggled and gave him an inane reply. He became quite irate at my reply and accused me of taking him for a fool. This incident presents an example of unexpected gifts during those bleak and desolate months. I went about my duties perfunctorily and tried to enter his world for some semblance of togetherness, by listening to his mutterings and joining in as best I could. Mostly I was unsuccessful. He would suddenly fix a penetrating stare on me and enquire whether I thought he was mad. I would attempt to placate him and explain that it was merely the madness of the morphine.

I received another, profound gift after we had entered the *second grieving*. Louis was now very ill and death was both threatening and elusive. One night, long after I had given up on ever seeing his eyes light up in a familiar way, I fell into fitful sleep. He was muttering in a drug-induced sleep, but seemed relatively peaceful. Just before midnight, I woke up to tender arms embracing me and smacking kisses raining on my face. I opened my eyes to see that familiar face looking down at me, aglow with love. Louis had returned from his dark wanderings. I was held and kissed repeatedly and I basked in the pure joy of his care. Then he left. He did not return again.

1.2.3   Death: a final grieving

Louis died at half past ten in the evening on 22 April 2005. It was a peaceful death. I watched him die and held him in my arms. The moment of death was gentle and fluid and not at all the way I had feared it would be. He took one last breath and left quietly. I held him until his body grew cold. Kübler-Ross (1969:276) describes the moment of death as 'the silence that goes beyond words' – a moment when we who witness a death are fully aware of our finiteness and our limited lifespan. The impact of that moment has remained with me. We are but a shooting star and I realize that the moment which matters is now and only now – that is all we have.

During the days following his death I probably reacted like most bereaved spouses – I was numb. I breathed, ate and slept fitfully. I felt lost, yet strangely at peace. I also, guiltily, experienced a sense of relief. Moskowitz and others (2003:476) note that the death of a chronically ill partner is often accompanied by feelings of relief from an extremely stressful period, a comment that validates those feelings which I did not dare share with anyone at the time. After the funeral service, I went home, excused myself from well-meaning family and friends and, in the solitude of our bedroom, where Louis had been bodily present a mere 72 hours earlier, I opened his letter to me, profoundly aware that this was the last letter I would ever receive from him.

1.3   MEANING-MAKING: PERSONAL REFLECTIONS

When I reflect on my story, I am confronted by the inordinate amount of time which has passed since I first began writing. Conducting this research has been both illuminating *and* taxing. I have ventured into a quagmire of painful emotions, but I have also gained profound insights which I discuss in Chapters 3 and 5. The most significant aspect of this study has been sharing the lived experiences of the research participants (see Section 1.12.1 below) and the way in which *telling* their stories has helped them to make meaning of anticipatory mourning (see Chapter 3).

Making meaning of bereavement in general and of anticipatory mourning in particular has been an ongoing process for me. Each time I tell my story, new or revised meanings emerge. It may be argued that my healing may therefore never be complete – and perhaps it is fitting that it should be so. Gergen ([1999] 2003:129) warns against traditional binary thinking in terms of opposites, for instance, the 'bereavement/healing' binary; and instead suggests that, rather than searching for a specific outcome such as healing, we declare ourselves open to any outcome which may present itself in interaction. My experience resonates with this contention. Healing for me therefore means embracing any form of meaning which emerges when I tell my story to another.

Upon reflection, I believe that I have found meaning or purpose in most aspects of Louis's death – I am, however, still in the process of making meaning of his suffering. In my experience, the suffering peaked during anticipatory mourning – both Louis's suffering *and* mine. I can now look back and admit that I was suffering too – as an impotent onlooker, as an over-extended caregiver, as a lover and as a wife. After Louis's death, I knew that his suffering was finally over and that I as the surviving spouse had begun the downward journey, albeit slow and painful, of the process of healing. Moreover, I could only grasp the depth of our suffering in *retrospect* and it is for this reason that I selected the participants (see Section 1.12.1 below) of this research to *reflect* on anticipatory mourning and meaning-making in retrospect.

When I reflect on meaning-making, I still find the concept difficult to define. Nadeau (1998:14) suggests that meaning-making is the process by which one arrives at an understanding of the *significance* of an event. Meanings are products of familial, societal, cultural and historical *interaction*. A search for meaning asks 'what does my life mean now?' (Nadeau 1998:14). For Gergen ([1999] 2003:145), meaning is made when one is able to say: 'Now I know how to go on.'

Meaning also seems transitory and temporal – it is always changing in the light of new insights. Meaning asks about the *purpose* (Golsworthy & Coyle 2001:188) of *now* but it also asks about the purpose of *tomorrow* within a historical and a spiritual context (see Section 2.3.8). Contextual meaning is always available to us, but the threat of *meaninglessness* may obscure opportunities for making meaning. In my experience, the threat of meaninglessness resided in Louis's suffering – and mine. Potential meaninglessness also resided in the anxiety, the loneliness, the many losses of identity, roles, spiritual confidence and daily predictability and, above all, the impending loss of a life mate. Nothing in her frame of reference can prepare a caregiver for this fearful experience. However, in a macabre sense, one is also intensely alive – each moment is both fleeting *and* endless.

In those endless moments I found meaning in laughter, overwhelming tenderness and other special moments. I began to refer to those moments of meaning as 'gifts'. I found that, when I tried to hold onto the moments, they evaded me. In 'storying' and 'restorying' them, however, I was able to build these fleeting moments into narratives of hope and meaning. They included a renewed sense of identity, a stronger albeit revised spirituality, a continued relationship with Louis, and an awareness of the societal discourses (see Section 2.3.7) that prescribed our actions and tended to marginalise the voice of my experience. Discourses may be defined as sets of meanings in language (Kotzé & Kotzé 1997:33) which are legitimised by society as 'knowledge' and enforced by society as 'truth', often denying people's internal and subjective knowledges in the process.

Despite many prescriptive discourses (see Section 2.3.7) that I was confronted with by well-meaning people who cared about me, the ability to language my story provided meaning to me, while the awareness of unexpected moments of resilience and laughter – the gifts – provided me with the glue that held the narrative of meaning together. Narratives of meaning are created through language in interaction with one another and therefore they continue to change in the light of the circumstances and the types of interaction people engage in (Burr 1995:40). Martin Payne (2000:29-30) suggests a bilateral relationship between narrative and meaning. Narrative provides the means by which meaning is made and meaning formalises a purpose to life and

joins everyday events into a story – the 'primary scheme by means of which human existence is rendered meaningful' (Polkinghorne in Payne 2000:30).

My stories of meaning rendered existence meaningful to me. However, the awareness that my stories were unique to *my* experience made me curious to discover how other caregivers (see Section 1.5 below) had made meaning during anticipatory mourning; how our adaptive meaning-making processes may have been marginalised or silenced by, for instance, medical, religious and mourning discourses (see Section 2.3.7); and how a pastoral counsellor may care *with* a caregiver in co-constructing meaning (Kotzé & Kotzé 2001:5-7). My motivation to explore non-judgmental and co-constructive pastoral care in the face of the impending death of a loved one was born from my personal need during anticipatory mourning. I had needed a pastoral carer to listen to my story and simply hold my pain. Instead, my experience of pastoral care included prescriptive prayer ('Lord, teach Louis and Estelle to accept your perfect will'), admonishments that 'now is not the time for tears' and exhortations that I should 'have faith' and 'be strong'. These ministrations silenced my voice and contributed to feelings of isolation – and as my sense of isolation grew, so my need for meaning increased exponentially.

1.4   RELEVANCE OF THE STUDY

The literature seems to concur that all people harbour an inherent need to make meaning of their lives. Victor Frankl ([1959] 2004:104) believes that the 'will to meaning' is a central human motive, while Erich Fromm (Bee 1996:329) holds meaning to be one of five central human existential needs. James Fowler asserts that 'we can't live without some sense that life is meaningful' (Bee 1996:329). A study conducted by Milton Yinger in 1977 (cited by Bee 1996:328) found that sixty per cent of his participants believed that 'meaning' is one of the fundamental needs of humanity. Although the search for meaning varies in intensity, most people seek to understand and come to terms with significant events in their lives (Davies 2000:143-144). 'Without understanding, we are lost...we cannot generate meaning together' (Gergen [1999] 2003:143).

In terms of anticipatory mourning, people need to know *why* a loved one is dying and they need to understand the deeper philosophical meaning which underlies the impending death (Davis & Nolen-Hoeksema 2001:729). Our inherent belief in justice, fairness and an ordered life leads us to want to believe that something as monumental as the impending death of our spouse *must* have a meaningful reason (Davis & Nolen-Hoeksema 2001:729). Hence, I believe that this study is relevant for two reasons. First, the *need for meaning* appears to be a universal need in humans and, because of its relevance for all, it is necessary to study the process of meaning-making. Second, research literature on *caregiver meaning-making* (Cheung & Hocking 2004:476) and pastoral care for caregivers in *anticipatory mourning* appears to be limited (Cheung & Hocking

2004:475; Hunt 2003:31; Kehl 2005:206; Kruse 2004: 216; Davies 2000:151). Indeed, De Jongh van Arkel (2000:284) asserts that most of the research available on the needs of the dying and their families is focused exclusively on the dying, and *not* on their loved ones. In the light of the above, it seems clear that there is a need for research and research literature on caregiver meaning-making in anticipatory mourning.

1.5   RESEARCH CURIOSITY

Based on my experience, the lack of research and a universal need for meaning, I therefore became interested in the meaning-making processes of other caregivers and the socially constructed meanings (see Chapter 2) which hampered or facilitated their meaning-making. This led me to the following research question:

> ***How did the caregivers of terminally ill spouses make meaning of their circumstances during anticipatory mourning?***

1.6   PURPOSE OF THE STUDY

In an attempt to answer the research question, the following research aims were formulated, namely to:

- explore the meaning-making process of caregivers and the knowledges they had gained in anticipatory mourning;
- describe the social constructs of meaning that influence the process of meaning-making; and
- discover how pastoral counsellors may participate with caregivers in co-constructing new or alternative meaning.

1.7   LITERATURE CONTROL IN PREFERENCE TO LITERATURE REVIEW

In order to realise the aim of the research project, my next step was to document the literature available on the subject of caregiver bereavement in anticipatory mourning. I was confronted with a choice between a traditional literature review, usually contained in a separate chapter (De Vos, Strydom, Fouché & Delport 2005:264), and a literature control, woven in throughout the study. I decided to use the literature control approach, where research findings from the literature are incorporated into the text as a part of the process of research writing (De Vos et al 2005:264), rather than in a separate section of summarised research contributions, as described by Reinharz (1992:150).

A *literature review* functions as a summary of the findings of significant studies which confirm arguments in a research study, but it also serves to question or contradict prohibitive discourses operating covertly in the literature and in researcher and participant responses (Reinharz

1992:150). A literature review may offer new ideas, examples of methods successfully used by other researchers, and interpretations, confirmation or complementation of one's research findings (Leedy & Ormrod 2005:65-65). A literature review also indicates possible gaps in research (as in the case of this research topic), as well as underlying assumptions of the research paradigm that forms a framework for the study (De Vos et al 2005:263).

A *literature control* serves similar functions to those of a literature review but, rather than offer a separate summary of research findings, a literature control becomes an integral part of the body of the research writing throughout the study. Since the final result of this phenomenological study presents a description of a phenomenon by people who have personal experience of that event, I believed that the findings should be *related* to and enter into a dialogue with a body of existing literature, as suggested by De Vos and others (2005:264), as if the literature and the research process journey together in a co-constructive conversation. Hence, the literature control became part of the process of meaning-making, which seemed to be the most appropriate approach to take in this study. As I continuously relate my findings to the relevant literature, this 'conversation' also functions as a meaning-making tool, creating a shared meaning in a trialogue between the literature, the reader and the writer. I would contend that, in this case, the literature control is supported by a feminist research orientation, which implies a focus on the *process* of research and the product is regarded as only a part of this journey, as suggested by Reinharz (1992:212). A separate literature review might therefore have represented a 'disembodied truth' rather than an *integrated part of the process*, interwoven throughout the research study, as Reinharz (1992:212) cautions.

My use of a literature control also implies that I *continuously* test my findings against the available literature *throughout* the research study (Alpaslan 2009:19). For this reason, Chapter 1 forms part of the literature control and it is of necessity longer than the traditional opening chapter of a research study. Chapter 2, which normally contains a separate literature review, is therefore an integrated part of the research study where the literature control continuously tests the research findings against the available literature.

The following section offers a conceptualisation, combined with a literature control, of relevant terms, which is intended to enhance the negotiation of shared meanings between you as the reader, the research participants and myself as both a participant *and* the researcher.

1.8   CONCEPTUALISATION AND LITERATURE CONTROL

Conceptualisation refers to the description of terms as they are 'used in relation to the researcher's project' (Leedy & Ormrod 2005:56). Please note that meaning and the process of

meaning-making are not conceptualised in this section, because they have already been described in Section 1.3 above and are dealt with extensively in Chapter 2.

This study focuses on *women* as caregivers to their dying spouses and, for ease of reading, the participants and caregivers are referred to in terms of the *female* gender throughout. The omission of the male gender in this study is *not* intended to imply disrespect for or a negation of a male caregiver experience. The following terms are conceptualised in the sections below, namely 'caregiving', 'anticipatory mourning' and 'bereavement'.

1.8.1   Caregiving

Larson (2000:379) defines caregiving as the provision of care to a person who faces a life-threatening illness. For the purpose of this study, the concept of caregiving refers to the actions of women who tend to the needs of their terminally ill husbands during anticipatory mourning. Five women participated in this study and they are referred to as the caregivers and/or participants (Section 1.12.1 below). It is contended that caring for a dying spouse means taking on the dual roles of caregiver *and* anticipatory mourner – these roles make large demands on the caregiver and place significant stress on the wife as spouse, caregiver and mourner.

Moskowitz and others (2003:476) as well as Ferrario and others (2004:129) have found that, compared to 'non-caregiving intimates', 'caregiving intimates' display heightened vulnerability to the deleterious effects of bereavement, due to psychological, social and physical depletion. They point out that caregiver intimates are at risk of becoming patients themselves. My experience of hospitalisation supports their contention (see Section 1.2.1.1 above).

In Section 1.8.2.1 below, I argue that there are differences as well as similarities between anticipatory mourning and post-death mourning. If anticipatory mourning and post-death mourning are accepted as distinct but also overlapping mourning states, then many of the negative effects cited in literature may be applicable to both. Among the deleterious effects cited are health problems, insomnia, drug and alcohol abuse, decreased social interaction, work disruption, anxiety, increased mortality, depression and suicide ideation (Moskowitz et al 2003:471; Potocky 1993:288). In addition, Gersia (1991:158) describes a 'paralysis of will' which often dominates the bereaved, as well as feelings of loneliness, lost identity and diminished social status.

Despite the high price which caregiving exacts from the bereaved, it also presents many gifts. Joseph Sharp (1996:221) suggests that accompanying a dying person is a true gift without conditions, since there is nothing that can be expected in return: 'It is a gift that expects no reciprocity, done purely for the respect and love of life itself. We are bestowing our most intimate

blessing in a very pure way. Our blessing is to honor and love, expecting nothing in return' (Sharp 1996:221). In my own experience, I found that unexpected rewards emerged from my act of caring for Louis: it provided us with precious time together; we were able to resolve issues of past hurts; caregiving allowed Louis the consolation of being in familiar and nurturing surroundings with his loved ones; and caregiving also allowed me the solace of knowing that I did the best I could – a final and meaningful tribute to the man I loved. These aspects of caregiving provided infinite meaning to me in my journey of anticipatory mourning.

1.8.2   Anticipatory mourning

Kehl (2005:206) asserts that controversy and insufficient research surround the concept of anticipatory mourning as a state significantly distinct from post-death mourning. In Section 1.8.2.1 below, I argue that anticipatory mourning (the period before death) and post-death mourning (the period after death) display many differences, but also areas of overlap. Fulton (2003:343) criticises the use of the concept of anticipatory mourning for a lack of specificity, its subjective nature and the lack of an operational definition. However, Kehl (2005:206) defines anticipatory mourning as 'the emotional response to the *threat* of death of a loved one', including the concepts of planning, reorganization and facilitating the process of dying.

Rando (2000:4) operationalises anticipatory mourning as a phenomenon

> …encompassing seven generic operations (grief and mourning, coping, interaction, psychosocial reorganisation, planning, balancing conflicting demands, and facilitating an appropriate death) that, within a context of adaptational demands caused by experiences of loss and trauma, is stimulated in response to the awareness of life-threatening or terminal illness in oneself or a significant other and the recognition of associated losses in the past, present and future.

Whereas anticipatory *grief* represents the experienced pain of loss, anticipatory *mourning* represents the creation of meaning through active coping strategies (Rando 2000:4-5). Thus anticipatory grief is the emotional reaction to loss, while anticipatory mourning is the struggle to understand, to cope, to plan and to negotiate the circumstances, the losses and relationships with God, the loved one, oneself and others.

If anticipatory mourning is accepted as a theoretical *and* an operational concept, the question of commencement and duration arises. Rando (2000:4) asserts that anticipatory mourning commences with the *awareness* of terminal illness and the *recognition* of associated losses. Elisabeth Kübler-Ross (1969:166) notes that a sense of loss may commence the moment a partner is bedridden or functionally limited. In my case, my anticipatory mourning commenced the day we received the verdict of *terminal cancer,* and it endured until the day Louis died.

Paradoxically, and in contrast to the many losses experienced during anticipatory mourning, increased intimacy between a caregiver and her spouse presents an infinite possibility. Thus, for the purposes of this research, it is further understood that anticipatory mourning encompasses both losses and gifts, such as a renewed love for one another. Sharp (1996:181) suggests that when a conscious awareness of death enters a relationship, 'true intimacy blooms brighter than we could have ever imagined'. Once we invite dying into our everyday lives, each moment of a lived life becomes weighted with significance – a sacredness within – God within (Sharp, 1996:29).

For Louis and me, the weighted significance of our time together became particularly meaningful. An opportunity to make relational meaning with Louis could only be used while he was still alive – and this presents one of the fundamental differences between anticipatory mourning and post-death mourning. The comparative framework in the next section highlights the similarities as well as the distinct differences between anticipatory mourning and post-death mourning.

1.8.2.1 The relationship between anticipatory mourning and post-death mourning

One of the most significant – and obvious – differences is that the loved one is still alive and present during anticipatory mourning, which makes it possible to engage in many of the mourning tasks confronting the caregiver, such as dealing with unfinished business, calling the loved one as a witness and co-constructing a legacy of the dying loved one (see also Section 4.4.4). A second significant difference between anticipatory mourning and post-death mourning is ever-accelerating anxiety levels during anticipatory mourning, resulting in a constant state of hyper-vigilance (Rando 2000a:25). Ambivalent feelings and anxiety during anticipatory mourning also accelerate markedly in terms of *intensity*, whereas anxiety during post-death mourning generally tends to decrease (Rando 2000a:25). In addition, anticipatory mourning has a definite ending, while post-death mourning may continue indefinitely. Interestingly, and in contrast to what has already been said, *mourning* does not necessarily increase as death approaches – this phenomenon may be ascribed to a balance between denial and acceptance, which facilitates grief work (Rando 2000a:25).

Personally, I experienced accelerated anxiety during anticipatory mourning which I would ascribe to the many losses which I *had* already experienced (Louis's social presence and his active contribution to our household), losses which I was experiencing *at that time* (a disruption of our normal activities), as well as anticipated *future* losses (loss of future plans, Louis's physical deterioration and, eventually, his death). Rando (2000b:54-55) suggests that the time foci, in terms of past, current and future losses, intensify the stress of the anticipatory mourning period and differ substantially from post-death mourning, where uncomplicated grief and stress may

gradually subside. However, this assertion excludes complicated grief characterised by distorted, compromised or failed mourning (Rando 2000c:169), or physical and/or mental illness (De Klerk 1972:147). Perhaps three of the most significant differences between anticipatory mourning and post-death mourning are the completion of unfinished business, reassurances of love and care, and drawing closer to the loved one - and these three aspects remain a veritable possibility until the moment of death.

Different opinions are expressed in the literature regarding the benefits which healthy anticipatory mourning may hold for post-death mourning. There seems to be an overall indication of a positive relationship between healthy anticipatory mourning and post-death mourning. Freud asserts that effective anticipated mourning could lead to reduced psychic pain in post-death grief (Kehl 2005:207). Prior studies of adult bereavement support the contention that anticipatory mourning as a 'forewarning of loss' may prove to be benign in its effect on adaptation in the 'post-mortem' phase of grief – Fulton (2003:345) cites Ball (1977), Bornstein, Clayton, Halikas, Maurice and Robins (1973), Friedman (1963), Gerber (1974), Glick, Weiss and Parkes (1974) and Parkes and Brown (1972) in support of the positive relationship between anticipatory mourning and post-death adaptation. A study by Rando (in Kehl 2005:208) also found a positive association between anticipatory mourning and emotional preparedness at death, as well as a reduction of grief after death. By contrast, some studies found a lack of evidence regarding the benefits of anticipatory mourning, citing emotional depletion, affective detachment and positive social support rather than effective anticipatory mourning as contributing factors to reduced post-death grief (Fulton & Fulton 1971:91-100).

Despite many differences, anticipatory mourning and post-death mourning also present areas of similarity or overlap. The most important of these may be physical depletion and feelings of loss, mourning and sadness. This overlap, I believe, intimates a common theoretical base; hence the focus on both psychological *and* theological theories of bereavement in the next section.

1.8.3   Bereavement

Bereavement is described as 'the pain of not having' (Gersia 1991:158). Hartshorne (2003:145) describes bereavement as 'the emotional reaction to a death, both psychological and physical'. In this study, bereavement refers to the experience and associated feelings of loss, through cancer, of a life partner. Bereavement will also refer to other perceived losses, such as the impending loss of the traditional family unit, the loss of familiar roles (such as wife and lover), the loss of *past* dreams, *present* life quality and *future* aspirations (Rando 2000d:307).

The literature appears to distinguish between bereavement as the state of loss and grief/mourning as the expression of loss. However, I use these terms interchangeably in reference to the losses experienced by the caregiver in anticipatory mourning.

In the light of multiple losses experienced on many levels, it is argued that the caregiver's bereavement commences with an *awareness* of inevitable and ongoing loss – hence the beginning of anticipatory mourning. The following sections explore different theoretical approaches to bereavement. These approaches identify stages or symptoms of grief and offer explanations for the ways in which people make meaning of bereavement.

1.8.3.1 Psychological theories of bereavement

Theories of bereavement present various areas of focus (Kastenbaum 2004:360), for example, Freud's intrapsychic focus, Bowlby's interpsychic attachment theory, Worden and Rando's task theories, Elisabeth Kübler-Ross's stage theory, Nancy Moos's integrated family model of grieving and Michael White's trauma theory. White's theory does not focus on bereavement *per se*, but it can be contended that anticipatory mourning is often accompanied by significant trauma (Rando 2000d:338) and Michael White presents a theory of trauma relevant to bereavement and the experiences of the caregiver in anticipatory mourning. These theories are discussed in more detail below.

a) Sigmund Freud

Freud focuses on personal, *intrapsychic* processes (Kastenbaum 2004:360). His concept of '*griefwork*' suggests a confrontation with, and letting go of, attachment to the lost object and a restoration of reality. Griefwork is time-consuming and difficult; and Freud contends that failure to do griefwork leads to pathological grief, which means that grief accelerates and intensifies instead of decreasing gradually. In his opinion, failure by the mourner to do griefwork may lead to a personality dysfunction.

b) John Bowlby

John Bowlby's focus is on the *interpsychic* relations (Millán & Millán 2004:157). His *attachment theory* suggests that the goal of attachment is the security and preservation of a bond with a significant other. A threat to the survival of the attachment will elicit emotional distress and action to restore the bond. If this action fails, it may lead to chronic stress and intense grief reactions, which I believe are particularly evident in anticipatory mourning.

c) William Worden and Theresa Rando

The *task theories* of William Worden and Theresa Rando (Kastenbaum 2004:363) suggest that life and grief present *tasks* such as accepting the loss, working through the pain, adjusting to and reinvesting in a new life and then placing the bereaved in the past, while still maintaining memories of the lost one.

d) Elisabeth Kübler-Ross

In contrast to the above, Elisabeth Kübler-Ross and other *stage theorists* espouse a theory of *stages* through which the bereaved moves, namely shock, numbness, disbelief and, finally, a physical and mental rebalancing (Kastenbaum, 2004:364). Contrary to stage theories, Wortman and Silver (in Bee 1996:426) suggest four distinct *patterns* of grieving, namely a normal pattern (high intensity but quick recovery), a chronic pattern (high distress over many years), a delayed pattern (low distress at first, increasing later) and an absent grieving pattern.

e) Nancy Moos

Nancy Moos discards stage theories in favour of an integrated family model of grieving. She identifies five *grief symptoms*, namely family isolation, confusion of family roles, reconnection to or disconnection from family members, and changes in communication (Kastenbaum 2004:364).

f) Michael White

Finally, a theory of trauma is espoused by Michael White (2004:70-71). White views trauma in terms of six *principles* of possible influence, namely i) *dissociation* (referring to a detached consciousness of personal reality); ii) *hierarchical dissolution* (chronic stress, loss of meaning and a loss of sense of self); iii) *uncoupling* (a detachment of a sense of 'I' from the relational part of 'me' leading to an inability to evaluate and reflect on one's own experiences); iv) *meaning* (usually negative since the trauma is irreconcilable with the familiar frame by which the caregiver *used to* make sense of her world); v) *devaluation* (negative conclusions about God, meaning of life and the self); and vi) *chronicle* (life viewed as a meaningless, problem-saturated and fragmentary series of events only). A narrative approach of telling, revaluing those aspects that the mourner regards as important, re-associating dissociated memories and a resonating, caring listener can reconnect the mourner to a new sense of self and of meaning (White 2004:71-72).

The theories above may be helpful in providing insight into the mourning process. However, because each person experiences grief in a unique way, the process of finding meaning in the face of death remains an existential challenge and it is therefore closely related to religious or spiritual beliefs (Doka 2000:105). The next section explores a theological approach to bereavement theories.

1.8.3.2 Theological theories of bereavement

According to McCall (2004:18), theology lacks spiritual models of bereavement when caring for the bereaved. Theological literature seems to indicate that some theologians use psychological theories of bereavement and then adapt those theories to theology. For instance, De Jongh van Arkel (2000:294-298) adopts the psychological bereavement theory of Worden (see Section 1.8.3.1 c) above) in respect of the four tasks of mourning, while Zuidgeest (2001:52) prefers the coping theory of Lazarus and Folkman (see Section 1.8.3.2 a) below). However, Zuidgeest also links this coping theory to a narrative concept of faith as a search for meaning in times of stress (Zuidgeest 2001:56). Such theological theories are discussed below.

a) Zuidgeest

Zuidgeest (2001:610) frames his bereavement theory in terms of three *forms of grief regulation*, namely i) *expressing feelings of grief before God* which provides release and connection with God; ii) *perceiving the loss in a new religious or spiritual perspective* through a focus on four metaphors of God, namely the kingdom of liberation, the resurrection of the body, a new heaven and earth and a new life in Jesus Christ; and iii) *accepting a relationship with God and with others.* He considers these acts of expression, of shifting perception and acceptance of new relationships to be meaningful in grief regulation. Zuidgeest (2001:610) also cites Bowlby's attachment theory and suggests that God may come to be regarded as an attachment figure that never leaves and can so be relied upon as a place of safety in times of grief.

Personal reflection

When I reflect on Zuidgeest's suggestions (2001:610), it seems possible to me that mourning not only includes the loss of the caregiver's spouse as an attachment figure, but also the simultaneous loss of God as a reliable attachment figure, especially when prayers for healing seem to remain unanswered. This notion is also expressed by C.S. Lewis (1966:9-10), reflecting on the death of his wife. Thus, in a sense, the caregiver loses God in order (hopefully) to find Him again through a revised framework of spiritual meaning.

The reflection above finds an echo in McCall's theory of stages below, relative to the *Dark Night of the Soul.*

b) McCall

McCall (2004:18), a theologian and director of pastoral services at New Hampshire Hospital, holds that bereavement is a spiritual experience and when it is met with a sense of God's presence, an ability to transcend the trauma, and sufficient resources, the process of healing

becomes a gift (McCall 2004:171). He suggests that there are six *stages of spiritual grief*, namely: i) *Awe* (Shock) signalling the commencement of something new; ii) *Disbelief* (Denial) likened to the experience of Moses climbing the mountain in the wilderness; iii) *Lamentation* (Feelings) signifying the experience of wailing in the midst of the awareness of the eternal power of God; iv) *Despair or the Dark Night of the Soul*, where surrendering to helplessness leads to the restoration of hope in God; *Discernment* where spiritual relationships are forged or discarded; a *Moment of conversion or calling* experienced as clarity, creative power and the return of God; v) *Renewal of beliefs* (Reorganisation) signalling growth, reflection and openness to new possibilities; and vi) *Healing connections* (Recovery) indicating spiritual energy, celebration and moving back into daily living (McCall 2004:167-170).

c) W J de Klerk

Like McCall, De Klerk (1972:126-132), a professor in theology, proposes a *four-phase stage theory* of mourning, namely: i) *Confusion* characterised by befuddled emotions and a sense of unreality; ii) *Searching* evidenced by an acute sense of loss, an obsessive replaying of memories and a search for God and for meaning; iii) a *Forming phase* of intense yearning, but the beginning of a future-orientation; and iv) an *Organising phase* evidenced by acceptance of loss and a new balance of being *in* God.

d) Walters

Finally, Geoff Walters (1997:55-56), a Baptist minister and theologian, explores the social *discourse* which prescribes that grief should not be expressed publicly. Walters ascribes the notion of non-expression of grief to Plato's theory of immortality which holds that the human soul is immortal and the body is a prison which hinders the soul's fulfilment. Death of the body should thus *not* be mourned. Grief is a *weakness*, representing a *faulty view* of God (Walters 1997:66), and grief expressed belongs in the realm of the uneducated. Walters (1997:63) writes that this 'disembodied' theory of mourning had a profound impact on the young Augustine, who began his career as a Christian priest and later became the Bishop of Hippo. Augustine's writings have influenced Christianity's view of mourning for fourteen centuries (Walters 1997:63), prohibiting the public expression of grief and silencing the voices of mourners.

If bereaved Christians today are still prohibited from expressing their grief openly, the question arises how the church can care for those that grieve. It has been contended that feminist theology provides a framework of meaning by which we may address the silenced voices of mourners and create space for a vivid expression of grief (Ackermann 2003:108). Section 1.8.4 below explores

the role of the pastoral counsellor in caring for the caregiver and creating space for grief expression and meaning-making.

1.8.4   Pastoral counselling – caring for the caregiver

My personal experience of prescriptive pastoral care (see the eighth paragraph of Section 1.3 above) and the need to make meaning of my grief despite pastoral remonstrations served as an impetus for me to find respectful ways of caring for caregivers. Thus this research project was guided, first, by the assumption that the *tribute* of caring for a loved one creates meaning in the face of many losses and much suffering and, second, by the desire to explore ways in which practical theology, and particularly pastoral care, can contribute to a richer and more meaningful experience of caregiving. De Jongh van Arkel (2000:34) distinguishes between pastoral care and pastoral counselling, but in this study, I use the two concepts interchangeably, based on the assumption that the *needs* of the *caregiver* dictate the pastoral response and *not* the reverse.

I propose that a feminist contextual approach to practical theology can provide a framework for respectful pastoral care in the context of each caregiver's meaning-making process. Despite the evidence (see Chapters 3 and 4) that pastoral care and counselling was made available to the participants of this study, it emerged from their stories and reflection that pastoral care and counselling sometimes offered *prescriptive* discourses rather than unconditional care. For instance, after her husband's death, Jakkie, one of the participants of this project, was instructed by her church minister to remove her husband's belongings from the bedside table. Jakkie lamented that the sight of her husband's personal belongings had made the pain of loss more bearable. However, unlike Jakkie, Elsa found pastoral care to be a facilitative vehicle for meaning-making. Contextual prayer remains a powerful act of care, and Elsa asserts that prayerful ministrations helped her survive the trauma of anticipatory mourning.

When pastoral counselling offers prescriptive care, as evidenced by Jakkie's experience, it may become a hampering rather than a facilitative aspect of meaning-making (see Sections 2.3 and 2.4). A contextual approach heralds an intrinsic attempt to heal those in emotional pain and to liberate the marginalised (Pattison 1994:31-35). Pastoral counselling should thus focus on healing, liberation and restoration (Ackermann 1998:83). The linking of the concepts of healing, liberation and restoration is also found in the description of pastoral care by Kotzé and Kotzé (2001:5-7) as a participatory and non-judgmental accompaniment of someone (the caregiver) so that oppressive discourses are collaboratively challenged and the voices of the marginalised are included. Empowerment counselling is done *with* and not *to* the other.

In Chapter 4, I argue for an alternative approach to *my* experience of pastoral counselling. In advocating doing pastoral counselling *with* the other, De Jongh van Arkel (2000:288) espouses an awareness of the fact that the mourner may question her faith, which might be in a process of transition. The perception of a 'punitive God' may exacerbate the mourning process. Opportunities have to be co-created for a re-assessment toward a modified and empowering faith – a faith that leads to a coherent future and a 'communication partner' in God (De Jongh van Arkel 2000:288), rather than a punitive parent. Healing is facilitated when you, as a pastoral counsellor, spiritually hold me while I thrash and rave in pain. It means that you view me with patience and acceptance while I wrestle with God about the meaning of it all. It means that you display your willingness to enter my dark night – never pushing or leading, but participating with me – carefully, respectfully – and at a pace which I can bear. Pastoral care also means that you embark on the journey from a practical theology of ethics and care for those voices which have been silenced by abusive discourses (Bons-Storm 1998:13).

The next section focuses on the ethical considerations which emerged in relation to this study.

1.9   ETHICAL CONSIDERATIONS

Voices which may have been silenced by abusive discourses may be unable to protest against abusive social practices or discourses and ethical conduct therefore demands constant reflective awareness of the possible marginalisation of any voices. Unintended marginalisation may be very subtle – as I write this research report, even my use of language confronts me with aspects of ethical conduct and signifies my privileged position. Expressions pertaining to '*giving* a voice' or '*introducing* the participants' to discourses signify my privileged position (Maguire 2001:62). In conducting this research, I attempted to remain as self-reflective, transparent and respectful as possible. I can only hope that any unwitting acts of power or disrespect toward the participants caused no harm.

With regard to the concept of harm, an important ethical issue arose in my interviews with the participants. Although I verbally confirmed with the participants that this research had not *harmed* them in any way (see Section 5.3.3.3 a), ethical conduct requires more: research should actively *benefit* the participants (Kotzé & Kotzé 2002:203). Martin Payne (2000:29-30) posits that there is a benefit inherent in the telling of one's story, and in how the narrative initiates and facilitates meaning-making processes. Four of the five participants of this research study confirmed that they felt better after the interviews (see Section 3.3.11, 4.3.1.1 & 4.3.1.2).

I am aware that, as an insider to this study *and* as a bereaved individual myself, it is possible that I might have tended to approach others' stories from a 'knowing' perspective. Griffith (1995:123)

asserts that 'it is therapists' certainty that oppresses and constrains opportunities to hear the story as the client experiences it'. Anderson and Goolishian (1992:25-39) suggest espousing a 'not-knowing' approach where conversational space is created in which 'newness' can evolve. When the researcher enters the participant's reality, the participant's coherent truths emerge from her narrative. I cannot ignore my 'knowing' status as a co-bereaved; however, I have attempted to remain aware of my own 'knowing' – I do not know whether I have been successful, but these assumptions on ethical conduct are tested against the actual research findings in Chapter 5 (Section 5.5.2). The next section sets out my epistemological and theological stance in this research.

1.10   POSITIONING

I chose to proceed from a Postmodern, Social Construction discursive position that holds that psychosocial phenomena cannot be studied empirically and analytically, but should rather be looked at contextually, subjectively and in a way that is unique to the experience of each person, as recommended by Sampson (1989:1-17), Burr (1995:1-77), Lowe (1991:41-52) and Rossouw (1993:894-907).

1.10.1 A Postmodern approach

My background in strict religious observation as a child and my training in traditional clinical psychology as an adult was informed by a Modernist discourse, signifying logical, rational thought and the notion of an absolute, objective and universal truth which can be empirically analysed and established (Erickson 2006:187-189). Brueggemann (1993:5) criticises this objective certitude and its implications by questioning the validity of the assumption that 'real' knowledge 'is written, universal, general and timeless; in other words, great truths operate everywhere and thus form a large, coherent whole', adding that in 'that world, practiced with shameless confidence, there is no need for insecurity, self-doubt or embarrassment'. I had, for some time, experienced discomfort with the contention of one truth only – do I deny my own subjective truth which often differs from the universal truth or is there room for more than one, equally valid truth? I have since found myself in a process of making a paradigm shift toward a Postmodern discourse which is opposed to fragmentation, analysis and objective truths. It restores the value of subjective realities, local knowledges and contextual experience, and focuses on participation in creating pluralistic meanings and a spontaneous, rather than a contrived order, within the chaos of multiple meanings (Burr 1995:3-4).

Postmodernism opposes the concept of objective science or 'truth', because it argues that 'truth' is dependent on language. Language is socially constructed and is thus unique to a specific

social group, a time in history, and a particular context; hence, 'objective truth' of necessity keeps changing. In the light of an ever-changing 'truth', Postmodernism questions the continuity and validity of knowledge as an 'objective truth' over time (De Vos et al 2005:8).

A Postmodern approach views the Christian Bible in a poetic and creative light, rather than in an analytical fashion, and focuses on narratives and depths of subjective meaning, rather than the literal or fundamental meanings of the Bible (Herholdt 1998:468). In view of the above, I was confronted with the choice of an epistemology which would support the intentions of this research study and would resonate with an overarching Postmodern approach. I found such an approach in Social Construction, which is described in the next section.

1.10.2 Social Construction

Social Construction resonates with and is informed by a Postmodern discourse. It examines taken-for-granted knowledges critically and holds that knowledge is *contextually* (culturally and historically) specific, and therefore dynamic. Knowledge is created and sustained through *social interaction* and, therefore, through *language* (Burr 1995:3-7; Kotzé & Kotzé 1997:28-30). Chapter 2 explores social construction more extensively.

In terms of researching the meaning-making processes of bereaved caregivers, it seemed appropriate to embark from a Social Construction point of view where, for example, religious, illness, medical and mourning discourses may be challenged in favour of subjective and contextual knowledges created by the real experts: the people who have actually *experienced* bereavement.

1.10.3 Theological orientation

My choice of theology thus needed to create room for the actual experts of bereavement to be heard. A contextual feminist theological approach (Keane 1998:123) and a liberational theological approach (Ferguson & Wright 1998:164, 355, 389 & Mbiti 1998:153) provided such a space by focusing on the subjective meanings of the caregivers and on the discourses which silence the voices of caregivers. Whereas a Biblical or evangelical approach may place a stronger focus on the dogma of salvation (*Sola Scriptura*, *Sola Gratia* and *Sola Fidei*), feminist theology focuses on the study of faith texts in terms of the marginalised or those who have been silenced by 'truth' discourses. Feminist theology also respects people's subjective experiences and regards 'people's statements about God and about faith in God' as important (Heyns & Pieterse 1990:3). In an attempt to focus on people's subjective experiences, their possible marginalisation, as well as their empowerment, I discuss some of the assumptions of feminist theology below as it pertains to my research.

1.10.3.1 *Feminist theology: towards transforming subjugating practices*

Feminist theology is a practical theology which strives toward a transformation of subjugating practices in society. This contention seems particularly relevant to my research, because the unique experiences of bereaved caregivers may have been subjugated by various discourses (Neuberger 2004:67-70). We can never stand outside discourse; and meaning-making always emerges within the framework of language and discourse (Kotzé & Kotzé 1997:38-39). An example of biblical religious discourse suggests a levirate marriage where a widow is expected to marry her dead husband's brother (Deuteronomy 25:5-10) in order to procreate and continue the family line. It is acknowledged, in context, that the scriptural prescription might have been valid for that specific era, when women were not economically self-sufficient. While this particular prescription is generally no longer accepted in the Western world, many other Biblical assumptions are still adhered to today, as if women's contexts have remained unaltered.

Thus feminist theology takes a critical stance *vis-à-vis* such discourses of subjugation. Moreover, it requires women to recognise ways in which they may have *benefited* from patriarchy, for example, many women may have chosen to be 'taken care of', thereby shirking their responsibility of self-governance. Murphy (1996:90) argues that women should become aware and accept responsibility for the ways in which the patriarchal system has rewarded them for their willing subjugation.

a) Creating meaning: a re-interpretative perspective

Thus, in order to foster an awareness of subjugative practices as well as the 'rewards' inherent in those practices, feminist theology approaches meaning-making processes of, for instance, suffering, self-identity and spirituality, from a re-interpreted perspective (Tatman 1996:221). A re-interpretative approach enables the bereaved to arrive at new meanings against a revised and sensitised awareness of oppressive discourses. For example, traditionally it has been accepted in theological circles that suffering is good and godly and that it is connected to personal sin (Tatman 1996:221). Feminist theology rejects the notion of 'suffering for sin' and offers the concept of 'love-with-passion' (Tatman 1996:221). In my personal experience, this refers to making meaning within anticipatory mourning by recognising the moments of respite and joy, loving them gratefully and building on them actively. Where love is absent, despair and apathy ensues. Compassionate love, justice, eternal remembrance and validation of the sufferer ensure an ongoing relationship between the carer and the sufferer, even after death (Tatman 1996:221).

b) Death: a revaluation of the dying

Feminist theology (McEwan 1996:39) encourages a celebration and revaluation of the dying person's life in the here and now, so that the mourner does not only have to be consoled with promises of a glorious afterlife. Instead, meaning can be made co-constructively, in the present, between the caregiver and her dying spouse. Revaluing the dying one also means co-constructing a legacy (see Section 4.4.4.4) of enduring qualities of his life which he prefers to be remembered by.

Feminist theology also critiques the traditional view of death, sin and rebirth. McEwan (1996:39) explains that traditional theology regards death as the cancelling of debts, where the hope of a Christian rebirth (and thus a rewarding afterlife), as opposed to damnation, demands adherence to the hierarchies and the structures of religion. McEwan (1996:39) responds: 'If there is celebration of life to the full in the here and now, which is no more seen as a "vale of tears", there is no need any longer to console the living [or the dying] with a vision of a glorious afterlife'

c) An ethic of care

A feminist response to the dominance of, for instance, patriarchal hierarchies, suggests an 'ethic of care' where women's roles [as caregivers] are 'revalued and re-appropriated' (Hogan 1996:57) through a focus on *stories* of care. In the process of revaluation, coherent meaning is restored to the caregiver's sense of self (Hogan 1996:57). When a person's sense of self is restored, the search for self transforms into a 'search for community' and an ethic of care for others, namely a 'common-unity' (Lee 1993:15). Revaluing caregiving as a contribution and a unique gift to her dying spouse (Sharp 1996:221) may help the caregiver to ascribe meaningfulness to the action of her care and may restore a sense of empowerment and purpose.

d) Relational meaning with God, self and others

When purpose and empowerment is restored, relationships with God, self and others gain renewed meaning. Sallie McFague (2001:12) contends that reality only becomes meaningful in loving *relationality* with one another and with God. That is the moment when an event which may otherwise seem utterly devoid of meaning (such as suffering) is suddenly illuminated with meaning. I would add that meaning is also created when the mourner enters into a loving relationality with *herself*. Meaning through relationality is created by an insistent engagement with God as well as the self, when a space for vivid expression of grief is appropriated (Ackermann 2003:108). An active language of lament creates the possibility of meaning in suffering which would otherwise appear meaningless. Suffering becomes meaningful when one takes it on voluntarily and finds a greater sensitivity and love for all within that suffering (Ackermann

2003:110). In addition, suffering gains meaning when it becomes relational through expression in language (Gergen [1999] 2003:145). D John Lee (1993:16) calls the act of expression a 'storying relationship'. An awareness of the language we use in storying ourselves and the discourses that our stories support thus becomes a vehicle for change and empowerment.

e) Empowerment: a deconstruction of religious language

Feminist theology creates a space for such empowerment through a critical view of, for instance, religious topics. When we look at topics, deconstruct them *and* reconstruct them again, we create a more meaningful understanding (McEwan & Isherwood 1996:ix-x) of religious language and a fresh insight into the language of the Bible (Trible 1984:3). For example, feminist theology suggests that traditional patriarchal language should be opened up by, for instance, deconstructing the male king model of God, and using inclusive language of male *and* female (Raphael, 1996:147). Gergen (2001:20) suggests a revised language of God where we trade the 'God's eye view for the Goddess's Hearth' in order to make new meanings of old concepts.

f) A revised language of grieving: toward coherent meaning-making

A revised inclusive language facilitates coherent meaning-making (Pratt 1996:108) according to one's own subjective reality and empowers previously silenced voices (Heyward 1996:52). By contrast, in Biblical times and traditionally since then, it appears that the grieving widow has been infantilised – she is to be pitied, aided and/or remarried. In the Christian Bible, she is grouped with the orphan child (Deuteronomy 10:18; Psalms 146:9 and 68:5), which, although well-intentioned, created a discourse of need and marginalisation. It may be argued that, in order for the bereaved caregiver to make meaning of her experiences of loss, an awareness of the marginalising and silencing nature of many reigning discourses should be fostered.

g) A critical orientation toward discourses

Feminist theology actively questions discourses – particularly discourses of faith (Bons-Storm 1998:15) and it espouses a 'hermeneutics of suspicion' (Ackermann 1998:353). Riet Bons-Storm (1998:15) maintains that to be faithful means to be critical to a Christian orientation. This allows every individual to find his/her own subjective meaning in such a way that suffering may be endured and life may be revised as meaningful to each individual. In feminist practical theology, meaning-making represents a pattern of action *and* meaning that is individually and culturally constructed. This implies that bilateral interaction is created between the individual's meaning-making *and* cultural meaning systems, enabling a conscious decision to accept or resist cultural meanings in the light of the individual's own, coherent meaning-making, in this case that of the caregiver (Bons-Storm 1998:15).

In the context of this research, a feminist approach to pastoral counselling could include challenging the oppressive effects of medical discourses (Section 2.3.6.1) where, for example, doctors may tend to infantilise women and patronise the dying (Jantzen 1996:130-134). The extent to which we are aware of discourses or linguistic practices and the extent to which we consciously accept or reject them, opens up an array of meaning-making resources. Any reality is open to alternative constructions of meanings through an awareness of discourses (Gergen 2001:31).

h) A contextual focus on lived experience

Traditional Christianity may have focused on hierarchy and the discourses of 'absolute truth'. Feminist theology places a strong emphasis on a contextual and inductive theology by focusing on people's *lived experiences* and honouring those experiences as their truth (King 1996:68). Praxis is simultaneously action *and* reflection, and it facilitates meaning-making (Ferguson & Wright 1998:527).

Coherent meaning, however, is never fixed (Burr 1995:40). At the same time as meanings are generated and recognised as internally coherent, they begin to change, depending on the circumstances and the people with whom the caregiver is interacting. Thus meaning-making becomes the site of flux, tension and disagreement between God, culture, oneself and others (Burr 1995:40-41). The question arises whether it is truly possible to arrive at shared meanings between people. Gergen ([1999] 2003:145) suggests removing the concept of 'meaning' from the heads of people and locating it relationally within co-ordinated action between people: '...in isolation I have no ability to mean anything; I gain my ability "to mean something" through the supplemental actions of others.' In line with the assumptions of feminist theology, the next section describes my preferred research paradigm, namely feminist, qualitative, phenomenological and participatory action research.

1.11   RESEARCH PARADIGM

In the light of the focus on relational action and subjective meanings of women in this research study, I was thus confronted with the choice of a research paradigm. In the light of my feminist orientation in theology, feminist research presented an obvious choice (see Section 1.10.3 above), but I felt reticent about such an approach at first, because I had already decided on qualitative phenomenology as a research method. In addition, the focus of my research was marginalised caregivers rather than issues related to gender inequality. However, I required an appropriate research *perspective* and I discovered that feminist research presented such a perspective (Reinharz 1992:241).

1.11.1 A Feminist research perspective

Feminist researchers focus on the experiences of women as interwoven with those of other women (Reinharz 1992:241). A feminist perspective attempts to give a voice to women and holds that women express and experience themselves differently from men (De Vos et al 2005:7). A feminist researcher would focus on issues such as i) *equality and connectedness* between the researcher and the participants; ii) *participation* in the research process by both parties; iii) an acknowledgment of *women's emotions*, intuition and experience; iv) a valuing of *women's knowledges*; v) *social change*; vi) giving a voice to the previously *marginalised* (De Vos et al 2005:7); and vii) the contention that *female researchers* are best suited to study women and their experiences (Mason 2006:192). With regard to this study, it may thus be argued that caregivers are best suited to understand other caregivers' experiences and their subjective *meaning-making* – hence the choice of qualitative research described in the next section.

1.11.2 Qualitative research

The significance of qualitative research is rooted in its preparedness to interpret subjective meaning-making and its reluctance to generalise research findings, because of the unique way in which people make meaning of their experiences (Mouton 1996:168-169). Mouton (1996:168-169) describes qualitative research as a *holistic* focus on *understanding* social phenomena in *context*, rather than explaining them. In terms of caregiver research, Hunt (2003:31) argues that, methodologically, the richness of qualitative data is preferable to quantitative measurement.

Qualitative research usually holds *rich descriptive* data, focusing on the individual – or a small group of people – and an *insider* approach where *meanings* and self-understanding are reconstructed (Neuman 1997:418-421). My approach resonates with this description which validates the experiential significance of mourning in terms of internal coherence, rather than analytic and quantifiable analysis. In respect of this research, I reasoned that meaning-making presents a concept which cannot be quantified nor generalised, because each caregiver makes subjective meaning in her own unique way. The intention was therefore to describe rich, interpretive data from an insider perspective, rather than an objective perspective. This does not mean, however, that stringent research rigour was neglected.

Borman, Clarke, Cotner and Lee (2006:130) claim that research rigour may be ensured by means of careful *design* construction, *ethical* and honest representation of data and appropriate *interpretations* of research findings. The researcher is the *instrument*, which implies that rigorous self-reflection regarding dependability and consistency is essential (Borman et al 2006:130). This approach dictates a clear statement of the researcher position in relation to the research theme

and the participants, rigorous self-reflection, and detailed data collection and analysis procedures (Borman et al 2006:130). Krefting (1991:215) suggests a different research language which replaces traditional terms such as 'reliability' and 'validity' with '*credibility, accuracy of representation, and authority of the writer*'.

Eisenhart (2006:574) asserts that three kinds of validity are relevant in qualitative research, namely descriptive, interpretive and evaluative validity. In all three instances, validity is established by consensual *agreement* between the researcher and the participants. Descriptive validity refers to the *factually accurate* rendering of data. Interpretive validity refers to *meanings* ascribed to the research data and evaluative validity refers to *moral judgments* – whether an action is good or bad. In terms of this research study, I negotiated both descriptive and interpretive validity with the participants by presenting the participants with transcribed versions of our interviews. I requested that they read the transcripts in detail and confirm the factual content, as well as the meanings and interpretations which I had inferred from their stories.

The next section discusses phenomenological research, which focuses on subjective meanings and interpretations.

1.11.3 Phenomenological research

In searching for an approach which validated the *meaning-making* processes of bereaved caregivers, I decided on phenomenological research because it presents an attempt to understand the personal *meanings* which people ascribe to an event (Leedy & Ormrod 2005:139). Phenomenological research is especially valid when the researcher has had *personal experience* of a phenomenon and wants to know 'what something is like' for others from an *insider* perspective (Leedy & Ormrod 2005:139). The phenomenological researcher places herself in the shoes of the participants and, using naturalistic methods of study such as participant observation and lengthy interviews, attempts to distil central meanings from the research data (De Vos et al 2005:270). For the purposes of this study, I engaged in lengthy interviews, whereupon correlative themes of meaning were extracted from the stories of the co-researchers and were described. Thus the research project focused on an emergent research design. This implies an *inductive* method where the research data informs the theory, design and research path. The sections below explore the implications of an insider perspective to phenomenological research, as well as possible discrepancies between phenomenology and Social Construction.

1.11.3.1   The researcher's voice: an insider perspective

In this section, I would argue that my insider (autobiographical) perspective necessitated my making my stance *visible* throughout – a stance which, on the one hand, may add rich description and depth to this research study but, on the other hand, may result in a lack of objectivity. For this reason, I have referred to myself in the *first person*. Reinharz (1992:258) holds that projecting the research in the researcher's *own voice* is more authentic when the researcher has *lived experience* of the research topic. It is argued that, if a researcher uses the third person when her lived experience is part of the research process, she may in effect be inadvertently or covertly *privileging* her own voice (as the researcher, the expert, the rational, objective, removed and therefore superior voice) over the subjective voices of the participants (Gergen [1999] 2003:185).

Gergen ([1999] 2003:74) criticises the traditional academic assumption that an objective researcher creates 'truth', while a subjective researcher arouses suspicion. I would argue that my research topic calls for subjective meaning, rather than objective truth. Golsworthy and Coyle (2001:186) confirm this position and argue that a phenomenological study calls for *subjective meanings*, *personal accounts*, *interpretations* and an *insider perspective*, rather than ostensibly objective analysis. Brueggemann (1993:5) argues that 'objectivity' presents a strategy to prevent the 'chaos' of multiple subjective meanings. This research study attempts to embrace the 'chaos' of complexities.

1.11.3.2   Phenomenology and social construction: possible discrepancies

In the light of my social construction paradigm, which denotes an exploration of complexities rather than analysis, the choice of phenomenology as a research approach poses a possible discrepancy. Although phenomenology does not negate the significance of social interaction, its focus on the individual's subjective experience may be regarded as somewhat individualistic (Gergen [1999] 2003:129). Social Construction is opposed to individualism and rather focuses on *relational* knowledge: 'There is no meaning that is not derived from relationship itself' (Gergen [1999] 2003:131). Thus, even *subjective conscious experience* is derived from and related to social interaction (Gergen [1999] 2003:128).

A second possible problem is presented by phenomenology's *analytical* methodology of extracted *essences/themes.* Social Construction is opposed to fragmentation, essentialism and analysis and suggests embracing complexity and multiple truths instead (Burr [2003] 2004:3-4). Phenomenology therefore does not present a perfect fit with Social Construction theory. However, because Social Construction creates space, by its own assumptions, for an eclectic and inclusive approach of *other viewpoints* in dialogue and thus an *opening up* of choices

(Gergen [1999] 2003:228), I would argue for a more eclectic approach to this research. Social Construction does not claim to be right, but rather attempts to present one of many different viewpoints. Thus the objective of exploring meaning-making is less about identifying internal meaning and more about finding a way toward collective, integrative and authentic meaning in ongoing dialogue (Gergen [1999] 2003:236).

In order for a phenomenological method of analytical themes to be brought into the realm of the relational, it was therefore necessary to co-construct, co-experience and co-reflect upon my extracted meanings *with* the participants. I presented the participants with the themes of this research, confirmed its subjective contents and meanings with them, and co-constructed a concept letter to 'pastoral care', expressing the collective needs of caregivers in anticipatory mourning (see Section 1.12.2 below). At this point the research moved from a subjective phenomenological focus toward participatory action research. Action research is defined as a form of *self-reflective* enquiry by the researcher into a practice of which she deems herself a part (compare my stance as researcher *and* participant), in order to *change* or improve such a practice (McNiff 1997:1-2).

1.11.4 Participatory action research

Action research thus refers to an applied research where the focus is on finding a solution to an observed or experienced problem in a local community (Leedy & Ormrod 2005:108). *Participatory* action research endeavours to empower disenfranchised or marginalised voices through direct involvement in *social investigation*, *educational work* and *action* (De Vos et al 2005:409) in order to bring about social change where the participants of the research are enabled to influence social action by creating knowledge together in an ongoing learning process (De Vos et al 2005:410).

It is argued that the participants of this research study were involved in collective *social investigation* by their reading, discussing and confirming (or disputing) the contents and accuracy of the extracted themes of meaning. The collective letter to 'pastoral care' addressing caregivers' needs represents an *educational* function in *action*. The research thus followed the path as described in the next section.

1.12   RESEARCH PATH

Neuman (1997:330-331) uses the metaphor of a 'path' to represent the research process. Quantitative research usually follows a linear path with clear signposts along the way. It makes use of 'reconstructed logic' (formal, systematic and with consistent rules). By contrast, qualitative research is non-linear and cyclical and uses 'logic in practice', which indicates an ambiguous and

sometimes messy research procedure from which subtle shades of meaning emerge (Neuman 1997:330-331). However, Neuman (1997:330-331) stresses that ambiguity is not an excuse for sloppy research. Qualitative research has its own discipline and rigour. Bearing this in mind, I shall now discuss the way in which the research process was conducted.

1.12.1 Sampling: Inviting the participants

In this study, the respondents are referred to as 'participants' or 'caregivers'. Participants in the post-death mourning period were selected in order to *compare* pre-death (anticipatory mourning) with post-death mourning. I also assumed that they could have gained greater clarity and made more meaning of anticipatory mourning in retrospect, considering the passage of time. The title of this dissertation is therefore significant in this regard, in that it refers to *reflections* by caregivers. In addition, meaning-making often takes place upon telling one's story, reflection thereof, retelling and reflecting once again (McCall 2004:262; White 2004:53). In order to avoid confusion, I have consistently referred to the respondents of this study as 'participants' and/or 'caregivers' throughout. However, it is worth noting that the act of co-constructing a draft letter to pastoral care (Chapter 5) transformed the participants from research participants into reflective, co-constructive co-researchers.

Based on the potentially traumatising and sensitive nature of my research, I chose a non-probability sampling method, namely purposive sampling, which means that I selected participants from a *'typical'* group (the bereaved caregivers) for a specific *purpose*, namely to explore meaning-making in anticipatory mourning (Neuman 1997:206). Purposive sampling also intimates that the theory or developing explanation is informed by the [phenomenological] data analysis of the research findings (Mason 2006:138).

Five participants were invited from Hospice-in-the-West where I have been active in volunteer counselling for the last two years. I discussed the research project with the Head Counsellor and the Director of Hospice and was given permission to contact suitable participants telephonically. The participants, whom you will meet in Chapter 3, were Priscilla, Rieda, Jakkie, Elsa and Mercy. The *criteria* for selecting participants were, first, that the bereaved individuals had acted as caregivers to their dying spouses; and, second, that the bereaved individuals had been widowed for at least three months (to allow for a measure of emotional distance and thus trauma minimisation), but not longer than one year (so that details were still clear in their memories). However, when Rieda told me that her husband had died five years earlier, I nevertheless decided to include her story, since I argued that this would offer a comparative measure of meaning-making juxtaposed to the stories of the women who were more recently bereaved.

The participants were contacted telephonically and I provided a brief outline of the research project to them. Once the selected participants had agreed to take part in the research, I made individual appointments with them and, upon meeting, presented them with a consent form, a declaration of confidentiality and a description of the process and their roles as participants.

1.12.2 The data collection process

The term 'data' may be regarded as an element of quantitative or modernist research, but I have chosen to retain the term to reflect my eclectic approach, as well as my desire to create familiar and shared meaning between reader and writer. Two phases of data collection were conducted individually; firstly, asking the caregivers to tell their stories and, secondly, confirming the factual and interpretive content of the transcribed interviews and co-creating a draft letter to 'pastoral care' reflecting to caregiver needs.

Individual interviews were conducted by means of phenomenological enquiry. This entailed an unstructured interview of approximately three hours with each participant, whereupon the interview took on a semi-structured format. In the light of the purpose of this study (see Section 1.6 above), I asked the participants questions about their personal meaning-making processes during anticipatory mourning and they responded freely. The participants and I thus worked together to arrive at the 'heart of the matter' (Leedy & Ormrod 2005:139), namely meaning-making during anticipatory mourning. I attempted to *bracket* my experience in order to gain understanding of their experiences (Leedy & Ormrod 2005:139), fully aware that my *insider status* provided unique insights and, conversely, possible researcher bias. I was also aware that I proceeded from a particular framework of reference and therefore could easily fail to recognise *alternative themes* which were not in line with my experiences.

The initial interviews were followed by a second group interview to check factual and interpreted content, thus enhancing descriptive *and* interpretive validity (Eisenhart 2006:574). This meant that the content as well as the meanings ascribed to the participants' experiences were accepted by the participants. In the light of the confirmed themes of meaning, the participants were finally requested, in the group session, to compose a collective, concept 'letter to pastoral care', suggesting ways in which they would have preferred to be cared for during anticipatory mourning. At the end of the final group session, I requested brief oral feedback in terms of what the research process had meant to the participants. I also offered them free individual therapy sessions, if they felt they required any. The first phase of data collection was video-recorded and the data was transcribed and analysed from the video-tape.

1.12.3 Interpreting the data

Extracting meaning from video footage has the advantage of providing a 'continuous and relatively comprehensive record of social interaction' while being, to some extent, 'phenomenologically neutral' (Erickson 2006:177). This means that there are no value-judgements in video footage, it is merely a pure recording of events (Erickson 2006:177). 'Neutral' data aids the researcher to determine how implicit meaning is interpreted by the participants. Paradoxically, however, the comprehensive nature of video footage may overwhelm the researcher with potential information beyond that which is humanly possible to assimilate (Erickson 2006:179).

In order to minimise the possibility of being overwhelmed by the data, I used the following steps in my phenomenological data analysis, as recommended by Leedy and Ormrod (2005:140): first, I *identified* statements relating to meaning-making; then I *grouped* statements in meaning units; next, I searched for *divergent* and unique meanings in data; and finally I *constructed* a composite synthesis of the phenomenon. When data is interpreted, the researcher gives *meaning* to the data, *translates* it and makes it *understandable*. In inductive phenomenological research, the meaning, translation and understanding is arrived at in a co-constructed fashion and evaluated reciprocally between researcher and participants (Neuman 1997:335).

Ken Plummer (1996:57) suggests the following domains of inspection for interpreting qualitative data. The first domain relates to *information by the participant* and inspects data for unintended misinformation, evasion, lying, fronts, taken-for-granted omissions, attempts to please the researcher, forgotten information and/or self-deception. The second domain inspects the data relative to the *researcher* in terms of background factors (race, class gender and age), demeanour (body language, dress and/or speech), personality (anxiety, approval needs, warmth or hostility), attitude (subjective discourses, tolerance, religion and/or politics) and researcher expectancy, based, for instance, on a specific theoretical stance. Finally, the third domain examines the *interaction* between the participants and the researcher for possible bias in terms of the physical setting, prior interaction, vocal behaviour and non-verbal communication.

The above domains of inspection by Plummer (1996:57) are corroborated by Neuman (1997:368-369), who cites measures of internal consistency in terms similar to the first domain above (a plausible, coherent picture of the data as a whole) and external consistency (data fitting coherently into the bigger context) in terms of cross-checking researcher findings with other reliable sources of data (such as literature studies and/or experts).

In the current study, external reliability was established by cross-checking my experiences and assumptions with the participants as the experts of the experience of anticipatory mourning. In addition, the co-constructed findings were cross-checked with relevant literature studies (see literature control, Section 1.7 above). Issues of validity and reliability would naturally provide an indication of the integrity of the research project, but perhaps more subtly, would also point to a measure of ethical researcher conduct. The following section will conclude this chapter with a brief outline of the structure of this study.

1.13   CONCLUSION AND OUTLINE OF THE STUDY

In conclusion, the study is structured as set out below.

Chapter 1 contains a discussion of my personal experience of anticipatory mourning and the way in which I had made meaning of my husband's impending death. Relevant concepts such as 'caregiving', 'anticipatory mourning', 'bereavement' and 'pastoral counselling' are conceptualised with the aid of literature control, and the research curiosity and aims of this study are set out. My theological and epistemological orientations are briefly discussed, followed by an outline of the research process.

Chapter 2 contains an in-depth exploration of *meaning* in terms of its social constructs, which may either hamper or facilitate adaptive meaning-making. I conclude with a discussion on the social construction of meaning in the context of anticipatory mourning. In Chapter 3, the participants are introduced and their stories are outlined. Phenomenological themes are identified and described and the chapter concludes with a synthesis of meaning relevant to each respondent. Chapter 4 argues the role of practical theology and pastoral care and concludes with suggested meaning-making strategies. In short, Chapter 2 focuses on the *theory of meaning,* Chapter 3 highlights the *caregivers' meaning-making*, while Chapter 4 focuses on ways in which we can *make meaning together*.

Finally, in Chapter 5, I reflect on the findings of this study relative to the main concepts, as well as on the theological and epistemological stance used in this research. I reflect on the research process, the methodology used and the effects of this research on the participants and on myself. In addition, the limitations and the ethical considerations of this research are reflected upon. The chapter concludes with a concept 'letter to pastoral care' that was co-constructed by all the participants of this study, in an attempt to raise consciousness with regard to the *needs* of caregivers in anticipatory mourning.