

CHAPTER 5: REFLECTIONS

*Death is nothing at all. I have only slipped away into the next room.
I am I, and you are you. Whatever we were to each other, that we still are.
Call me by my old familiar name, speak to me in the easy way which you always used to.
Put no difference in your tone, wear no forced air of solemnity or sorrow.
Laugh as we always laughed at the little jokes we enjoyed together.
Play, smile, think of me, pray for me.
Let my name be ever the household word that it always was.
Let it be spoken without effort, without the trace of a shadow on it.
Life means all that it ever meant.
It is the same as it ever was; there is unbroken continuity.
Why should I be out of mind because I am out of sight.
I am waiting for you, for an interval, somewhere near, just round the corner.
All is well.*

Henry Scott Holland
Canon of St. Patti's Cathedral 1847-1918

5.1 INTRODUCTION

As I draw to the close of this study, I am confronted by conflicting emotions. My personal involvement as both researcher *and* insider caregiver has proved difficult and I feel relieved that the research has finally been completed – and yet it has been a close companion for more than two years. I stand in awe of the research process which seemed to have gained a momentum of its own. Conducting this study has proved to be an infinitely ‘stretching’ exercise for me, both in terms of the methodology and emotional content; and the ambiguity of the ethical demands throughout these chapters has alternately enthralled and dismayed me, but has never allowed me to be comfortable.

I would like to summarise the research journey at this point. Chapter 1 contains the background to the research question, the research aim, the argument for using a literature control throughout this study instead of doing a contained literature review, the methodology, the epistemological and theoretical framework, the research path and a discussion of the main concepts of this research study, namely caregiving, anticipatory mourning, bereavement and pastoral counselling. Chapter 2 focuses on the social construction of meaning, discourses which influence meaning-making and social constructions specific to anticipatory mourning. Chapter 3 retells the unique stories of the participants of this study, and presents common phenomenological themes which emerged from the interviews with the participants. Chapter 4 focuses on practical theology and co-constructed pastoral care for caregivers in anticipatory mourning.

Chapter 5, the final chapter of this study, reflects on the findings of the research with regard to three areas of focus. The first area is a focus on the main concepts highlighted in the study (as contained in Section 1.8), namely caregiving, anticipatory mourning and meaning-making. The second area of focus is feminist theology and a contextualisation of the theological assumptions to the *lived* experiences of the caregivers in anticipatory mourning. The third area of focus is the process and methodology followed in this research, with particular reference to i) the research aim; ii) the ethical considerations I was confronted with in conducting this study; iii) limitations of the study as well as directions for further studies; iv) the contribution of the study to the world of research; v) the possible effects of this research on the wider community; vi) the possible impact of this research on the participants; and vii) a reflection on the impact of this research on my personal process. The chapter concludes with the voices of the participants in a collective and symbolic 'letter to Pastoral Care'. I chose to refrain from reflection on this letter as it seems fitting that the participants – the experts of anticipatory mourning – should have the final, unedited word.

Section 5.2 below contains a summary of the research findings of this study, which will be cross-referenced and reflected upon in later sections.

5.2 SUMMARY OF THE FINDINGS OF THIS STUDY

Seven main findings arose from this research – two of which emerged spontaneously and unexpectedly (Findings 3 and 5), as follows:

Finding 1: Anticipatory mourning is a distinct state of mourning (reflected on in Section 5.3.1 below) which is separate and different from, but also overlaps with, post-death mourning.

Finding 2: The act of caregiving seems to add meaning to the experience of anticipatory mourning and loss (reflected on in Section 5.3.2 below).

Finding 3: The *outcomes* of meaning-making appear to be diverse, subjective and unique (reflected on in Section 5.3.3.1 below).

Finding 4: The *process* of meaning-making, however, seems to take place in a shared context of spirituality and relationality (reflected on in Section 5.3.3.2 below).

Finding 5: Telling equals meaning-making (reflected on in Section 5.3.3.3a) below).

Finding 6: Various discourses can hamper or facilitate meaning-making (reflected on in Section 5.3.3.3b) below).

Finding 7: The participants needed a different kind of pastoral care from the care they had received during anticipatory mourning (reflected on in Section 5.4 below).

5.3 REFLECTIONS ON THE MAIN CONCEPTS IN THIS RESEARCH

The research focused on the processes of *meaning-making* by spousal *caregivers* in the context of *anticipatory mourning*. Upon reflection, the experiences of the participants (Section 3.3), and the processes of making meaning have shown areas of overlap; hence, specific suggestions for co-constructed pastoral care (Section 4.4) are made. However, the outcomes of meaning-making have been unique and diverse. I have tabulated them in order to illustrate the breadth of that diversity (Table 2 in Section 5.3.3.1).

The following section reflects on Finding 1, namely that anticipatory mourning is a context that is different from post-death mourning.

5.3.1 Anticipatory mourning as a distinctly different context

Finding 1: Anticipatory mourning is a distinct state of mourning which is separate and different from, but also overlaps with, post-death mourning (also see Section 1.8.2.1). When I reflected on the interviews with the participants, I realised that they spent significantly more time talking about the period before their husbands' deaths than about the period after the deaths. The participants also confirmed verbally that the anticipatory mourning period was more difficult for them than post-death mourning (Section 3.2.5, Personal reflection). Although Mercy asserted that she had found post-death mourning more difficult, she proceeded, in the same sentence, to mention particular hardships which she experienced in the anticipatory mourning period, and not the post-death period. Thus, if the greater part of the caregiver's story focuses on the pre-death phase of anticipatory mourning, then this has significant implications for context-specific pastoral care.

Although, as I have already conceded, one cannot generalise the findings of this study to a population of caregivers (Section 1.11.2), it appears from the stories of the participants – and from my own experience – that the anticipatory mourning period is characterised by heightened intensity of stress, ongoing trauma and anxiety (Section 3.3.6), compared to that in post-death mourning. If this contention is accepted, then meaning-making during anticipatory mourning takes on added significance in respect of how to fulfil the need for pastoral care. The next section reflects on Finding 2, which highlights the value of caregiving.

5.3.2 Caregiving

Finding 2: The act of caregiving seems to add meaning to the experience of anticipatory mourning and loss. Four of the five participants asserted that they would not have changed the experience of caregiving if they were given a choice (Section 3.3.9.5), which suggests that the

participants found meaning in the act of caregiving. Additional meaning-making is implied when the participants pointed out the unexpected attributes and abilities which they discovered in themselves in the process of caregiving during their anticipatory mourning (Section 3.3.9.4).

The sections below reflect on meaning-making as diverse (Finding 3), but also as over-archingly spiritual and relational (Finding 4), as well as the contention that meaning is often created through storytelling (Finding 5) and is influenced by our discourses (Finding 6).

5.3.3 Meaning-making

One of the fundamental human needs is a need for meaning (Section 1.4). Upon reflection however, meaning-making appears to be an abstract concept which is difficult to define. We often talk as if we have intimate knowledge of the concept and yet we cannot agree on its definition. We practice the concept throughout our lives, yet rarely with awareness. Collective meaning-making appears to take place continuously, but often in an unconscious hit-and-miss fashion. Mostly, we make meaning without intending to – and yet we seem to make sense of significant events in our lives on an ongoing basis through storytelling (Section 4.3.1.1). As mentioned in Chapter 2 (Section 2.2.2, Personal reflection), what is recalled in a story has already, by virtue of its recollection, been constituted as meaningful (Kleiman 2004:10). Therefore it seems that a simple listening presence (Section 4.3.1.2) is often adequate for the narrator of a story to begin to make meaning. After having studied the concept in this project, the importance of meaning-making has become a conscious awareness for me. The next section reflects on Finding 3, on the variety of unique descriptions of meaning that are possible.

5.3.3.1 Descriptions of meaning

Finding 3: The outcomes of meaning-making appear to be diverse, subjective and unique. In this section I tabulate the various descriptions of meaning and meaning-making which I encountered in the literature and referred to in the chapters in this study, as a reflective act to illustrate the diversity of meaning-making outcomes. One word or phrase is selected for each author to represent the diverse descriptions of meaning in the literature. When I reflected on the descriptions of meaning given by the participants, I found that, despite reasonable homogeneity regarding background, race, gender, age, experience and religious observation, each participant nevertheless reached an outcome of meaning unique to her own subjective reality (see Table 2 below). Rieda preferred not to describe her own meaning-making which, perhaps paradoxically, supports the contention that the outcome to meaning-making remains unique. The table below also reflects the Social Construction framework which emphasises subjective knowledges and the possibility of many truths (Sections 1.10.2 and 2.2), rather than one universal truth.

Table 2: Descriptions of meaning

Descriptions by authors:	
Meaning = spirituality (Bee 1996:329)	Meaning = purpose (Frankl [1959] 2004:85)
Meaning = story-telling (Seaburn, Lorenz & Kaplan 1992:392; Kleiman 2004:10)	Meaning = safety (Golsworthy & Coyle 2001:188)
Meaning = retelling (Frank 1998: 207)	Meaning = relationship (Doka 2003:46; Gergen [1999] 2003: viii; Barkway 2001:75; Stelter 2000:66)
Meaning = planning/information (Rando 2000b:81)	Meaning = relational (Rando 2000b:66)
Meaning = a sense of order (Golsworthy & Coyle 2001:184; Nadeau 1998:29)	Meaning = hope (Lester 1995:81)
Meaning = that which can be recalled (Kleiman 2004:10)	Meaning = life satisfaction (Haley 2003:221; Hunt 2003: 29)
Meaning = social support (Neuberger 2004:65-71; Zilberfein 1999:74)	Meaning = contribution to life of another (Möller 1995:247)
Meaning = predictability (Danforth & Glass 2001:521)	Meaning = healing (Danforth & Glass 2001:189)
Meaning = forgiveness (Kruse 2004:218)	Meaning = values (Möller 1995:248)
Meaning = lack of boredom (Möller 1995:247)	Meaning = benefits/rewards (Doka 2003:48; Davis & Nolen-Hoeksema 2001:726)
Meaning = sacrifice (Frankl [1959] 2004:117)	Meaning = reduced depression (Hunt 2003:29)
Meaning = that which is significant (Kruse 2004:217)	Meaning = dynamic/transitional (Frankl [1959] 2004:124)
Meaning = understanding (Gergen [1999] 2003:143; Stelter 2000:66; Davies 2000:143-144)	Meaning = knowing how to go on (Gergen [1999] 2003:145)
Meaning = positive appraisal (Hunt 2003:30)	Meaning = constituted by language (Kotzé & Kotzé 1997:31-32)
Meaning = rites and rituals (Imber-Black 1991:207)	Meaning = caregiving (Cheung & Hocking 476)
Meaning = love and care (Möller 1995:247)	Meaning = acceptance (Sorajjakool & Seyle 2005:180)
	Meaning = special knowledge (Hunt 2003:30, 31)
Descriptions by participants:	
Priscilla: meaning = telling; guidance; and purpose	Mercy: meaning = independence and freedom
Jakkie: meaning = acceptance of God's providence	Elsa: meaning = telling and trusting God
Rieda: declined to specify any meaning made	

The table above illustrates the diversity and uniqueness of the *outcomes* of meaning-making. However, the next section reflects on the *process* of meaning-making, which seems to take its course in a global and shared context of spirituality and relationality (Finding 4).

5.3.3.2 Spirituality

Finding 4: The process of meaning-making seems to take place within a shared context of spirituality and relationality. Throughout this study, the literature control (Section 1.7) seems to suggest that meaning-making takes place in a global context of spirituality (Sections 1.8.3.2, 2.3.3, 2.3.7.6, 2.4.3, 2.4.4 and 3.3.10). Thus, although the outcome may not necessarily indicate

expressed spirituality (Table 2), there appears to be a universal need for people to believe that they are connected to a higher being who is in control of everything. This seems to provide a context for meaning-making.

Upon reflection, I was struck by the way in which the Christian ethic and the theodicy question operates in the lives of the participants. For instance, I asked the caregivers if they found it acceptable to 'wrestle with God' in an effort to make sense of trauma. Priscilla felt that it was acceptable to question God, but the other participants disagreed strongly. Although Rieda was seemingly disinterested in religion, she was adamant that God is not to be questioned. Elsa and Jakkie both stressed that they thought it was unacceptable to question God. Jakkie repeatedly asserted that *'it is not for us to know God's ways'* (Section 3.3.10). The position of refusing to question God may provide macro meaning in an over-arching way (Section 2.4.4, Personal reflection), but it may also allow the caregivers to abdicate their responsibility of actively making meaning in the face of trauma. In other words, they may feel that meaning-making in the now is unnecessary, since God will explain the loss in the hereafter.

Personal reflection

In traditional Christian religion, a refusal to accept God's providence may indicate an act akin to sin, but it also means acknowledging and taking responsibility for our questions and our anger, which many of us may be hesitant to express for fear of divine retribution. However, if we blindly believe in God's providence, it lets us off the hook of meaning-making – to the extent that we would rather accept meaninglessness than accept responsibility for asking questions. If and when we dare to raise such questions, our religious discourse may cause us to feel infinitely guilty. It is also possible that, when we find ourselves in the throes of trauma, however, it could seem that the worst is happening in any event and this belief may liberate us from the fear of God's retribution. A caregiver may thus be freed to 'have it out with God' or to suspend meaning-making until the hereafter. In my experience, I felt liberated, since I was losing my husband in any event, to question God and so find a new, revised sense of spirituality.

The concept of 'suspended meaning' (Section 3.3.10) seems to belong mainly to the domain of the spiritual, since it is in view of their belief in an afterlife that many people are prepared to suspend their immediate need for meaning. It also seems that part of suspended meaning is the assumption that we are not permitted to question God. Adhering to a sense of suspended meaning seems to broaden the repertoire of meaning-making. Priscilla is unable to verbalise the sense in Attie's death. However, she believes that she will understand in the afterlife: *'I will ask God one day when I get to heaven,'* she says, adding *'Attie is in paradise.'* Jakkie's grandson wrote a note to his grandfather and placed it on his coffin at the funeral. When I read the letter, the following sentence arrested me – it seemed to contain a world of hope and the very essence

of suspended meaning: *'Dedda, look in heaven's mirror – you are whole again.'* The next section reflects on a continuation of Finding 4, namely the relational context of meaning-making.

5.3.3.3 Relationality

Finding 4 (continued): The process of meaning-making seems to take place within a context of spirituality and relationality. It has become clear from this research that meaning-making is inter-subjective and relational (Section 2.3.2), whether in relation to God or to others. Upon reflecting on the stories of the participants, I found that their meaning-making took place in the context of their relationships with God, their spouses, their loved ones, medical personnel and/or 'expert voices', as well as the voices of discourse (Section 3.3.3). The extent to which meaning-making appears to stand in a relation to another emerged prominently when I noted repeated expressions of appreciation and gratitude from the participants after they had been given the space to tell their stories (Section 4.3.1 and 4.3.1.2). These expressions of gratitude were repeated in our final group interview. I realised that meaning had been made in relationship, while the participants were relating their stories in detail, and I marvelled at the unintended therapeutic effect that participatory telling and listening had wrought. In the next section, I reflect on the fifth finding, which proved to be the most unexpected and profound in its simplicity, namely the meaning-making effect of telling one's story.

a) Participatory telling and listening

Finding 5: Telling equals meaning-making. Kaethe Weingarten (2003:232) calls true, participatory listening 'compassionate witnessing'. She asserts that compassionate witnessing is profoundly energising for both the teller and the witness. I agree with her contention. After three hours of intense concentrative telling and listening during the research interviews, the participants appeared energised (Section 3.3.11) and I certainly felt energised and stimulated. Meaning had not only been made for the participants, but also for me – as I listened to their stories, so I also heard parts of my own story retold (Section 4.3.1.2).

Personal reflection

After the first two interviews where both participants thanked me repeatedly and told me how much better they felt, I felt pleased with myself and my 'interviewing skills'. By the end of the fifth interview I realised that it probably had very little to do with my competence as an interviewer or therapist, but everything with the fact that the participants had been allowed to simply tell their story without judgement or time constraints. I felt grateful that our interaction had benefited them. Most of the interviews lasted up to three and a half hours, during which time the participants were simply allowed to talk. (Continued)

For the first time I realised just how powerfully therapeutic it is to be allowed the space for telling (Section 4.3.1.1). I recall at one point experiencing an emotion akin to envy when I realised that I had not created sufficient opportunity for myself to tell someone my story from beginning to end. Perhaps I created that opportunity for myself in Chapter 1 by including my own experiences in this study.

In telling my story, it seems that meaning-making presents a type of layering of meanings where the key to meaning is the act of telling a story and the gateway is a participatory listener (Section 4.3.1.2). Each time a mourner is permitted to tell her story, a thin layer of added meaning is created. The listener offers the accepting slate on which the teller can write a framework of meaning. A few processes – each process adding a layer of meaning – transpire almost simultaneously, namely the factual telling; recalling or creating a revised framework of reference and assessing the contents against the framework; and evaluating the fit of the content within the framework. Upon each subsequent revisiting of the story by retelling it to a participative ear (Frank 1998:207), another layer of meaning is added as the teller adjusts her framework and the factual content to create a meaningful fit. Meaning-making is thus never complete, but is a constant process of editing, adding and assessing through telling and retelling (Danforth & Glass 2001:513).

If we make meaning by telling, then the more we tell our stories, the more meaning we make. Indeed, retelling *is* meaning-making (Frank 1998:207). This raises the possibility that so-called pathologies such as ‘depression’ may reflect a lack of meaning-making (Hunt 2003:29) and, by implication, a lack of participatory listeners. That would imply that the act of meaning-making brings healing (Golsworthy & Coyle 2001:188; 189).

There are different ways of making meaning, as is evident from the findings of this study (Sections 2.4 and subsections; 4.4.4.7 and subsections). Identifying the gifts or benefits within loss, for instance, presents one form of meaning-making (Davis & Nolen-Hoeksema 2001:726). When we repeatedly tell someone about the gifts within loss, we thicken the story until the meaning of the gift becomes significant enough to render the trauma of the loss a little less traumatic. This dynamic may explain the therapeutic effect of ‘confronting our fears’: when we keep returning to our fears, we begin to make meaning, layer by layer. However, we cannot operate or make meaning outside of discourse (Section 2.3.7). The next section reflects on the discourses (Finding 6) which have emerged as strong influencers of meaning for the participants in this study.

b) Discourses

Finding 6: Discourses can hamper or facilitate meaning-making. Suspended meaning and macro meaning (Section 3.3.10 and 2.4.4, Personal reflection) present an example of positive and helpful discourse embedded in theology (Doehring 2006:112). The converse also occurs. One of the reasons why there appears to be such a prominent need for caregivers to tell their stories

may be that dominant social discourses dissuade them from making others uncomfortable by telling them a dismal story (Section 3.3.3).

Upon reflection, I find it ironic that the *bereaved have to make space for the discomfort of the non-bereaved*. Priscilla, for instance, verbalised the discourse restricting her when she said: *'It has helped me to tell my story. I am always concerned that I will irritate people... I respect that. Yes, people do not want to listen to your story all day long....'* This is an example of the deterministic nature of discourse. This also presents a reason why friends and family (Section 3.3.9.3) may sometimes strengthen such an oppressive discourse, rather than provide succour (Frank 1998:208).

Discourse is not only negative however. It also provides a *framework and boundaries for our meaning-making processes* (Section 2.3.7 and subsections). We make meaning by virtue of our discourses. Discourse therefore functions in paradoxical ways. On the one hand, socially constructed discourses may invest a person with an identity (as in 'Mr A's wife, married woman – a stable and trustworthy member of society'). On the other hand, that same discourse can become a person's enemy (when Mr A dies and the *status quo* changes, that discourse turns on Mrs A, and where it initially conferred an identity on her, it now strips her of that identity. Mrs A becomes the negated widow, *sans* identity and *sans* social standing). Priscilla, despite her strong identity as an economically active widow, nevertheless indicated her sadness at being ignored by friends and acquaintances once she no longer occupied the role of Attie's wife: *'Friends no longer invite me... I do not really fit in I suppose...'*

For the dying spouse, his identity, constructed in social discourses, as *'a man, breadwinner, husband and head of the household'* is deconstructed violently. The dying person is stripped of power. Medical discourse dictates continued treatment (Rando 2000d:321) despite his terminal status and the dying may be trapped between the devastation of treatment for the sake of his family and his own desire to terminate treatment. Some spouses reaffirm their power when they make the decision to terminate treatment. For instance, Rieda and Elsa's husbands decided to terminate chemotherapy. Louis, my husband, decided to refuse tube feeding. Such a reaffirmation of power represents a deconstruction of the power of medical discourse (Section 2.3.7.1).

In the stories told in the course of this research, the power of medical discourse at times deconstructed itself by affirming and validating the caregiving efforts of the participants. An example of the positive power of discourse presented itself when the medical personnel at the hospital told Priscilla that she had brought about a *'miracle'* when she rubbed Attie's legs and the swelling subsided. Elsa would reiterate throughout the interview how her *feelings of impotence*

translated into thoughts of her insufficiency as caregiver. She holds onto the fact that the staff at Hospice had repeatedly commended her: *'We could not have cared for him better than you have... What we saw on our visits... you did your best.'* This is an example of the positive function of expert power discourse. However, Elsa also commented on the way in which the discourse that her daughter, Amelia, communicated to her dissuaded her from expressing her sorrow – an example of prohibitive discourse. When she would break down in tears, Amelia would insist that Elsa remain strong and in control (Section 3.3.9.3).

Trippany, Barrios, Helm and Rowland (2004:37) describe how *societal discourse prescribes the emotions which are allowed as well as the permitted period of grieving* (Section 2.3.7.3). Once again I find it ironic that the non-bereaved is permitted to dictate the rules for bereavement. Society also prescribes a time limit during which a widow may express emotions, and after that period ends, grieving is regarded as pathological. Priscilla reiterated five times in the interview that she would not cry for fear of falling apart. I asked her if this fear were part of our Afrikaner or gender discourse and she agreed. It is also part of her personal discourse, as she noted, since she had taught herself throughout the years of Attie's heavy drinking bouts to remain strong and in control. This discourse might have prevented her from expressing her emotions in tears, but it also mobilised her to start a profitable business. She also proudly states that she organised Attie's funeral by herself. Priscilla comments that it is sad, however, that Janke, her daughter, has followed her example and does not allow herself to cry. Thus Priscilla's discourse has both enabled her to become financially independent, and disabled her from expressing her emotions and so make meaning of her sorrow.

A powerful and *positive deconstruction of medical discourse* is contained in Jakkie's story with regard to the attitude of the staff in the intensive care unit where Jakkie's husband, Alex, spent his last two days. The nurse encouraged Jakkie to cry as much as she needed to, whereas the medical doctor instructed her to refrain from crying for fear of upsetting Alex (Section 3.3.3). Alex was very weak by this time. He could not speak, but he was still conscious. Jakkie's daughter, Amanda, lives in Australia. The nurse allowed Amanda to telephone her father every day (sometimes twice a day) on the nurse's personal cell phone. She would then hold the phone to Alex's ear. He could not respond verbally, but the tears would stream down his face upon hearing his daughter's voice. Jakkie kept reiterating how much the warmth, humanity and care of the nursing staff had meant to her and her children. According to Jakkie, the *'black sister was just as kind...'* (a deconstruction of racial relations) and when Alex died, both nurses put their arms around the family and cried *with* them – an example of participative care. This experience infused those last two days with meaning for Jakkie and her family. The staff also showed a

preparedness to enter Jakkie's personal faith discourse, whatever their own religious discourses might have been. When Jakkie phoned the hospital on the night before Alex's death, the nurse said: *'He is not with us – he is speaking with God.'* This gave Jakkie peace, she said. The staff managed to transform a potentially traumatic deathbed scenario into an experience of calm acceptance and meaningfulness. Jakkie says that she will never forget what the staff meant to her and her family: *'There was such an... air of calm when we pulled the sheet over his face.'*

An awareness of the positive function of power discourse may enable the individual in power to use that power to validate the marginalised. In an attempt to normalise Mercy's feelings of guilt, I remarked that *most* caregivers appear to experience feelings of guilt. Mercy responded: *'If you say so, then I will look at it differently.'* I realised how potent power discourses are. Her perception of me as researcher seemed to place me in a power position. My words were therefore perceived as weighted, significant and true – no matter what I suggested.

Patriarchal discourse also seems to have played a strong role in the lives of the caregivers and their spouses. Mercy said that, during their marriage, *'Bruce would never go anywhere... so we always stayed home.'* She now asserts herself and does what she enjoys, like going out often. *'Bruce definitely underestimated me. We are always to be known as the weaker sex,'* she stated. Mercy's words encapsulate patriarchal dominance – hence the choice of feminist theology in this research study.

The next section reflects on some of the assumptions of feminist theology as described in Section 1.10.3.1, and the way in which these assumptions spontaneously emerged within the experiences of anticipatory mourning. These assumptions are also supportive of the finding that the participants had needed a different kind of pastoral care during anticipatory mourning (Finding 7).

5.4 REFLECTIONS ON FEMINIST THEOLOGY AND PASTORAL CARE

Finding 7: The participants of this research study needed a different kind of pastoral care from the care they had received during anticipatory mourning. Upon reflection, the needs of the caregivers in terms of pastoral care emerged more eloquently in the group interview. The draft letter in the epilogue compiled by the participants confirms this finding. As an alternative to the kind of pastoral care – or the lack of pastoral care – which the participants, with the exception of Elsa, received, Feminist theological assumptions (as set out in Section 1.10.3.1) can provide a contribution to the *meaning-making processes* of the caregivers in anticipatory mourning. The sections below relate Feminist theological assumptions and pastoral care to the experiences of the participants in this study.

5.4.1 Feminist theological assumptions as an alternative to traditional pastoral care

I would contend that each of the assumptions of feminist theology (Section 1.10.3.1) could assist a caregiver in the process of meaning-making.

For instance, feminist theology presents a *transformation of subjugating practices* (Section 1.10.3.1). Its assumptions provide a participative, non-prescriptive alternative to prescriptive care. The transformation of patriarchy (as one of the theological assumptions) becomes an enforced occurrence in the lives of a caregiver when a spouse can no longer fulfil the traditional role as 'head of the household'. Thus anticipatory mourning spontaneously deconstructs patriarchy when a female caregiver is forced to become the decision-maker in the family. She may subsequently discover many talents and personal attributes which she may not have been aware of before (Section 3.3.9.4). If the pastoral counsellor is aware of the way in which caregiving in anticipatory mourning deconstructs many discourses and reconstructs them via the assumptions of feminist theology, the process of meaning-making may be deepened and accelerated co-constructively.

Anticipatory mourning causes caregivers to *revalue* themselves as well as their dying husbands (Section 1.10.3.1b). Both Mercy and Elsa spoke proudly of the way in which they had learnt to cope with ordinary 'handyman' and gardening tasks (Section 3.3.9.4) and how much closer they had become to their life partners (Sections 4.3.2 and 4.4.4.5). Priscilla also presents an example of a *revaluation* of the dying (Section 1.10.3.1b). She celebrated Attie's life while he was still alive through photographs, videotapes, diaries and a co-creation of his legacy: '*Attie was not like every other man who gets sick and dies - he had a calling which he fulfilled... he left a great legacy....*' (Section 3.3.11, text box).

An example of a *re-interpretive* perspective (Section 1.10.3.1a) is mentioned above, where Mercy muses that Bruce underestimated her as '*the weaker sex*'. A second example of a re-interpreted perspective is when Mercy, in the second interview, confirmed that meaning to her meant independence and freedom, without guilt (Table 2 above). In addition, re-appropriating their value as caregivers through an *ethic of care* can be found in the retelling by Elsa and Jakkie of the stories of how both Koen (Elsa's husband) and Alex (Jakkie's husband) verbalised their appreciation of their spouses' caregiving (Section 4.4.4.3). Furthermore, Rieda's pride in creating a practical way to hoist Archie out of the bath (Section 4.3.2, ninth paragraph) presents an example of her personal (re)valuation of caregiving. Retelling her story to me caused her to revalue this event and so create added meaning.

Relational meaning (Section 1.10.3.1d) with God and others is illustrated in the way that Elsa, Jakkie, Mercy and Priscilla contended that they had become much closer to God and to their dying spouses during anticipatory mourning and thereafter.

Empowerment (Section 1.10.3.1e), a *revised language of grieving* (Section 1.10.3.1f), and an *awareness of discourse* (Section 1.10.3.1g) are illustrated by the way in which Jakkie insisted on crying openly, despite the prohibition of such crying by medical and social discourses. Finally, a *contextual focus on lived experience* (Section 1.10.3.1h) was illustrated when the research interviews provided space for each participant to tell her story at her own pace and in her own unique way, without judgement – thereby creating yet another layer of contextual meaning.

The next section reflects on the meaning of the research process as envisaged in Chapter 1 of this study. The research aim, methodology, ethical considerations, research limitations and contributions of this research project are evaluated. In addition, the caregivers are given a voice to comment on the effects of this research on them. Finally, I discuss the research effects on my personal process.

5.5 THE RESEARCH PROCESS AND METHODOLOGY

An integral part of the research process and methodology in this study is the use of the available literature in order to support or contradict assumptions and findings. In Section 1.7, I explained why I used *literature control* throughout this study, rather than a literature review. When a literature control is used in research, themes are highlighted and supported by direct quotations or stories from transcribed interviews, as well as appropriate literature that supports or contradicts a theme (Alpaslan 2009:45). This guideline has been adhered to throughout the study, but especially in Chapter 3, where the participants are introduced and the phenomenological themes are discussed and supported by appropriate literature and direct quotations. Upon reflection, the choice of a literature control added to the epistemological integrity of this study, since Social Construction advocates holistic and contextual integration, rather than separated summaries of objective truths (Section 1.7, 1.10.1 and 1.10.2).

I must point out that, because of the limited availability of studies on intimate caregivers and anticipatory mourning (Section 1.4), I have felt compelled to include both recent literature and studies conducted prior to the year 2000. If the exclusion of people on the basis of personal differences is regarded as unethical, then it may also be unethical to exclude older studies in favour of more recent studies. If we do so, then we imply that older studies hold less significance than recent studies. For the added reason of inclusivity, as well as overlap (Section 1.8.2.1), I have therefore also used older literature studies. Sections 5.5.1 and 5.5.2 below reflect on the

research aims (as set out in Section 1.6) and whether they have been met in this study, the methodology used, and the ethical considerations that applied to this research.

5.5.1 Reflection on the research aim

The primary aim of this study was to explore the meaning-making processes of caregivers and the knowledges they gained in anticipatory mourning. This aim has been met throughout this research project, but particularly in Chapter 3, where the experiences of the participants were discovered, related and organised into themes of meaning. Correlations between the different experiences were conducted on an ongoing basis and, in an effort to remain true to the holistic quest of a Postmodern epistemology, I attempted to create a synthesis of individual meaning-making (Section 3.3.11, text box). A secondary aim was to discuss the social constructs of meaning and the influence of discourses on meaning-making (Section 1.6) which was described in Chapter 2. The third aim was to discover how pastoral counsellors can participate with caregivers in co-constructing new or alternative meanings. Chapter 4 discusses narrative and contextual ways of co-constructing pastoral care which emerged from the needs expressed by the caregivers, as well as the available literature. The next section reflects on various aspects of ethical conduct within the methodological and research process.

5.5.2 Reflection on ethics

Ethical considerations encompass the whole process of research. For instance, the research process requires ethical conduct toward the participants, in respect of the integrity of the research project and toward the researcher herself. Below, I reflect on my ethical conduct and the way in which this study has been conducted in respect of the participants' experiences (see also Section 1.9).

In terms of my methodology, I am confronted by my *insider research status* (Section 1.11.3.1). Meneley and Young (2005:4) suggest that insider status can ensure depth of understanding and insight. I found this assertion to be valid. In fact, one of the reasons why I connected strongly with the participants was precisely due to my status as an 'insider'. This is where the ethical dilemma enters: Can I as an insider researcher be reflective and open to new knowledge, or did I subconsciously manipulate the co-researchers and data to confirm my personal experiences? Did I extract themes that resonate with my frame of reference? Ackermann (2003:38) warns that 'the trap that tempts us all is to assume, even for a split second, that my experiences are the norm for others'. It is my contention, in retrospect, that I have remained reflectively aware, however, the possibility that my framework of reference and subjective meanings may subconsciously have influenced the course and the conclusions of this research continues to concern me.

A second ethical consideration relates to my *choice of participants*, namely Christian women over the age of 49 years. I chose these participants because the discourses which dictate caregivers' lives need exploration (Section 2.3.7 and subsections) and many of those discourses may be age-, gender- and culture-specific. For instance, Bee (1996:332) found an increase in religious awareness and participation in middle age. I therefore attempted to use as homogenous a group as possible in order to control for age-related or developmental discourses. I acknowledge that other groups (such as Black women) and/or men may have vastly different, but perhaps also similar experiences. However, using women from a similar background and religious convictions brought culture- *and* gender-specific discourses to the fore with greater clarity. The sections below reflect on the choice and the ethical application of phenomenology; ethical conduct in data collection; and the ethical considerations in validity assessment, pastoral care and telling.

5.5.2.1 Phenomenology as ethical conduct

Galvin and others (2005:4) reflect on the methodology of phenomenology in practice and describe it as moving back and forth between parts (details of reflections) and the whole (themes of meaning). My choice of a Post-modern Social Construction epistemology led me to have a few misgivings about a phenomenological methodology which analyses, takes apart and extracts essences. In a sense, this seems contrary to the holistic, non-essential and non-analytical values of my epistemology (Section 1.10 and subsections). For that reason, I felt compelled, after having extracted themes from the interviews, to create overall abstractions for each participant (Section 3.3.11, text box). In this way, the research moved between its parts and the whole – the 'hermeneutic circle' of reflection (Gerkin 1984:138).

Upon careful reflection on the process and based on the literature, I concluded that phenomenological research (Section 1.11.3), has proved to be a respectful and reciprocal way of co-constructing the expert knowledges of bereaved participants within the framework of qualitative research. Bless and Higson-Smith (1995:60) point out that the narrow focus of phenomenological research precludes a generalisation of research findings. They also point to possible bias arising from the close and subjective relationship between the researcher and participants (insider researcher bias). Throughout this study I have been aware of the possibility of researcher bias due to my subjective relationship with the participants but, upon reflection, it seems that possible bias has been outweighed by the unique depth of findings and the positive effect which this research has had on the participants (Section 5.5.6 below) and on me as the researcher (Section 5.5.7 below).

5.5.2.2 Ethics in data collection

The process of data collection is vulnerable to unethical conduct, since interaction between a researcher and the participants is usually private and thus not open to scrutiny. In terms of my ethical conduct during the data collection process (Section 1.12.2), I found the video footage of the interviews quite unforgiving. When I reviewed the footage on the interviews with Mercy and Elsa in particular, I was shocked to discover that I had repeatedly interrupted the participants during the interviews. The purpose of these interruptions, in retrospect, was aimed at avoiding excess emotional distress. However, choosing the topic of bereavement was in itself infinitely distressing – perhaps I would have done better had I remained quiet and simply listened. The alternative explanation for the interruptions could relate to my being intent on achieving the objective (namely to argue for anticipatory mourning as a state distinct from post-death mourning), which could be regarded as unethical conduct. I do not know. What I do believe is that true participatory listening participates *actively* in the co-constructed telling, forgets the self and has no objective but to enter the teller's story wholly and, in entering wholly, occasional interruptions may illustrate interest, absorption and co-construction – thus constitute reflective, rather than prescriptive listening.

5.5.2.3 Validity as ethical conduct

Reflective listening includes checking with the narrator whether the listener's interpretation(s) of the story correlates with the narrator's. After I had completed Chapter 4, I scheduled a second (group) interview (Section 1.11) and handed each participant a typed transcript of her own story for verification of factual (descriptive validity), as well as meaning content (interpretive validity) (Eisenhart 2006:574). Apart from a few factual and interpretative changes which were suggested and agreed to, the participants confirmed the content. I resolved, in future, to be even more precise in handling personal data. I also asked the participants whether my interruptions during the interviews had in any way seemed troublesome or manipulative. They replied in the negative. I am aware however that 'social desirability' might have dictated their response. I can only resolve to learn from the video footage and hope that my conduct afforded them the ethical respect they were truly entitled to.

5.5.2.4 Ethics in pastoral care and discourse

Another ethical dilemma arises with regard to the specific suggestions for pastoral care and consciousness-raising (Section 4.4 and subsections). It may be argued that creating awareness and raising consciousness may not necessarily be ethical. I am reminded of the suggested yardstick for ethical conduct by Kotzé and Kotzé (2002:6): 'Who benefits from what counts as

knowledge?’ I was also aware that, in creating awareness of discourses and of how they affect the participants as women and as caregivers, I may be adding another discourse to the participants’ already overloaded awareness, namely the discourse of ‘deconstructing discourses’. In any event, ‘Who decides that the caregiver should be enlightened?’ (Section 4.4.4.1, Personal reflection). Upon reflection, an intense awareness of the caregiver’s subjective state and a truly respectful and participatory consciousness (Heshusius 1994:15) has unquestionably proven to be more therapeutic than suggested therapeutic guidelines. An example of ethical conduct as sensitivity and respect for the subjective needs of the participants arose in the event described in the next section.

5.5.2.5 Telling as ethical conduct

I set out with a structured set of goals to be met during the second interview. As stated above, validity feedback was required from the participants and we needed to structure the draft letter to pastoral care. The participants seemed to connect with one another and I suggested that each provide a brief summary of her story by way of introduction. I felt in control and on course until the participants began to tell their stories – at length. Our time was running out and the draft letter had not been focused on yet. I became anxious. I decided that I would have to interrupt and terminate the story-telling in order to achieve our research objectives and was on the point of doing so when the realisation dawned on me that these women *needed* to retell their stories. They *needed* to add another layer of meaning and my scientific objectives had to bow to the ethical requirement of foregrounding their voices. The interview was concluded with a brief focus on the letter to pastoral care – however, the participants once again verbalised how good it felt to tell their stories. I felt disappointed about the apparent lack of interest in constructing the letter to pastoral care, but I also realised that it would have been unethical to enforce my research objectives to the disadvantage of the participants’ needs.

The unexpected gift which arose in this interaction with the participants is their apparent relief at having been able to tell their stories without time constraints (Finding 5). I referred to this phenomenon in Section 2.2: meaning is always under construction through language in interaction with others. Here the true significance of telling emerged – a significance which was unanticipated. Although I voiced the hope that our interaction would actively benefit the participants, I had no idea of the powerful effect our interaction would have on their meaning systems. I would have been happy to take credit for this phenomenon, but these interviews took the form of free story-telling and I did not deliberately intervene in a therapeutic sense at all. At most, I afforded the caregivers space in which to create their own subjective meaning. The stories

developed in their own organic and life-giving authority and this contributed to the participants' agency in authorship.

In terms of ethical conduct, I also had to ask myself whether I have used this dissertation as a platform to tell my own story. If I weigh my need to tell my story against my desire to make a difference in others' lives, these needs prove to be interwoven and difficult to isolate. Upon reflection I may have started out for the personal reasons of writing my story and connecting with others who have also experienced caregiving in anticipatory mourning. From there the research process gained a momentum of its own and the depth of the findings (Section 5.2) emerged from this organic process.

Finally, I also have to examine my ethical responsibility toward the participants. I shared approximately three hours of the deepest grief and emotions with each of the participants. The interviews proved to be a gift to us as participants and I feel the compulsion to continue the connection with each participant. I have made appointments with Mercy and Rieda, who have both expressed a desire to talk to me. In the next section, I briefly discuss possible limitations of this study and make recommendations for further research.

5.5.3 Limitations and directions for further studies

Proponents of Modernist or quantitative approaches to research may criticise this study as lacking in generalisability. However, by refusing to generalise the findings of this research, respect and validation for the subjective truths of each participant is illustrated, in keeping with the epistemological stance of this research. I have clearly indicated from the outset that it is not my intention to generalise these findings, but to create awareness, consciousness-raising and the need for pastoral care and further study.

Validity (Sections 1.11.2 and 1.12.2) was established through consensus between the participants and it has thus not been confirmed conclusively. However, if we honour the contributions of the participants of this study as the 'expert' voices of caregiving in anticipatory mourning, then their confirmation of validity can be argued to be equal to scientific validation.

The homogeneity of the participants in terms of race, culture, religion and gender excludes many caregivers of different races, gender and colour. Thus a recommendation for future research is the inclusion of pastoral care for people of colour and caregiving males in anticipatory mourning. Men grieve differently to women (Neuger 2001:212) and, since this research study focused exclusively on white women, there is a need for research focusing on the excluded populations.

Finally, the topic of this research study is universally relevant and meaningful for all. As a part of humanity, we share a common predicament: the certainty of losing a loved one at some stage in our lives to a chronic illness such as cancer. Thus many people will have to deal with the loss of a loved one and a large portion of these individuals may take on the caregiving role of a loved one. Since no-one is excluded from the possibility of caring for a loved one, further studies on pastoral care with caregivers during anticipatory mourning is necessary and relevant (Hunt 2003:31). It is also imperative that we, as researchers and members of our community, create awareness of the needs of the bereaved within communities of faith and among social researchers. Our responsibility as researchers and pastoral counsellors, in keeping with Finding 7 of this study, must include a focus on participative pastoral care strategies to aid, accompany and care *with* those who are confronted with the impending death of a loved one. The next section reflects on the contribution of this research to the world of knowledge.

5.5.4 Contribution to the world of research/knowledge

This study supports the notion of anticipatory mourning as a phenomenon deserving of situation-specific pastoral care, as anticipatory mourning has distinct characteristics and subjects a caregiver to escalating stress levels (Rando 2000a:25). I believe that this research has contributed to the world of research by contributing a number of insights:

First, sufficient pastoral care during anticipatory mourning may aid a caregiver with *post-death adjustment* (Section 1.8.2.1).

Second, enhanced post-death adjustment poses *economic implications* for the wider community – at the most practical level, if pastoral care during anticipatory mourning can accelerate recovery from post-death mourning, the mourner may (re)enter the work market sooner, thereby saving money and ensuring increased productivity; and sufficient pastoral care during anticipatory mourning may save psychologists' consulting fees and therefore lighten the burden on medical aid companies and the bereaved. This assertion does *not* imply that the caregiver should be placed under pressure to become economically active prematurely. Instead, it presents an attempt to acknowledge the wider context of communities and institutions which are affected by bereavement.

Third, a better *understanding of caregivers' experiences* through further research will aid and empower pastoral counsellors and helpers to assist caregivers during anticipatory mourning. The study also highlights the need for *participative* rather than prescriptive pastoral care during anticipatory mourning.

Fourth, the study provides the disciplines of psychology, nursing, social work and theology with insight into the world of caregivers during anticipatory mourning.

Fifth, *meaning-making* is one of the most important human needs (Bee 1996:329). Frankl ([1959] 2004:9) quotes Nietzsche, who said: 'He who has a *why* to live can bear with almost any *how*.' A conscious awareness of making meaning throughout life may ensure a contented, more purposeful and fulfilled life. Upon reflection, the participants clearly indicated the benefits they derived from telling their stories and making meaning of those stories. Bee (1996:329) cites studies which show that adults who have a clear direction, purpose and meaning to their lives remain healthier and can handle stress better than those who are less clear on their life's purpose. I hope that this study may also begin to generate a general awareness of conscious meaning-making, as well as the art of practising death (Section 2.4.11) throughout life.

Finally, if this research study has in any way served to *illuminate the plight of female caregivers* during anticipatory mourning (Chapter 3), then it makes a contribution in the form of a sharpened focus on the world of spousal caregivers in anticipatory mourning. In addition, since there is only limited literature on caregivers in anticipatory mourning and their experiences (Section 1.4), I trust that this study has contributed to the *body and collection of research* pertaining to this topic. Sections 5.5.5 to 5.5.7 below examine the effects of this research on the wider community, the participants and on me.

5.5.5 Possible effect of the research on the wider community

As a member of my community, I am confronted with the fact that we need to be made aware of dying, loss and how to deal with those who are mourning. The Church should lead a consciousness-raising movement, since loss confronts us with existential questions of spirituality and meaning such as: 'Where is God?', 'Who am I?', 'What is my purpose?', 'What is the purpose of life?' and 'What is the purpose of death?' We live our losses every day (Section 2.4.11) and this brings us all together (grievers and non-grievers alike) in a shared experience of loss. If we can learn to consciously live our daily losses (Kastenbaum 2004:41) like a practice run for the significant, life-changing losses such as death, we will find ourselves better equipped and less afraid to deal with loss. And perhaps, then, we may feel empowered to be fully present and available to another's grief.

5.5.6 The participants: effects of the research on their process of mourning

The most powerful element that emerged from this research project was the 'unintended' therapeutic effect that the telling of their story seemed to have on the participants. I intentionally refrained from stepping into the 'counselling' role but, the fact that I was not attempting therapy

during the interviews allowed me to enter their stories in true participatory fashion – and that, paradoxically, proved therapeutic to the participants. At the end of each individual interview, the participants would express feelings of relief. Jakkie said: *'Things feel normal again.'* She added in the group session that *'the interview that we discussed made me calm and peaceful.'* Elsa said: *'I found that, to talk more about it had made it more comfortable... it hurt a lot... but that is normal. It was good to speak to you... you understood because you have been through the same thing.'* Priscilla said: *'To talk to you helped to calm me. Thank you, you made a difference.'*

It seemed that in merely allowing each co-researcher uninterrupted time to tell her story, she could make additional meaning of her trauma (Section 4.3.1.1). Frank (1998:198) asserts that the greatest thing one can give another human being is listening attention without judgement. In addition, my assumed 'status' as a researcher and pastoral therapist gave weight to my words and, once again in an unintended way, legitimised my discourse of normalisation and care.

Mercy may have made an assumption about my 'expert status' and my words subsequently provided a significant affirmation of her worth. Coupled with the therapeutic effect of an affirmative power discourse, an unbiased ear enabled Mercy to assert her new-found independence, knowledge and regard for herself. As I asked her questions about her resources and we unpacked the concept of her guilt, her voice grew stronger in conviction as she constructed an alternative story for her life: *'You have made me realise the gift that Bruce had given me [the gift of finances and complete independence].'* She then proceeded to 'thicken' the story herself by telling me about ways she had devised of turning Bruce in bed and putting on his nappies during anticipatory mourning. She concluded: *'I feel a lot more at ease and comfortable. Not so bitter about myself any longer.'* When I suggested that guilt feelings were a normal part of caregiving, she said: *'For someone who has been through that [loss of a spouse] to tell me so [that guilt is normal]... I feel so much better and I realise now that nothing I felt was abnormal.... I honestly feel now there was a reason behind it – there really was a purpose to Bruce's dying. You have done me the world of good and I feel good about myself now. I do not feel I am useless.'* I felt grateful, but I also realised that the stated benefit to Mercy's meaning-making process was attributable to the relational process of a storyteller and her inserted listener and not to me as therapist or researcher – and that freed me from trying too hard in my work as therapist. The next section reflects on the effect of the research process on me as a person, an insider, therapist and researcher.

5.5.7 Effects of the research on my personal and professional development process

The most important effect of the research on me was the impact of telling and listening, providing moments of profound connection with the participants. Denise Ackermann (2003:23-63) asserts

that we begin to *do theology* when we truly *listen* to another. To her, the starting point of practical theology is when people test and revise their experiences in conversation with another. I find it liberating to note that it is not the listener who tests and revises the experience, but the teller and owner of the story. I simply had to be truly present (Pembroke 2002:74; Frank 1998:198). As a therapist, I was awed at the realisation that struck me when I read Ackermann's work – I had not merely been doing therapy when I entered into conversation with a client – I had been doing practical theology! How liberating for all if the interface between practical theology and therapy could be its non-directive, non-judgmental, self-reflective and all-inclusive nature. As discussed in my personal reflection (Section 4.3.1), this process has liberated my 'need to heal' during therapeutic encounters and replaced it with a witnessing presence, in awe of the life-giving process of telling and listening.

Gerkin (1991:74-75) regards pastoral care for a suffering person, in this case a caregiver in anticipatory and/or post-death mourning, to be a *prophetic ministry* when suffering is recognised and responded to. From that moment of recognition, the consciousness of the pastoral counsellor begins to transform. If meaning-making happens when you tell and retell your story, then we as pastoral counsellors should, rather than try and resolve an issue as quickly as possible, continually return to the story until the client has made meaning. Upon reflection, what transpired during the second (group) interview when I initially became anxious due to time constraints, was the necessary return by the caregivers to their stories in order to continue the meaning-making process. I am grateful that I was able to recognise this need, rather than pursue my research objectives.

As a therapist, the awareness that meaning-making transpires spontaneously in the telling and retelling of a life story has *liberated* me from the need to structure or hurry therapeutic encounters. Frank (1998:209) holds that 'discoveries of meaning' happen when people are ready to make meaning at *their* pace, not ours. We should therefore 'extend our *not* understanding as long as possible so that the people we are listening to can themselves develop an understanding of their meaning' (Weingarten 2003:198).

With regard to my therapeutic approach, a significant shift has taken place since I conducted the interviews and reflected on the process. During therapeutic encounters, I would often experience tension in terms of the therapeutic technique or strategy required of me. Upon witnessing the powerful effect of simply entering into the stories and listening in a participatory fashion, I have learnt to relax and trust the process of meaning-making in telling. I no longer take notes during therapy – I simply enter and listen. After the client has left, I write a report from memory, trusting that the significant matters will remain in memory.

As a researcher, this research has presented me with the experience of simultaneously occupying the roles of author, witness and participant. I am the author in terms of my control and assessment of the content, but in terms of generating self-reflection, I have also been a witness to a process where the research process has gained a momentum of its own, independent of my input. In terms of an *inner process of self-reflection*, I have witnessed the way in which *my* story continues to shift as new insights are gained. In addition, I have experienced the position of a participant where invisible inner processes have been at work, causing incremental shifts in terms of my personal meaning-making – the detail of which I have yet to understand fully.

Eisenhart (2006:573) suggest that the goal of qualitative participatory research is to learn something new about a setting or a group through direct participation. In this way the researcher directly penetrates the group and is penetrated in turn. Researcher transformation is the inevitable result. Conducting this research study has rewritten my personal experience of anticipatory mourning as I experienced each co-researcher's story vicariously. In listening to their stories, I often heard my own story told, as is also described by Doehring (2006:25). I found both similarity and uniqueness; and each time I revisited their stories, my personal story was present too and an added layer of meaning was created for me personally. Most importantly, the *meaning* of meaning-making became conscious, empowering and infinitely significant.

When I set out to explore this theme, I suspected that it would be extremely taxing to revisit my experience of losing Louis, from an emotional point of view. At times I have been quite fearful of conducting this study and feeling the emotions it elicited. At times I have felt overwhelmed. At times I have wept and tried to ignore the pressing completion of this study. I have had to manage my own fear of going back to the pain and I have been forced to develop the awareness needed and the willingness to change and to be changed by my interaction with this project and with the participants. I suspected that it would be difficult to work from an insider perspective – I had no idea how careful and aware I would have to be in my attempt to remain true and ethical.

Finally, I agree with Ackermann's (2003:40) contention that meaning continues to change as one visits and revisits one's story. As I visit and revisit the chapters of this study, I find myself making minute shifts in perception and values each time. Matters which made sense to me one year ago have taken on new hues and shifting meanings; and chapters written a few months ago have taken on added meaning or become obsolete in the light of new insights.

5.6 CONCLUSION

In conclusion, I am assailed by conflicting feelings. I feel satisfied that I am finally at the end of a very difficult and stretching exercise. I feel awed at the effect this exercise has had on my consciousness. I feel insecure about the quality and ethics of this research, although, upon reflection, I would have conducted it in the same manner if I were to repeat it. I feel a strange sense of loss that this study will no longer be my constant companion.

I stand in awe of the process and the life-changing effects of this study. When it comes to loss, the mourning process is never over and complete – it changes in character and intensity but a memory pops into your head at the most unexpected times, bringing the loved one back into your life; and, for a brief moment, the mourning starts all over again, not as an excruciating pain but as a gentle reminder that your loved one will always be a part of you, a part of your story.

Just before the study went to print, Mercy let me know of the tragic death of her granddaughter in a car accident. Her courage surpasses my understanding. I salute you, Mercy, and I salute you, Priscilla, Rieda, Elsa and Jakkie for your preparedness to share your grief and your hope. It is my fervent hope that I have done you justice.

Thank you, Faure, my supervisor, for your patience, your insights and your support. Thank you for the continued deconstruction of your expert status and your respectful approach as co-creator of meaning. Most of all, thank you, Louis, for sharing your life, your care, your suffering and the gifts that cancer brings, with me. I resonate with the words of Holland at the opening of this chapter – ‘all is well’. Whether we are here or in ‘the next room’, our relationships continue and the impact we have on each other’s lives remains – indelibly, profoundly.

I end this research with a draft letter to pastoral care, co-constructed by the participants and fellow researchers of this research study, explaining their needs during anticipatory mourning. The letter is brief, but I would like to privilege their voices as the voices of the bereaved *and* as the authentic voices of the participants of this study, journeying the stories of their loss toward new meaning.

EPILOGUE: A LETTER TO PASTORAL CARE

Dear Pastoral Caregiver

We as caregivers and co-constructors of meaning are collectively writing this letter to you in order to make you aware of some of the needs of caregivers in anticipatory mourning. We have all agreed on the needs expressed in this letter. The letter is in keeping with the findings of this research study (Section 5.2) and, in the process of co-constructing this letter to you, we have also become co-researchers of this research. This research has found that the state of anticipatory mourning is distinct from post-death mourning; and that our meaning-making processes have shown areas of overlap, but that the outcomes of our meaning-making are unique. We have discovered that relationships and spirituality have been our mainstay in making meaning of our trauma and that telling our stories has brought us much peace and relief. We have also become aware of many discourses that have hindered and helped us in making sense of the loss and, although we have also experienced positive pastoral care from you, we have often needed a different kind of care – hence the creation of this letter to you.

First of all, thank you for the times when you have been present to us and for helping us carry the burden of our loss. At times your presence has helped more than you can imagine, but at times your prescriptions have harmed and confused us. Please remember, when next you visit us during anticipatory mourning, that we need more prayer (Elsa) and less prescription (Jakkie). We need you to create opportunities for us to express our pain and to mourn our loss without guilt or prohibition. We also need more counselling – especially family counselling – but, most of all, we need laughter (Jakkie). Help us to make meaning, by creating something physical to hold onto, for instance, a CD of the story of a loved one's life, or something (Priscilla), and do not add to our guilt by reprimanding us (Mercy). Please remember that we should not have to say 'sorry' for expressing our feelings and our grief (Rieda), so – no more pastoral prescription. Rather suggest something fun – something that involves communion with others (Rieda).

Lastly, we need gentle guidance from you to know what to do while we wait in darkness. We need to know how to go on from there (Priscilla). Please affirm rather than constrain us; encourage rather than isolate us with discourse (Priscilla and Jakkie). And remind us, without prescription, that we are on the right path.

Kind regards

The Participants, Caregivers and Meaning-makers of Anticipatory Mourning