

CHAPTER 4:

PASTORAL CARE AND COUNSELLING FOR CAREGIVERS IN ANTICIPATORY MOURNING

'In the godforsaken, obscene quicksand of life, there is a deafening alleluia rising from the souls of those who weep and of those who weep with those who weep.'
(Ann Weems in Ackermann 2003:121)

4.1 INTRODUCTION

Chapter 3 introduced the caregivers and invited you to share in their experiences of anticipatory mourning. You were also introduced to their experiences of pastoral care, which appeared to be sincere but were often prescriptive (see Section 3.2). The caregivers expressed some of their practical *and* spiritual needs and, judging by their responses at the end of the interviews, the need which emerged most profoundly was for someone simply to listen while they tried to make sense of their loss (see the final paragraph of Section 3.3.11). In line with the caregivers' expressed need for non-prescriptive care, this chapter focuses on three areas. The first is the role of practical theology, which is related to examples from Chapter 3 and other chapters. The second is the role of the church and pastoral counsellors in caring for caregivers. The third is suggestions for co-constructed pastoral care negotiated between the caregiver, spouse, pastoral caregiver and God.

4.1.1 Mourning states

The discussion of pastoral care below refers to the literature focusing on anticipatory mourning, as well as on post-death mourning. In Section 1.8.2.1, I argued that there are distinct differences between anticipatory mourning and post-death mourning, but also some areas of overlap. Some aspects of post-death bereavement counselling may thus be valid for spousal caregivers in anticipatory mourning as well. If we do not distinguish between anticipatory mourning and post-death mourning and remind ourselves that they may overlap, but are also distinctly different periods, pastoral care and counselling during anticipatory mourning may remain inadequate (as was evidenced by the caregivers' experiences as retold in Section 3.2) and valuable opportunities may be lost to prepare caregivers for the final challenge of bereavement (Hamilton 2005:169) and beyond. This brings me to the role of the church and practical theology. I would contend that the church's response to the suffering of anticipatory mourners requires, first and foremost, a preparedness to listen and lament *with* those who suffer (Ackermann 2003:122) according to their unique context and needs. This calls for a practical theology of context and participation. The next

section discusses practical theology and argues the need for a participatory and contextual theology relevant to this study.

4.2 PRACTICAL THEOLOGY

Practical theology can be described as the reciprocal relationship between theology and practice, where practice informs theology and theology informs practice (Sinclair & Wright 1998:525). Practical theology attempts to relate pastoral care to contemporary psychology, social and even political disciplines (in the case of liberation theology, for example), thereby creating an interdisciplinary, holistic approach to care (Sinclair & Wright 1998:525). The next section briefly compares different approaches to practical theology.

4.2.1 Approaches to practical theology

Different approaches to practical theology include the *confessional* approach, which focuses on the Bible as a central object of study (Wolfaardt et al 1992:7); the *correlative* approach, which focuses on active communicative empiricism as the object of study (Van Wyk 1995:91); the *contextual* approach, which focuses on the community as the object of study and attempts to bring about social change within that context (Bosch 1991:421); and the *participatory* approach, closely linked to the contextual approach, which focuses on *doing* theology (Bosch 1991:427) in an interdisciplinary fashion (Tracy 1983:76) – *with*, rather than *for* another (Kotzé & Kotzé 2001:7). We construct theology through our experiences *with* one another *within* the context of our local and spiritual communities (Roux, Myburg & Kotzé 2002:59). After reviewing the different foci of practical theological approaches, I chose a *participatory* and *contextual* approach for the purposes of this study. The two sections below discuss these approaches to practical theology.

4.2.2 A participatory approach

Pembroke (2002:17) describes participation as discovering depth of meaning through togetherness as follows: 'It is the relationship expressed by the preposition "*with*" that is eminently inter-subjective' and meaningful. Pembroke (2002:14) sees participation as a precondition to meaning-making: 'At the heart of an encounter is the discovery of depth together, and how can two people who live on the surface ever hope to descend to the inner meaning of their existence?' True participation is described as a self-commitment to fully immerse oneself in the other's drama through sharing so intimate that 'one's very being is defined by the participation' (Pembroke 2002:15). 'Participation in being, in life, is the discovery of depth in togetherness. Ultimately it is a participation in Being-Itself, in God' (Pembroke 2002:18). Sections 4.2.2.1 to 4.2.2.5 describe different aspects of a participatory approach relevant to the caregiver in anticipatory mourning. These aspects include the concepts of *inclusivity* (Pembroke 2002:31),

care for the *marginalised* (Poling 1991:186), an 'I-Thou' attitude of *communion* (Pembroke 2002:33), journeying *with* others to find their *voice* (Neuger 2001:71) and a *spiritual, ethical* approach in which the encounter is beneficial and therapeutic for all concerned (Kotzé & Kotzé 2001:9).

4.2.2.1 Participation as a spiritual and an ethical approach

Sorajjakool and Seyle (2005:185) suggest that the existential struggle which ensues when cancer enters a family's lives may be even greater than the physical suffering. It is necessary that a counsellor remains aware of the spiritual and theological struggle of meaning-making by all family members in anticipatory mourning. The 'illness of the spirit' needs to be treated in addition to the mourning of the soul and the anguish of the psyche (Sorajjakool & Seyle 2005:185). A pastoral counsellor may only be able to experience the anguish of a caregiver when the pastoral counsellor is willing to enter her pain in an ethical fashion, without prescribing to her how to experience or deal with her pain. Thus the concept of ethical action is central to the concept of practical theology (Sinclair & Wright 1998:525) as respectful and non-prescriptive care.

Kotzé and Kotzé (2002:203) argue that pastoral care and counselling must extend to ethical-political practices. Such ethical practices include a contextual and respectful approach, always to the *benefit* of the client. Ethical-political practices also require sensitivity to the discourses of the caregiver and a refusal to enforce personal, theological and/or societal discourses as truth which might result in harm to the client. Riet Bons-Storm (1998:19) explains that she measures truth – whether in societal discourse or as a personal belief – by its liberating, inspiring and challenging qualities for the most vulnerable of people. In the context of this study, the vulnerable may be regarded as caregivers struggling with physical, emotional, psychological and spiritual losses, as well as the possible pain of enforced discourses from society, religious institutions and pastoral counsellors.

Personal reflection

This reflection presents an example of an unintended ethical transgression where my personal 'expert' discourse took precedence over the voices of the participants. When I had completed Chapter 3 of this study in which the five participating caregivers are introduced, I arranged a group meeting with the intention of presenting each participant with the transcribed version of her story. The intention was to confirm the accuracy of content with the participants. In preparation, I read through the chapter in search of statements which could have a negative impact on the participants. I found myself confronted with and acutely aware of a few assumptions which I had confidently posed in the chapter but, in the light of the impending meeting, suddenly raised ethical question marks. For instance, I assumed that Rieda had made less meaning of her experience than the other participants because of what I had read as her negative

disposition. However, the awareness that Rieda was about to read my transcript of her story brought me to the uncomfortable realisation that I had assumed an 'expert' role, thereby silencing Rieda's voice.

Ethical practice also implies freedom of spirituality. I would thus argue for a dynamic concept of spirituality as an ethical approach to practical theology in order to include plurality and avoid prescriptions of truth (Kotzé 2002:13-18). Doka (2003:45) asserts that 'spirituality is the act of looking for meaning in the very deepest sense, and looking for it in the way that is most authentically ours'. There should therefore be no 'recipe' for spiritual meaning-making in suffering and we, as pastoral counsellors, must refrain from an attempt to prescribe meaning-making to any caregiver.

4.2.2.2 Participation as an 'I-Thou' communion

When intimate thoughts and feelings are shared [between a counsellor and a caregiver], an extraordinary 'peak experience' of true relational meeting ensues, namely an 'I-You' relationship (Pembroke 2002:32). Pembroke (2002:32) contrasts this type of relationship with an 'I-It' relationship which objectifies the other. When the intention is to manipulate the other – as in prescribing how the other should act or feel – it 'produces a soul-destroying sense of alienation' (Pembroke 2002:32). True participation with another is humanising, affirmative and unmediated (Pembroke 2002:32-33). For Pembroke (2002:33) an I-You communion means the absence of goals, purposes and preconceptions and an entry into an unconditional union with another. Martin Buber (1970:165-166) extends this concept, suggesting that when a person addresses another with her/his whole being, every meeting with a 'You' addresses the absolute, eternal You, namely God-in-you. Thus the meeting becomes an 'I-Thou' communion, '...a form of God in the world' (Buber 1970:166). Idette Noome (2009:s.p.) adds to the concept of I-Thou by suggesting that the English usage of 'thou' in prayer actually indicated complete intimacy rather than the archaic version of respectful but remote formality.

Heshusius (1994:17) believes that true participation with another means entering the other's world with complete attention. This leads to a recognition of a deeper kinship with another, blurring the boundaries which constitute the 'self'. Consciousness then becomes a 'self-other' participation where the pastoral carer becomes temporarily inserted into the life of the other and is able to enter the person's life (in this case, the caregiver's grief) willingly (Heshusius 1994:17-19). A willingness to be inserted into the life of another requires a lot from a pastoral counsellor in terms of emotional availability, but to be brave enough to enter into another's pain (in this case, that of the caregiver) is perhaps the ultimate gift of care that one may bestow upon another. Jakkie's experience of care by the medical sisters in the intensive care unit (see Section 5.3.3.3b)

is an example of self-other participation. The staff demonstrated a willingness to be inserted into the grief of Jakkie and her family when, upon Alex's death, both sisters wrapped their arms around the family and wept with them.

4.2.2.3 Participation as inclusivity and mutuality

A participatory encounter also means that no-one is excluded. Lester (1995:96) holds that relationships which imbue hope and meaning are characterised by the mutuality of care and respect. Traditionally, women and people of difference have been excluded from ordained church ministry. Churches often welcome 'everyone like us' to the exclusion of others (Gerkin 1991:73). By contrast, an inclusive practical theology 'seeks justice, peace, healing and wholeness for all' (Cochrane, De Gruchy & Petersen 1991:96).

According to the participants of this study, the church appeared to welcome them. However, an undertone of prescriptive care prevailed which in effect declared: 'We know better – deny your reality and do it our way' (see Sections 1.3, 1.8.4, 2.3.7.5, 2.3.7.6 and 3.2). Clerical prescription silences the voice of the caregiver and marginalises her experiences. Conversely, hope and meaning are ignited when there is mutuality within a relationship. Elsa seemed to experience mutuality of respect and gentle care in her pastoral relationship with her church community while Koen was dying (see Section 3.2.1). When people are meaningfully connected to one another, it produces hope – as Lester (1995:95) suggests, '[p]erhaps it is impossible to really despair *with* someone', since deep despair can only prevail in isolation, exclusion and marginalisation.

In terms of this research, an inclusive participatory approach was established when the participants co-constructed a concept letter to pastoral care (see Chapter 5, epilogue) to create awareness of caregiver's needs in anticipatory mourning. In that act of participation, the participants became co-researchers and presented a final voice of meaning.

4.2.2.4 Participation as care for the marginalised

When the unheard voices of the marginalised are included through constructive participation and reflection within a 'living community', practical theology is enriched (Poling 1991:186). Ackermann (2003:33) claims that Jesus himself taught care for the marginalised. She believes that a theology which does not take responsibility for the suffering of the marginal has lost its footing. Practical theology should care for the marginalised by holding the 'continuities, dissonances and differences that make up the often untidy and tangled experience of living in conversation with the Christian faith' (Ackermann 2003:34). In other words, an inclusive approach towards caring for caregivers requires continued cognisance of the unique nature of caregivers' experiences and a constant reminder that one approach *cannot* possibly be applied to diverse contexts.

An awareness of the variety and dynamic nature of stories and contexts also requires a participatory ethical approach which is critical of assumptions of 'being right' (Browning 1990:365-366) and values each woman's voice, viewed within her particular context. The discourse of 'being right' is illustrated by Alex's doctor, who prohibited Jakkie from crying in front of Alex (see Section 3.3.3). For Jakkie, the marginalising experience of 'being wrong' was only transformed into a validating experience of care and empowerment when the nurse said: '*Nonsense, cry!*'"

4.2.2.5 Participation as regaining voice

A participative approach co-constructs ways for women to regain their power or voice by *hearing* themselves speak (Neuger 2001:68). The ability to regain one's voice in order to name oneself, one's God and one's chosen environment is one of the primary objectives of feminist theology (Neuger 2001:71). For a caregiver, regaining her voice not only refers to hearing herself speak – it also refers to ways of finding language and the models which validate a woman's experience so that she learns to *believe* in the truth of her long-denied voice (Miller-McLemore 1996:22; Neuger 2001:68-71). Mercy found her voice after Bruce's death when she began to live her life according to her own rules. '*He [Bruce] definitely underestimated me!*' she asserts (see Section 4.4.4.3 below). When a woman begins to believe her own truth, she *lives* meaning and faith within her own context.

Section 4.2.3 and its subsections describe the meaning of a contextual approach in practical theology which includes the awareness of multiple truths in context; placing discourses in context; and the context of the invisible bereaved (Walsh & McGoldrick 1991:6).

4.2.3 A contextual approach

A contextual approach to practical theology means 'faith lived in context' (Bons-Storm 1998:14-15). Faith in context also means to be – and remain – critical of the norm and a refusal to view people's behaviour in the light of dominant discourses, but instead to contextualise stories that 'go against the grain' (Bons-Storm 1998:14-15) of prescribed discourses. As an example relevant to this study, faith in context would require a validation of Jakkie, who refused to adhere to the prescribed norm of stoic Afrikaner calm and allowed herself to weep expressively when grief overwhelmed her during anticipatory mourning. Ackermann (2003:108) suggests that women need a new language to mobilise them from passive endurance to humanised suffering – the language of freely expressed lament. In freely expressed lament, a caregiver can honour and live her own truth within her own context.

4.2.3.1 Multiple truths in context

Faith in context would also require a non-judgmental approach to humanised suffering, as one enters the caregiver's story and her context with complete attention (Heshusius 1994:17) while maintaining an awareness that there are many truths for different people (Burr [2003] 2004:3-4). A contextual approach to practical theology holds that people's behaviour and their stories cannot be interpreted nor understood in isolation, but only in that moment when the context of the person is considered (Van den Blink, cited in Couture & Hunter 1995:200). Thus 'being right' (Browning 1990:365-366) is replaced with an acceptance of multiple truths in context. When practical theology departs from the 'atomised individual or community' and considers how people feel, what they are going through, how they are suffering, how they perceive suffering and how they respond to that suffering, there is a 'moment of insertion' – a direct confrontation with another's unique truth – and a 'beginning in context' (Cochrane et al 1991:17). A contextual approach thus refuses to adhere to a single prescribed standard of practice but rather advocates a willingness to change within context (Bons-Storm 1998:18).

Personal reflection

Riet Bons-Storm (1998:18) defines 'truth' as 'the ultimate value, which becomes the point of orientation of one's endeavours to give meaning to all one's experiences'. Values are dynamic and subjective; therefore truth is contextual. 'Taking over a truth from another context means to live in conflict and pain between one's own truth and the imposed truth of a dominant discourse' (Bons-Storm 1998:18). Thus the caregiver must contend with the pain of her daily losses, the impending loss of death and the pain of her own negated truth in favour of enforced discourses from others, no matter how well-intended they may be. In terms of 'God's truth', I would like to argue for a God of context and therefore a truth of context. If truth is contextual, then it is also dynamic. Would a loving God create us as contextual, dynamic beings and then give us one absolute truth and expect us to live in pain as it conflicts with our own dynamic truth? If God expected us to hold onto one truth he would not have created us as dynamic and contextual beings. In addition, if God made us dynamic and changeable, then we, as 'the image of God' represent God – who must surely then also be dynamic and changeable. Could true freedom, which is repeatedly referred to in the Christian Bible, reside within a willingness to embrace the changeable?

4.2.3.2 Placing discourse in context

Faith in context also holds an awareness of religious and societal discourses which oppress women in terms of, for instance, their expression of grief. Priscilla represents an example of how the discourse of mourning has constructed her experience of grief (see Sections 3.2.2 and 3.3.3). When we explored Priscilla's inability to cry, she recalled how her life experiences had taught her

to equate tears with weakness. This prescriptive discourse has not been life-giving to Priscilla and it needs to be deconstructed (Burr [2003] 2004:18) *and* reconstructed to fit authentically with her own subjective frame of meaning.

4.2.3.3 The context of the invisible bereaved

My subjective experience, corroborated by the related experiences of the participants, reveals that caregivers and their suffering often become invisible, partly due, perhaps, to patriarchal, mourning, medical and death discourses (see Section 2.2.2), and partly due to an all-encompassing focus on the dying loved one. Elsa recalls: *'I felt so tired... running back and forth. I could not cry... I just had to be strong. People told me to be strong but sometimes I felt as if I was... sort of, see-through, you know?'* Kellett (2000:322), in a study on family caring, found that, when caregivers felt invisible and 'not heard', seemingly insignificant issues had the potential to develop into overwhelming feelings of frustration and insufficiency, leading to the 'invisible community of the bereaved' (Walsh & McGoldrick 1991:6).

A caregiver's feelings of invisibility, marginalisation and suffering co-exist with the need for meaning. When meaning is made, the suffering becomes bearable and acceptable. Indeed, the experience of losing a spouse to cancer may be more of a *theological* than a physical or emotional journey (Sorajjakool & Seyle 2005:185); hence, the role of pastoral care and counselling gains an even greater significance. The next section briefly looks at various approaches to pastoral care.

4.3 PASTORAL CARE AND COUNSELLING

In the literature, there are many divergent approaches to pastoral care. The Reformed and Fundamentalist/Confrontational approaches focus on the Bible and sin and may tend to simplify human problems by relating them to sin and the prescriptive admonishment of sin (Louw 1998:27-34), whereas the Charismatic approach may tend to be elitist in its emphasis on the use of glossolalia (Spittler 1990:141). The Bipolar/Hermeneutic approach has been criticised for its tendency to reduce people to 'sinners and beggars' (Louw 1998:34), while the Client-centred and holistic growth approach may tend to 'psychologise' sin (Louw 1998:135) to the exclusion of God's grace. With regard to marginalised caregivers in anticipatory mourning, it may be contended that participative and contextual care calls for a narrative hermeneutical approach that focuses on meanings, interpretations and continued reflection on the stories of our lives (Gerkin 1986:52). Section 4.3.1 and its subsections explore a narrative hermeneutic approach to pastoral care, illustrated with examples of the participants' experiences of telling their stories.

4.3.1 A narrative hermeneutic approach

Doris Nauer (2007:183) describes pastoral care as 'soul care', which includes a 'common search for traces of God' in the everyday stories of our lives. Carrie Doehring (2006:67) notes that people in crisis tell stories in order to make meaning. Thus pastoral care is more than crisis care – it offers a supportive and sustaining presence as people tell the stories of their lives in order to make sense of what has happened to them. Lester (1995:81) writes of a close relationship between hope and meaning. When people experience life as meaningless, it indicates that their life story has become unclear. Hence pastoral care should focus on creating a 'future story' of hope and meaning (Lester 1995:103), which includes a 'theology of human story-telling', and a model of hope and 'human enquiry' into the stories people tell, namely a narrative hermeneutic approach (Graham 1996:120-122).

For Gerkin (Graham 1996: 119), a pastoral hermeneutic (or interpretation) is eclectic and interdisciplinary, which complements the epistemological stance of this research study (see Section 1.10). Gerkin (1986:22) contends that narrative is the primary creator and interpreter of meaning and thus the pastoral task is to relate human behaviour to underlying meanings through interpretation, and so create a 'horizon of understanding' (Lyll 2001:57). Creating a 'horizon of understanding' implies, among other things, that the pastoral counsellor as well as the care-seeker are changed at a fundamental level of meaning by opening up new visions and wider possibilities of meaning (Lyll 2001:57). The process of opening up new visions through narrative hermeneutics suggests a continual interpretation and re-interpretation of the stories people tell (Roux et al 2002:47). We create meaning and continuity when we tell our life stories (Gerkin 1986:52). We 'live in a story' and during counselling and negotiated dialogue; the stories of God, the counsellor and the client fuse into a new, alternative life story of the client (Gerkin 1986:59-64).

Personal reflection

I found Lyll's assertion (2001:57) that both parties emerge changed to be highly relevant in my counselling sessions with clients. After witnessing the profound yet unintended effect of telling their story on most of the participants in this research study, I found myself releasing the need to 'cure' and simply trusting that the process of telling and listening would open up new possibilities of meaning for the clients. The process of telling one's story seems to gain a life of its own, sets its own pace and I merely become the appreciative witness of the healing process.

4.3.1.1 Telling

Thus telling one's story to an inserted listener (Cochrane et al 1991:17) generates healing. Weingarten (2003:199) posits a neurological basis for the healing effects of telling, citing neuropsychological research which found 'social cooperation... intrinsically rewarding to the human brain'. Weingarten (2003:199) asserts that true listening creates relationship, connectedness and validation: 'For people who are suffering..., being listened to in this way is like being thrown a life preserver in choppy seas. The life preserver is a connection to another person; the experience of aloneness abates.'

During the initial individual interviews, the participants spontaneously commented on the beneficial effects of telling their stories (see the final paragraph of Section 3.3.11). In the group interview, I enquired about the effect of the interviews on the participants in retrospect. Mercy said: *'I found the whole interview extremely comforting and it has given me so much more trust and belief in God.'* Brueggemann (1993:21) describes the process of telling the life story as 'talk-therapy'. He describes the process as follows: 'And out of these little bitty pieces of memory [the stories] may come the stuff of new self-discernment, and eventually, of new self... and if one is blessed, they contain the hint of a massive reordering of one's self.' It is not necessary for the counsellor to know in advance, since even unguarded memories may 'trigger an insight... that liberates and heals' (Brueggemann 1993:21-22). An example of a reordering of the self is evidenced in Mercy's story. In our first interview, Mercy seemed ridden with guilt (see Section 3.2.3). During our second interview, Mercy asserted: *'I have become very independent. I now have the freedom to come and go as I please, without feeling guilty.'*

Personal reflection

Meaning-making does not seem to require our conscious effort – it appears to take its course whether we are present to it or not. The critical ingredient seems to be a participatory listener (Pembroke 2002:15). If we as listeners bring in our own personal and societal discourses, we may enforce a framework lacking a congruent fit with the teller's contents. This may cause such inner incongruence that it leads to confusion and a lack of meaning. It seems to be the experience of all the participants, as well as my own, that true non-judgmental participative listening is rare but imperative. Indeed, one may argue that, in the absence of a participatory listener, we may be unable to shift or move forward in our meaning-making.

Weingarten (2003:233) supports her neurological argument on the benefits of telling and listening with neuropsychological research findings that any type of ritualised behaviour (such as telling and listening) produced a neurological perception of unity and increased connectedness with

others. The experience of unity with another reminds me of a poignant unnamed poem by an anonymous poet (cited by Noomé 2002:310):

Slowly, slowly
we grow together,
skin over the wound
of our separateness.

4.3.1.2 Listening

Thus the participatory process of telling, rather than the expertise of the counsellor, brings healing when the counsellor becomes an empathic listener. Empathic listening means entering and 'temporarily living in the other's life, and moving about in it delicately without making judgments' (De Jongh van Arkel 2000:226). Gerkin (1984:125) describes the counsellor or listener as an interpretive conversation partner – thus a hermeneutic circle of telling, listening and interpreting and retelling, listening and reinterpreting is forged: 'Caregivers who listen carefully... find themselves hearing their own stories told' (Doehring 2006:25).

Listening with awareness also challenges pastoral caregivers to ask questions from a non-assuming perspective, allowing the teller the opportunity to develop her own meaning even as she is telling her story to the listener. Priscilla said that it was important to her to speak about Attie: *'[After Attie's death], I spoke much about Attie and I felt that everyone who had known him had become tired of my continual stories about him... Being able to speak about him was my way of thinking about all the good things... and my way of saying goodbye.'*

'It may seem contradictory to the task at hand [to understand the person], but in order to listen well to another, we have to be able to 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). Arthur Frank (1998:198) explains the need for an inserted listener as: 'the story I could not tell unless they listened. A story needs a listener. I needed their gift of listening in order to make my suffering a relationship between *us*, instead of an iron cage around *me*'. During our second interview, Priscilla spoke about her iron cage: *'...I think the fact that I could not cry made it imperative for me to speak. Telling my story to you helped me to come to peace... it made a difference....'* Elsa said: *'I found that, to speak more about it brought me comfort even though it hurt...it was good to speak to you because you have been through the same.'* And Jakkie confirmed this: *'... the interview made me calm and peaceful. It took me a long time before I could accept that Oom Alex's place is empty and his voice is still.'*

The section above describes the meaning which the participants made in telling and interpreting their own stories. The next section describes an example of a hermeneutic or interpretative approach to meaning-making which complements the pastoral stance of this study.

4.3.2 A logotherapeutic approach: an example of interpretative meaning-making

Meaning-making may be described as understanding the world (Stelter 2000:66) through positive interpretation (Hunt 2003:30). Victor Frankl, a prisoner of a Nazi war camp and a psychiatrist, presents an interpretative approach to meaning-making which he calls logotherapy. Although this approach is not theological in origin, it nevertheless provides valuable insights into the interpretations of meaning, in an eclectic and multi-disciplinary fashion.

Frankl ([1959] 2004:104) suggests that the most important motivational force in humanity is the need to find meaning. There are four significant ways in which meaning may be found, namely in *work*, in *love*, in *suffering* and in *death*. If *work* involves wholehearted and intentional activity, it becomes meaningful, but when a person does not find meaning in work, an existential vacuum (frustration and neurosis) ensues, which in turn blocks the person's ability to bring meaning to life (Möller 1995:247). Work becomes meaningful when it is interpreted as a contribution to the well-being of others. In terms of a caregiver and her work of caring for her partner, a monumental contribution is made to the life (and death) of her spouse. It may be contended that when the caregiver performs the work of caregiving with total commitment and intention, an awareness that her activities are meaningful becomes visible (Cheung & Hocking 2004:476). The pastoral counsellor may thus attempt to make the caregiver's contribution visible both to her and to her spouse.

The second area of meaning-making relates to the spiritual experience of *love* (Frankl [1959] 2004:116; Möller 1995:247) where potentialities and traits are recognised and actualised in the other and the self. Love is interpreted as significant and meaningful when it is selfless and a person is prepared to sacrifice her/himself for the sake of the beloved. When the caregiver is confronted with the impending death of her spouse, she may discover a new dimension of love for her husband. I experienced a profound deepening of my love for Louis. Priscilla and Jakkie reported a similar experience. Cancer somehow opens up the opportunity to experience a new depth of emotion and, in journeying with the loved one until death, it becomes the ultimate sacrifice and the ultimate gift to him (Sharp 1996:221). If the pastoral counsellor makes the extent of the gift visible to the caregiver, her sacrifice may also become one of her most significant tools in personal meaning-making.

The third significant area of meaning-making is represented by *suffering* (Frankl [1959] 2004:116). 'When a person faces an unavoidable situation, he/she is called upon to realise the highest value and to fulfil the deepest meaning of her/his life' (Möller 1995:247). If the caregiver is made aware of the opportunity for growth within her suffering, she may consciously begin to make interpretative meaning of the situation – not in spite of her suffering, but *because* of her suffering (Frankl [1959] 2004:119). Traditional Christianity teaches us to accept God's ways and to identify with the suffering of Christ as a stoic victim (Murphy 1996:91). This intimates a silent suffering and suggests, in effect, a negation of the need to question God.

Jakkie recalls that, when Alex became resentful and asked 'why', she would admonish him not to question God. If one is not permitted to question God, then one may effectively be voiceless and powerless to make meaning. Elsa would repeatedly intersperse her story with self-admonishments: '*It is not for us to know God's ways.*' Elsa's response offers an example of embedded theology. The concept of *embedded theology* represents internalised, theological suppositions that require little thought (Doehring 2006:112).

By contrast, *deliberative theology* suggests purposefully thought-out ideas and unpacked beliefs. In this manner, a personal crisis may lead to a critical awareness of embedded theology and the creation of a new, more meaningful deliberative theology (Doehring 2006:112). Embedded theology may also prohibit the freedom of wrestling with God in search of meaningful answers. This may prevent effective meaning-making and delay healing. Ackermann (2003:112) argues for a God of context and a language of lament that does not turn away or 'let God off the hook' but wrestles with God until a sense of meaning emerges from the trauma.

The fourth and final area of interpretative meaning is *death*. An awareness of the transience of life imbues us with an appreciation of the value of time (Möller 1995:248). In my story (see Section 1.2), I point out how time in terms of the immediate moment took on a different, heightened meaning for me. Priscilla and Mercy both pointed out how finite our time on earth is and how important it is to appreciate each moment. An awareness of the inevitability of death can imbue the moment with gratitude for life. The caregiver can be made aware of the responsibility that she has to realise her potential in the light of the transience of life.

Frankl (Möller 1995:248) argues that people's values are important, because they reveal the aspects which contain meaning for a person. Values are interpreted meanings shared by other human beings. He cites three kinds of values: creative values, experiential values (receptivity in appreciating things in the world) and the highest value, namely attitude values (choosing our attitude when faced with unavoidable suffering). Our attitude values are always accessible to us and they give meaning to our suffering. *Creative values* emerge in caregiving, for instance, when

Rieda devised a way to hoist Archie out of the bath. Her obvious pride in showing me the chair she used and explaining her strategy to me indicates that she ascribed meaning to an otherwise traumatic occurrence. The meaning of *experiential values* becomes evident in Priscilla's recognition and active creation of the gifts (jokes, videos and touch) during anticipatory mourning and Elsa's appreciation when Koen had told her that she looked pretty. *Attitude values* are interpreted values and they emerge in the participants' statements (Elsa, Jakkie and Priscilla) that they were grateful for time together to say goodbye.

Values also intimate spiritual theodicies of suffering and death. Cook and Wimberley (1983:222) conducted a bereavement study and identified three types of mourning theodicy. The first is belief in a reunion with the loved one in an afterlife. The second is the belief that his death was because he was called for a great purpose. The third is death as punishment for sin committed by the dying or those immediately involved. Using one or more of these theodicies, the mourner incorporates the meaning into his/her personal framework of reality and so the religious interpretation brings a level of meaning (and sometimes compensation) to the death of a beloved.

Cook and Wimberley (1983:223) draw on an exchange perspective. When a person experiences any type of loss, the person's overall level of life satisfaction diminishes. Actions which are interpreted as rewarding now become more valuable and are performed more frequently or intensely, in turn increasing the overall level of life satisfaction. From an exchange perspective, the interpretation, recognition and creation of gifts (moments of joy and respite) during anticipatory mourning become intensely rewarding and infinitely meaningful: 'It is in the context of authentic, personal meaning that the spiritual gifts of caregiving can best be defined' (Doka 2003:46).

Section 4.4 focuses on the process of co-constructing pastoral care between the pastoral counsellor, the caregiver, her loved ones, her community and God. The discussion highlights the importance of creating an awareness of choice and hope which finds its roots in community and in sharing relationships (Lester 1995:94-95).

4.4 CO-CONSTRUCTING PASTORAL CARE WITH WOMEN IN ANTICIPATORY MOURNING

The relationship of care and self-sacrifice in anticipatory mourning may imbue the caregiver's experience with meaning and hope. Conversely, the caregiving relationship may also lead to a loss of sense of self, of an awareness of one's own needs, an over-functioning on behalf of the dying one, while under-functioning on behalf of the self, and a loss of voice (Gill-Austern 1996:310-313). In addition, self-sacrifice can undermine the capacity for mutuality and can lead to

an abdication of the caregiver's responsibility to take control of her own life. Finally, self-sacrifice may also invite domination within relationships by another. When a spouse consistently subjugates her own needs and desires, she effectively silences her own voice, which may lead to feelings of anxiety, resentment and depression. Gill-Austern (1996:311) explains that women's willing subjugation may be attributed to their being socialised into 'either-or' extremes of total self-sacrifice or complete egoism: 'The real question is not whom do I put first, but how do I care for the other and myself?' (Gill-Austern 1996:311). This crucial question may guide a pastoral carer to deconstruct the caregiver's paradoxical way of viewing the world and to co-construct healthy self-care.

Moessner (1991:216) asserts that women in crisis require three things from their pastoral caregiver(s): first, a theology of hope and grace; second, connectedness and acceptance within her church; and third, reinforcement of her relationship with God. These requirements, coupled with the expressed needs of the caregivers in this study (see Section 3.2 and 4.4.3 below), underscore the need for participative and contextual pastoral care. Sections 4.4.1 to 4.4.4 below discuss the *need* for pastoral care; the *constraints* to pastoral care during anticipatory mourning; the process of *co-constructing* pastoral care within the context of loss and trauma; and *consciousness-raising* regarding significant aspects specific to anticipatory mourning.

4.4.1 The need for participative pastoral care in anticipatory mourning

Assessment of and follow-up care for the caregiver has long been recognised as a pressing need by the international psychological community, but, given the shortage of counsellors, care for caregivers has not been readily available (Ferrario et al 2004:134). The onus therefore remains on pastoral counsellors to address the need for pastoral care in anticipatory mourning. People become aware of their need to create meaning during a crisis in their lives, but issues about faith and meaning are often ignored by medical and psychological caregivers (Doehring 2006:111). Theology and pastoral care therefore offer a vehicle to address these issues, but a question that must be asked is: 'Do their religious faith and practices give people new life or exacerbate already painful circumstances?' (Doehring 2006:111). In this regard, I want to refer back to Jakkie's experience of pastoral prescription (see Section 3.2). Erecting a 'shrine' on Alex's side of the bed was Jakkie's way of making meaning for the moment. Her minister not only forced *his* discourse onto her in a nouthetic, confrontational way (Roux et al 2002:39), he also dismantled her efforts and debilitated her in her own meaning-making attempt. The participants' experiences of pastoral care (see Section 3.2), as well as my own experience (Section 1.3), suggest a pressing need for ethical, non-prescriptive and co-constructed care for caregivers.

4.4.2 Constraints to pastoral care in anticipatory mourning

In the process of co-constructing pastoral care, it is imperative for pastoral counsellors to remain aware of the ethical risk of creating yet another silencing discourse and of time constraints, as well as the physical and emotional depletion which caregivers are subjected to. Rando (2000d:332) warns that pastoral care with an anticipatory mourner may be very different, more risky *and* more complicated than pastoral care with a post-death mourner. When the death is a *fait accompli*, a post-death mourner may have more time and less fear to explore therapeutic issues. In anticipatory mourning, a caregiver may fear and restrict any activity which she believes could adversely affect her spouse, her family or her own precarious hold on reality (Rando 2000d:332). Other problems which may interfere with pastoral care efforts include bereavement overload (being overwhelmed by multiple losses), exhaustion, traumatisation and a lack of knowledge and planning (Rando 2000d:325).

Personal reflection

In our interviews, the participants were unanimous that time is a rare commodity during anticipatory mourning. I believe that this is where practical theology and pastoral care must be willing to get their hands dirty, literally. If a contextual feminist theology (see Section 1.10.3.1) focuses on the marginalised and a participative commitment to doing theology (Kotzé & Kotzé 2001:4; Roux et al 2002:70), then I would argue that doing theology includes practical help where needed. In other words, pastoral counsellors should be prepared to enter into conversation with a caregiver while helping her wash dishes, prepare meals or even wash faeces or urine from the bed of the dying loved one, thus doing as well as talking pastoral care. In my case, a formal sit-down therapy session would have been impossible: there simply was no time. Also, a constant state of anxious hyper-vigilance may preclude a caregiver from benefiting maximally from any type of formal pastoral care.

4.4.3 Co-constructing pastoral care

In the light of the care-seeking constraints and ongoing losses experienced by a caregiver, co-construction of care is imperative. Awareness of the types and levels of losses is also important in constructing care. Rando (2000d:309) argues that a caregiver's multiple and ongoing losses are mourned at three contextual levels, namely the *intrapsychic* level (emotions, cognitions, adaptation to, or defence against the impending threat, and planning for the future); the *interpersonal* level (help, care, attention and energy directed toward her dying spouse and resolving unfinished business); and the *systemic* level (family, religious, social, political, educational and/or economic institutions).

In addition to the *levels* of loss, Doehring (2006:74-76) points to *types* of loss which the caregiver may be experiencing, such as *material* loss (for example, assets); *relational* loss (the ending of intimacy); *intrapsychic* loss (such as the loss of an ideal of future togetherness including planning trips and/or retirement); *functional* loss (of bodily functions for instance) and *role* loss (such as losing the role of lover to the dying one). It is evident from the above that the caregiver suffers all these kinds of loss, except for functional loss, during anticipatory mourning, and it is therefore important to ascertain continually what the areas of greatest discomfort and/or stress are. Co-constructing pastoral care thus presents an ongoing process of construction and (re)adjustment. The way in which a counsellor can ascertain the direction of care and counselling is through *listening* awareness and interconnectedness with the caregiver (Pembroke 2002:87), as well as a hermeneutic co-interpretation and re-interpretation of the caregiver's storied experiences. Gerkin (1984:138) describes this activity as a 'hermeneutical circle' of endless cyclical reassessment of memories, experiences and relationships (see Section 4.3.1.2 above).

Trauma often leads to feelings of disconnectedness from parts of ourselves, our significant others and our community. When we are witnessed and truly listened to, the disconnected parts of ourselves are once again restored or 're-membered' (Weingarten 2003:196). Jakkie's words at the end of our first interview conveyed an experience of restoration: '*I am glad I spoke to you... things feel **normal** once again*' (Jakkie's emphasis). When we feel connected and whole, options for action become visible (Weingarten 2003:196) and meaning-making possibilities emerge.

In co-constructing pastoral care, the first aim is thus to establish the needs of the caregiver (Wright 2003:14). When I asked each co-researcher what her needs during anticipatory mourning had been, the co-researchers all spoke of the *need to talk* to an unbiased and *available* listener (Pembroke 2002:74). A second need that was voiced by four of the five participants was the need for spiritual sustenance, planning and social support. A third need voiced by Elsa, Mercy, Priscilla and Jakkie was the need to hold onto an ongoing relationship with the deceased. Financial resources seemed important, and all except Rieda expressed the need for practical help with cleaning, cooking and other caregiving duties. Mercy expressed the need for social support and '*someone to give advice, help and care*'. Rieda needed more '*social and emotional support*'. Jakkie could have done with some practical help, namely a '*warm plate of food*' and Priscilla felt that it would have helped if someone had '*brought some food, provided emotional support, people to come and pray and... Hospice... or any help*'.

A final pressing need voiced by Elsa, Mercy and Rieda was the need for knowledge – especially medical knowledge. My experiences resonated with theirs. Understanding the progression of cancer empowers the caregiver with a sense of predictability in an otherwise uncontrollable and

unpredictable world. Rieda, Elsa, Mercy and Priscilla said they would have preferred better communication from medical personnel and doctors. The participants commented on intense feelings of uncertainty – about the future, what to expect, the course of cancer, and who to contact for help. It thus became evident that, in addition to empathic listening and participative care, the participants also needed knowledge, awareness, resources and practical help to plan and prepare for the time of death and beyond.

4.4.4 Consciousness-raising: significant aspects in caring for the anticipatory mourner

As discussed previously (in Section 2.4.1), loss presents an overarching presence within which all the events (Section 3.3) and contexts (Section 2.4) of anticipatory mourning transpire (Rando 2000b:59). Sections 4.4.4.1 to 4.4.4.8 contain a discussion of meaningful aspects which emerged from our experiences as caregivers. They are intended to create awareness within pastoral care and are representative of the voices of the caregivers and participants in this study. Thus, consciousness-raising has a twofold objective, namely first, to create awareness of needs and both prescriptive and appreciative discourses, and, second, to bring to light knowledge from the real experts (Reinharz 1992:220-221) of anticipatory mourning, namely the participants of this study. The aspects of caregiving in anticipatory mourning that emerged from our conversations (discussed in more detail below) were the importance of knowledge; dealing with emotions and identity; calling the loved one as witness; co-constructing a legacy of the loved one; dealing with unfinished business; taking stock of resources; becoming aware of the gifts within anticipatory mourning; and planning for a future without the loved one.

4.4.4.1 The importance of knowledge and awareness

Knowledge and awareness help to keep us in the present, but also help us to transcend trauma. Awareness represents a state of alertness which may aid in reducing the physiological arousal caused by anxiety and trauma: 'Awareness, then, includes the ability to anticipate and realise danger on the one hand and the capacity for knowledge and transcendent feeling on the other' (Weingarten 2003:164).

Personal reflection

Awakening awareness also heralds an ethical dilemma for the pastoral counsellor: Who decides that the caregiver should be enlightened? Does it always benefit her (Kotzé 2002:6) or could it harm her if she were, for instance, deeply embedded in denial as a coping mechanism? Would the caregiver have preferred to remain in a state of ignorance?

(Continued)

Aware of the ethical dilemma, the counsellor would have to be acutely sensitive to the needs of the caregiver and refrain from simply adding another prescriptive discourse. In order to prevent harm to the caregiver, it is suggested that the needs of the caregiver are established continually and that the counsellor allows a non-judgmental 'insertion' (Cochrane et al 1991:17) into the life of the caregiver. Thus the caregiver and the counsellor proceed together to co-construct the required care.

Knowledge and awareness spark an inner dialogue, sometimes an inner war (Ackermann 2003:54). Inner dialogue may not be comfortable, but it can empower a caregiver by opening up choices. If the caregiver is familiar with the course of the disease and what to expect, it may help her to make meaning of anticipatory mourning (Rando 2000b:81). Specific and detailed information makes the impending death real to the caregiver. This in turn enables her to begin to make meaning of the trauma and to commence with the tasks of mourning (Rando 2000d:355). The provision of knowledge corrects misinformation and deconstructs discourse (Rando 2000d:373). The caregiver feels less overwhelmed if she has a framework of meaning and information to draw from, and knowledge promotes healthy mourning and normalises aspects of mourning which the caregiver may erroneously have regarded as abnormal (Rando 2000d:373).

Widely accepted ideas (discourses) obscure inequality and power imbalances (Burr [2003] 2004:83), creating a distorted consciousness. It is necessary to become aware of the underlying discourses which frame our lives, in order to 'think, argue and make up our minds about our own views' (Burr [2003] 2004:94). A simple co-constructed exploration of the discourses which underlie her actions can empower a caregiver to become aware of choices and the possibility for change (Burr [2003] 2004:122). Thus knowledge and awareness of discourses present a potential site of infinite empowerment or acute marginalisation.

In a hierarchical dominant society, people at the lower end (such as female caregivers) are stigmatised, which has a great impact on their self-esteem (Castillo 1997:42). For these people, the world can be an alienating and hostile place. They may thus try to hide their status or emulate the dominant group for fear of further stigmatisation (Castillo 1997:42). It is contended that, even though a caregiver may be treated kindly but patronisingly by society in general, the stigma of temporary mental imbalance (see Section 2.3.7.5) may lead a caregiver to forbid herself to express her grief in public. She may in fact imitate the dominant group (in this instance the group who propound the discourse which dictates that males do not cry) to the extent that she becomes unable to express grief at all. The prohibitive discourse of non-expression of grief presents a reason why it may be therapeutic for a caregiver to express her emotions in a way she is comfortable with, as in telling her story to a participative pastoral caregiver.

4.4.4.2 Dealing with emotions and self-identity

The life story as 'narrative truth' presents a possibility of self-identity (Lieblich, Tuval-Mashiach & Zilber 1998:8-9). When unconditional space is provided for a caregiver to tell her story, it encourages her to express her accompanying emotions as well. If telling one's story enables meaning-making (Danforth & Glass 2001:515; Seaburn et al 1992:392-393), then the authentic expression of the life story *and* its accompanying emotions also creates meaning.

Castillo (1997:61) uses Levy's three-stage model to illustrate the assessment of emotions and their appropriate expression in mourning. In the *initial appraisal* stage, the cognition of loss becomes apparent. In the subsequent *emotional feeling* stage intense emotions are experienced, often translating into physical sensations of discomfort and/or illness. In the final stage of *culture-based behaviour*, a person assesses her emotions and adjusts the expression thereof according to the rules of the dominant group. If an open or prolonged expression of grief is assessed as culturally unacceptable, then the caregiver may suppress the emotions altogether or the emotions may find expression in various other ways, such as somatisation or dissociation (Castillo 1997:60). When emotions are expressed *to* another human being, feelings of dissociation may decrease to a point where the caregiver feels in touch with herself, and meaning-making as a coping resource becomes available to her once more.

Patterson and McCubbin (cited in Rando 2000d:314) use the term of stress 'pile-up' to describe a condition of being overwhelmed when multiple stressors coincide with little prospect of relief, as in the case of anticipatory mourning. Coupled with traumatic stress, anticipatory mourning signifies a combination of loss and trauma (Rando 2000d:333). These two components and the resulting emotions are the main sources of adaptational demands for a caregiver. Trauma may lead to hyper-vigilance and anxiety, while a combination of loss and trauma may lead to feelings of anger and/or guilt (Rando 2000d:344-350) which in turn affect a caregiver's meaning-making and her sense of self. Mercy presented an example of the way in which feelings of guilt may erode self-esteem – she believed that she '*should have done more*', which affected her effectiveness as a caregiver and thus her sense of self. Her words at the end of the interview expressed her relief at having been validated: '*... and I feel good about myself now... I do not feel I am useless.*'

Doka (2003:46) suggests that the gift of caregiving supports and reaffirms the sense of self; and this enables meaning-making. The value of self-sacrifice (transcending the self) also enhances self-esteem and creates meaning (Frankl [1959] 2004:117). Dunne (2004:45) uses Bowlby's attachment theory to explain the sense of self in grief. When a person (in this case, a caregiver) is

confronted with the loss of an attachment, the survivor wonders who she is and what her worth is without that attachment. If one considers that anticipatory mourning heralds past, present and future losses, it may compound the question of 'Who am I?' and it may also compound feelings of worthlessness without the attachment to one's life partner.

The following concept of self-coherence may enable the pastoral counsellor to co-construct ways in which the caregiver's sense of self may be strengthened. Aaron Antonovsky (cited in Castillo 1997:78) focuses on the concept of self-coherence in healing. A sense of coherence leads to a healing of the self which consists of three components, namely *comprehensibility* (a sense of order), *manageability* (a sense of control) and *meaningfulness* (a sense of purpose) (Castillo 1997:78). During the trauma of anticipatory mourning, all three these components may be absent, leaving the caregiver with feelings of meaninglessness and of being overwhelmed. A counsellor may assist the caregiver to create a *sense of order* through the daily rituals of touch and care with the dying, but also rituals of self-care and respite. A *sense of control* may be cultivated through increased knowledge of medical matters; advocacy, on behalf of the loved one, with medical or other institutions; and *meaningfulness* may be cultivated through spirituality and care (Castillo 1997:78).

Janoff-Bulman (cited in Danforth & Glass 2001:521) suggests that we have three core beliefs about ourselves and our world. The first is that our world is *benevolent*. The second is that our world has *meaning*. The third is that we are *worthy*. Self-worth is gained and maintained through the predictability of our lives, our actions and the relationships we surround ourselves with. Danforth and Glass (2001:521) suggest a reconstructed reflection on the self. Instead of equating self-worth with the loss/survival of the significant other, a new sense of self as survivor of trauma may be fostered.

4.4.4.3 Calling the loved one as witness

Reflecting on the self as survivor brings awareness and meaning. Reflections on affirmations by her spouse may endorse a caregiver's valued sense of self (Danforth & Glass 2001:522) and may imbue the caregiver's world with meaning. In the face of anticipatory mourning, a pastoral counsellor may call upon the dying spouse as a witness to the life and value of his wife, the caregiver. His living testimony may be used to reinforce the caregiver's sense of self. In our interviews, I asked each co-researcher to relate positive affirmations which they may have received from their husbands.

Mercy could not recall any positive affirmations, so I suggested that she try to imagine what Bruce would say of her now, in hindsight. She stated hesitantly: '*Bruce would say... that I have a lot of*

guts... yes! I did things I could not have done when he was alive, like going to the bank, drawing a lot of money, visiting the children, coming home after dark... He definitely underestimated me! Elsa said that Koen had thanked her for her consistent care, saying that he would have done the same for her. Alex thanked Jakkie for her care and told her that she had been a good person and a good wife: *'Thank you my wife – I love you,'* he would repeat. *'I will never forget those words,'* Jakkie mused.

Positive affirmation does not necessarily have to be verbal. Priscilla's husband, Attie, smoothed her feet with a pumice stone. *'Was that his way of conveying his love and gratitude for your care?'* I asked. She agreed: *'Yes, he had made up [restitution for the unhappy years]. He smoothed my feet. Then he fell asleep. It made him happy. That was a special moment,'* she smiled.

Rieda's husband, Archie proved to be a potent witness of her worth through his eyes. Shortly before his death he told her: *'There is no one else on this earth who has more luck than you!'* Archie had been painfully shy throughout his life. A few years before his death, he had said to Rieda: *'If I must die, I wish to die before you. You can go outside to the bus stop and speak to anyone... you can walk down the street and speak to anyone... I can't. I hope I die before you.'* Rieda recalled that he had rarely shown her appreciation or consideration during their life together, but those words conveyed the measure of his reliance upon her and suggested that he had been a witness of her as a fortunate and socially proficient person. Positive affirmations from a loved one may thus become part of an active co-creation of meaning between the caregiver, her spouse and the counsellor and a co-creation of the legacy the dying one wishes to leave behind may become an infinitely meaningful act between the caregiver and her spouse.

4.4.4.4 Co-constructing a legacy

The presence of our loved ones in our lives creates a legacy which we take with us when they die – they have influenced us, inspired us and shaped our characters and, when they die, they leave us with the 'fruits of their lives' (Attig 2000:120-121). Thus a legacy is much more than an inheritance of characteristics or possessions, as it includes the values our loved ones lived by, the examples they set and the way they touched our lives (Attig 2000:120-121). The *New Practical Standard Dictionary* (Funk 1951:763) defines a legacy as 'something left by will'. Co-constructing a legacy thus implies a negotiation with the dying one about the kind of life story he would *wish* to leave behind. Co-constructing a legacy also enriches and deepens shared memories in an infinitely meaningful way.

The co-construction of a legacy may help to create meaning in two main ways. First, a legacy may represent an idea, a teaching, an example or characteristic that a person's descendants can

hold onto after his death. It thus ensures a continuance of his memory which endures and gives meaning to the loss (Attig 2000:120). Second, a legacy is not only important in terms of precious memories or great examples of callings fulfilled, it also ensures an ongoing relationship with the deceased. We constantly keep others alive through our reflection on their lives – who they were, their achievements, their influence upon us and their impact on society (Wright 2003:59). By virtue of the way in which the dying's legacies are defined, they retain the power to influence and inspire us long after death (Attig 2000:120). As we hold their legacies close to our hearts, our love for them deepens 'as we allow their values and meanings to permeate our lives' (Attig 2000:121). The stories of their lives become a gift which continues to inspire and shape our lives as 'we become their living legacies' (Attig 2000:121).

In the interviews, I asked the participants about the legacies their husbands had left and if that brought meaning to their lives. Elsa said: *'There are so many things – his jokes, his love for his children... he would move mountains for them – so would I.'* Among other meaning-making tools, Priscilla seems to have made meaning through Attie's legacy: *'Attie is not like an ordinary guy who became ill – he left many things behind... he had a calling which he fulfilled. His legacy was my healing,'* she mused. Golsworthy and Coyle (2001:188-189) confirm that healing brings meaning. Priscilla also confirms that holding onto Attie's legacy imbues her with a sense of continued relationship. Death may mean the biological end to a life but not to a relationship. Jakkie holds onto the meaning of Alex's legacy of love and care for his children and for her. Conversely, the painful memories of Archie as a heavy drinker and insufficient provider may prevent Rieda from making meaning of his death and his legacy.

Counsellors can review the past with the caregivers and so help to foreground cherished experiences that the caregiver may wish to take with her and share with others, thus enriching the shared memories of a life now ending (Attig 2000:131). Co-constructing an enduring legacy of the dying spouse may also deepen the relationship between the intimate caregiver and her dying partner, thereby opening up avenues to deal with unfinished business.

4.4.4.5 Unfinished business

A willingness to repair relationships is one of the most meaningful gifts one may bestow upon one's loved ones (Weingarten 2003:153). Issues that are avoided or remain unspoken cause various degrees of disconnection which other members in the family unit may be aware of, leading to feelings of separateness (Weingarten 2003:153). The caregiver may also, in an attempt to protect her spouse from further trauma, be reticent to address past issues. At a time when the caregiver may feel overwhelmingly isolated and alone, even with social support, a

repaired spousal relationship may contribute to her adaptation and meaning-making in mourning. It may also ensure a vibrant legacy and loving memories of a spouse who has died.

Priscilla, Jakkie and Elsa believe that they dealt with past hurts during anticipatory mourning. This enabled them to either extend or gain forgiveness. Priscilla spoke at length about the way in which her family had made meaning of unfinished business: *'We had bad times with Attie – it is nonsense to pretend now that he was the angel Gabriel. After Attie had stopped drinking, I told him: "You must make amends." He never did. He was so busy reaching out to other people that he never gave the children attention. That was wrong. That was sad. The children wrote him a letter and read it to him... the tears just flowed that night. He asked their forgiveness... and that gave them closure.'*

Attig (2000:128-129) points out that it is vital to come to terms with past offences, rifts and distressing feelings within the relationship during anticipatory mourning. Although it is still possible to come to terms with past hurts *after* the death of the loved one, unfinished business may lead to a preoccupation with unresolved emotions during post-death mourning and prevent the caregiver from making the transition to 'loving in absence' (Attig 2000:128-129). Caregiving presents a unique context for forgiveness when the search for meaning and new beliefs may facilitate discussions and understandings around unfinished business (Kruse 2004:218). Sometimes unfinished business may refer to matters which may simply need expression (Worden 2000:274). For instance, although Jakkie and Alex dealt with past hurts, Jakkie still expressed regret at her failure to assure him of her love more often. *'That Sunday we spoke much. He knew that he was going to die soon. He said that I should look after myself. What one should have said, you delayed. Every day we sat and talked... and we sorted it all out – all the unfinished business. The family too... I just wish I had told him more how much I loved him,'* Jakkie wept.

Rieda still experiences feelings of ambivalence towards Archie. She mourns her absence at the moment of death, but she also feels angry with him for the difficult and wasted years in their marriage. Rando (2001d:345) asserts that feelings of anger may prevail if the spouse has not dealt extensively enough with unfinished business. This includes disappointment over unfulfilled ambitions or expectations and a lack of closure. Although Rieda extended her forgiveness to Archie, they never discussed issues of past hurts: *'When he was sober, you could not get him to speak and when he was drunk, you could not get him to shut up!'* she said. Shortly before Archie's death, he asked for Rieda's forgiveness. She broke down in tears. *'Oh Archie,'* she sobbed, *'you have done so much hassle to me all my life, but I forgive you.'*

Melges and Demaso (1980:54) believe that unfinished business is an obstacle to meaning-making and the normal resolution of grief. The bereaved keeps the deceased alive in order to

express love and forgiveness which they might have withheld when the deceased was alive. Mercy in particular suffers from guilt over unfinished business with Bruce: *'I felt that I was not doing enough... felt terrible guilt. I wish I could have spent more time with him. I just feel... ah... I really, really wish I could have spent every minute awake with him.'*

Personal meaning-making requires an active attempt to deal with the unfinished business of the past (McGoldrick 1991:72). Rando (2000d:364) argues that finishing unfinished business may be one of the most important tasks of anticipatory mourning. Conversely, she also warns that airing explosive matters may cause more harm than good. It may therefore be advisable to ask the caregiver to imagine which issues she thinks will trouble her six months into the future. Those matters may need to be addressed with the loved one. Thus the resolution of past hurts presents a significant resource of meaning-making for the caregiver (Rando 2000d:364).

4.4.4.6 Taking stock of resources

An assessment of resources, both external and inner resources, may aid in the meaning-making process and presents another aspect to be considered in pastoral care. Lazarus and Folkman (cited in Bee 1996:360) assert that it is not necessarily an event itself but the subjective *appraisal* of the event *and* the availability of personal coping resources which determine the amount of stress experienced, in this case, in anticipatory mourning. Danforth and Glass (2000:523) suggest that reflection on the self as survivor leads to an awareness of an inner resource of knowing and relying on the self. This contention resonates with Antonovsky's 'sense of coherence' (Castillo 1997:78), namely the belief that one has adequate access to resources to survive, cope and make meaning of any situation.

Zilberfein (1999:74) asserts that the resource of social support and the awareness thereof in terms of pastoral care is important and can alter the course of mourning. Social support thus presents a significant resource in meaning-making (Neuberger 2004:65-71). A counsellor may encourage a caregiver to join support groups offered by institutions such as hospitals and Hospice (Zilberfein 1999:74). Weingarten (2003:212) suggests that self-help groups may provide a significant source of social support. These groups consist of people confronted with a similar life challenge and may be particularly helpful when its members experience themselves as marginalised (Weingarten 2003:212). However, as mentioned earlier, time constraints (see Section 4.4.2) may prohibit the caregiver from joining a support group – and this makes the role of the pastoral counsellor as listener, supporter, and co-constructor of meaning even more important.

In addition to social support, financial resources or a lack thereof may prove crucial in determining the level of caregiver adaptation and meaning-making. In terms of pastoral care, helping the caregiver to assess her financial situation may be constructive. If finances are lacking, it may be advisable to suggest that she finds employment. Kim, Baker, Spillers and Wellisch (2006:801) found that employed caregivers may have higher levels of adjustment to the stresses of caregiving than non-working caregivers. Higher levels of adjustment may be ascribed to periods of respite from caregiving, as well as added support from work colleagues. Higher levels of adjustment may also lead to greater life satisfaction, which in turn generates meaning (Haley 2003:217; 221).

Finally, spirituality provides one of the most important resources of coping in anticipatory mourning. However, in a modern western country where religion's impact is decreasing, the meaning-making possibilities of people are likewise inhibited (Romanoff 2006:311). An assessment and unpacking of *embedded* versus *deliberative* religious beliefs (see Section 4.3.2 above) may offer a caregiver the freedom to construct new thoughts around her spirituality that are more congruent with her subjective reality.

4.4.4.7 Gifts – a positive appraisal

An important aspect of meaning-making which I experienced in a profound way (see Section 2.2.2.1) was a positive appraisal of the gifts of anticipatory mourning. The recognition of moments of respite such as unexpected laughter and intimate declarations of care between Louis and me presented gifts of infinite value and became a well-spring of survival resources during those dark days of impending death. Hunt (2003:29) found that the way in which a caregiver appraises her daily tasks, in terms of 'uplifts' or gifts (joy, satisfaction or gladness), as opposed to the 'hassles' of caregiving, can create a positive psychological resource in meaning-making and buffer the negative effects of caregiving. The way in which we cognitively appraise a situation determines our emotional resources, our coping strategies and ultimately our meaning-making.

Doka (2003:46) points out that the self-sacrifice that caregiving requires represents a potential gift. Caregiving may actually strengthen the sense of self by reaffirming worthiness, strengths and a deepened spiritual connection. These aspects aid in creating meaning. In Davis and Nolen-Hoeksema's (2001:726) study on meaning-making in bereavement, they found that many did *not* find meaning in the loss, but they identified *benefits* in the loss, for instance, financial benefits and/or psychological benefits such as increased independence. Identifying benefits can therefore also be equated with positive meaning-making. If benefits can be identified, then a meaningful purpose to the trauma begins to emerge (Frankl [1959] 2004:85). A study conducted with caregivers in Australia found that the way in which they appraised a situation presented a

stronger predictor of the outcome than objective aspects such as the symptoms of illness, dependence or caregiver strain (Hunt 2003:30).

Lazarus and Folkman (cited in Rando 2000b:66) suggest three forms of appraisal. *Primary appraisal* looks at the event and determines what is at stake. *Secondary appraisal* weighs up available resources and coping actions. *Tertiary appraisal* or *reappraisal* evaluates and/or changes the event in the light of new and current information. When gifts are recognised and focused upon, reappraisal changes the outcome of a traumatic event and stimulates meaning-making. It is contended that positive appraisal also aids a caregiver in accepting meaninglessness when there simply is no meaning to be made.

In the interviews, the participants were asked to recall special moments which stood out in memory during anticipatory mourning. Each woman recalled incidents that touched her deeply – moments embedded in meaning. These moments were the gifts to which they held fast, both during anticipatory mourning and after the death of their loved ones.

Elsa mused that Koen had never been demonstrative towards her. However, she recalled instances when he would ask her to simply sit with him. They would talk at length about the family and everyday matters. Koen would make jokes and this would bring a measure of normality to their days. She recalled a poignant moment close to his death, when he asked to see his granddaughter, Chimone: *'Jis... no... look... that was... [tears] Chimone stood there and spoke with him. He just rubbed her knee... so she stood there and he just rubbed her knee... [tears]. After that... his whole body just shut down... he no longer recognised anyone.'* Elsa recalls a second significant moment when she was dressing for church. *'He had never been a... you know... romantic man. He would never tell you that he loved you. That Sunday, for the first time, he said: "Do you know that you look pretty?"'*

Priscilla returned to the incident when Attie smoothed her feet with a pumice stone. She added that Attie had loved touching. He would repeatedly ask her to hold him or *'cuddle up behind his back'*. Priscilla also recalls the humour in their togetherness: *'...he was always making jokes,'* she smiled. She had held a wake for Attie two months after his funeral and she recalls how everyone had laughed in memory of Attie's jokes.

Mercy and Rieda could not really recall any particularly special moments. The moments that Rieda could recall were interspersed with sadness and irony: *'I suppose I am luckier than most people... hey, at least he kissed me goodbye... I suppose I am luckier than most people....'*

4.4.4.8 Planning

A final aspect of meaning-making refers to planning and rehearsal for the moment of death and beyond. Rando (2000b:81) asserts that planning is a necessary and integral part of anticipatory mourning. Appropriate planning may have a direct influence on adaptation in anticipatory mourning *and* after death (Rando 2000b:81). Once again, it is important to be aware of the caregiver's specific needs. She may be more concerned with planning for practicalities such as adequate transport for her child from school than with how to tell her child that her father's condition is deteriorating (Rando 2000b:82). In addition, planning rituals such as family reunions, celebrations and rituals of care may alleviate the stress of anticipatory mourning and may enhance feelings of control and predictability (Rolland 1991:161), which in turn creates meaning (Danforth & Glass 2001:521).

Planning takes place on three levels, namely the *intrapsychic* level (planning emotional and appraisal responses), the *interpersonal* level (planning to attend to unfinished business and spending quality time together) and the *systemic* level (planning familial and communal activities) (Rando 2000b:82). Planning also extends to balancing self-care with 'other-care'. Indeed, planning for self-care and respite activities is just as important as care for the dying loved one (Galvin et al 2005:7; Gill-Austern 1996:311).

Personal reflection

It may be advisable for the pastoral counsellor and the caregiver to co-construct short-term, medium-term and long-term planning. Short-term planning may involve discussions with the dying one relating to things he would still like to do, planning for self-care, respite breaks, visitors and rituals of care and togetherness. Medium-term planning may involve 'practice runs', for example, phoning the funeral home to prepare for the death, envisaging the moment of death and mentally preparing for it, 'to-do' lists, and telephone lists of people to contact for help. Long-term planning may refer to envisaging life without the dying spouse, preempting problems as well as possible gifts, and taking an imaginative stroll into the future. Anticipatory mourning also presents the opportunity for 'anticipatory socialisation' where future roles, relationships and activities may be deliberated and decided upon (Rando 2000b:81).

A final and important part of planning is the co-construction of a 'future story' (Lester 1995:103) beyond death and beyond mourning. A future story presents the central area for creating hope and meaning. 'The future is perhaps one of the most gratifying subjects for therapeutic conversations. It is a country which no one can own and which is therefore open to all possible ideas and imaginings' (Lester 1995:106). Planning restores feelings of order, control and predictability (Danforth & Glass 2001:521; Nadeau 1998:29) and a sense of predictability in turn

summons meaning and hope. Lester (1995:83) writes: 'Without hope, achieving life that has purpose and meaning is impossible. In fact, where there is no hope, sustaining human existence is difficult. Without hope, [humans] function at a level of existence which may produce illness or even death.'

4.5 CONCLUSION

In this chapter, the role of practical theology and pastoral care for anticipatory mourners was explored, as well as dialogical, conversational co-construction of meaning between the pastoral counsellor, the caregiver, her terminally ill spouse and God. Significant meaning-making aspects relevant to anticipatory mourning were discussed, such as an awareness of mourning tasks, discourses, gifts, rituals, attitudes and planning. Co-constructing pastoral care for a caregiver in anticipatory mourning presents, in effect, a co-construction of meaning. Chapter 5, the final chapter in this research project, reflects on the process, the content, the methodology and the findings of this study.