

## CHAPTER 2:

### THE SOCIAL CONSTRUCTION OF MEANING

#### **A metaphor of meaning**

*A storm is brewing. The sky is an ominous grey and the lightning plays like nimble fingers across a bruised and angry sky. You stand in an open field and feel the wind tugging at your clothes. Deep-throated rumblings of thunder accompany the howling wind. The sounds of birds and animals cease and all activities seem to be suspended. An uncanny silence follows... and then the storm breaks loose with a deadly ferocity. A clap of thunder strikes next to you, startling you into activity. You look around, but there is no refuge. You are at the mercy of the storm.*

*The wind gains in strength and twirls an old piece of corrugated iron like a fluttering leaf. A wild panic mobilises you and you begin to run. The wind chases you and you feel the fear burning in your throat. The next moment a gust of wind lifts you off your feet and vaguely you become aware of flying 'missiles' around you. You are powerless in the midst of a raging storm.*

*Then, suddenly, you are flung against an old wooden fence. The splinters rake your skin but you are unaware of the pain. Gratefully you wrap your arms around the fence post and press your face against its rough surface. The splintered old fence anchors you and, in that moment, you begin to love it.*

#### 2.1 INTRODUCTION

The metaphor above represents my social construction of meaning-making during anticipatory mourning. The threatening storm symbolises the day Louis was diagnosed with terminal cancer. As we moved into the twilight of anticipatory mourning and approaching death, the storm gained relentless momentum. I felt helpless. The flying missiles represent the previously predictable and controllable aspects of my life which now seemed utterly out of control. None of my previous meaning-systems made sense and God felt starkly absent. Then, as the awareness of multiple losses began to surface, I realised that I was in danger of losing not only Louis, but also my sense of self. I could no longer make meaning of God, life or death. Kenneth J Doka (2000:103-104) asserts that anticipatory mourning heralds not only the mourning of daily losses, but also the mourning of a *loss of meaning*. In desperation I began to hold on to the only aspect in my life which I could still control – my attitude and awareness of the value of the moment. Frankl ([1959] 2004:116) suggests that one can find meaning in suffering by changing one's attitude when one can no longer change the circumstances.

In each moment I experienced the paradox of *fleeting eternity*. I experienced how fleeting the precious moments with Louis were and I felt how eternal they were in their indelible significance. I began to string together precious moments by deliberately and consciously replaying them in my memory. Each time I replayed them, they gained in significance and meaning and gradually grew into an infinitely powerful resource of memories which I could visit and revisit. The awareness of

the moment occupied my thoughts constructively and helped me to keep negative ideation at bay – the knowledge that I was in control of this thought activity alleviated my anxiety levels.

In retrospect, I recognise that keeping my mind occupied created a cognitive pattern of positive appraisal (Hunt 2003:29) and, coupled with feelings of gratitude and control, created meaning (Golsworthy & Coyle 2001:184; Nadeau 1998:29). The 'gifts' that positive appraisal brought to the fore became my fence post in the storm: an unexpected awareness of resources, moments of respite and laughter, and fervent but increasingly disoriented declarations of love by my dying husband. These gifts provided pristine moments of joy in the landscape of my memory; and each memory eternalised a precious moment of my relationship with Louis.

In this chapter, I start by discussing the social construction of meaning and its descriptions (see Section 2.2) and then look at the *process* of meaning-making in terms of its attributes and characteristics (in Section 2.3). Finally, I explore the social construction of meaning relative to the context of anticipatory mourning (in Section 2.4).

## **2.2 SOCIAL CONSTRUCTION**

Social Construction emphasises the importance of relationships. In fact, every act of meaning is regarded as a relational act (Gergen 1994:264-269). A Social Construction orientation regards knowledge or discourse as a historical artefact of social interaction, during which people come to understand, explain and so make meaning of the world in which they live (Gergen 1985:266). According to Social Construction theory, discourse or knowledge conveys a shared meaning which is culture-specific and subjective. The theory is critical of taken-for-granted knowledge (Burr [2003] 2004:2). Knowledge, shared meanings and multiple truths are created and conveyed *through* language, *in* social interaction. Since meanings are continuously created and revised in interaction, it may be inferred that meanings keep changing in the light of the *kind* of social interaction one engages in, as well as the *person/s* one is interacting with (Burr [2003] 2004:31). Section 2.2.1 below discusses meaning-making as an inherently social process and looks briefly at a few social descriptions of meaning.

### **2.2.1 Meaning as social interaction**

My meaning-making processes, as described above, are informed by my relationships with God, Louis, other loved ones, illness, suffering, death, mourning and the way in which meanings of relationships are socially constructed. My chosen epistemology, Social Construction, refers to the way people construct shared meaning in interaction, through the use of language symbols (see Section 1.10.2). In this way, sets of socially constructed ideas, which are also called discourses, develop around a specific topic, such as mourning. On the one hand, discourses can serve a

positive function by providing us with shared frameworks upon which we may continuously weave the viscous fabric of our subjective meaning-making (Burr [2003] 2004:122). On the other hand, discourses may also be used to enforce social control (see Section 2.3.7 below). We cannot operate outside of discourse, which implies that an awareness of discourses and the choices they prohibit or enable, is important. For instance, Social Construction itself presents yet another discourse with the potential of yet another set of legitimised 'truths'. The critical question which should be asked in order to maintain awareness of discourse is this: 'Does this discourse obstruct or enable my personal meaning-making?' When I therefore refer to the *social construction* of a concept in this study, I am referring to the way in which society has collectively constructed these frameworks or discourses and the way in which the discourse has come to be regarded as 'truth'.

The third section of this chapter presents a critical view of the social construction of discourses and their effects on people, particularly caregivers. The fourth section expands the framework of discourse, and thus meaning-making possibilities for caregivers, through consciousness-raising. Reinharz (1992:220) argues that consciousness-raising is a feminist method of research which enables women to understand their experiences from their own unique viewpoints. Consciousness-raising also means creating an awareness of meaning-making possibilities against the social construction of reigning discourses, as well as an awareness of *choices* in creating alternative, more internally coherent systems of meaning (Burr [2003] 2004:122). In addition to serving as a consciousness-raising exercise for caregivers, Chapter 2 is therefore also intended to alert pastoral counsellors to the way in which 'truths' are socially constructed and enforced when ministering to a bereaved caregiver or a caregiver who is about to be bereaved.

As was already indicated in Section 1.7, Chapter 2 does *not* present a concentrated literature review. Instead, a *literature control* has been implemented throughout this dissertation. The next section explores the social constructs, as descriptions of meaning, which emerged from the literature.

## **2.2.2 Descriptions of meaning**

The subject literature tends to present broad descriptions, rather than definitions, of meaning. Golsworthy and Coyle (2001:184-190) equate meaning with a sense of order, purpose, safety and healing and describe meaning-making as an adaptation to and reinterpretation of a belief system that has been disrupted (by a traumatic event, for instance). The *New Standard Practical Dictionary* defines meaning as 'that which is intention, aim, important, significant, understandable, purposeful or accepted' (Funk 1951:827). Nadeau (1998:14) describes meaning as the effort to understand the significance of an event and 'what my life means now' in relation to that event. Victor Frankl ([1959] 2004:85-90) explains meaning as a sense of purpose, future hope, the

dignity of suffering and asking what life expects from us. Finally, Stelter (2000:63-64) describes meaning as 'understanding the world'.

#### **Personal reflection on descriptions of meaning**

*When I reflect on the descriptions above, I conclude that meaning does not necessarily seem to connote a positive purpose or an adaptive response, but may simply reside in that which is experienced as significant, or that which can be measured by its profound impact on our lives. Therefore, even if a significant event appears purposeless, the experience alone contains a 'knowledge which no-one else can represent', signifying that to us it is a meaningful event (Galvin, Todres & Richardson 2005:8). Meaning therefore represents what is important to us (Kruse 2004:217), whether we experience it as positive or negative. Burch (cited in Kleiman 2004:10) expresses a similar idea when he explains that 'what can be recalled must have already been constituted as meaningful'. If Burch's assumption is accepted, then recalled narratives of people's lives represent meaning. If this argument is taken further, it may be assumed that the process of relating a story or an event – whether positive or negative – creates meaning. Likewise, Frankl (in Möller 1995:247) also suggests that meaning may be found in both positive and negative events, adding that true meaninglessness resides in boredom, never in a significant event.*

The above descriptions do not provide an operational definition of meaning – an operational definition can be described as the transformation of a theoretical concept into 'concrete, observable behaviour', so that those who observe the behaviour may come to a shared understanding of the phenomenon (Welman, Kruger & Mitchell 2006:28). For the purposes of this study, I would argue that meaning does *not* present an observable phenomenon and *descriptions* of meaning have therefore been used to move toward a shared understanding (Burr [2003] 2004:122). The next section looks critically at the process of meaning-making and how the *meaning* of meaning-making has been socially constructed.

### **2.3 THE SOCIAL CONSTRUCTION OF MEANING-MAKING**

Section 2.2 above discussed meaning as residing within significant events. The current section focuses on the *process* of creating meaning. Interestingly, every description of meaning-making denotes active agency. Frankl ([1959] 2004:85-95) describes meaning-making as *finding* a purpose to life, death and suffering, *creating* a future hope, and *living* for one's values and ideals. Thompson and Janigian (in Nadeau 1998:29) define meaning-making as 'a process of *changing* [my italics] the life scheme, or one's perception of the event so that feelings of order and purpose are restored'. As evidenced in the following sections (Sections 2.3.1 to 2.3.9 below), a general review of the literature on meaning-making shows that meaning-making can be described as an *active spiritual* performance whereby a new or revised *language* of values and understanding is constructed. Meaning-making creates its narrative in *relation* to God, the self and/or others and remains a *fluid* language under construction. In other words, as we continue to revisit a significant

event – either in memory or by telling and retelling our story, we gain new insights, and so our language of meaning-making continues to shift. Throughout the process of constructing meaning, we remain the active agents of our creation of meaning.

### **2.3.1 Meaning-making: a social construct of activity**

In the literature, the concept of ‘meaning-making’ is invariably accompanied by the notion of action. The present participle or gerund ‘meaning-making’ denotes the active creation of meaning. Patricia Barkway (2001:75-76) quotes various grieving individuals in the process of making meaning, and in each case the quotation suggests a form of activity: ‘*Fundraising* [my italics] for the Children’s Hospital has given some purpose to Alex’s life...’; ‘*Writing* [my italics] this book has given meaning to her life...’; and ‘Trying to *do* [my italics] something with my grief... I would like to *channel* [my italics] it into positive emotions and outcomes’. Making meaning is an active creation of a system of thought (thus a new or revised discourse and a resource), always in a relation to someone or something, whether to God, another person, the world or the self.

### **2.3.2 Meaning-making: a social construct of relationality**

Every experience takes place within a particular context and making meaning of that experience must therefore, of necessity, transpire *in relation* to a context and its actors or the co-constructors of meaning. Helping others in similar circumstances presents an example of active and relational meaning-making in loss (Barkway 2001:75). Stelter (2000:64) asserts that one *gives* meaning through conscious action *in relation* to the self and one’s context. Meaning-making is an essential human action and characteristic which is always created *between* people and never *within* an individual (Cotter, Asher, Levin & Weiser 2004:5-6).

Gergen (1994:264) confirms the relational quality of meaning-making. He uses the term ‘a relational theory of human meaning’ to argue his contention and explains the theory by means of seven assumptions: First, because we are always on a relational footing with others, a person’s utterance or gesture only gains meaning when it is relationally contextualised; thus ‘Hi’ is a meaningless utterance by Mrs A unless it is said in the context of meeting Mrs B. Second, the potential to gain meaning is achieved when another person responds through affirmation, action or gesture (a supplementary action), for instance, when Mrs B responds with a greeting in turn. ‘We thus find that an individual alone can never “mean”; an other is required to supplement the action and thus give it a function within the relationship’ (Gergen 1994:264-265). Third, the response by the other can create meaning or hamper meaning. For instance, if Mrs A says ‘Hi’ but Mrs B responds with a stare, it may restrict the creation of any further relational meaning. This is why an awareness of others’ discourses relative to their responses is imperative in order to

understand their points of view, yet maintain the freedom to *choose* those discourses which create, rather than hamper meaning. Fourth, any supplementary action generates further supplementation. For instance, when Mrs B returns Mrs A's greeting, it stimulates further action by Mrs A. Fifth, the ritual of supplementation causes meanings to change as interaction expands. Sixth, meanings are created and maintained according to the *order* within the exchange. For instance, if Mrs A throws a ball at Mrs B, meaning is created when Mrs B throws the ball back at Mrs A and so forth. Seventh, as the order of exchange continues, so the meaning of the exchange becomes *transparent* to the participants. This allows for a consensus of understanding, but also for possible misunderstanding between participants in terms of, for instance, the context, culture and spirituality.

### **2.3.3 Meaning-making: a social construct of spirituality**

In addition to the element of activity and relationality in meaning-making, there seems to be a consensus in the literature that making meaning holds a strong spiritual component (Bee 1996:329; Golsworthy & Coyle 2001:184; Doka 2000:104-105; Romanoff 2006:311-313). People often turn to spirituality in their quest for meaning, because one of the key functions of religion is to offer answers to the most fundamental questions of meaning and purpose in life (Bee 1996:329). Romanoff (2006:313) also asserts that religions present a wellspring of resources to draw from in adversity. However, he also points out the shortcomings of religions in that most of them focus on a future life beyond death, thereby signifying that the current experience is less important than that transcendent future hope.

A critical life event or trauma may force us out of our taken-for-granted meaning systems, forcing us to re-assess the spiritual meanings we make of ourselves and our experiences in the world. Illness, chronic pain, the death of a loved one, a prolonged crisis (as in anticipatory mourning) and other peak experiences propel us into spiritual transitions from one state of meaning-making to another (Bee 1996:349). Spirituality as a discourse, as well as a resource for meaning-making, is explored more extensively in Sections 2.3.7.6 and 2.4.3 below.

### **2.3.4 Meaning-making: a constantly changing process**

Spiritual transitions present possibilities for actualising inherent potential (such as the potential to transcend the self and so find meaning in caregiving) and once actualised, the possibilities of meaning-making become the immortal realities of the past, rescued from their transitory nature (Frankl [1959] 2004:124). In other words, although the meanings ascribed to past events continue to change in the light of current insights, meaning-making in anticipatory mourning creates a new language that, once learnt, provides us with a permanent resource that we can always rely on in

adversity. We are not locked into one true self, one true knowledge or one true world, but inhabit a 'multiverse' of changing realities and possibilities; and meaning-making thus remains in continual, fluid transition as a never-ending, relational process (Cotter et al 2004:7), using language as a vehicle to create and transmit meaning. There is no distinction between meaning and language, since meaning and language inform one another (Stelter 2000:63-64).

### **2.3.5 Meaning-making: a fluid language 'under construction'**

Language constitutes meaning and understanding. Meaning is always in the process of being constructed and informed *by* language *in* interaction between people (Kotzé & Kotzé 1997:31-32). 'People live, and understand their living, through socially constructed narrative realities that give meaning and organisation to their experience' (Anderson & Goolishian 1992:26). Language is more than a way of connecting individuals – it is a way of creating meaning, which is never fixed, always fluid. According to Social Construction theory, we exist *in* language (Anderson & Goolishian 1988:377). Thus, if our lives and experiences are given meaning through language, then both are open to infinite possibilities. Language does not reflect meaning, it *produces* it. Understanding ourselves *and* another in interaction is therefore always a process, never fully achieved – and this ensures that we tell and retell our stories to each other in ongoing dialogue (Kotzé & Kotzé 1997:31-32).

### **2.3.6 Meaning-making as narrative**

When we tell our life stories, we use narratives to reconstruct our realities and beliefs and create new meanings which are compatible with our changing circumstances (Cotter et al 1994:7): 'We assume that our primary vehicle for organising meaning are the narratives and stories we socially construct to provide ourselves [with] a sense of coherence, meaning and identity.' Stories organise our experiences temporally (chronologically in time); they connect our past to our future by providing continuity; they serve as a guide for the future; and, because they are evolving, ever-changing social constructions, they are pliable enough to fit unexpected events into our lives (such as losing a loved one to cancer) in order to make sense of it (Cotter et al 1994:8). The value of storytelling which emerged from the interviews with the research participants is explored in Section 3.3.11 (last paragraph) and in Sections 4.3.1.1 and 4.3.1.2.

Gergen (1994:186) argues that we live by telling stories to each other; hence we live out our relationships with each other in narrative form. Stories provide a resource for conversation, and self-narratives present a form of self-accounting and public discourse. Narratives create a sense of 'what is true' (Gergen 1994:189) and because of this, the potential for abusive and prescriptive social practices exists when our stories are socially accepted and institutionalised as 'truth' –

hence the need for consciousness-raising through an awareness of oppressive discourses (Burr [2003] 2004:122).

### **2.3.7 Meaning-making as prescribed by discourse and societal policing**

Discourses refer to a system of thoughts which becomes institutionalised and is then perpetuated and maintained as an instrument of 'truth' and domination (hooks 2000:7)<sup>1</sup>. Discourse may also be defined as a set of *meaning systems* in language (Kotzé & Kotzé 1997:33). These meaning systems are wielded as a source of power by individuals purported to have the *knowledge* (such as people in authority) and are in turn legitimised and institutionalised by society and often enforced as 'truth'. Foucault (Rabinow 1984:74) refers to dominant discourses as a 'regime of truth' (such as patriarchal discourse which asserts that women are inferior). At any given time, a specific concept (such as anticipatory mourning) may be surrounded by many different discourses, each affecting the identity and the experiences of individuals in a myriad of ways. For instance, if the caregiver expresses her emotions openly and strongly, she may encounter abusive discourses which could affect her self-identity detrimentally. She may come to view herself as weak, overly emotional or even unbalanced. Societal discourses often operate invisibly and shape the personal discourses of people's lives and their identity (Rabinow 1984:74).

In addition, many discourses surrounding mourning 'police people's grief' (Walter 1999:119), because people can experience the 'gaze' of others – always judging and evaluating whether they are abiding by the rules of the dominant discourses (Lechte 1994:113-114). With regard to an anticipatory mourner, society's prescriptive attention toward her becomes this 'gaze'. A prime example of 'the gaze' is presented by the discourse of mourning in which one of the assumptions of 'truth' asserts that appropriate mourning lasts one year, whereupon the mourner must 'let go' and re-enter society (Neuberger 2004:70). If the caregiver re-enters society too quickly or too late, she may be judged as insensitive or uncaring on the one hand or emotionally unbalanced on the other. A second example of a discourse enforced by 'the gaze' is the cultural discourse in the Western world which simply denies death and treats mourning as a private matter, thereby prohibiting public expressions of grief (Walsh & McGoldrick 1991:5). The denial of death results in an 'invisible community of the bereaved' (Walsh & McGoldrick 1991:6) where, due to continued sanctioning discourses, the bereaved become silent and marginalised.

Because of the invisible influence of discourses, it is important that a caregiver becomes aware of societal discourses *and* personal discourses in order to assess their influence on her meaning systems. If she does so, she is empowered, through consciousness-raising, to make conscious

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<sup>1</sup> Please note that bell hooks chooses to spell her name in lower case.

and informed choices about the extent of the influence of existing discourses on her meaning-making (Burr [2003] 2004:122). For instance, illness is not so much a physiological phenomenon as a social matter. When we say someone is ill, we make a judgement based on cultural norms, values and prescriptions which direct our actions or inhibitions (Burr [2003] 2004:37). Countless discourses may influence the caregiver's mourning process, however, judging from personal experience, six of the most pervasive cultural discourses which may confront the caregiver are medical, illness, mourning, gender, abnormality and spiritual discourses.

### **2.3.7.1 Medical discourses**

Medical discourses refer to the socially legitimised way in which medical personnel regard and treat the chronically ill and their immediate family members. Medical personnel tend to focus on treating the physical body, often with little regard for the suffering of the person or the meaning of the illness for the person. This process dehumanises the ill and often compounds their distress (Kleinman in Frank 1998:198). Meaning is made through storytelling, and if physicians do not *listen* to the stories of their patients, they hamper the meaning-making process and intensify the isolation of the dying and their caregivers (Frank 1998:198). Stories reveal the meanings constructed around a specific concept, but they also show a person's desire to be in a relationship with those who care for that person. Frank (1998:201) goes so far as to claim that when 'people have no story to tell, they are isolated in their suffering; they can achieve no critical distance from their pain' and may thus be unable to make meaning. Frank (1998:198-199) describes isolated suffering as the 'iron cage around me' and suggests replacing an isolation narrative with the story of 'my suffering as a *relationship* between us'.

In South Africa, a scarcity of funds and medical personnel precludes physicians from spending time *listening* to the ill and so the onus rests on pastoral counsellors to *listen* to the stories of the dying and their caregivers and so to facilitate the meaning-making process of a caregiver and her dying spouse.

### **2.3.7.2 Illness discourses**

Illness discourses refer to the prevailing set of cultural meaning systems surrounding chronic illness. Weingarten (2001:121-122) picks up on Frank's ideas and suggests that in a Western culture, illness discourses favour a 'progressive narrative' of medical treatment followed by physical improvement. A 'regressive narrative' of steady decline is shunned and therefore the caregiver's regressive narrative of a dying husband may be prohibited, resulting in social isolation, marginalisation and the stifled meaning-making of an untold story (Frank 1998:198).

### **2.3.7.3 Mourning discourses**

Discourses on mourning present another area of normative prescription and disempowerment (White 1998:18). Society regulates, controls and prescribes how a mourner should feel, think and behave (Dickenson, Johnson & Katz 2000:323). Neuberger (2004:92) explored discourses surrounding religious beliefs and customs to examine the history of mourning in Western Christianity. She found that Puritan Protestantism resulted in a 'buttoning up' regarding grieving emotions. Communal aid and involvement in mourning were replaced by a private and personal process of mourning. This hampered meaning-making as the story of mourning was located *within* the person and thus the mourner was removed from communal care (Neuberger 2004:92). In the South African context, there are very different discursive positions regarding mourning, particularly in most of the cultures that originate in Europe as opposed to the African cultures. It is possible that the potential assimilation by a traditionally White Western culture of various ethnic customs may well herald a new era of public and private lament, freely expressed. Emotional expression is a way of storytelling, and deep keening and public lament shared with others (Ackermann 2003:113) present a vehicle for self-validation and meaning-making.

### **2.3.7.4 Discourses on marriage and gender**

Patriarchal discourses on marriage and gender prescribe that when women marry, women (who are historically deemed to be naturally illogical, emotional and vulnerable) enter an unequal economic arrangement in which the woman is supposed to provide free nurture, care and domestic duties in return for financial care from a male head of the household (Burr [2003] 2004:74-75). It is understood that men make the decisions and should be freed from childminding and domestic duties in order to enter the 'marketplace' and provide for their families (Burr [2003] 2004:74-75). Admittedly, revised and egalitarian discourses are beginning to form around marriage and other unions. However, patriarchal gender and marriage discourses are still prevalent in many South African households and are usually underscored by the Christian view that women should submit to their husbands (Ephesians 5:24; 1 Peter 3:1).

### **Personal reflection**

*The (still) prevailing patriarchal marriage and gender discourses now confront the caregiver with the following dilemma: If she remains a 'good Christian' – and she feels compelled to, since she needs God and fellow believers on this dark and isolating journey – she must adhere to the dominant discourse of willing submission to her husband. In practical terms, however, the converse is taking place in her life. As her husband progressively grows weaker, the caregiver is forced to take over leadership of the household. She must also take control of the children, decision-making, her spouse's medical treatment and caregiving. Patriarchy is literally replaced with matriarchy (Smith 1996:130).*

*However, most women learn from childhood on that they should subjugate their needs to those of their husbands (Murphy 1996:90) and therefore many women may be ill-equipped to deal with their new role as head of the family and decision-maker, contributing to anxiety, fear and even guilt. In addition, systemic role reversal may lead to resistance from other family members (Rando 2000b:77), adding to the caregiver's distress. Such negative emotions may threaten to overwhelm the caregiver and may preclude her from making meaning of caregiving.*

### **2.3.7.5 Abnormality discourses**

Women have also been socialised to believe that they are weaker than men, physically, mentally and emotionally. For instance, there is a discourse of mental illness which has traditionally ascribed mental illness mainly to women. Many more women than men have been diagnosed with mental illness (Jantzen 1996:134), and this may be one of the reasons why grief and mourning are often equated with temporary abnormality, especially in a grieving *widow*. The assumption that people are not permitted to grieve expressively lest they are regarded as abnormal has found fertile ground in the traditional Christian Church (Walters 1997:56; 68; 183). It has also found fertile ground in the *Diagnostic and Statistical Manual of Mental Disorders (DSM IV)*, the official diagnostic handbook for psychological practitioners. Gergen ([1999] 2003:39) notes that over 300 mental illnesses have now been identified in the *DSM IV*. These include 'gambling', 'academic deficiency', 'inhibition of orgasm' and '*bereavement*'.

Paul and Paul (in Walsh & McGoldrick 1991:6) argue that, of all the topics relating to family processes, bereavement is regarded as 'least normal and most abnormal'. However, Arnason (2001:299) debunks the myth that grief is a pathological reaction to trauma and offers an alternative discourse of grief as a natural and ordinary process.

### Personal reflection

*I recall an incident after Louis's death when I happened to tell a group of friends that I still talked to Louis as if he were alive. They looked at me warily and sorrowfully. One friend suggested that I refrain from 'such talk', since people may regard me as unbalanced. I believe that this incident represents one of many examples where the voice of an adaptive bereavement response is silenced in response to societal discourses.*

### 2.3.7.6 Religious discourses

Religious discourses may also silence the bereaved. For instance, traditional Christian religion claims that we need to pray and believe, and God will give us our heart's desire (Bouwes 1996:92). This faith discourse places the church, the dying and the caregiver in untenable positions. If healing is only procured through faith, it prohibits the caregiver from preparing and planning a meaningful death, since any act of preparation may illustrate a lack of faith in God's ability to heal her husband. In the Christian Bible, healing by God is seen as a restoration of the right relationship between God and man (Bouwes 1996:92). It may thus be assumed that, if a person is not healed, her/his relationship with God is to blame. I read this religious discourse in many well-meaning eyes – the belief that Louis was not healed because he was not 'right with God'. I experienced an intense internal resistance to the determinism of this discourse and it opened the way for me to revise my assessment of an embracing spirituality of care and build an awareness of what Crago (2003:177) calls a 'profound mystery at the heart of all existence'.

The discussion above presents a few discourses which may *hamper* the meaning-making process. However, other discourses may *facilitate* meaning-making by providing a secure frame upon which the caregiver creates her subjective meaning. The overarching discourses of religion, for instance, may provide a secure and irrevocable 'truth' at times when the caregiver may find it impossible to create meaning. The deciding factor is whether the caregiver experiences internal coherence between the external framework of societal discourse and her own subjective truth (Burr [2003] 2004:60). When a discourse proves to be prescriptive and incongruent with the caregiver's personal beliefs, it may cause internal dissonance and exacerbated grief in anticipatory mourning (Ashton & Ashton 2000:446). Thus it is not people's consciousness which should be changed, but the *production* of institutionalised regimes of truth. This explains the need for a deconstruction of discourse, as recommended by Foucault (cited in Rabinow 1984:74).

### **2.3.8 Meaning-making as a deconstruction of discourse**

Discourses can only survive as long as they are sustained by cultural beliefs and the taken-for-granted truths in which they are embedded. In order to identify these taken-for-granted beliefs, it is necessary to take apart the broader culture of beliefs, ideas and practices (Morgan 2000:45). Deconstruction may thus be described as 'undoing' systems of meanings rather than as 'destroying' them. Derrida, a French philosopher, attempts to undo or unpack the meanings of traditions which dictate western society (Kotzé & Kotzé 1997:36). Hidden assumptions are revealed when a dominant discourse is unpacked. In order to deconstruct systems of meanings, it is useful to realise that the opposite of what is said is always implicitly present (for instance, when 'light' is present, the concept of – and potential for – 'darkness' is implicitly present too). In order to discern how discursive power is wielded over us, we need to become aware of the 'not said' (the opposite meaning) as well as the 'voicelessness' of the marginalised (Kotzé & Kotzé 1997:36). For the purposes of this research project, it is assumed that the caregiver in anticipatory mourning often represents the voiceless and the marginalised and, for this reason, awareness of discourses and how they operate in our lives as well as tools to deconstruct harmful discourses may be helpful to the caregiver in anticipatory mourning (see Section 4.4 & subsections).

### **2.3.9 Meaning-making according to cultural and individual values**

The regulatory, controlling and prescriptive nature of many societal discourses is based on cultural beliefs and values, which provide a context for meaning-making but actively inform (and may inhibit our meaning-systems which, in turn, inform or revise the values we hold. Cultural meaning-systems also have a positive function. They define our communities and they provide coherence, identity and credibility to us within our communities. We must, however, actively challenge our cultural meaning-systems in order to free ourselves from restraints on meaning-making (Cotter et al 2004:16-17).

Cultural meaning systems are transmitted to the members of a given culture through language and through organised structures such as religious, political, economic, art and social formations (Castillo 1997:20). For instance, Chapter 3 describes how one of the cultural meaning-systems of one participant (Priscilla) inhibited her: the stoic Afrikaner resistance to public displays of grief prohibited her from finding a meaningful expression of her grief. Priscilla's resistance presents an example of a cultural meaning system informing a person's values. Priscilla has however become aware of an inner incongruence, causing her to question her own values, as well as the overarching cultural meaning-system which prohibited her from expressing herself. Thus with awakened awareness, a revised meaning system can gradually begin to form against the *context*

of norms, culture, understandings, social realities, beliefs, worldviews and stereotypes (Nadeau 1998:15). The next section explores how meaning is socially constructed *within* the context of anticipatory mourning.

## **2.4 THE SOCIAL CONSTRUCTION OF MEANING IN THE CONTEXT OF ANTICIPATORY MOURNING**

This section explores social constructions of meaning in context according to the available literature, the experiences of the participants of this research study, as well as my personal experience. The social constructs may challenge the meaning-making process but, based on the caregiver's appraisal, may also facilitate meaning-making (Tebes, Irish, Vasquez & Perkins 2004:770). In Chapter 1, anticipatory mourning was discussed from my personal perspective (see Section 1.2), as well as from an academic perspective (see Section 1.8) and many of the social constructions related to anticipatory mourning are mentioned. In this section, relevant social constructions of meaning are explored further in the contexts of loss, suffering, spirituality, theodicy, family relationships, spousal relationships, caregiving, meaninglessness, ongoing relationships, coping strategies, rites, rituals and 'practising death'.

In a sense, anticipatory mourning may be regarded as a stopover where one 'practises loss' – 'a kind of rehearsal or prior imagination of the loss' – so that one may be better prepared emotionally for the final event of loss (Connor 2000:254-255). However, as will become apparent in the sections below, anticipatory mourning not only offers a place of rehearsal, it also holds profound and multiple experiences of loss that are particular and unique to the state of anticipatory mourning itself.

### **2.4.1 Loss**

Indeed, loss presents an *overarching* presence within which all the events (see Section 3.3) and contexts (see Section 2.4 above) of anticipatory mourning transpire (Rando 2000b:59). Thus loss and the ensuing grief are fundamental experiences to which caregivers are repeatedly and traumatically exposed throughout anticipatory mourning. Elisabeth Kübler-Ross (1969:166) notes that a sense of loss may emerge when the caregiver's partner becomes functionally limited. Kruse (2004:216) describes the experience of loss when a family is 'hit' with a cancer diagnosis. Indeed, every moment of anticipatory mourning is fraught with past, present and anticipated future losses (Corr & Corr 2000:235). Perhaps the most pervasive effect of ongoing losses in anticipatory mourning is the potential for loss of meaning (Doka 2000:103-104; Sorajjakool & Seyle 2005:180).

Loss may be categorised temporally (see Section 1.8.2.1) or typically. Rando (2000b:60) categorises the concept of loss in terms of a physical loss (such as the loss of income from a partner who is no longer able to work) and psychosocial or symbolic loss (such as the loss of a dream or future hope). Rando (2000b:61) also suggests that secondary loss as a result of an initial loss may be prominent. For example, an *initial* physical loss (or primary loss) of income invariably heralds a *secondary* loss, such as the loss of a particular living standard and, upon personal reflection, I would suggest a *tertiary* psychosocial loss of, for instance, peace of mind. In fact, one may continue to drill down to many levels of loss and the further one drills down, the greater the risk of loss of meaning. The final level of loss may be a perceived sense of meaninglessness.

An important secondary psychosocial loss in response to initial/primary loss is known as 'assumptive world violation' (Rando 2000b:61). An assumptive world refers to a person's frame of meaning references and contains a mental schema of all that a person assumes to be true about the self, the world and everyone in it. When the caregiver experiences an assumptive world violation, there is an acute threat of loss of meaning. Rando (2000d:324) uses a potent illustration of temporal, primary and secondary loss. She asserts that the death of a father, for instance, destroys that part of the interactional self that was a son *to* that father. In the context of anticipatory mourning, a caregiver progressively (temporally) loses that part of her interactional self which was a wife, lover, friend and supporter *to* her husband (secondary loss) at the same time as she struggles to make meaning of the primary loss of her partner, lover, friend, husband and protector.

## **2.4.2 Suffering**

Meaning-making in anticipatory mourning thus centres around loss, suffering, chronic illness, anxiety, uncertainty and deterioration (Doka 2000:107). Doka (2000:107) suggests that suffering encompasses the subjective response to a multitude of psychological, social, emotional, spiritual and even financial pain experiences. Witnessing her spouse's suffering compounds a caregiver's suffering. Kastenbaum (2004:132) addresses a discourse of faith which proclaims that 'suffering is good for us' and proposes outright rejection of that discourse. Suffering may, however, also serve a functional role, namely to create the awareness that the beloved other is about to die and to subsequently make the necessary psychological, social and behavioural changes in order to accommodate the reality of impending death (Rando 2000b:62). In anticipatory mourning, a caregiver may find meaning in the sacrifice of caring for her spouse and so make meaning of suffering (Cheung & Hocking 2004:476) – '[i]n some way, suffering ceases to be suffering at the moment it finds a meaning, such as the meaning of a sacrifice' (Frankl [1959] 2004:117). Despite

the opportunity for meaning-making in suffering, it is necessary to remain aware that the caregiver, in addition to witnessing the suffering of her dying husband, may experience emotional pain on many levels as she struggles to cope with her own suffering, a multitude of losses, and a spiritual search for a just God who is present in suffering.

### 2.4.3 Spirituality

Waldron (1996:64) describes spirituality, in terms of a definition from the *New Dictionary of Catholic Spirituality*, as the 'striving to integrate one's life in terms of self-transcendence towards the ultimate value one perceives'. Isherwood (1996:65) explain spirituality as 'imagining wholeness'. In order to broaden the social construction of traditional religion so that none are excluded in this study, I use the concepts of spirituality and religion interchangeably, while remaining aware that religion may be spiritual, but that spirituality may not necessarily represent a specific religion.

Searching for meaning in religion or spirituality denotes an attempt to transcend the fear of trauma. Augustine describes transcendence as looking *within* for God and/or resources, rather than at reality *outside* (Isherwood 1996:226). For a caregiver in the twilight of anticipatory mourning, it may be a particularly relevant but difficult exercise to connect to an inner spiritual sustenance and so transcend her trauma. When a traumatic experience threatens the predictability of life, one is forced to transcend the self in order to explore deeper spiritual levels of meaning-making (Bee 1996:327). Witnessing the dying of a loved one confronts a caregiver with the requirement to make meaning on two fronts: her spouse's dying as well as her own inevitable death. This compound struggle lies at the heart of all religion and spirituality (Doka 2003:46). The pain of the impending death of a spouse is the source of a spiritual pain; and making meaning of that death and that pain represents a 'spiritual act in the deepest most authentic sense of being' (Doka 2003:45-46). Thus a quest for meaning and purpose may be found in the connection to a higher being who integrates both meaning and purpose into life (DiJoseph & Cavendish 2005:147).

A paradox is also present: when people suffer, a critical questioning of previously-held religious beliefs may arise, leading to a loss of faith and possibly a loss of meaning. C S Lewis, the Christian apologist, was an impotent onlooker in the suffering of his wife. He writes about his personal faith discourse: 'Not that I am (I think) in much danger of ceasing to believe in God. The real danger is of coming to believe such dreadful things about Him. The conclusion I dread is not that "so there's no God after all", but "so this is what God's really like". Deceive yourself no longer' (Lewis 1966:9-10). Lewis's sense of an unfair God and his search for a *just* God raises questions about God that are explored in the section below.

#### 2.4.4 Theodicy

The term 'theodicy' refers to a search for God's goodness in the face of the world's evil and an attempt to 'justify the ways of God to man' (Ferguson & Wright 1998:679) by asking the central question of a theodicy: *Where is God in suffering?* Christians have been struggling with the theodicy question for centuries. Neuberger (2004:86-87) suggests that the theodicy question gains meaning if one can hold onto the concept of an afterlife (such as heaven) where the suffering will be duly rewarded. Müller (2007:148-162) posits that, in the process of a mourner's struggle with the theodicy question, 'God dies' and a revised faith is resurrected as the bereaved wrestles with the meanings of death and suffering. Tavard (2003:707) concludes that there simply *is* no answer to the theodicy question, save to hold onto God's providence and hope in the midst of despair. Ferguson and Wright (1998:679) confirm the stance of holding fast to the mystery of God's providence in the face of suffering. D J Louw (1985:35-36) insists that God remains faithful in suffering and that God leads us to his will through suffering. Thus, the question is not *why* we suffer but rather *how* we suffer and with *whom*, so that we may transform suffering into a therapeutic process from resistance toward renewal (Louw 1985:35-36).

A study on theodicy and a religious response to cancer (Moschella, Pressman, Pressman & Weissman 1997:17) found that the majority of the respondents believed that God had a reason for their suffering, although the reason was unclear and could not be explained. In all the theological theories about suffering, two main assumptions emerge, namely, first, that suffering is necessary as a path to God or to reveal God's love; and second, that utter estrangement between God and humanity leads to suffering (Tatman 1996:11).

Cook and Wimberley (1983:224) quote a study on levels of bereavement adjustment relative to various explanatory theodicies. The study found that 'God-blaming' was connected to both positive and negative outcomes, while 'self-blaming' was connected to poor adjustment. The belief that there was a divine purpose to the death, although it appeared meaningless, suggested a positive adjustment outcome (Cook & Wimberley 1983:224)

A qualitative study with breast cancer patients and their intimate caregivers found that the participants, without exception, voiced a strong need to connect to the constant source of a 'higher power' (Sorajjakool & Seyle 2005:176-181). Three main theodicies emerged, namely, first, that *God causes cancer* (as a test, to turn people toward him, or to refine them through suffering); second, that *God does not cause cancer* (bad things happen to good people), but that he is always with his people in their suffering; and, third, that *Cancer is just part of life* with neither a positive nor negative value assigned to it – 'it just is' (Sorajjakool & Seyle 2005:180). The group that believed that God causes cancer had more difficulty accepting the reality of their illness,

while the group that believed that God does not cause cancer had less difficulty making meaning of their illness. The last group, who just accepted that life has overall meaning, even in the face of the meaninglessness of suffering, coped well with an acceptance of their illness.

The study above also found that the spousal caregivers' spiritual needs and meaning-making followed a similar pattern to that of the patients themselves. It may thus be assumed that many of the patients' processes are mirrored by the processes of the caregivers (Sorajjakool & Seyle 2005:180). The findings of their study are not only significant in terms of individuals' modes of meaning-making, but they also indicate the need for pastoral counsellors to address the theodicy questions of both the dying and the caregiver, since both may follow a similar pattern in meaning-making.

#### **Personal reflection**

*In terms of my initial journey of caregiving, and upon hearing the dreaded verdict of terminal cancer, I opted for the 'traditional' route of praying, supplicating and bargaining angrily with God (Kübler-Ross 1969:1-123). Then something changed. Perhaps I simply became too tired to keep asking God for Louis's healing. Perhaps I realized that the cancer was too powerful to resist any longer.*

*However, as I moved into the moment, inhabited it fully and simply observed the fear and the anger, I found a measure of acceptance and peace – and an awareness of a new spirituality emerged.*

*Upon reflection, it seems that the connection to a higher power and the overarching meaning system it provides may be described as macro meaning-making, indicating meaning-making against a broad discourse of religion. In contrast, micro meaning-making may refer to the active, subjective and unique creation of personal meaning systems (the way we understand ourselves in the world). If a caregiver fails to make subjective meaning of a loved one's impending death, the acceptance that God or a higher power is in control may provide some sense of coherence to her. Jakkie and Elsa, two of the co-researchers in this study, remain in the process of struggling with their personal meaning-making (see Chapter 3). Neither of them quite understands the loss of her loved one on a personal level. However, both Jakkie and Elsa assert that God should not be questioned. They believe that they will understand the meaning of their husbands' suffering in the afterlife. Thus it appears that when subjective or micro meaning-making fails, for example, when a caregiver can make no logical sense of the death of a loved one, she may resort to overarching macro meaning-making systems which then allow her a second-order opportunity to find meaning. On the macro meaning level she finds meaning within existing religious discourses, whereas on the micro level she creates meaning through telling her story to another and so reframes her personal value-systems and perspectives in the process (see Section 3.3). If telling one's story to another presents a significant aspect of meaning-making, then relationships are of primary importance in creating meaning.*

#### **2.4.5 Familial and spousal relationships**

The spousal relationship between the caregiver and the dying person is the most significant relationship in terms of creating meaning (Rando 2000b:67). Supportive and accepting

relationships are of primary importance in caregivers' coping perceptions (Rando 2000b:66). The positive cognitive appraisal of her relationships may greatly affect a caregiver's adaptive meaning-making. Cognitive appraisal of anticipatory mourning consists of 'person factors' and 'situation factors' (Lazarus & Folkman, cited in Rando 2000b:66). 'Person factors', such as relationships, confer meaning on an event, while 'situation factors' assess potential threat. Thus significant meaning is made when a focus on *relationship* replaces a focus on the circumstances (Lazarus & Folkman, cited in Rando 2000b:66).

Bee (1996:371) found that the social support of a partner or spouse is more meaningful than the support of friends or family. However, in the absence of spousal support, support from the caregiver's parents or the support of a similarly bereaved individual (someone 'who has been there') appears to be more meaningful than random support from friends and family (Bee 1996:371). This does not mean that a pastoral counsellor should refrain from active intervention during anticipatory mourning, but rather that her/his approach should be respectful of the caregiver's process of meaning-making.

In contrast to the *benefits* of social support, possible traumatisation through a close relationship can also become evident. In 1985, Figley (in Rando 2000d:316) wrote about the *chiasmal effect*, which is very similar to post-traumatic stress disorder, except that it represents secondary rather than primary exposure to trauma. The chiasmal effect refers to a person's knowledge of a trauma suffered by a significant other and, by virtue of her/his desire and efforts (and feelings of impotence) to help that person, is traumatised by the *reactions* of the significant other to the trauma (Rando 2000d:316). Feelings of traumatisation may impede meaning-making. It is like being 'sucked into a whirlpool' from which there is no escape (Frank 1998:202). Upon reflection, I realised that I too experienced the chiasmal effect in Louis's suffering when the cancer attacked unexpectedly and Louis would scream in agony.

In addition to being exposed to the loved one's suffering in anticipatory mourning, the caregiver is also exposed to her own suffering, where she not only becomes physically, mentally and emotionally depleted through caregiving, but she also has to mourn the loss of her spouse's role, her own role in *relation* to her spouse, her own role in *relation* to the family unit as it had existed until then, as well as the loss of the family unit, the identity of which has been changed forever. The context of the spousal relationship may thus hamper meaning-making by adding additional coping demands. Paradoxically, the spousal relationship may offer rich opportunities for meaning-making in anticipatory mourning; and it is this awareness of possibilities which the pastoral counsellor may foster during anticipatory mourning.

A family caught up in the crisis of losing a loved one may experience itself as a set of disorganised individual members and not necessarily as a unit of support (Nadeau 1998:24). Despite the presence of her family, the caregiver in particular may experience a sense of isolation. My experience resonates with this contention. Although I knew myself to be part of a family, I experienced myself as isolated, to some extent, from the social support of the other grieving members of the family. Kastenbaum (2004:132-133) stresses the importance of supportive relationships and, in terms of the spousal relationship, adds that some relationships may strengthen to the deepest levels of response. This in itself creates a strong sense of meaning during caregiving. Priscilla (see Section 3.3.11) provides a striking example when she suggests that the deepening of her relationship with her husband Attie compensated for the unhappy years of their marriage and contributed to her healing – and meaning-making – in anticipatory mourning.

#### **2.4.6 Meaning in caregiving**

‘There is nothing in the world, I venture to say, that would so effectively help one to survive even the worst conditions as the knowledge that there is a meaning in one’s life’ (Frankl [1959] 2004:109). The act of caregiving offers infinite opportunities for meaning-making (Barkway 2001:75; Möller 1995:247). Kruse (2004:220) regards the unconditional gift of a wife’s bearing witness to a spouse’s suffering as a way of affirming the worth and value of his experience. However, caregiving also represents escalating levels of anxiety, which may deter meaning-making (Rando 2000c:163). Anxiety is described as ‘the apprehension cued off by a threat to some value that the individual holds [to be] essential to his[her] existence as a personality’. If the caregiver’s sense of her personal value is bound to her role as nurturer, spouse and caregiver, this perceived threat may seriously hamper meaning-making (Rando 2000c:163).

A study conducted by Cheung and Hocking (2004:478) explored the meaning which caregivers made in anticipatory mourning. They contend that home-based care of the terminally ill has been increasing globally and that the pressure on life partners to care for a dying loved one leads to significant carer stress. In terms of meaning-making, it was found that the overarching meaning which caregivers made of caring in anticipatory mourning was ‘caring as worrying’ (Cheung & Hocking 2004:478). Through ‘worrying’, caregivers expressed their concern for the deteriorating health of their partners. Worrying also increased the anticipation of their partners’ needs, as well as their commitment to their loved ones. Carers experienced intense and consistent worry about their partners, their future, their own health and, particularly, their relationship with their partners and how deteriorating health would affect their relationship (Cheung & Hocking 2004:480). Satisfaction with coping resources and consistent social support appeared to enable caregivers to

cope better. Rando (2000b:67) found that healthy anticipatory mourning was predicated upon active involvement with the dying spouse. This confirms the contention that caring for a terminally ill spouse may assist in creating meaning (Cheung & Hocking 2004:476).

A study by Mayeroff (cited in Cheung & Hocking 2004:476) confirmed that caregivers found meaning and solace in the very act of caregiving. Mayeroff contends that, through caregiving, 'a man [woman] lives the meaning of his[her] own life'. Finding meaning in caregiving offers one discourse of facilitative meaning-making. Other ways of making meaning in anticipatory mourning are discussed throughout this research project, particularly in Section 4.4.

#### **2.4.7 Meaning-making as acceptance of meaninglessness**

Creating meaning in a seemingly meaningless event may be one of the most challenging *and* imperative activities in dealing with grief (Dawkins 2004:187; Nadeau 1998:1). Meaning-making may occur as an active process of adaptive appraisal, but it may also denote a simple acceptance of the meaninglessness of loss (Sorajjakool & Seyle 2005:180). Romanoff (2006:310) describes the meaninglessness of suffering as an encounter with a void: 'All of a sudden we realise we have nothing to hold on to anymore. Consequently meaning can no longer be derived from who I am or what I have attained or acquired.'

Nadeau (1998:164) studied bereavement and found that despite expressions of meaninglessness, some people nevertheless continue to attempt to make meaning by using 'not-statements' for instance: 'I do *not* believe that it was God's will to take him.' Negative statements seem to continue the meaning-making process by ruling out various possibilities which appear to be incompatible with their personal meaning-making (Nadeau 1998:164).

In a study on meaning-making in loss, Davis and Nolen-Hoeksema (2001:731-733) found that five per cent of the respondents felt no need to make sense of the loss of a family member. In other words, they made sense by *accepting* that there is no sense to be made of death. For some caregivers, such acceptance could present a possible resource which may be as valuable as active meaning-making. C S Lewis, witnessing his wife's slow cancer death, accepted the mystery of apparent meaninglessness with these words: 'We cannot understand...the best is perhaps what we understand least' (Doka 2003:47). In the process of making meaning in anticipatory mourning, every caregiver, it seems, confronts feelings of meaninglessness. Elizabeth Neeld (cited in Danforth & Glass 2001:513), a middle-aged widow, states: 'I had not only lost a husband, I had lost the very purpose and shape of my life. My life no longer had contours; there was nothing into which I could fit... the nothingness of life.'

#### **2.4.8 The meaning of an ongoing relationship**

If the loss of a spouse equals the loss of meaning (Doka 2000:103) then the continuance of a relationship may equal continuance of meaning, albeit revised meaning (Kunkel & Dennis 2003:6). 'A sense of connection with the dead is...felt to protect and nurture the living' (Lifton 1996:98). During anticipatory mourning, the perception that my relationship with Louis would not be terminated upon death afforded me an endless resource of peace and consolation. I held fast to the belief that our relationship would continue, albeit in an altered form. The knowledge imbued our last days together – and the desolate days after his death – with infinite meaning. Walter (1999:106) cites the possibility of continuing bonds with the deceased and argues that the purpose of grief is not to sever ties with the deceased, but rather to integrate the deceased into the survivor's everyday life. A positive reappraisal of the 'terminated relationship' may therefore be the key to distress alleviation, in that the relationship is reconsidered and placed in a larger context rather than discarded or terminated, in an 'inner representation of the deceased' (Kunkel & Dennis 2003:6).

In the past, the dominant discourse regarding continuing bonds with the dead criticised such an option as a form of denial or a sign of unresolved mourning (Fisher 2001:557). However, contemporary grief theory holds that maintaining bonds with the dead is a healthy part of mourning (Fisher 2001:558). Michael White (1998:19) not only sees an ongoing relationship as an aspect of healthy mourning, but proposes a *celebration* of continuing bonds. White suggests a metaphor of 'saying hullo' instead of 'saying goodbye' to the loved one, where memories of the deceased, the continuing relationship, as well as newly discovered aspects of the bereaved, are celebrated (White 1998:19). During anticipatory mourning, a conscious co-construction of their ongoing relationship may be negotiated between the caregiver and her spouse, presenting a valuable resource of coping with the impending death.

#### **2.4.9 Coping strategies**

Making meaning of an impending death has been identified as a critical aspect of coping (Nadeau 1998:1). The loss of a spouse is regarded as the highest possible stressor on the Holmes and Rahe Social Readjustment Rating Scale (Bee 1996:360), as daily cumulative stressors lead to an experience of major stress or anxiety (Bee 1996:360). Using coping strategies therefore becomes significant in anticipatory mourning, as they facilitate meaning-making by restoring a sense of calm and control (Rando 2000b:64). Coping strategies are defined as the efforts a caregiver makes to deal with the demands of caregiving and impending death (Rando 2000b:64).

In the academic literature, one finds different ideas about ways to cope. Bee (1996:374) suggests two types of coping, namely 'approach' coping (confronting feelings) and 'avoidance' coping (repressing feelings). However, she asserts that in some cases where nothing can be done to address the problem (as in impending death), both denial and/or avoidance coping may prove helpful in buying time for the mourner to come to terms with reality and to begin to make meaning of her situation. Rando (2000b:64) cites three types of coping: problem-focused coping (altering the conditions in order to change the problem), emotion-focused coping (altering the emotional response to the problem, especially when the problem cannot be changed) and appraisal-focused coping (attempts to find meaning in the trauma). In anticipatory mourning, the option of problem-focused coping is not available to the caregiver. She must therefore alter her emotional response to the impending death and/or find meaning in the trauma.

Lazarus and Folkman (cited in Bee 1996:360) assert that it is not necessarily the event itself, but the subjective *appraisal* of the event *and* the availability of personal coping resources which determine the amount of stress experienced in anticipatory mourning. In a study by Holly Prigerson (cited in Greenberg 2003:45), people who found meaning in loss through spirituality were able to cope more effectively. Tebes et al (2004:770) found cognitive transformation in one's view of the world and of oneself, a strong predictor of resilience and reduced risk of negative adaptation. The results of positive cognitive transformation refer, for instance, to an awareness of personal growth through trauma, increased self-understanding, trust, maturity and closeness to one's spouse (Tebes et al 2004:770).

There seems to be general agreement in the literature that *social support* presents one of the most effective coping strategies, in that it buffers the effects of elevated stress in individuals (Bee 1996:368; Danforth & Glass 2000:515; Moskowitz et al 2003:475; Rando 2000b:67; Tebes et al 2004:772; Weingarten 2003:68). When stress is alleviated and a sense of order is restored, meaning is made (Golsworthy & Coyle 2001:184; Nadeau 1998:29). The social relationship must, however, be of an intimate nature for the buffering effects to emerge.

Danforth and Glass (2001:513) found that perspective transformation (assessing whether basic perspectives are still adequate in the light of the current trauma) and creating new life meaning and perspectives of the self as a survivor added to the abatement of grief. The following coping tasks create meaning during anticipatory mourning: i) continued involvement with the dying loved one; ii) remaining separate as well; iii) adapting to role changes within the family; iv) dealing with emotions such as grief, loss and anxiety; v) beginning to accept the reality of the impending death; and vi) saying goodbye to the dying loved one, especially in the form of a significant rite or ritual (Lebow in Rando 2000a:27).

#### 2.4.10 Rites and rituals

An appropriate goodbye in the form of a rite or ritual may be one of the most important meaning-making tasks of the caregiver, as 'such rituals, composed of metaphors, symbols and actions in a highly condensed dramatic form, serve many functions. They mark the loss of a member, affirm the life lived by the person who is dying, facilitate the expression of grief in ways that are consonant with the culture's values, speak symbolically of the meanings of death and ongoing life and point to a direction for making sense of the loss while enabling continuity for the living' (Imber-Black 1991:207). Shared rituals between the caregiver and her dying spouse may be invaluable, creating connective space and serving as a meaning-making context for both of them.

Rites and rituals can take any form. Hedtke (2000:12) tells of a caregiver who, as a last rite to her dying husband in hospital, played her husband's favourite polka music to 'send him off'. The caregiver imagined that it brought him comfort and the thought comforted her too.

##### **Personal reflection**

*In my experience, caring for my dying husband represented a protracted goodbye. I found that I ritualised many of the processes of saying goodbye during anticipatory mourning. I created rituals around our time spent together, such as Louis's bath time. I elaborately tended to his hands and feet and rubbed his body with oil. I structured my days around these rituals and Louis seemed to draw comfort from their predictability. Louis's comfort, coupled with the predictability, order and purpose of these rituals (Golsworthy & Coyle 2001:184-188), created meaning for me.*

In respect of last rites, Neuberger (2004:51) contends that the dying and their loved ones can draw great comfort from the ministering of a priest, irrespective of their religious beliefs. In other instances, death rituals (or planning them) helps to create an interpretation, understanding and meaning of the loss and of the world in general (Stelter 2000:63-64). The main function of rituals is to reduce anxiety and to create the illusion of control, thereby creating meaning (Kastenbaum 2004:107). My experience resonates with this idea – creating rituals proved to be both therapeutic and calming to us. In addition, I imagined these rituals as a succession of 'last rites' to Louis.

*Collective rituals* (such as church attendance or collective prayer) seem to bring great comfort to some people as well. The motivation behind rituals represents both a quest for meaning and structure, and a need to be with others in a shared experience of prayer, worship or care (Kastenbaum 2004:392-394). Weingarten (2003:233) expresses a similar idea as Kastenbaum, as she believes that an experience of closeness and unity ensues in shared ritualisation. She adds that, on a neuropsychological basis, the brain 'can be provoked' to experience connectedness, and a sense of connectedness creates meaning (Rando 2000b:66).

Rando (2000d:325) points out that the lack of predictable, step-by-step rituals and processes can have a negative impact on the caregiver's meaning-making in anticipatory mourning. I believe that practical 'to-do' lists and practice runs (as in my telephone call to the manager of the funeral home to introduce myself) can be regarded as a form of ritualised behaviour, creating predictability and security. Throughout anticipatory mourning, when anxiety became unbearable, I would repeatedly take out the list and telephone numbers and that would help to calm me. In a sense, the context of rituals of practice may be regarded as 'practising death'.

#### **2.4.11 'Practising death'**

The concept of 'practising death' can be explained as rituals of endings and beginnings which foreshadow the final journey of death (Kastenbaum 2004:25). These rituals of endings and beginnings include moving home, leaving school, saying goodbye to a friend or family member, or retiring for the night. Children's play such as hide-and-seek, popping out of dark closets or feigning death by lying motionless may be a way in which we practise death from childhood (Kastenbaum 2004:39). Every day life is full of 'little partings' (Kastenbaum 2004:39). The act of saying goodbye to our spouses in the morning represents a 'little parting' and the way in which we support each other through the little partings may have powerful effects on the way we handle the final passage (Kastenbaum 2004:30). These experiences all herald endings and beginnings – 'partial rehearsals for the final passage to Hamlet's unknown territory' (Kastenbaum 2004:30). Death is therefore not altogether without precedent, especially if we practise death with a conscious awareness (Kastenbaum 2004:25).

We also practise our death strategies on other bereaved people by our uncertainties of how to deal with them, almost as if they, in accompanying their dying loved ones, have been contaminated by death (Kastenbaum 2004:40-41). One of the ways in which we try to deal with the 'contaminated' caregiver is through our prescriptive discourses of death and mourning. When we talk 'discourse', we are saved from drawing close and simply sharing her pain.

Bedtime presents a daily ritual which requires that we close our eyes to the familiar world and relinquish our conscious control to sleep (Kastenbaum 2004:27-29). Peaceful and structured bedtime rituals are important, for example, taking stock of the day, and a gentle unwinding that precedes sleep. The bedtime ritual presents a metaphor for the way in which the dying and his loved ones may deal with unfinished business, talk peacefully about relevant matters, and find spiritual courage to relinquish conscious control to death itself. If feelings of control are equated with meaning (Nadeau 1998:29), then relinquishing the need for meaning means embracing and/or accepting the presence of meaninglessness. On a practical level, the caregiver practises the death of a myriad of past roles, predictable rituals and future dreams. The context of

'practising death' is therefore ever-present and the conscious awareness thereof offers a unique opportunity to make meaning of the little endings and beginnings, despite the trauma of anticipatory mourning.

Upon reflection, the awareness of practising death has both liberated me from the fear of the unknown, and entrenched an appreciation of the sacredness of life. Death is no longer the unfathomable mystery. Death is something we have been practising since childhood and it is something we practise daily.

## **2.5 CONCLUSION**

In this chapter, I have explored the social construction of the concept of meaning and meaning-making. Some of the discourses which prescribe our actions have been explored in terms of their hampering or facilitative effects on adaptive meaning-making in anticipatory mourning. Chapter 3 introduces the co-researchers and their stories of meaning and trauma. Significant phenomenological themes of meaning are highlighted, explored and juxtaposed to the themes of meaning which emerged from the literature control in Chapter 2.

As I conclude this chapter on meaning-making, I am confronted with much that has been left unsaid due to the limited scope of this dissertation. I am also confronted with my personal discourses, as well as familial and societal discourses which have served (and failed) me in terms of overarching meaning systems. I am aware of the way in which some of these discourses have facilitated meaning-making, but also that some prevented meaning-making. Each of us creates our own unique meaningfulness by continually revisiting our life stories: 'If life is a journey, then, it is not a pilgrimage but an odyssey in which one leaves and returns home again. Each step may be a circling back, a remembering of the *still point* within' (T S Eliot, cited in Bee 1996:351).