

## **CHAPTER 3:**

### **MEETING THE PARTICIPANTS: THEMES OF MEANING**

#### **3.1 INTRODUCTION**

Chapter 2 explored the social construction of meaning and presented an attempt to raise consciousness by exploring meaning-making possibilities in the context of anticipatory mourning. Chapter 3 introduces the caregivers and participants in this study and explores the themes of meaning which emerged from their stories. Two of the five participants, Rieda and Mercy, are English-speaking; and Elsa, Jakkie and Priscilla are Afrikaans-speaking. They come from middle-class, Christian backgrounds, and their ages range from 49 to 75 years. I had hoped initially to include two more participants, a black and a coloured participant, to obtain a wider spread of culture and experience in this study, but both withdrew shortly before the scheduled interviews.

The interviews lasted between two to three hours each. The interviews were videotaped, transcribed and documented. For the sake of confidentiality, the participants' names and those of their spouses and other loved ones have been changed. Direct quotes pertaining to the Afrikaans-speaking respondents have been translated as accurately as possible, and my personal reflections were put into text boxes. To overcome the possibility of a loss of meaning of some 'intranslatable' words/phrases in the translation process, where necessary, I have included the original word/phrase in Afrikaans in parenthesis. The next section introduces the participants in this study and presents a summary of their stories of loss and meaning-making.

#### **3.2 MEETING THE PARTICIPANTS**

The research participants were Elsa, Priscilla, Mercy, Rieda and Jakkie. These five women acted as intimate caregivers of their dying spouses for periods ranging from six weeks to four months. They have emerged as survivors of trauma and makers of meaning. I salute them.

##### **3.2.1 Elsa**

Elsa lives in an affluent suburb in the West Rand. She is an Afrikaans-speaking 62-year old widow. Her husband Koen died of liver cancer with metastasis to the brain. Koen was diagnosed on 20 February 2007 and died on 20 June 2007, a period of four months during which Elsa cared for him. Koen was a police officer and Elsa a home-maker. In the traditional religious sense, Koen was the head of the household but, in terms of financial resources, he made insufficient provision for Elsa. She now owns a paid-up house, but she struggles financially.

Elsa has always been a stalwart member of her church. Her extensive involvement in the church afforded her social support from fellow believers during her anticipatory mourning. In addition, she is part of a close-knit family with three married children and three grandchildren. Elsa has always had a deep and abiding faith, which has grown over the last year and has proved to be her main resource for making meaning. Koen found 'peace with God' during the last days of his life and that has helped Elsa to make meaning of his death to some extent.

Elsa's experience of pastoral counselling has been very positive. During the last weeks of Koen's illness, a young minister from Elsa's church visited them daily. The minister's visits supported Koen, and Elsa found great comfort in his prayers and ministrations as well: *'Henk [the minister] is very different from other ministers... very gentle. His whole attitude and everything was different. He always had special verses that gave one courage... that helped one to find courage again. A person who does not believe in God... I don't know how you get through such a thing... I don't know.'*

### **3.2.2 Priscilla**

Priscilla, a vivacious and attractive widow of 49, lost her husband, Attie, to pancreatic cancer on 14 January 2007. She cared for him from 6 December 2006. Priscilla asserted that the six weeks of caregiving were the *'most intense six weeks'* of her life in terms of the physical and emotional demands.

Priscilla appears to have found her own unique ways of making meaning of her trauma. I was interested to find out how she had managed to make meaning of her experience. Firstly, she contended, she has always been financially independent (she runs her own consulting business). She had therefore never been reliant on Attie for finances or decision-making. Secondly, Attie had been a heavy drinker for most of their married life, forcing her to become more self-reliant. *'[The] first part of our marriage was miserable,'* she said. Attie would usually arrive home late and inebriated. Priscilla recalls how she had often *'arranged his funeral in [her] head'* when he failed to return home.

However, Attie had stopped drinking eight years previously, and their relationship had changed for the better. They became very close and he actively began to assist and support others with alcohol problems. Priscilla believes that her husband *'had a calling'* to support others and that he has fulfilled that calling. She recounted how Attie would send approximately 80 cell phone messages daily to people struggling with alcohol addiction. She spoke extensively of the legacy he has left, and that seems to provide meaning to her. Priscilla contends that she keeps memories of Attie alive through photographs and video clips of their last months together. She

also seems to take great pride in the fact that she arranged a special funeral for him – *‘the best funeral ever, according to the ladies from Al Anon!’*

Priscilla’s experience of pastoral care was supportive but prescriptive at times. People from her local church would periodically visit and pray for Attie. When I asked Priscilla what *she* would have needed in terms of pastoral care, she replied that she would have appreciated more unconditional emotional support and prayer. One particular incident which Priscilla found disconcerting was when a bereavement counsellor from a local organisation visited her. Two of Attie’s family members were present and the counsellor insisted that they all cry in order to release the grief. *‘If all three of you do not cry, then I have not done my job...I am not leaving until you have cried,’* the counsellor announced. Priscilla felt confused and she tried to comply. However, she could not bring herself to cry.

### **3.2.3 Mercy**

Mercy’s husband, Bruce, died of spinal cancer on 10 February 2007. Bruce required intensive caregiving for a period of two months. Mercy and her husband lived in a retirement village in the West Rand. She has a family of three married daughters, one son and eight grandchildren.

To Mercy, the worst part of anticipatory mourning was witnessing Bruce’s suffering. *‘Seeing his suffering... all I could remember was how he had suffered.’* Mercy also seems ridden by a sense of guilt with regard to her care of Bruce. *‘I felt that I wasn’t doing enough... felt terrible guilt.’* Her feelings of guilt seem to derive from an occurrence she spoke about at length, namely cleaning out his garage and giving away much of its contents a few days before his death. He was *‘very, very cross’* with her. Despite the attacks of guilt, however, Mercy has grown in her sense of agency. She now goes out often (sometimes till dark), something Bruce had been unwilling to do, and she told proudly of her accomplishments in repairing various objects and appliances around the house.

Although caregiving and loss brought Mercy much closer to God, Mercy’s experience of pastoral care amounted to three visits during Bruce’s illness and a prayer by their minister when Bruce died. One particular incident which proved very meaningful to both Mercy and Bruce was when their church minister visited them a month before Bruce’s death and anointed him with oil: *‘...that brought me comfort and it brought peace to Bruce....’* Upon further enquiry, however, she admitted that she had needed more social support and *‘someone to give advice, help and care’*.

### 3.2.4 Rieda

Although Rieda's husband, Archie, had died in 2002, I felt that it was significant to include her story in this research study, based on my assumption that five years might have allowed Rieda sufficient time to make meaning of Archie's death. I was interested in comparing her meaning-making process over the years with that of the other caregivers who had lost their husbands more recently.

Rieda is a 75-year old widow who, over a period of two years, lost her husband, two of her brothers and her youngest son to cancer. Her husband, Archie died of oesophageal cancer with metastasis to the lungs. Four years earlier he had been diagnosed with oesophageal cancer, which was removed surgically. His stomach was pulled up and attached to the oesophageal stem. This meant that Archie was compelled to sit up and wait for four hours after a meal to ensure that the food had been digested. If he did not do so, the undigested food could flow into the lungs and cause pneumonia. Four years later the cancer returned with a vengeance.

Rieda's marriage had been *'very unhappy'*. Archie, a heavy drinker, had been unable to secure financial independence for them, with the result that they had been forced to move in with their children in 1994. *'All I ever wanted was a house of my own,'* Rieda said. She expressed both relief and sadness at Archie's death, saying that *'If perhaps he had died ten years earlier, I could have found happiness with someone else...'* Rieda does not believe that she ever loved Archie – she married him to escape a restrictive parental home. Rieda also asserted that she does not really miss Archie. *'The bastard left me nothing,'* she said. Now Rieda mourns for a life lost: *'It has been a long time... and [there is] nothing really left of life anymore.'*

Rieda did not experience sufficient support from her local church and her sole source of support were the staff at Hospice, of whom she said: *'... they know and understand me.'*

### 3.2.5 Jakkie

Jakkie is a 64-year old widow. Her husband, Alex, died of brain cancer on 21 May 2006. The cancer spread to his face, causing significant disfiguration. The cancer then attacked his colon and his lungs. Alex eventually died of double pneumonia. They fought the cancer for fifteen years, but Alex finally succumbed to the disease. Jakkie cared for him intensively during the last six weeks of his life. She is part of a family with four married children (two sons and two daughters). One daughter has emigrated to Australia. Jakkie found her family to be a strong source of support during anticipatory mourning.

Jakkie keeps Alex's memory alive with an intense focus on photographs of Alex and family. During our interview, she would repeatedly interrupt herself to fetch photographs of Alex and of her family. In telling her story, she continually returned to the disfigurement of his face. *'In our youth,'* she reminisced, *'he was a beautiful man.'* After the cancer had ravaged him and doctors had repeatedly attempted to surgically remove the cancer from his face, people would stare at him in horror. She hated that. *'He had often asked me if I minded his patched face [lappiesgesig]. I would say no, he still looked the same to me as always.'* She smiled.

Although Jakkie is not able to verbalise the meaning of Alex's death, she seems to find meaning in the knowledge that he is still with her. She says that she experiences his presence in a physical way: *'I get a hot flash and then I know that he is here with me.'* She also finds great comfort in the knowledge that Alex is with God and there, she believes, he is once again the handsome man of her youth. When she feels like giving up, the thought of Alex in heaven sustains her, and she vows that she *'will not disappoint him'*.

Jakkie talked of positive pastoral support for both Alex and herself. However, in response to a request for elucidation, she also told me about a prescriptive visit by her church minister. After Alex's death, Jakkie had created a memory shrine of him next to his bed. She had placed a bouquet of flowers, Alex's dark glasses and his hat by his bedside. Her minister admonished her: *'Tant Jakkie, you have done wrong now. You are going to remove all Alex's things right now.'* Jakkie complied but says softly: *'I only wanted to remember him and the way he had looked... the way our story had gone.'*

#### **Personal reflection**

*The stories of the participants above tell, among other things, of ways in which they had needed and received pastoral care during anticipatory mourning. The stories represent a commendation of pastoral care but also an indictment against prescriptive, rather than co-constructive care. The stories of the participants also confirm that anticipatory mourning was more difficult to deal with than post-death mourning (see Section 1.8.2.1). Both Elsa and Jakkie were adamant that anticipatory mourning was more traumatic than post-death mourning. 'Definitely before the death... it was harder... there was no time to think,' Elsa said. Jakkie agreed that the caregiving period was worse than the post-death period. She found it very difficult 'when his face became so disfigured and people would stare at him and whisper...'. She recalled that she had always been a tense kind of person and her anxiety reached unbearable levels during anticipatory mourning. Priscilla maintained that the last six weeks of caregiving were 'the most intense' of her life. Rieda could not really tell. However, when the participants told their stories at length, I was confronted by the disproportionate amount of time they spent on the period before death as opposed to the time after death.*

*(Continued)*

*Mercy asserted that the post-death period was worse for her than anticipatory mourning. One should bear in mind, however, that the period after death is closer in temporal proximity and thus possibly in emotional*

*intensity. 'I think after the death is worse. I felt that I wasn't doing enough... because he was so heavily sedated...felt terrible guilt.' It is interesting to note that although Mercy asserted that the post-death period was worse for her, she continued, in the same breath, to refer to the anticipatory mourning period when Bruce was heavily sedated and she felt that she was not doing enough for him.*

The stories of the participants also indicate ways in which each caregiver attempted to make meaning of her experience of loss. When I transcribed their stories, I was confronted with a multitude of meanings which seemed overwhelming (Erickson 2006:179) at first glance. However, upon further exploration of the participants' stories, clusters of meanings which seemed to cut across most of the texts (Cheung & Hocking 2004:478) emerged spontaneously and connected to form the themes of meaning discussed below.

### **3.3 THEMES OF MEANING**

Many of these themes were corroborated by my own experience of anticipatory mourning and caregiving. The themes were selected in a phenomenological fashion (see Section 1.11.3) and on the basis of the subjective significance of certain events to which the caregivers returned repeatedly in relating their stories. These significant events were selected using an 'open coding' process of close examination of data, a comparison of concepts and a grouping together of data into categories, as proposed by Henning, Van Rensburg and Smit (2004:131): 'Put more accurately, coding represents the operations by which data are broken down, conceptualised, and put back together in new ways.'

The significance of returning to certain events in the stories we tell is corroborated by the following quotes from the literature: 'Meaning is created through the back-and-forth process of telling and retelling...' (Seaburn, Lorenz & Kaplan 1992:391) and '[r]ecollection implies that what can be recalled must have already been constituted as meaningful' (Burch, cited in Kleiman 2004:10). However, returning to a significant event does not mean that the caregiver has completed her meaning-making process. It could imply that, despite having constituted a recalled event as meaningful, the caregiver has not formulated its meaning as yet and, in applying language to a recalled event in repetitive fashion, she continues the ongoing process of meaning-making (Seaburn et al 1992:392).

Kruse (2004:217) studied the meaning which caregivers ascribed to the process of 'letting go' of a loved one and uses Parse's theory of human becoming as the basis for the following three propositions about meaning: first, meaning is created *relationally* through storytelling; second, *paradox* is an integral part of our lives (see Section 3.3.9 below); and third, we live, and thus make meaning, according to what is *significant* to us. Hence, in the analysis of the interviews, the

themes of meaning were selected in terms of significant relational events and meaningful ways in which the caregivers attempted to shape their lives during anticipatory mourning (Kellett 2000:318). The main themes were identified as those cutting across all or most texts, as recommended by Cheung and Hocking (2004:478). These main themes were: i) *The significance of time*; ii) *Challenges and gifts*; iii) *Witnessing the decline*; iv) *Paradoxes*; v) *The significance of the spousal relationship*; and vi) *Spirituality*.

Sub-themes were selected from the stories of the participants and sorted under the main relational themes (see Table 1). As will become evident from the table below, a number of sub-themes were *repeated* under more than one heading, since they seemed to connect to more than one main theme. For instance, every sub-theme noted in Table 1 may be regarded as relevant to the main theme of 'spousal relationships'. The table summarises the main themes of meaning as well as the sub-themes.

**Table 1: Relational themes and sub-themes of meaning**

<p><b>Time</b></p> <p>The day the sky came down (Section 3.3.2)]</p> <p>'Each moment – so precious' (Section 3.3.4)</p> <p>Signposts – 'time is running out' (Section 3.3.7)</p>	<p><b>Challenges/Gifts</b></p> <p>Silent tears in the toilet (Section 3.3.3)</p> <p>Impotent witness (Section 3.3.5)</p> <p>Too busy to think, too tired to mourn (Section 3.3.6)</p>
<p><b>Witnessing</b></p> <p><i>Impotent witness</i> (Section 3.3.5)</p> <p>'He lost his job today' (Section 3.3.5.1)</p> <p>'It is just you and me now' (Section 3.3.5.2)</p> <p>'If only you would eat!' (Section 3.3.5.3)</p> <p>'I feel so helpless... ' (Section 3.3.5.4)</p> <p>'Oh God, he suffers so!' (Section 3.3.5.5)</p>	<p><b>Paradoxes</b></p> <p><i>Paradoxes</i> (Section 3.3.9)</p> <p>'I wish this were over' (Section 3.3.9.1)</p> <p>Guilt versus 'I did my best' (Section 3.3.9.2)</p> <p>Loved ones – a comfort and a curse (Section 3.3.9.3)</p> <p>Loss of self versus 'I never knew I could do this' (Section 3.3.9.4)</p> <p>'I would choose this again' (Section 3.3.9.5)</p>
<p><b>Spousal relationship</b></p> <p>Touching – the warmth of his body (Section 3.3.8)</p> <p>'Visitations, coincidences and strange occurrences' (Section 3.3.11)</p>	<p><b>Spirituality</b></p> <p>Spirituality and suspended meaning: 'It is God's will' (Section 3.3.10)</p> <p>'Visitations, coincidences and strange occurrences' (Section 3.3.11)</p>

The main themes above presented a thread which ran consistently through all the sub-themes, connecting them into narratives of trauma, meaning-making and survival. In the next section, I focus briefly on an argument for compatibility between Social Construction and phenomenological research, whereafter the themes of meaning as they emerged from the stories of the participants are described.

### 3.3.1 The intersection between Social Construction and phenomenology

In Section 1.11.3.2, possible discrepancies between Social Construction and phenomenology are pointed out. In that section, I argued that Social Construction creates space for other viewpoints, such as phenomenology, in dialogue (Gergen [1999] 2003:228) and that adopting a Social Construction approach thus allowed for an inclusive, eclectic approach in this study.

In further support of the argument for Social Construction and phenomenological research, the concept of meaning and meaning-making, as the main theme of this study, offers an important intersection between the two perspectives. Both approaches focus on meaning and the creation of meaning. Phenomenological research seeks to understand the personal, subjective *meanings* which people ascribe to an event (Leedy & Ormrod 2005:139), while a central focus of Social Construction is relational *meaning* 'as solidified within a group' (Gergen [1999] 2003:235). Gergen ([1999] 2003:129) argues that, although phenomenology never fully relinquishes its subjective individualist focus, it nevertheless makes a significant contribution toward the concept of relational meaning: phenomenology holds that our experiences are relational because we are always directed toward an object or a person in the external world; thus self and other (or subject and object) are united in that experience (Gergen [1999] 2003:128). Therefore, it may be argued that, rather than oppose phenomenology, Social Construction *extends* the concept of subjective meaning by 'remov[ing] meaning from the heads of individuals, and locat[ing] it within the ways in which *we go on together*' (Gergen [1999] 2003:145).

In terms of the themes of meaning, I refrained from clustering sub-themes under main relational headings (as they appear in Table 1) and chose to present them in the same narrative format as they were related to me by the caregivers, because, in keeping with my epistemology of Social Construction and Feminist theology, I wanted to foreground the voices of the participants in order to remain as close to *their* realities as possible. As a result, the sub-themes are presented below in the same chronological order as the unfolding events of the caregivers' stories. The first sub-theme to emerge was the day the cancer was diagnosed – 'the day the sky came down'. I use Priscilla's metaphor to illustrate the commencement of a journey into the 'twilight zone' of cancer and, finally, death (Becker & Knudson 2003:702).

### 3.3.2 The day the sky came down

*'I saw his face... and I knew. I could not find the strength to walk to him. "They are admitting me for pain control," he said. Those words spoke volumes...that was the day the sky came down.'* (Priscilla)

Kruse (2004:216) describes caregivers' experience of the cancer diagnosis as 'being hit by darkness from an angle they never expected, which dismantles their sense of belonging and connectedness'. The terminal diagnosis of a loved one can be described as a phase of spiritual crisis (Doka 2000:106-107). For instance, the patient and his family may experience the diagnosis of terminal illness as a punishment for wrongdoing (Seaburn et al 1992:391). The first encounter with the possible death of a spouse raises a review of the past, the present and the future: 'What have we done wrong?', 'Our lives were going so well now', 'How will this change our lives?' and 'Why is this happening?' These questions are accompanied by varying degrees of traumatic shock and disbelief, as the caregivers attempt to integrate the reality of the diagnosis into their existing framework of meaning (Doka 2000:106-107). Attempts by the caregivers to make meaning of the day their husbands were diagnosed with cancer emerge poignantly in the descriptions below.

Rieda recalls how Archie was tested for cancer after he had repeatedly complained of difficulty swallowing. The doctor promised to phone her the following Friday if cancer was found – if it was not cancer, he would phone her the Monday thereafter. Friday came and went and Rieda was relieved: *'It must be good news,'* she thought. Archie's doctor telephoned on the Monday. The verdict was cancer. *'But you told me you would phone on Friday if it was Cancer! He should have phoned me on Friday!'* she exclaimed. Rieda struggles to make sense of an event which may seem trivial in the face of her greater loss and trauma. However, she repeatedly returned to the omission by her doctor to phone on the designated day.

Jakkie's husband, Alex, fought cancer for fifteen years. When he developed excruciating headaches, tests revealed a 'bubble' on the cerebellum of his brain. The bubble was removed surgically and a stainless steel clamp was glued to this area. Alex failed to recuperate and tests revealed that the glue had caused brain cancer: *'His head and face just fell full of holes. That morning the doctor said that he could not operate again. The cancer had also spread to the colon. He could do no more. Then I knew... it is over.'*

Elsa tearfully recalled the day when Koen was diagnosed as terminal. Despite an earlier cancer diagnosis, she had not really believed that the cancer would kill him: *'It remains in the back of your mind but you keep hoping that the medication will help. After six treatments, he [the doctor] said it had not helped... it had not helped, it had spread! That day I said God! No! Ah-ah... what can you do?'*

Mercy's husband, Bruce, was diagnosed with advanced spinal cancer on 14 December 2006. He had complained of persistent back pain for some time. Mercy said she realised that *'something was very wrong'* when he began to fall repeatedly. When the diagnosis of advanced spinal cancer was delivered, she found it incomprehensible. *'Until the last minute, I could not... I could not believe that he was dying!'* she exclaimed.

After the initial shock and disbelief, spiritual outrage at the unfairness of the diagnosis may ensue as people have to incorporate the present reality of terminality into their sense of past and future (Doka 2000:107). The expression of emotions becomes critical in order to process the trauma meaningfully. Unexpressed feelings and concealed grief prevent social sharing, comparing and normalising of fears, and fosters an experience of uniqueness and isolation (Larson 2000:383). Expressing grief through tears may strengthen social support and break the sense of isolation.

### 3.3.3 Silent tears in the toilet

*'I could not cry. Crying makes me sick... I fall apart. That night at Kwa Maritane... I thought: it is all over. That was the most traumatic moment of my life. I sat and cried... and cried in the toilet. The cleaner came in and held me. That... was the last time I cried....'* (Priscilla)

Priscilla has, until today, been unable to express her grief in tears. After the news of Attie's terminal diagnosis had been given to them, they went away to Kwa Maritane for the weekend. After two glasses of wine, Priscilla allowed herself to cry alone in the toilet. *'I felt so... alone,'* she recalled. Feelings of isolation when the caregiver is confronted with the verdict of cancer are further intensified by cultural and societal prescriptions of acceptable and 'normal' mourning practices. Kruse (2004:216) asserts that *'there is no normality to grieving; rather it is an open process that both the dying person and their ... caregivers cocreate'*.

In the interviews, all the participants voiced their experience of being patronised and of social disapproval when their emotive expression became 'uncomfortable' to others (Kastenbaum 2004:40-41). Thus, not only does the caregiver have to deal with overwhelming and traumatic feelings; she must also find ways of containing them in order to protect others against the 'discomfort' of her grief (Neuberger 2004:71). Jakkie experienced the discomfort of her doctor when he conveyed the news of Alex's terminality: *'The doctor said: "Don't cry, Aunt Jakkie, especially not in front of Alex", but the sister said: "Nonsense, cry!" I did.'*

Rieda's daughter Gayle admonished her to stop crying whenever she broke down in tears. Ironically, the caregiver has little choice but to adhere to social prescriptions. If she refuses to adhere to them, the threat of secondary social loss (Rando 2000b:61), namely disapproval from

loved ones, may complete her isolation, as in Rieda's case. Haley (2003:221) found that negative social interaction or sanctioning during anticipatory mourning were associated with increased levels of depression. Barkway (2001:66) conducted a study with mothers who had lost their babies, and describes the 'silencing' effect on grief expression when family, friends and cultural practices prohibit prolonged grieving. In Barkway's (2001:66) study, people would, for instance, refuse to respond when the bereaved spoke about the loss, or the bereaved would be told to 'pull themselves together'. This effectively silences the teller (Barkway 2001:66).

Neither Elsa nor Rieda allowed themselves the freedom of expressing their grief openly, for fear of upsetting others. Rieda in particular has never received emotional care from either her husband or her daughter. Over the years, she had taught herself to contain her tears – only in her most private moments would she allow herself the luxury of tears. *'I do not cry. I only cry at Hospice,'* she said. *'They know and they understand me.'* It seems that the care from Hospice staff compensated to some extent for a lack of pastoral care and counselling.

In contrast to Rieda, Elsa, and Priscilla, Jakkie allowed herself to cry openly during anticipatory mourning – and yet she apologised to me when her tears overflowed: *'Sorry if I cry... I am missing him again this week. They say the longer, the worse it gets....'* She recalled, however, that when fear and hopelessness threatened to overwhelm her during anticipatory mourning, she would cry *with Alex*. I asked her if mourning *with Alex* had brought them closer together. Jakkie confirmed that the shared tears *did* bring them closer and made them realise how precious their time together was.

#### **3.3.4 'Each moment – so precious'**

An awareness of precious moments may emerge both sweetly *and* threateningly. Some manage to make more sense of the fear of the fleetingness of time by actually distancing themselves through work or other activities (Kruse 2004:220). For instance, Kim (2006:800) found that caregivers who maintain the added role of employee in addition to the role of caregiver seemed to make more sense of the impending death of a spouse than those who were solely in the role of caregiver. The added support from colleagues, the comparative normality of the work environment and respite from the intensity of caregiving seem to account for this finding. By contrast, some caregivers may purposefully refrain from social contact in their concern for time lost, and may become isolated in the process (Rando 2000b: 54-55; Rando 2000d:368).

Mercy said that she had not realised, right up to the morning of Bruce's death, that he was really dying. By contrast, Elsa, Jakkie and Priscilla recalled a profound awareness of time running out. Jakkie and Elsa deliberately spent memorable time with their spouses. Priscilla consciously

savoured precious moments with the awareness that she could hold onto these memories after Attie's death (Hunt 2003:29). She also actively *created* precious moments, realising that she would treasure them even more during post-death mourning: '*When Attie became ill, I began a diary where I wrote everything that happened... all the wonderful things. In the hospital, I slept behind his back. I lay with him the whole day and night and read to him... he made jokes all the time.*' Priscilla smiled.

#### **Personal reflection**

*I found that time takes on a new dimension – it stretches both interminably and races by fleetingly. Similarly, each moment gains an ominous, as well as an infinitely precious dimension. I felt tired and stressed beyond measure, yet I was an intensely alive occupant of each moment, each hour, each day. I attempted to weight each moment through a desperate preparedness to identify with Louis, as also described by Fulton (2003:346), and enter the 'time warp' of approaching death with him. Upon entering, however, the thought of returning to the 'land of the living' without my life partner was profoundly terrifying. Identification intensified the significance of moments spent together. Paradoxically, it also confronted me with feelings of infinite helplessness – the helplessness of an impotent witness.*

### **3.3.5 Impotent witness**

Meagher and Quinn (2000:498) asserts that experiences of powerlessness in witnessing the slow death of a loved one produces feelings of a loss of control – and a loss of order and control signifies a loss of meaning (Golsworthy & Coyle 2001:184). A sense of control requires an awareness of choice (Meagher & Quinn 2000:498), such as an awareness of the gifts of witnessing. Kruse (2004:220) regards the gift of bearing witness as an act of meaning-making and sees unconditional witnessing as a way of affirming the worth and value of a loved one's experience. In the absence of an awareness of choice, a learned helplessness may develop, where the caregiver abdicates her need for control and mutely witnesses unfolding events.

Personally, my experience of caregiving propelled me forward and backward between helpless witnessing and a desire to remain actively present to Louis's experience. Mostly, feelings of helplessness prevailed. Similar feelings were also confirmed in the stories of the participants. Thus helplessness was one of the most prominent themes to emerge from this study, heralded by specific events which seemed to mark the impotence experienced by the caregivers. These markers of impotence became visible as events such as those described below unfolded.

#### **3.3.5.1 'He lost his job today'**

One of the markers of impotent witnessing for three of the caregivers emerged the day their spouses lost their jobs. This change heralds the loss of a lover and partner and replaces him with

a patient who needs full-time care (Cheung & Hocking 2004:479). Elsa recalled that Koen had insisted on going to work the day after his last chemotherapy. By midday he was sent home, unable to continue. He would not eat again, no matter what she offered him.

Priscilla recalled the effect on Attie the day he lost his job: *'He sat on the steps outside his office – a bewildered little body. That was worse for him than the cancer news.'* In addition to her personal loss, the caregiver also bears witness to her husband's distress. Job loss confirms social isolation, empty time, a loss of self-respect, productivity, identity and usefulness (Smyth 1994:45-46). Jakkie remarked that Alex had always been a very strong-willed man. He had fought the cancer courageously for fifteen years, *'but the day Alex lost his job was the day that broke him,'* she says.

### **3.3.5.2 'It is just you and me now...'**

When a spouse loses his job, it has important implications for the caregiver, not only in terms of witnessing his grief, but also in terms of the increased demands on her time as caregiver. Caring for her spouse now becomes a 24 hour occupation (Cheung & Hocking 2004:479). All the participants spoke of the fear of being alone with Cancer and her spouse, as well as the fear of upsetting him, juxtaposed against the need to talk to him about significant matters. Discussions become narrow (such as family, food and household matters) as partners attempt to normalise their day, and the reassignment of roles (where the husband becomes the dependent and the caregiver the provider) calls for a new language of communication (Rando 2000d:368).

#### **Personal reflection**

*The loss of their partners as lovers (Cheung & Hocking 2004:479) and the reassignment of roles emerged poignantly from the stories of the participants. In their new roles as caregivers of a dying man, it seemed as if these caregivers intensified care to the point of infantilising their husbands. Cheung and Hocking (2004:476) found that intensive acts of care create structure and meaning for caregivers. Rieda, for instance, would dust Archie with baby powder during their bath-time ritual. In reference to her husband, Priscilla repeatedly spoke of Attie's 'bewildered little body'. I would repeatedly rub Louis's body with baby oil as I would that of a little child.*

The caregivers also spoke of a strong desire for mundane and ordinary topics of conversation during the times they spent with their spouses. The topic of food increased in significance and the participants would repeatedly return to this topic. And soon the next marker of impotence came: the caregiver's spouse would refuse food and in so doing, the door would shut on a significant

part of the caregiver's meaning-making, namely her power to care effectively (Cheung & Hocking 2004:478).

### **3.3.5.3 'If only you would eat!'**

In my experience, our cultural discourse of care prescribes food as cure or comfort for physical and emotional maladies. Doka (2004:46) holds that caregiving gives meaning to a person's life. However, if the caregiver's spouse loses his appetite, the caregiver becomes limited in her caring options and this may lead to distress and worry (Cheung & Hocking 2004:478). The five participants of this research study became distressed and tearful when they described their efforts to tempt their spouses to eat as death drew near. In telling their stories, they provided laborious and detailed accounts of their culinary efforts, as if they attempted to keep their spouses *alive* with care. *'He had a bitter, bitter suffering. Everything tasted of cancer. He could not eat... the "Oom" ate very badly... then I... could not eat either,'* Jakkie wept.

The participants described how their spouses would request a specific dish which they would gratefully prepare – only to find that, when they presented the meal, their spouses had lost their appetites. Rieda would prepare endless bottles of soup. *'Today, I cannot stomach soup,'* she shuddered. The day before Archie died, he requested a bottle of rollmops (pickled herring). Rieda went in search of pickled herring and became quite frantic when the first few stores she visited proved to be out of stock. By late afternoon she eventually found some pickled herring and triumphantly presented Archie with her trophy. *'He stuffed the whole bottle of herring down his throat. It made him very ill. The next day he died,'* she sighed.

When the caregiver becomes increasingly limited in her ability to care, a complex relationship of feelings of responsibility and worry causes her to lose a significant part of her sense of agency and her perception of control (Cheung & Hocking 2004:478). If her sense of identity and meaning resides in her ability to care adequately for her dying spouse, she also becomes limited in her ability to make meaning of her trauma when he refuses food. In addition, the caregiver is painfully confronted with her own helplessness and the realisation that she is incapable of keeping death at bay. Rando (2000c:211) refers to this feeling of helplessness as 'secondary traumatic stress', which is similar to post-traumatic stress disorder.

### **3.3.5.4 'I feel so helpless...'**

*'You realise that he is actually dying and there is... nothing you can do. It feels as if you are going insane. It feels as if you just have not done enough.... you... just have not done enough...'* (Elsa)

When caring options become limited (Cheung & Hocking 2004:478) and life is no longer predictable and safe (Golsworthy & Coyle 2001:188), it may lead to loss of meaning. To the caregiver, meaning may be equated with a sense of control (Golsworthy & Coyle 2001:184), predictability (Danforth & Glass 2001:521), understanding the world and unfolding events (Stelter 2000:66), purpose (Frankl [1959] 2004:85), agency (Barkway 2001:75) and hope for a future (Frankl [1959] 2004:89). These aspects of meaning-making may be eroded by helplessness and despair.

#### **Personal reflection**

*The caregiver may also be faced with perceptions that life is out of control, that she is unable to care effectively, and that she is unheard, invisible and 'existing in a limbo' (Kellelt 2000:322). Invariably, moving into the caregiver role denotes cultural meanings of care and cure. This assumption is supported by the way in which we often greet an ill person: 'Are you feeling better today?' thereby effectively enforcing a positive response. Sadly, the caregiver occupies a role where failure – in terms of a cure – is inevitable.*

Priscilla recalled that the most impotent and traumatic moment of her experience proved to be the afternoon at Kwa Maritane, following the dreaded diagnosis of cancer. She realised that her husband was going to die. *'That was the most traumatic moment of my life,'* she recalled. *'There was nothing I could do to make it better... nothing I could do.'* However, Priscilla seemed to find meaning in agency (Barkway 2001:75-76, such as rubbing Attie's legs to drain the lymph and running to fetch ice cubes for his parched mouth. She seemed to create meaning in activities focused on alleviating his suffering; and when her caregiving role became limited as the disease progressed, she created new ways of caring and making meaning such as writing a memorable diary, taking many photographs of Attie and making video recordings of their time together.

#### **3.3.5.5 'Oh God, he suffers so!'**

Priscilla was able to create meaning within Attie's suffering. However, bearing witness to a loved one's suffering may be so traumatic that meaning-making becomes increasingly difficult. Certain stages in anticipatory mourning herald particularly high levels of anxiety, such as the acute crisis phase of the diagnosis (the period to which I refer as the *first grieving*), as well as times of relapse when the caregiver remains an impotent onlooker to her spouse's suffering (Rando 2000c:163). Suffering not only indicates physical pain – it encompasses a subjective response to a variety of physical, social, psychological and spiritual forms of pain (Doka 2000:107).

After the diagnostic phase, treatment begins and the couple must contend with the disease, the side effects of treatment and the demands of everyday life. Doka (2000:107) describes this period

as the chronic phase in which questions of meaning centre around suffering, physical decline, chronicity and impending death. Kruse (2004:220) suggests that, when witnessing the suffering and decline of a loved one, meaning may still be found in remaining 'attentive and respectfully present' rather than withdrawing from him. In this way, the caregiver creates meaning by bearing witness and acknowledging the worth of the loved one and the value of his experience (Kruse 2004:220).

The participants agreed that witnessing their spouses' suffering and physical decline was one of the most traumatic aspects of their caregiving experience. Added to the suffering which cancer brings, medical interventions present a unique dynamic of suffering as all attempts at treatment must be exhausted before capitulation becomes an option (Neuberger 2004:12; 70). For Elsa, the horror of chemotherapy and its effects on Koen's quality of life proved to be an added trauma: *'What he had to endure, I would not be able to take... I really could not take it... I could not take it. The first six chemo treatments were okay. Then the blood tests revealed that the cancer had spread. So they gave him an even stronger chemo treatment... that broke him. I am telling you, that chemo killed him... it killed him.'* In addition to witnessing the suffering of her spouse, the caregiver struggles with aspects of her own suffering – among others, the rapid depletion of her physical and emotional resources.

### **3.3.6 Too busy to think, too tired to mourn**

Caregiver burdens expose the caregiver to physical demands as well as chronic stress, which depletes her mentally, physically and emotionally. In addition, it has been found that caregivers underreport their own physical and emotional problems, partly due to denial and partly due to a lack of awareness of the deleterious effects of caregiving (Hunt 2003:31). Mercy corroborated this finding. She insisted that she never felt tired, anxious or overwhelmed by her caring duties: *'No, I felt quite calm'* and *'I never felt tired or that I could not cope...'* However, Mercy's family noticed that she was looking ill and had lost 11kg in weight. They sent her to a medical practitioner who insisted on hospitalising her.

By contrast, Rieda admitted to feelings of extreme stress. Shortly after Archie's death, Rieda was admitted to hospital for a double heart bypass. For Jakkie, the worst part of her experience was the physical demands and the unbearable stress during anticipatory mourning. Her health was severely affected and she still suffers from insomnia and hypertension, two symptoms that Moskowitz et al (2003:476) also report. Jakkie contended that she has only recently begun to feel physically stronger and in control of her life again. During caregiving, she said, *'...it felt as if my brain was taken out of my head and put back again. Everything was spinning around me. The doctor said my blood pressure was so high... so much stress...'*

Rando (2000d:353) suggests that making meaning of mourning requires energy – a luxury which an emotionally and physically depleted caregiver simply does not have. Four of the five participants reiterated how tired and physically stressed they were during anticipatory mourning. When I asked the respondents if they recalled mourning the loss of their husbands in anticipation, they contended that they had simply been too busy to think and too tired to mourn. Priscilla said: *'I had no time to mourn, not at all... I was too busy... and so tired. It felt as if I was outside my body... the way I was running around.'*

#### **Personal reflection**

*My experience resonates with that of Priscilla. I recall the sensation of bodily dissociation, to a point where it feels as if one is observing oneself from a distance. The state of dissociation may also be a necessary coping mechanism as the caregiver keeps herself too busy to mourn. Lifton (1996:175-176) describes dissociation as 'a numbing of the mind' which represents a 'severance of the self's history... a disintegration of crucial components of the self'. Dissociation is a protection measure while the psyche separates from the self and its history (Lifton 1996:175-176).*

And as specific events brought numbness or feelings of increasing anxiety and helplessness for the participants, so the following signposts emerged along the way, heralding that time was running out and death was closing in.

#### **3.3.7 Signposts – 'time is running out'**

*'The thing I dreaded most was that he should fall off the bed... and that Monday he fell off the bed. "Rieda, Rieda!" he cried. I ran to him, picked him up and put him back in bed... he was only 35kg. "For God's sake, lie still now!" I said. He lay down and smiled – as if he was not there, you know, like when a baby has a wind, and it smiles...' (Rieda)*

The awareness of approaching death heralds an abrupt end to the motion of life. Lifton (1996:109) describes the anticipation of death as the dialectic between sameness and vitality, between 'holding firm' to life and 'moving on'. Thus as the signposts begin to appear in rapid succession, an attempt to hold firm to the moment juxtaposes itself to a sense of impending and unavoidable change, the 'twilight between living and dying' (Becker & Knudson 2003:702). Increased caregiver demands may heighten feelings of being trapped (Cheung & Hocking 2004:478), but may also aid the caregiver in letting go (Kruse 2004:216). Letting go implies that meaning has been made or that meaninglessness has been accepted (Sorajjakool & Seyle 2005:80) and that 'life unfolds with a new view' (Kruse 2004:220). Experiences of the signposts remain traumatic, however, and, in telling their stories, the caregivers repeatedly returned to the following signposts of impending death:

### **3.3.7.1 'Today he fell in the bathroom'**

Elsa, Rieda and Mercy told of the trauma when their spouses became too weak and disoriented and began to fall, usually in the bathroom. *'I just heard this loud thud... and I knew it was him. He had fallen against the door of the bathroom. He could not move and I could not get in... I could not get to him!'* Elsa cried. After Elsa's husband had fallen in the bathroom, it frightened her so much that she would not *'leave him alone for one minute'*.

Mercy recalls how Bruce fell in the bathroom and literally tore the toes from his foot. The 'tear' never mended and remained until the day he died. The second time he fell next to his bed: *'...he was fighting the rails [of his bed]. "Get me out of this bed!" he said. He did not want to die... he did not want to die. He really did not want to die. But the day he fell next to his bed... Bruce asked for a gun... just too much pain. He realised then that he could not help himself anymore.'* Falling and the implications thereof seem to be a theme throughout our experiences – a theme so frightening and beyond the caregiver's control (Golsworthy & Coyle 2001:184) that meaning-making may prove to be impossible at that time. And as the caregiver struggles to make sense of her husband's increased weakness, the next signpost of loss is upon her – he fails to recognise her face.

### **3.3.7.2 'He no longer recognises me'**

Failure to recognise his spouse and caregiver presents a sudden and unexpected loss which the caregiver is ill-prepared for. I refer to this loss as the second grieving (see Section 1.2.2). Meaning-making becomes increasingly difficult and it is only through being truly present to the moment and the experience thereof that the caregiver may begin to find moments of respite and even joy (Kruse 2004:221). An example of such a respite becomes evident in my story when I unexpectedly woke up one night to Louis's tender embrace, long after he had stopped recognising my face (see Section 1.2.2.1).

Both Priscilla and Jakkie deemed it a gift that their husbands remained conscious of them, almost to the end. However, during the last few days, both Attie and Alex became disoriented and confused. They no longer seemed to recognise their spouses. *'Then I knew that he was dying...'* Priscilla said. Elsa was unsure whether Koen recognised her. He seemed confused and unable to speak. She became visibly upset: *'He was so confused... I knew this was the end.'*

### **3.3.7.3 'The pain intensifies'**

*'Those last days I heard every moan... it kept waking me up. He would... shudder throughout the night. I thought: Oh God, is he afraid to go now?'* (Jakkie)

The final signpost emerges when the pain reaches a climax. I found that witnessing the pain of a loved one heralds from the sanctums of hell itself and it represents another example of secondary traumatic stress (Rando 2000c:211). However, the converse also presents itself, namely finding meaning in the sacrifice of caring (Frankl [1959] 2004:117). Both Priscilla and Elsa commented on the unearthly groans of pain that issued from Attie and Koen at night, toward the end. Both commented how traumatic that was for them and that all they were able to do was to try to comfort their dying husbands with touch, hence the next theme, namely the significance of touch.

### **3.3.8 Touching – the warmth of his body**

Touch represents one way of remaining truly present to a loved one's dying. Surrendering to that which cannot be controlled (Kruse 2004:221) may create meaning. Kruse (2004:216) cites a study with intimate caregivers on ways to improve the death experience of their loved ones and found that touch seemed to calm the dying, which in turn gave meaning to the living, the caregiver. The participants of that study felt that it was imperative to convey their care in rituals of touch (Kruse 2004:221).

#### **3.3.8.1 Rituals of touch**

Ashton and Ashton (2000:447) suggests that touch brings comfort not only to the dying, but also to the survivors. The caregiver may experience rituals of touch as an event which she can still control (Golsworthy & Coyle 2001:184, 188) and this may become a meaningful act of care. Rituals of touch keep partners connected and dissolve tension and fear. Some people use music and massage to care for their dying (Ashton & Ashton 2000:447), while others simply hold onto their loved ones. In a study with caregivers, Kruse (2004:2191) found that touching, caring and being present day by day helped caregivers to let go of their loved ones, while meaning was made in the knowledge that they were doing all they could. Rituals during anticipatory mourning can become precious post-death reminders and meaningful validation of the losses which the caregiver experiences throughout anticipatory mourning (Ashton & Ashton 2000:447).

Mason and Haselau (2000:283) assert that healing rituals symbolise relational connections, comfort, warmth and support. In addition to relational connection and support which may provide meaning to the caregiver (Barkway 2001:75; Stelter 2000:66), the knowledge that she is contributing to the life of another may also enable the caregiver to create meaning (Möller 1995:247). Rituals serve as a process which facilitates the transition from one world into another (Mason & Haselau 2000:283), in this instance, the caregiver's return transition from the 'twilight world of impending death' to the world of the living. In addition, rituals serve as a process which

facilitates the transition for the dying, *from* the world of the living to the world beyond (Mason & Haselau 2000:283).

As was mentioned in Section 3.3.5.2 above, Rieda created a daily touch ritual during Archie's bath times: *'I would bath him, dry him, comb his hair and dust him with baby powder all over,'* she said, smiling. For Priscilla, touching was an essential part of the special moments which she memorised during anticipatory mourning. Her touch rituals included stroking and massaging Attie's body, crawling into bed behind his back or merely adjusting his oxygen tubes. Attie welcomed her touch and Priscilla recalled that she and *'family members would touch him constantly. Our touch brought him comfort beyond words'*. In addition to expressing care, touching becomes a welcome confirmation that the loved one is still alive. Elsa recalled a significant moment of touch the day before Koen died: *'He reached out his hand and I took it. It was so cold. We slept like that, that night – his hand in mine... it never grew warm again.'*

Rieda, Priscilla and Jakkie recalled how they would wake up at night with an overwhelming fear that their spouses had died while they had been asleep. They would heave a sigh of relief as they felt the warmth of his body – he was still alive! However, that relief was juxtaposed to profound fatigue and a guilty wish that this were over – an example of the 'web of paradoxes' (Cheung & Hocking 2004:478) experienced in anticipatory mourning. The next section describes the theme of paradoxes which emerged prominently during the interviews, indicating contradictory feelings experienced by the participants during anticipatory mourning.

### **3.3.9 Paradoxes**

Caregiving presents many paradoxes which may aid the caregiver in letting go (Kruse 2004:220), but may also foster pronounced feelings of guilt (Rolland 1991:150-157) in anticipatory mourning. The caregiver must try to make meaning of her loss of a functional partner and the many roles which he has occupied in her life, *and* she gains a changed person to care for. She may feel trapped and thoughts of divorce may be common (Cheung & Hocking 2004:479). The act of letting go of her loved one while simultaneously drawing closer presents a paradox of movement in two opposite directions. Hence, it is only in being fully present in caring and touching that the caregiver is able to surrender to the dying process and so make meaning of caregiving and the paradoxes confronting her (Kruse 2004:221).

#### **3.3.9.1 'I wish this were over'**

Despite many opportunities of finding meaning in caregiving, wishing for the end to come is a very 'normal' part of anticipatory mourning (Rando 2000d:353-354). In addition, as the caregiver's emotional, financial and physical resources begin to dwindle, the emotional anticipation may shift from a fear of death to a wish for death, which may lead to overwhelming feelings of guilt (Rolland 1991:150-157). Normalising these emotions to the caregiver may contribute to a restored sense of meaning and self-worth (Rolland 1991:150-157). Mercy expressed her paradoxical feelings of holding on while letting go in the following way: *'All I could remember was how he had suffered. That way it helped me – he had lost his dignity. I was not hoping for a miracle... no. I saw how he suffered. It is horrible to say... but I almost accepted it.'*

Lifton (1996:172) describes 'paradoxical guilt' as being 'stuck' between the horror and the guilt of surviving her husband and the experience of 'relief, even joy or exhilaration' at the release of death. I asked the other participants if they had wished the ordeal to be over at any stage. All of them agreed that, particularly at times of severe physical and emotional exhaustion, they would wish both for their own relief *and* for the release of their husbands.

### **3.3.9.2 Guilt versus 'I did my best'**

Caregiving provides a vehicle for meaning-making by expressing love and care (Möller 1995:247). However, it also provides rich subsoil for feelings of guilt which may erode meaning-making. Mercy recalled the oncologist's words: *'Now is quality time – give him what he wants... but I never realised that one month later he would be dead. I had not done enough... Everyone said I had done enough... did the very best I could. Still inside I feel that feeling... could I have done more?'*

Rando (2000d:349) explains that spousal caregivers almost always experience guilt with regard to feelings, thoughts and behaviours which are in fact a common reaction to caring for a dying intimate. The caregiver's survivor status in itself creates guilt and a 'numbing of the mind' (Lifton 1996:175). In addition, prescriptive discourses from well-meaning friends and family members may often exacerbate existing feelings of guilt.

Conversely, some discourses may also function as a form of consciousness-raising by introducing us to other knowledge systems of understanding (Burr [2003] 2004:122) which create meaning (Stelter 2000:66). The positive functions of discourse – especially power or expert discourse (see Section 2.3.7) – became clear from the stories of the participants. Expert discourse may enable meaning-making by affirming the value and purpose of the participants' love, care (Möller 1995:247) and sacrifice (Frankl [1959] 2004:117). An example of the positive function of power discourse was relayed by both Elsa and Jakkie. The staff at Hospice confirmed

to Elsa that she had done her best in caring for Koen: *'I could not have done it any better, they said. No, I could not have done it any better....'*

Jakkie recalled that the doctors had told her that no-one could have done better than she had done: *'Dr Botha... in front of all the people in the waiting room, said: 'We have never seen a woman who stood by her husband like you, Tant Jakkie! Throughout the most difficult times, you never turned your back on Oom Alex. You never gave up hope.'* The two women repeatedly told and retold these 'power discourses', which suggests that these discourses ascribed meaning and value to their caregiving. I asked Jakkie if this brought meaning to her caregiving and she agreed: *'Yes, it is a comfort to know I did good. "I love you my wife, always... I do not know how long I will be with you" and what the doctors told me – that I never turned my back on him.'*

### **3.3.9.3 Loved ones – a comfort and a curse**

The section above illustrates how positive support from experts can affirm the caregiver, alleviate guilt and so assist in the meaning-making process. Studies have shown that unconditional support from loved ones may be even more important in assisting a caregiver to make meaning (Kellett 2000:318). However, the converse, namely the negative effect of prescriptive support, is also possible. Haley (2003:221) found that negative social interaction increased feelings of depression and meaninglessness in caregivers. Rieda related an incident illustrating the effect of negative social interaction with her daughter, Gayle: *"Something is wrong with your father," I said to my daughter, Gayle. "No, he is sleeping. Come on, let's go out [of his room]," she said. But he is ice cold! I began to cry. "What the hell are you crying for?" she snapped. "He is not dead, he is just sleeping!" We left the room.'*

Rieda lives with her daughter, Gayle. They have a troubled relationship and were not able to support one another during Archie's illness and death. The social support of loved ones is usually informed by various discourses which may provide prescriptive, rather than unconditional support (Neuberger 2004:136). Elsa, for instance, experienced both positive and prescriptive support from her family: *'Don't cry Mom! You have to be strong now!'* her daughter admonished when Elsa phoned her at a particularly low point during anticipatory mourning. Priscilla described how many of her close friends withdrew from her – as if they did not know how to deal with her at this time, a phenomenon also described by Kastenbaum (2004:40-41).

Mercy contended that she is grateful for the consistent support of her family during this time. However, she also recalled, in minute detail, the fight which she and her daughters had on Christmas day when her daughter berated her for being tearful: *'It turned so ugly! We all said things we did not mean.'* Conversely, validating social support presents one of the most important

vehicles for meaning-making (Cheung & Hocking 2004:476; Haley 2003:216; Kellett 2000:318). Jakkie believes that the gentle support of her loved ones enabled her to become significantly stronger and more empowered than she had ever believed possible. Meaning and a sense of self is thus socially constructed in reciprocal negotiation (Stelter 2000:69) but a lack of supportive social interaction may result in a lack of meaning and loss of self.

#### **3.3.9.4 Loss of self versus 'I never knew I could do this'**

A caregiver experiences loss on two levels. The first level is presented by the declining repertoire of caregiving options (Cheung & Hocking 2004:478), for instance, a loved one's failing appetite narrows the possibilities for care. The second and perhaps more profound level presents a loss of self-identity. Niemeyer (2000:552) asserts that the loss of a partner indicates the loss of the self-narrative (the context of shared memories and values) and thus self-identity. The caregiver has to make new meaning by 'relearn[ing] the world and the self [and] finding new existential grounding for her self-concept and life direction' (Niemeyer 2000:552). Jakkie seems to have 'relearnt her self' through a new-found financial empowerment. Her husband, Alex, had always dealt with all financial issues. She has now '*learnt to work prudently [with money]: 'I easily gave away money before. Now I know I have to be prudent,'* Jakkie said. She recalled her feelings when she realised that she could no longer rely on her husband to deal with financial issues: '*My head just left me. Lord, why must I now do everything – I don't know how! Why did you take Alex? Why should I struggle so? Then I just... had...to learn...how. Now I no longer ask God...the questions I must resolve myself... all the problems... and I can!*'

I asked the respondents to reflect on their self-image and whether new personal resources had emerged during anticipatory mourning. Elsa reflected that she would not have believed that she could deal with the loss of her husband. However with '*grace from above*' she was able to cope. Losing Koen brought out her personal strength, she said. She also commented on her newly-discovered ability to use power tools. '*...and I can do it! I can do it, you know!*' she said, smiling. Although Priscilla had always been self-contained, she remarked how her values and her framework of meaning have changed. She now values a few close friends who affirmed her – '*people who mean something in your life*' rather than many acquaintances, and she makes a greater effort to spend time with those special people.

Mercy is particularly proud of the fact that she can '*fix things around the house*' and that she goes out often and stays out till dark without being fearful. When I asked her about other resources she had become aware of, she said: '*Faith, guts and love for my children – all of them.*' Elsa, Jakkie, Mercy and Priscilla confirmed that they had all experienced an enhanced sense of self-agency and this proved meaningful to them. In the light of these gifts of anticipatory mourning which

became visible, I wondered if they would have chosen a different experience of loss if they had been given a choice. Priscilla, Mercy, Jakkie and Elsa asserted that they would have chosen the same experience of loss because it allowed them time to say goodbye.

### **3.3.9.5 'I would choose this again'**

The awareness of time featured prominently in all the stories of the participants. The literature confirms the importance of an awareness of time in losing a husband to cancer. Time allows for the creation of meaning through planning (Rando 2000b:81), forgiveness of past hurts (Kruse 2004:218), and expressions of love, care (Möller 1995:247) and sacrifice (Frankl [1959] 2004:117). Elsa is emphatic that she would not have had it any other way: '*No, no...I would have chosen it this way again! It allows one time to realise what you may have lost in each other and what you should recapture... before it is too late.*'

Jakkie and Priscilla were also adamant that they would not have had it any other way, since cancer and caregiving provided them with the most precious commodity, namely time to say goodbye and deal with unfinished business. Time provided them with a valuable gift: they were given ample warning of their husbands' impending death. The warning element of anticipatory mourning may aid meaning-making, since it provides the caregiver with a sense of predictability and order (Nadeau 1998:29).

#### **Personal reflection**

*My experiences resonate with those of the participants of this study. Despite the enormity of our trauma, Louis and I had time – the most precious commodity of all in the face of cancer – and I was able to convey my love for him through caregiving (Möller 1995:247). This provided meaning to me. Upon reflection it appears from our choosing the same trauma that these caregivers and I deemed the experience meaningful. The awareness of time to say goodbye to a loved one may therefore be one of the greatest meaning-making tools in anticipatory mourning.*

### **3.3.9.6 'To be there when he dies' – a final goodbye**

The final tool of meaning-making in anticipatory mourning presents itself at the moment of death. Being present to a loved one's death means that the loved one does not have to go through the dying process alone (Kruse 2004:220) and it represents a final act of love (Möller 1995:247) and respect where nothing is asked in return (Sharp 1996:221). Being present also intimates the final paradox of anticipatory mourning – accompanying the dying one while letting go at the same time (Kruse 2004:220). All the participants stressed the importance of being present at the moment of death. Again my own experience resonated strongly with this sentiment. The overriding thought in

my mind throughout anticipatory mourning was my desire to be with Louis at the moment of his death. Rando (2000d:353) confirms the desire to be present to a dying loved one as a very meaningful and important need in intimates.

Although Rieda seems to harbour no guilt or doubt regarding her caregiving efforts, she talked tearfully about her absence the night Archie died: *'I gave him the pill and he puckered his mouth for a kiss. I kissed him. "Thank you Rieda. Now I am going to sleep"... that was the last time I saw him alive.'* Rieda wept when she spoke about Archie's dying alone: *'She [her daughter] didn't tell me that! [that Archie had died]. It was so wrong! I wanted to be there. I didn't want to go to sleep. I wanted to be there for him [tears]. But there you are... that's how it is'*. Elsa described how she had intensified her caregiving efforts toward the end of Koen's life. She would not allow anyone else to take care of Koen for fear that he would die in her absence. Priscilla and Jakkie expressed satisfaction that they had been present at the moment of death. Both marvelled at the quiet and gentle way of dying they had witnessed. I asked the caregivers if they had been able to make meaning of the death itself. They could not. *'I don't know why the Oom had to die but one day we will understand... It is God's will,'* Jakkie said quietly. The next section focuses on the importance and meaning of spirituality (Golsworthy & Coyle 2001:188; Bee 1996:329) to the participants of this research study.

### **3.3.10 Spirituality and suspended meaning: 'It is God's will'**

The belief that the loss of their husbands was part of a bigger plan provided a certain amount of meaning to an otherwise meaningless event. It was also significant for Jakkie, Priscilla and Elsa that their husbands had 'come to peace with God'. Elsa recalled that her church minister would visit Koen daily during the last two weeks of his life. On the morning of his last visit, the minister asked Koen what he should pray for. *'Pray for grace... that is all,'* Koen replied. Elsa's husband was also at peace with God and she found significant meaning in this knowledge.

Steinhauser (in Kruse 2004:216) studied aspects regarded as important by intimate family members of the dying. He found that 'coming to peace with God' was regarded as one of the most important requisites for meaning-making by survivors *and* patients.

During the interviews, the participants repeatedly returned to the meaning of their faith. For Elsa, Priscilla, Mercy and Jakkie, spirituality seemed to be the main tool of meaning-making, albeit suspended meaning.

<b>Personal reflection</b>
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*I use the term 'suspended meaning' to convey the implicit acceptance of the presence of meaning in the absence of the experience of meaning – in other words, the certain knowledge that something will make sense in the future, even if it makes no sense right now. For example, Jakkie and Elsa contend that they do not understand the meaning of the death of their spouses. However, they hold onto the hope that their loved ones are with God and that God will explain the meaning of their loss in the hereafter.*

Jakkie shook her head when she talked about meaning: *'He had a bitter suffering... could not eat. Everything tasted of cancer. ...I do not understand why... but it is God's will... His works. We may not get angry. He [God] will tell me why, one day. Alex is in a better place... he has no more pain.'* When personal meaning-making proves insufficient, a preparedness to suspend meaning-making until the hereafter appears to form part of macro meaning (discussed in Section 2.4.4).

DiJoseph and Cavendish (2005:147) assert that spirituality is universal. People need to believe that they are connected to a higher being who is in control of all. This belief provides meaning and wholeness to their lives. Mercy asserted that her faith in God has grown stronger and she has experienced greater access to God. Jakkie, Elsa and Priscilla reported that their spiritual walk with God has deepened. Elsa believes that she now feels even closer to God than before: *'Hmm... listen... much closer. Not that one wasn't close before, but something like this shakes you...listen... it shakes you!'* Jakkie agreed: *'After the Oom's death, I said:" God, now I have to live with you... I cannot live without you." So now I do not ask why anymore... I leave it all in His hands'*. Priscilla contended that she has *'a lot to be thankful for...do not blame God. He has a road for each one who wills...'*

Niemeyer (2000:553) studied meaning-making in survivor caregivers and found that initial spiritual interpretations provide impromptu explanations for the death of a partner. This serves as a coping mechanism for the surviving partner, a suspended kind of meaning. Later, however, these spiritual meaning frames become infused in the existence of the survivor, often resulting in a deep sense of purpose and connection to God, others and their deceased loved ones. The importance of a sense that the connection to a loved one continues beyond death is borne out in the following section. The objection may be raised that this section belongs to post-death mourning rather than anticipatory mourning, but it supports the contention of an ongoing relationship – an 'inner representation of the deceased' (Kunkel & Dennis 2003:6) – as a significant part of meaning-making which may already be cultivated during anticipatory mourning.

### **3.3.11 'Visitations, coincidences and strange occurrences'**

The notion of an ongoing relationship has been found to alleviate stress (Kunkel & Dennis 2003:6) and therefore presents a rich opportunity for meaning-making. Belief in an ongoing

relationship (see Section 2.4.8) is borne out by the following recounts of visitations by the deceased loved ones. Jakkie, Elsa, Mercy and Priscilla substantiated their belief in an ongoing relationship by recalling stories of 'visitations' from their deceased spouses. It was interesting to note how the participants adjusted their traditional framework of meaning and religious discourse to accommodate explanations of revisits by their departed husbands. In terms of the traditional Christian discourse as expressed in Deuteronomy 18:11 and Isaiah 8:19, for example, it may not be 'acceptable' to communicate with the dead (Thompson 1983:1734). Yet, even Jakkie and Elsa, who appeared more conservative in their religious discourse, recounted visitations from their deceased spouses with conviction.

Elsa told how Koen visits her in her dreams. She has had many vivid dreams and discussions with him during those visits. She said that she sometimes sees him standing in the hallway, saying: *'Are you coming to bed, or what?'* Priscilla holds on strongly to an ongoing relationship with Attie. She has experienced repeated and vivid dreams of Attie where she becomes agitated and he kisses her to calm her, as he had done in life when she had had a bad dream. She also showed me a framed A4 photo of Attie which fell from the wall twice. It looked as if strong metal hooks had been torn from the wooden frame. She had replaced the hooks, and the photo had fallen from the wall again. She believes that it could be Attie's attempt to make contact with her.

Mercy claimed that she had experienced two fully conscious instances of visitation by Bruce. The first instance occurred when she had just gone to bed and she saw Bruce standing next to the bed wearing his black cremation suit. The second visit occurred during the day. Mercy was on her knees, sorting through his personal belongings, when he appeared in the hallway: *'He looked so happy. Afterwards I felt a feeling of fear... I did not want to see him again.'* When I probed a little more, Mercy explained that she had been afraid that she was dying and that Bruce had come to fetch her. Jakkie is often aware of Alex's presence. She believes that she has had two visitations from Alex – one in which he was lying in bed next to her, sick and deformed as he had been before his death, and one in which he was standing next to her bed, *'the most beautiful, beautiful man – as I remember him years ago'*.

Castillo (1997:74) notes that many non-western cultures will naturally maintain contact with a deceased ancestor. Indeed, it would be regarded as perfectly natural to hear an audible manifestation of the ancestral voice. In Western culture, however, a claim of a post-death visitation might be regarded as a sign that the recipient of the visitation is mentally unstable. Melges and Demaso (1980:52) suggest that perceptions of visitations may be ascribed to loss of reality-contact caused by grief. A study by Rees (Melges and Demaso 1980:52) found that 47 per cent of bereaved respondents reported a 'sense of presence' or auditory and visual hallucinations

of the deceased. Nadeau (1998:110-111) asserts that dreams, visitations and 'coincidancing' are strategies employed by the bereaved to make meaning of the loss and to ensure an ongoing relationship. Whether the experience of visitations presents a function of emotional instability or an ongoing relationship, meaning-making attempts by the caregivers become evident when traditional frameworks of meaning and religious discourses are assessed and *amended* to fit inexplicable events. Amending one's framework of meaning ensures the survival of the relationship with the deceased (Nadeau 1998:110-111). In the text box below, the participants' belief in an ongoing relationship is evident.

The textbox below presents a synthesis of multiple meanings which emerged from the caregivers' stories. The synthesis is in keeping with Social Construction which embraces complexity (Burr [2003] 2004:3-4), rather than analytical reduction (see Section 1.10.2).

A phenomenological study where meanings are distilled and extracted from raw data could be regarded as an antithesis to postmodern theory which focuses on holistic synthesis rather than extraction of essences (Burr [2003] 2004:5-6). The following synthesis represents a fusion of multiple meanings emerging from each respondent's story to form an encompassing proposition (Kruse 2004:219-220) of each participant's meaning-making:

**Elsa** seems to focus her need to make meaning on delayed or suspended meaning, signifying that she is prepared to suspend her need to understand Koen's death until God makes it clear to her in the hereafter.

**Priscilla** seems to find meaning in the concept of a legacy left and a life fulfilled: '*Attie was not like every other man who gets sick and dies – he had a calling which he fulfilled and he left a great legacy – that was my healing,*' she asserted. Priscilla also seems to find meaning in the continuity of an ongoing relationship.

**Mercy's** need for meaning seems to centre on feelings of guilt – '*I did not do enough. If only I could have him back for one hour.*'

**Rieda** seems to present a focus on paradoxical meaning: '*It was a very hard life – I am not sorry he died*' versus '*If only I had been there when he died!*'

(Continued)

**Jakkie's** main theme centres on the concept of suspended meaning: '*He was so ugly and I still loved him. Now he is with God and he is whole again.*' The idea of hanging on during hard times (Kruse 2004:219) so that she does not disappoint Alex in heaven also present an important concept of meaning to her. Jakkie seems to enhance her meaning-making by focusing on an ongoing relationship with Alex: '*I get a hot flash... and then I know that he is with me...*'

At the conclusion of the interviews, three of the participants remarked on the benefit of having told their story. Priscilla said that it '*felt good*' to tell her story. She usually felt reticent to tell others about Attie for fear of being tiresome. Both Jakkie and Mercy voiced similar sentiments. Mercy

said toward the end of a three-hour interview that telling her story had done her *'the world of good. I feel a lot more at ease and comfortable... not so bitter about myself any longer'*. Jakkie expressed her appreciation: *'I am glad I spoke to you. It was sad but things feel **normal** once again.'*

### **3.4 CONCLUSION**

I felt infinitely grateful for the unintended benefit which Jakkie, Priscilla and Mercy derived from our interviews, especially since my initial intention was simply to cause no harm and I did not set out actively to benefit the participants. Upon reflection, it seems as if the simple act of telling one's story has a powerfully therapeutic effect on the narrator. Upon further investigation, I found literature which corroborated the contention that telling creates meaning. The next chapter explores practical theology; pastoral care and the benefits of telling one's story; and, in the light of the participants' experience of pastoral counselling and care (see Section 3.2 above), explores ways in which pastoral counsellors may participate in creating meaning *with* caregivers in anticipatory mourning.