

Chapter 1

INTRODUCTION

The death of a significant other is arguably one of the most stressful and overwhelming experiences a person faces in life (Parkes 1972). Exposure to bereavement may shatter the very foundations that had once provided support and purpose for living (Janoff-Bulman 1992). In spite of an increase in research interest and literature in the bereavement field, it is still uncertain how people move from their distress to adaptation following bereavement. Traditional grief theorists emphasise the need for the bereaved to traverse a universal path with designated stages in which they ultimately relinquish ties to the deceased. Post-modern grief theorists have challenged the tenets of the traditional approach arguing that a continuing relationship to the deceased may facilitate adaptation (Klass 1993; Klass, Silverman & Nickman 1996). However, both approaches have received limited empirical support (Schut, Stroebe, Boelen & Zijerveld 2006). The therapeutic goals of the traditional and post-modern approaches to bereavement therapy differ markedly. One aims to facilitate relinquishment, the other a continuing bond.

This study argues that there is a need for research to explore the complex ways in which the lived experience of bereavement unfolds. Counsellors and therapists need to understand more about what supports adaptation to

grief and an ongoing commitment to life. Put simply, counsellors and therapists working with the bereaved need to know what really helps and conversely, what does not.

Aims and Scope of the Project

This project aims to explore the experiences of those who have suffered a difficult grief reaction associated with the death of a loved one. A major focus of the project was on the bereaved person's construction of their journey from prior to the death of a loved one up to the time of interview. The study particularly focused on the experience of connection with the deceased, and how this sense of connection changed over time. The participants' perceptions of factors contributing to their sense of coping/recovery were identified, and explored. It is hoped that findings inform and guide current practice in counselling those bereaved under the care of the Central Coast Bereavement Service¹, situated within the Northern Sydney Central Coast Area Health Service (NSCCAHS) as well as agencies and clinicians working with the bereaved in other Area Health Services.

¹ The Central Coast Area Bereavement Service is uniquely resourced comprising of two bereavement counsellors a coordinator of bereavement, and bereavement trained support volunteers. The service was initially inspired by the Silver Chain Palliative Care Service in Perth, Western Australia (which incorporated a central volunteer training service, including an annual memorial service). Funding and ongoing support for the volunteer arm of the service is provided by and independent source: The Central Coast Hospice Palliative Care Service Inc.

Rationale

Whilst research has affirmed that most people adapt to bereavement without the need for professional assistance (Raphael, Minkov & Dobson 2001), and are resilient (Bonanno 2004), between 10-20 percent of those exposed to the death of another, face increased continued distress, experiencing problems with physical and/or mental health (Bonanno Wortman & Nesse 2004; Parkes 1996; Prigerson & Jacobs 2001). Despite the large amount of literature on loss and bereavement, many questions regarding how people adapt following exposure to bereavement remain unanswered. Even less is known regarding how those experiencing a traumatic or difficult bereavement response, move from their distress to adapting to the loss.

Previous qualitative research in bereavement has been limited by its tendency to use broad, generalised samples (eg. anyone experiencing conjugal bereavement). This study's aims were to build on past literature by utilising a targeted sample of participants identified through a regional palliative care service who have been assessed by their therapist as suffering a difficult grief reaction.

There is a need for the studies undertaken in Australian settings to gain more information regarding the needs of family members and carers as they face the illness and death of a loved one. Most bereavement studies have been conducted overseas in countries such as the United States

(Rosenblatt 1996:56). Constructivist theorists have highlighted the significance of social context as contributing to the shape of grief responses (Doka 2002; Neimeyer 2000a; 2001b). For example, research studies indicate that the spiritual belief and religiosity of Australian people is diverse (Ata 1994) and differs markedly to that of populations in the United States as well as that of other developed countries. Each person's spirituality, and/or religious beliefs and practices arise and exist within a social/religious context (Neimeyer 2000:110). Using a constructivist approach in this study allows social context to be explored.

Background to the Study

This research will include participants drawn from a local area bereavement service who: a) have lost a significant other, through either the palliative care service, or sudden death b) have responded to an invitation or referral to receive counselling support c) have been further assessed by the treating counsellor as suffering a difficult grief reaction, and d) have received six or more sessions of counselling e) have experienced counselling as beneficial and have shown improvement.

Findings from the project will be used to support and improve the work of the local bereavement service through creating insights and a deepening of understanding into how those experiencing a difficult grief reaction, survive their ordeal and adapt. This information will be used to further develop and fine tune therapeutic practices. It is also hoped that insights from the

research will assist with ongoing client assessment and interventions with bereaved clients. Greater insight will lead to further refinements in the tracking/monitoring of the bereaved person's processes and change. Findings will also have implications for the direction of service development and policy.

These issues were explored through in-depth narratives where the bereaved were invited to tell their story of their experiences through the use of open-ended, invitational questions. The proposed questions allowed for participants to expand on their own thoughts and feelings, whilst avoiding the imposition of potential bias that comes with suggestive or leading questions. It is hoped that the information rich data will contribute to the bereavement recovery debate.

Definitions of key terms

It is worthwhile to provide some definitions of key terms used in this thesis. These definitions are not static but encapsulate the issues as they are discussed in the present project.

Bereavement:

In the bereavement literature, the term bereavement refers directly to the situation of being exposed to the loss of someone significant through their death (Stroebe, Hansson & Stroebe 2001:6). The word bereavement is of old English origin, with its root meaning being linked to "deprivation".

Bereavement is said to involve the “objective” state of being “deprived of” a close relation or friend through death (Doka 2004).

Grief:

Grief is a natural, normal response to loss and can result from circumstances that include non-bereavement loss: such as through divorce, physical illness, such as loss of a limb, loss of a job, loss of social standing etc. Grief has been defined in the literature as a kind of “stress” reaction that is subjective and personal (Doka 2004:1028). The word grief is usually connected to negative emotions such as anguish and sadness however, grief may also involve feelings of relief (DeFrain, DeFrain & Cacciatore-Garard 2005). In this project grief encompasses the multiple reactions people have to the death of another person who is significant to them. These reactions include the bereaved’s physical, affective, psychological, behavioural and spiritual responses to the loss. Grief has been described as an “amalgam” involving various feelings and thoughts which are blended in differing ways and change over time (Rosenblatt 1996).

Mourning:

Psychoanalytic practitioners and theorists have tended to use the term grief and mourning interchangeably (Stroebe et al. 2001:6). However, I will be using the term mourning to refer to “social expressions or acts expressive of grief that are shaped by the practices of a given society or cultural group” (Stroebe et al. 2001:6). Mourning is a social phenomenon that involves the

culture around those experiencing loss. Mourning traditions prescribe the socially sanctioned expression of grief following the death of a loved one. Cultures can vary greatly in what is viewed as socially acceptable or allowable regarding the expression of emotions following the death of a loved one or significant other. Mourning includes the use of rituals which “allow structure and support to the expression of grief” (Doka, 2002:8). For example: the funeral, or wake represents an important social act where the bereaved are publicly acknowledged and supported as people who are grieving.

Organisation of the thesis

This thesis is organised into six chapters, the first of which introduces the topic including key terms, rationale for the project and organisation of the thesis. Chapter two begins by presenting a review of the grief and bereavement literature and places the approaches of theorists in the field of grief and bereavement within a historical and social context. Models of grief are examined which encompass early modernist approaches to the conceptualization of grief and bereavement through to the post-modern constructions that have challenged these earlier approaches. Gaps within the literature are identified and explored, forming the basis of the research which this project has sought to answer.

Chapter three presents the methodology. In this chapter the reasons for selecting a narrative approach as a methodology are justified and

explained. The approach to the collection and analysis of data is presented in detail. This chapter also includes information on the ethical issues raised through the nature of the project. Steps taken to address these issues so that the rights of participants were protected are detailed.

Chapter four presents the individual narratives arising from the interviews with participants. Each participant is introduced, along with their story of bereavement beginning prior to diagnosis and moving through to their experiences of death and bereavement.

Chapter five examines the group narratives which have been constructed from the participants' stories with an emphasis on "collective voices". This chapter examines connecting storylines exploring the four overlapping aspects of their experiences, which included the changing nature of the relationship with the person who died; the bereaved's experiences of loneliness; the paradoxical nature of bereavement; and experiences of counselling.

Chapter six discusses the findings from the project examining these results within the context of existing literature. The contributions made by this research are detailed and explained, including the place of the project within the broader scope of the literature. Recommendations for counsellors and therapists working with the bereaved are presented and explicated. Additionally, recommendations are presented for others in contact with patients and their carers/bereaved encompassing medical staff

(directly treating the patient/family/bereaved) working in health care settings, to wider government and business organisations in the bereaved's broader social context.

Certain questions arose during the project that went beyond the scope of this research. These questions deserve further exploration and are detailed as they arise. Additionally, recommendations for possible future research are outlined. The thesis concludes with a reflection on the methodology and the journey of the researcher herself.

Chapter 2

LITERATURE REVIEW

This chapter presents a review of the literature on grief. It begins with a presentation of the conceptualizations of grief, from the development of the modernist “grief work” approach by Freud to the expansion of stage and developmental models consistent with this framework. The chapter then details recent challenges to “traditional” approaches, from the post-modern “constructivist” paradigm. Issues and questions regarding how people adapt to bereavement that have developed out of the literature are raised which form the basis and situation from which this project has grown.

The Traditional View

The development of the “grief work” approach began with the work of the founder of psychoanalysis, Sigmund Freud, who published his thoughts on the reactions of people to loss. Freud noticed that within those exposed to loss there were two broad groups that appeared almost indistinguishable. However, on closer examination there were significant differences between them. His thinking on loss crystallised with the publishing of: “Mourning and Melancholia” (1917/57). Freud focused upon distinguishing “normal grief” from “abnormal grief” which he labeled melancholia. Since Freud’s work the term depression has somewhat controversially replaced the term “melancholia” (Brendel 2003) with some theorists arguing that the terms are

not easily interchangeable² (Radden 2003). Freud began a tradition that has dominated the field over much of the 20th century in which grief has been conceptualised within a medical “disease” model. From this perspective grief was a type of illness or affliction from which one needed to recover. Freud postulated that for recovery from the affliction of grief to occur, the griever needed to work toward decathecting from that which had been lost. Freud characterised the work of grief as involving repeated reality testing where tension between wanting to avoid the reality of the death is pitted against the movement toward facing this “reality”:

Reality-testing [following the death of a loved one] has shown that the loved object no longer exists, and it proceeds to demand that all libido shall be withdrawn from its attachments to that object...When the work of mourning is completed the ego becomes free and uninhibited again (Freud 1917:23).

Freud was concerned with conceptualising the differences between “normal” grief responses and those involving “pathology”. Freud saw that “melancholia” differed from normal mourning in two distinct ways. Firstly the “melancholic” had a sense of diminished self-worth, or low self esteem, and secondly a sense of self-reproach in which the melancholic feels deserving of punishment.

Other theorists have further developed grief theory that is consistent with the grief work paradigm such as Lindemann (1944), Bowlby (1969, 1973, 1980),

² The term “melancholia” dates back to the canonical writing on melancholia by Hippocrates, Aristotle and Galen (Radden 2003:38). Melancholia was commonly used until the 19th century where it began to be replaced in the medical literature by the term depression. There are both similarities and differences between the term melancholia and the term depression. For example, melancholia has included obsessive and compulsive symptoms, and paranoid thought each of which have since been conceptualised under other mental disorders. It is argued that historically melancholia has been associated with male gender, and linked to genius (Klibansky, Panofsky & Saxl 1964 cited in Radden 2003:40) whereas depression has a lower status and is seen as a disease that affects primarily women (Radden 2003:40). Focus on the issue of terminology with regard to the terms “melancholia” and “depression” go beyond the scope of this thesis. For a detailed discussion see Radden 2003 and Brendal 2003.

Kubler-Ross (1969), Parkes (1972), and Worden (1991, 1996). Traditional “grief work” theorists view “normal” grief as a universal process in which the bereaved person moves through stages, tasks or phases that begin when the loss takes place. Grief is viewed as being an individual, intrapsychic process also connected to the body being likened to a wound:

On the whole, grief resembles a physical injury more closely than any other type of illness. The loss may be spoken of as a “blow”. As in the case of a physical injury, the “wound” gradually heals; at least, it usually does (Parkes, 1972:25).

Consistent with Freud’s (1917/1957) approach, “grief work” proponents have argued that the work of grief involves the bereaved facing the pain of their loss and moving toward effort-fully letting go and detaching from the person who has died. Through the process of facing pain the bereaved is believed to proceed towards recovery (Engel 1964; Freud 1917/57; Lindeman 1944; Parkes & Weiss 1983; Raphael 1983; Rando 1984; Sanders 1989; Worden 1991). An overview of the stage based models that have been proposed by the above theorists working within this “grief work” paradigm is presented in Table 1. Each model is developmental in nature involving a progression from one task, sequence or phase to the next.

In the first stages or phases of the traditional models, the bereaved person experiences shock and numbness as they are faced with the death. At this point the bereaved may feel a sense of disbelief that the death has actually occurred. In the middle or successive stages the bereaved person moves to express deep emotion as they repeatedly face the absence of the deceased. There is a preoccupation with the deceased during this time. In Lindemann’s (1944) second stage of grief the goal is for the bereaved to move from

preoccupation with the deceased to a place of release and distance from the deceased. This shift in energy or investment in the deceased is viewed as an integral task that must be achieved in order for the bereaved to successfully adapt. Rando (1984:19) argues that:

The single most crucial task in grief is “untying the ties that bind” the griever to the deceased individual. This does not mean that the deceased is forgotten or not loved; rather, it means that the emotional energy that the mourner had invested in the deceased is modified to allow the mourner to turn it towards others for emotional satisfaction...detaching and modifying emotional ties so that new relationships can be established and the mourner is not tied non-therapeutically to someone who is no longer alive...The energy that previously went into keeping the relationship with the deceased alive now must be channeled elsewhere, where it can be returned.

This “grief work” approach has tended to pathologise mourners continuing to feel a connection to the deceased, or a continued sense of (the deceased’s) presence in their lives. Criticism may range from accusations that the bereaved person is not facing the loss, or adequately grieving, to suggestions that they are becoming stuck in a stage:

Persons attempting to maintain ties with the dead are likely to be viewed as suffering from complicated mourning or pathological grief. They may be further perceived as possessing a tenuous grasp on reality of attempting to deny their loss (Vickio 1999:161).

Additionally the traditional view of mourning holds that the presence of ongoing emotional pain, such as bouts of sadness when thinking about the deceased tends to indicate that “grief work” is incomplete with more still to be accomplished (Parkes 1972).

Table 1. The Grief Work Paradigm: Phases, Stages, and Tasks of Grief.

Theorist	Model	Individual Phases / Stages / Tasks					
Lindemann (1944)	<i>Stages</i> (3)	Shock and disbelief	Acute mourning (intense preoccupation with the deceased)	Resolution			
Engel (1964)	<i>Sequences</i> (6)	Shock and disbelief	Developing awareness	Restitution	Resolving the loss	Idealization	The outcome
Pollock (1961)		Shock	Grief	Separation	Reparation		
Averill (1968)		Shock	Despair	Recovery			
Bowlby (1961)	<i>Phases</i> (3)	Urge to recover the lost object	Disorganization & despair	Reorganization			
Kubler-Ross (1969)	<i>Stages</i> (5)	Denial & isolation	Anger	Bargaining	Depression	Acceptance	
Parkes (1971)		Numbness	Searching & pining	Depression	Recovery		
Bowlby (1980)	<i>Phases</i> (4)	Numbness	Yearning & searching	Disorganization & despair	Reorganization		
Worden (1982)	<i>Tasks</i> (4)	To accept the reality of the loss	To experience the pain of grief	Adjust to an environment where the deceased is missing	To withdraw emotional energy and reinvest it in another relationship		
Parkes & Weiss (1983)	<i>Tasks</i> (3)	Intellectual recognition & explanation of the loss	Emotional acceptance of the loss	Assumption of a new identity	Reorganization		
Rando (1984)	<i>Phases</i> (3)	The avoidance phase	The confrontation phase	The reestablishment phase			
Sanders (1989)		Shock	Awareness of loss	Conservation-withdrawal	Healing	Renewal	
Worden (1991)	<i>Tasks</i> (4) <i>reviewed</i>	To accept the reality of the loss	To work through the pain of grief	To adjust to an environment in which the deceased is missing	To emotionally relocate the deceased and move on with life		

In these models emphasis has been placed on the emotional processes involved in grieving, with successful outcomes being linked to the ability of the bereaved person to move against the pull to deny the loss, or avoid pain. The goal involves the bereaved displaying strength through approaching the loss and allowing for the facing of the reality of the deceased's absence (and the embracing of pain). Grief work is viewed as involving the exertion of much energy and time, until a point is reached where the bereaved is able to separate themselves from the deceased, returning energy to current life interests, investing energy into new or other relationships. The deceased is moved to a place of "the past" where a considerably smaller amount of energy is invested in remembrance. Within this traditional grief paradigm mourning is aimed at conservation and restoration of the bereaved's prior equilibrium, rather than being transformative or creative (Neimeyer 2000:17).

Complicated grief is believed to result when the bereaved become stuck in the "phases, stages or tasks" by attempting to avoid facing their pain, and/or avoiding taking in the reality that the loss has taken place (Rando 1984). Avoidance is believed to inhibit the process of letting go/detaching thereby stalling the resolution of grief. Complicated grief may also be viewed as the result of a grief that has become fixated for example, where grief is felt too strongly or for too long. Several forms of complicated grief have been listed in the literature ranging from absent, inhibited or delayed grief to conflicted, chronic and unanticipated grief (Anderson 1949; Parkes 1965; Parkes & Weiss 1983). Unanticipated grief results from the sudden

and unexpected loss of a person, in situations that may be experienced as highly traumatic. Examples include: car accidents, sudden infant death, major heart attack, and suicide etc. which have been linked to heightened levels of distress, symptoms of post-traumatic-stress (PTSD) and difficulties in adapting (Neimeyer 2005/2006; Rando 1996).

Over time, the concept of delayed grief has been challenged with some theorists arguing that it is highly uncommon (Bonanno & Field 2001). However, chronic grief has received considerable and continuing attention in the literature having been linked to the morbidity and mortality of bereaved survivors (Clayton 1974; Lundin 1984a; Parkes & Brown 1972). Chronic grief is said to involve a high level of yearning and pining for the deceased that continues in an unremitting manner. Chronic grief is believed to result from a dependent connection between the bereaved and the deceased where the level of emotional investment in the relationship may have been excessive (Rando 1984:61).

According to Bonanno, Holen, Keltner and Horowitz (1995), conceptualisations around how the bereaved develop complicated grief have been underpinned by three hypotheses. The first being that avoiding the feeling of negative emotion prolongs grief with the potential of damaging the bereaved (Rando 1984). The second hypothesis argues that avoiding distress in the early days/weeks after a death may initially work however, the distress will eventually return. The third hypothesis postulates that avoided emotion is linked to somatic symptoms. Each of

these hypotheses has been ubiquitously accepted by the majority of researchers and practitioners in the field of grief and bereavement (Bonanno et al. 1995:976). However, on the basis of reviewing the research the authors claim:

It has been pointed out that little empirical evidence for any of these hypotheses is actually available. Furthermore, recent reviews of the existing empirical literature have not supported the compatible assumptions that the absence of emotional distress during bereavement leads to more problematic outcomes or that “working through” the emotions associated with grief is essential for its successful resolution (Bonanno et al. 1995:976).

Bonanno and colleagues (1995) have challenged these hypotheses arguing that having emotional time out from loss may actually be adaptive. Distraction might benefit the bereaved by allowing them to integrate the loss whilst regulating or “dosing” (Bonanno et al 1995:984) their exposure to the pain of grief. Through time out and distraction the bereaved may be better able to maintain optimum levels of functioning in their roles and responsibilities to others (Bonanno et al. 1995).

Coping efforts to achieve time out may include the use of positive imagery and pleasant memories occurring outside of the current setting/place and paying attention to external stimuli for example, noticing positive aspects of one’s environment such as a sunset, garden etc. These strategies involve “dissociation” or cutting off from pain by turning attention to other aspects of experience which Bonanno and colleagues (1995) argue as forming an adaptive short-term way of coping with sorrow. These strategies may have the power to reduce levels of distress and assist those suffering difficult grief responses to cope:

...severely grieved individuals might develop the means to defer or minimize emotional processing of the loss and to reconstitute a more normative pattern of emotional regulation (Bonanno et al. 1995:986).

However, avoidance may encapsulate behaviours which are not “adaptive”. For example those who deliberately avoid disclosing emotion to others, and who ruminate and worry, have been found to be at an increased risk of experiencing heightened levels of distress (Pennebaker & O’Heeron 1984; Pennebaker 1989 cited in Bonanno et al. 1995).

Efforts to address some of the pervasive assumptions about adaptation to bereavement began with the work of Wortman and Silver (1989) who argued that five myths had dominated thinking about the grieving process. One myth concerned the belief that grief should unfold in a fairly short period of time. Wortman and Silver (1989:349) assert that such expectations may inhibit the offering of social support whilst increasing opportunities for the bereaved to be labeled as pathological in their responses to bereavement. Other myths include the belief that recovery is an end point which all people reach; that it is important to work through the loss; that distress or depression is inevitable and that all people should fully recover. These authors questioned the universality of people’s responses to bereavement, suggesting the need to investigate possible variations in the ways that people grieve, including what constitutes adaptation.

In the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), a “complicated” or “pathological grief” reaction has been linked closely

to a “Major Depressive Episode”. The DSM-IV suggests that grief moves from being “normal” to “abnormal” when the bereaved display symptoms of feeling guilty about their actions or non-actions around the death; when thoughts connected with death go beyond a general sense that it would have been better not to have survived; continuing feelings of worthlessness that do not abate; slowed movement; functional impairment that persists and the experience of hallucinations that go beyond transient encounters where the deceased persons voice or image is sensed (APA 1994:702). However, the normality of “sensing” the presence of the deceased has been overlooked by proponents of the grief work tradition.

The view that dominates scientific discourse is that these experiences are illusory-symptoms of broken hearts and minds in chaos, or part of the futile searching for the deceased that characterizes the early stages of grief (Bennett & Bennett 2000:139).

In Richards (2001) study 125 participants were interviewed and over 50% described experiencing spiritual “sensing” phenomena that arose without the topic being elicited through direct questioning (Richards cited in Gillies & Neimeyer 2006:39).

Rees (1971) concluded that the experiencing of “sensing experiences”³ “hallucinations” was a normal aspect of bereavement experience, and not to be labelled pathological. Rees (1971) cites a cross-cultural study which found that 90% of Japanese widows felt the presence of their deceased spouse (Yamamoto et al 1969 cited in Rees 1971), and that

³ Rees termed the bereaved’s “sensing experiences” as “hallucinations” in keeping with the dominant medical language around sensing phenomena.

no participant questioned their mental health over these experiences.

Rees (1971:41) concluded that:

Hallucinations are normal experiences after widowhood, providing helpful psychological phenomena to those experiencing them...Hallucinations are common experiences after widowhood, they occur irrespective of sex, race, creed, or domicile.

Several “grief work” theorists have hypothesised that recovering from grief entails “identity re-development” and a rebuilding of self in the wake of the deceased’s absence. (Lindemann 1944; Parkes & Weiss 1983; Rando 1984; and Worden 1991). The redevelopment of aspects of identity is believed to assist the bereaved in achieving greater independence from the deceased, leading to a resolution of their grief. Reaching independence involves the dissolving of parts of the bereaved’s old identity that had been highly dependent on the deceased person. For example, in the case of the death of a spouse, the old connections between a wife and her husband are gradually relinquished and replaced by new and different connections to others.

Theorists who emphasise the importance of achieving distance and independence from the deceased (for example: Freud 1917/57; Rando 1984) label those retaining a bond as requiring counselling or therapeutic intervention (Stroebe, Gergen, Gergen & Stroebe 1996:34). Underpinning this approach are unstated beliefs about the nature of relationships. For example emphasis is on the need for relationships to be reciprocal, whereby each person is able to give and receive in the relationship, and that a relationship with the lost person lacks this reciprocal dimension.

An issue that has been linked with the development of “complicated grief” involves the bereaved’s experience of loneliness. Three major theories have been applied to the conceptualisation of loneliness, with each attempting to uncover possible factors reducing levels of distress. The first involves cognitive stress theories (Lazarus & Folkman 1984), in which the difficulties of a situation go beyond an individual’s capacity to cope. Within this approach social support is viewed as a “buffering model” that has the potential to reduce loneliness. However, findings on this approach have been inconclusive. Stroebe, Stroebe, Abakoumkin & Schut (1996:2178) argue that: “Studies of social support in bereavement have not confirmed the stress-theory assumption that social support buffers persons against the deleterious effects of bereavement”. In their study on loneliness and suicidal ideation these authors found that whilst social support helped to reduce levels of suicidal ideation, the effects were equal for those married and conjugally bereaved. However, the impact of social support did not reduce the presence of intense emotional loneliness, a factor also linked with suicidal ideation and the distress of bereavement.

A second approach which has been applied to the study of loneliness and social support is the “Theory of Mental Incongruity” (TMI). TMI has been linked to situations where the need for individuals to adapt and reorganise following major life events is viewed as central (Van Baarsen, Smit, Snijders & Knipscheer 1999). This theory is described as a “cognitive motivational model” where emphasis is on the person obtaining balance

after having experienced “mental incongruity”. In TMI the concept of “mental incongruity” involves discrepancies between the situation a person is facing, such as bereavement, and the belief the person has about how their life situation should be (which is referred to as the person’s “standards”). In this theory:

..the *loneliness* [original emphasis] a widow(er) experiences after the loss of the partner is interpreted as an incongruity in personal relationships, a ‘discrepancy between the relationships one has and the relationships one wants’...Relationships with others may be a source of incongruity when the widow(er)’s expectations of support are not met by the actual support received (Van Baarsen et al. 1999:446-447).

According to Van Baarsen and colleagues (1999), this approach is useful for understanding the responses of people in varying types of conjugal relationships. For example a person in a dependent relationship with the deceased prior to the death will experience greater incongruity than a person who is comparably independent. TMI proponents argue that other aspects of experience such as the ill health suffered by the surviving bereaved will deepen mental incongruity. For example, poor health has the capacity to reduce the bereaved’s opportunities for interacting with others thereby limiting openings to their receiving support (Van Baarsen et al. 1999:448). In this model social support is believed to reduce experienced loneliness, with the beliefs and expectations of the bereaved mediating their perception of received support.

In Van Baarsen and colleagues (1999) approach the experience of loneliness may be exacerbated when the expectations of the bereaved survivor are not met by others within the bereaved’s social/interpersonal

network such as family and friends. This may result in the bereaved feeling further isolated in spite of the efforts of others to reduce the bereaved's loneliness. In Van Baarsen's (2002) study it was found that levels of loneliness prior to a loss predicted levels of loneliness experienced after. The role of self-esteem was also implicated as a mediating factor where lower levels of self esteem following a loss were linked to the experience of both social and emotional loneliness. Van Baarsen (2002) argues that the loss of a partner may challenge the identity of the survivor as they attempt to adapt.

A third approach to conceptualising loneliness involves the application of attachment theory (Bowlby 1960a, 1960b; Weiss 1975). The attachment approach markedly differs from the above approaches in that the support offered by friends and relatives is not viewed as ever forming a substitute for the lost primary attachment figure. Weiss (1975) conceptualised loneliness as involving two distinct aspects. The first is social isolation, or social loneliness. The second is emotional loneliness:

Those experiencing emotional loneliness are apt to experience a sense of utter loneliness whether or not the companionship of others is in fact accessible (Stroebe et al. 1999:1242).

Stroebe and colleagues (1999) found overwhelming support for the attachment construction of loneliness whereby social support assisted people by reducing levels of social loneliness, but failed to ameliorate the intensity of emotional loneliness.

Loneliness has received “limited academic attention in the literature” (Costello 1999:219) in spite of early bereavement studies identifying loneliness as an acute phenomenon (Clayton 1975; Glick, Weiss & Parkes 1974; Maris 1974; Parkes 1972). Bowlby (1980:95) summarised findings from these studies stating that each of the aforementioned researchers found that loneliness was common, and most acutely felt during the night-time hours. Bowlby’s emphasis on loneliness concerned the strain that widows/widowers feel as they attempt to (re)connect with others in their social world. For example in meeting with mixed sex groups the conjugally bereaved are painfully reminded of the absence of their spouse, their loss of being a couple, and transition to being a single person in a coupled world which may be overwhelmingly painful.

Previous conceptualisations of loneliness have centred on loneliness as a secondary category linked to other more primary aspects of the bereavement experience (Lopata cited in Parkes 1986:30). For example, loneliness has been linked to deprivation, such as the loss or deprivation of roles, for instance experiencing sexual frustration that may result from being deprived of a sexual partner (Parkes 1986:30). However, loneliness appears to be receiving renewed interest particularly in connection to bereavement (Stroebe et al. 2005).

In her writing on grief and loss McCabe (2003) acknowledges recent changes in conceptualisations of loss. However, McCabe makes the point

that the traditional grief models still hold sway, citing both DSM-III-R and DSM-IV, as reflecting their continuing support:

The DSM criteria reflect some of the same tendencies toward linearity, finitude and normalization found in most prominent grief theories, the cardinal principle being that, normally grief ends. While a trend is rising against these notions and a new paradigm is gradually emerging, it is evident that traditional grief theory still informs practice and public policy (McCabe, 2003:3).

Like Neimeyer (2001b), McCabe believes that a major problem of traditional approaches involves the underlying assumptions supporting the theory not been explicitly and critically examined (2003:4).

Our attitudes to bereavement are linked to our beliefs about death. A person's view of death itself has arisen out of a cultural context. Gire (2002) suggests that our view of what happens at death is connected to the way we approach life, and the way that people grieve. Culturally we can be placed along a continuum. At one end death is accepted as a normative part of life; at the other end death is denied. Where we are on the continuum, and what we believe, in turn influences the anxiety we feel around death. Death anxiety has been defined as:

...a multifaceted construct that is not easy to define but has been conceptualised to include: fear of death of oneself, fear of death of others, fear of dying of self, and fear of the dying of others (Gire 2002:5).

Death anxiety is not experienced at the same level across differing cultures and religions. For instance Parsuram and Sharma (1992, cited in Gire 2002), found that in a study comparing Hindus, Muslims and Christians in India, those who had the greatest belief in life after death had the lowest

anxiety about death. High death anxiety may be expressed in avoidance, for example refusing to visit relatives or friends who are dying, or failing to attend funerals, or “death defying” behaviours such as parachuting and rock climbing or speeding in cars (Gire 2002:6). Extreme death anxiety can be distressing, perhaps even pushing some people to take risks that eventuate in their premature death. However, the presence of death anxiety may have benefits, for example in motivating people to live fulfilled lives with fewer regrets (Kalish 1987).

Constructivist and Postmodern Challenges to Traditional Approaches

During the past 15 years an increasing number of studies and clinicians have challenged central tenets of the developmental “grief work” approach. A prominent and influential voice in the field has been Robert Neimeyer. Like Bonanno and colleagues, Neimeyer (2001) has argued that traditional grief work approaches have been underpinned by a number of continuing beliefs and assumptions. These assumptions range from the appropriate length of the grief process itself (being under or around a year) to beliefs about the nature of recovery and the concept of “resolution”. For example, recovery has been said to occur when the bereaved person reaches a state of functioning that existed prior to exposure to the death. Resolution is seen as an end point rather than being continuous. Other assumptions that Neimeyer has challenged include: grief is predictable and follows a set process; avoidance or denial of grief leads to pathology and the development of “abnormal grief reactions”; and that successful

mourning requires the expression of negative emotions (Neimeyer 2001b:18-19; Wortman & Silver 1989:351). Neimeyer summarises the assumptions underpinning the traditional approach stating:

...grief in the standard model is primarily a physical aspect of mourning, closer to a bodily function than to thought or language...grief has no communicative or relational function being inherently an internal process. Mourning is painful and sad rather than involving a range of affects...the expression of pain and grief is indicative of successful mourning. Other affects-such as humor, pleasure, and even joy-are viewed as aberrations or resistances to normal mourning (Neimeyer 2001b:18-19).

Traditional grief approaches have been criticised for overlooking the role of cognition in grief and its potential role in adaptation, or conversely the development of a difficult grief reaction. For example, ruminating has been linked to negative bereavement outcomes, where ruminating increased levels of psychological distress, interfered with problem solving abilities and was related to more prolonged levels of distress (Nolen-Hoeksema, McBride & Larson 1997; Nolen-Hoeksema, Parker & Larson 1994).

As identified, one of the traditional grief assumptions concerns the length of time required to grieve being limited to weeks and months. However, longitudinal studies measuring symptoms over several years have found it common for the conjugally bereaved to still be suffering several years after the death occurred. While improvement in symptomatology may be recorded, it is clear that for some bereaved, prior functioning levels may not be realistically reached, yet for others life improves beyond what was experienced prior to the death. In the literature improvement has been referred to as a kind of “post traumatic growth”:

The transformative nature of loss, then can be viewed as a process whereby the lives of some people are imbued with an enhanced sense of meaning and purpose (Neimeyer 2001b:161).

However, there is still much that is unknown about post-traumatic growth, and it is clear this kind of growth comes at a cost. The pattern of those reporting post-traumatic growth does not necessarily match up to corresponding patterns of psychological adjustment (Calhoun & Tedeschi 1998 cited in Neimeyer 2001b).

Many aspects of the traditional western “grief work” approach have been challenged by numerous researchers and theorists in the field (Doka 2001; Field, Nichols, Holen & Horowitz 1999; Fraley & Shaver 1999; Klass Silverman & Nickman 1996; Neimeyer 2000c, 2001a; Shaver & Tancredy 2001). Research has burgeoned leading to what Hagman (2001:13) describes as a “sea change”:

...a new wave of grief theory is emerging which reflects a changing *zeitgeist* about the role of loss in human experience...A prominent theme in these new models is their insistence that symptoms have significance...Viewed in its broadest terms, this suggests the gradual emergence of a new paradigm for grief theory, research, and practice, one founded on the postulate that *meaning reconstruction in response to a loss is the central process in grieving* [original emphasis] (Neimeyer 2001:3-4).

Recent questions have raised concerns around how loss is best coped with, including debate over the existence of an endpoint or “resolution” to grief (McCabe 2003; Neimeyer 2001b). As stated earlier, the “grief work paradigm” put forward the belief that successful grief resolution was reached when the bereaved untied bonds to the deceased. However, the work of several recent theorists suggests that ongoing connection to the deceased significantly contributes to the bereaved person’s adaptation and

recovery (Fraley & Shaver 1999; Klass et al. 1996). The focus of grieving in this approach has been shifted from a “letting go” process to a complex experience involving “meaning making” (Davis, Nolen-Hoeksema & Larson, 1998; Neimeyer, 2000a; 2000b; 2001a) along with the need for continuation and connection:

Emphasis on the need to detach from the lost object has obscured another aspect of the work of mourning, which is to repair the disruption to the inner self-other relationship caused by the actual loss...This is the task I call “creating continuity” (Gaines 1997:549 cited in Neimeyer 2001:21).

The above approach stresses the importance of the preservation of ties between the deceased and bereaved, because the adaptation to bereavement involves efforts to transform and restructure attachments as opposed to their relinquishment (Neimeyer 2001b:22).

Other criticisms of the traditional grief approach concerns its oversimplicity and the possibility such an approach risks inflicting further pain on people whose experiences do not match the prescribed processes. It is expected for instance, that grief lessens over time. When interviewed by Bryant (2003), researcher and therapist Kathleen Gilbert suggests that for certain groups of people such as the parents of young children, grief may actually increase, recurring many years after the death:

Grief is far more complicated than any stage model can suggest...in fact, trying to harness such complex feelings into a sequential, linear pattern may do more harm than good...Grief is like a river, not a ladder. When you suffer a loss and experience grief, you enter that river for good. It's not a steady stream: There are raging rapids of boulder-sized heartbreak and shallow pools of peace, where you get a chance to enjoy what's around you. But you are always on the river; there is no going ashore to return to a life without loss (Gilbert quoted in Bryant 2003:5).

Neimeyer (2001a), along with several other theorists (Davis 2001; Doka 2001; Moos & Schaefer cited in Neimeyer 2001b), asserts that adapting to

loss requires grappling with issues of meaning, and meaninglessness for many people. Meaning is a complex term that some theorists have struggled to define as involving the story (including reasons) that a person constructs about how and why loss has happened. The anguish of facing the death of a significant other can challenge the beliefs and meanings underpinning life previously held by the survivor (Neimeyer 2001a, 2001b). A belief system that functioned adequately prior to the death through providing sufficient support for a meaningful life, may suddenly prove to be inadequate failing to account for the new experientially different world faced by the bereaved.

The presence of “counterfactual thoughts” has been linked to heightened distress in the bereaved and their inability to process meaning. Counterfactual thoughts (Tait & Silver, 1989) are thoughts connected to a trauma or tragedy where the surviving person focuses on their failings or limitations⁴. For instance, the survivor may lament actions that they did not take that could have prevented tragedy, and go over the event repeatedly in their mind. The struggle to find meaning in trauma, and overcome counter-factual thinking have been linked to complicated grief:

For many...the haunting counterfactual thoughts and a pervading sense of meaninglessness are perceived as major issues and impediments to the healing process...future research will need to focus on how people attempt to come to terms with them (Davis 2001:149).

Gillies and Neimeyer (2006) reviewed empirical studies (using qualitative, quantitative and mixed methods) on the meaning making processes that

⁴ The term “counter factual thoughts” refers to the survivor’s preoccupation with “if only” or “what if” thinking that runs “counter to the fact” of what has happened (Davis 2001:140).

people engage in when grieving. They identified three activities of meaning construction which comprise of: “sense making”, “benefit finding” and “identity change”. These processes involved the bereaved reframing and interpreting their experiences to assert control and order over a situation of meaningless suffering (Thompson & Janigian 1988; Folkman 2001).

Gaps in what was known about how people construct meaning were recognised such as the nature of the relationship between meaning making and distress. For instance, it is not known if this relationship is uni-directional with distress precipitating the action of meaning making, tapering off when sense making occurs resulting in a drop in distress (Gillies & Neimeyer 2006:46). It was suggested that research should examine how particular meanings surrounding events surface over time (Gillies & Neimeyer 2006:35).

The construction of meaning is central to the way in which events are experienced and interpreted. It is significant that in many westernised countries today, the incidence of child mortality is very low particularly when compared to rates that existed just over a century ago. Child death was far more common, with many not living to see adulthood due to poor sanitation and the high prevalence of infectious diseases and/or birth defects which are now considered as preventable or routinely treatable diseases (Bi, Whitby, Walker & Parton 2003; Center for Disease Control 1999). Similarly, maternal and infant mortality during pregnancy and childbirth has been markedly reduced. The advances in medical science, technology and public

health have enabled the survival of the vast majority of children, including those prematurely born, whilst women can expect to survive pregnancy without fear of major complications.

As a consequence of these enormous improvements in survival, premature or unexpected deaths are largely viewed as falling outside of normal human experience for most in westernised countries. It has been argued that people may develop “positive Illusions” where they perceive themselves as having greater control over their future which distances them from the realities of death (Tomer 1994:13). As a result people today may be less prepared in knowing how to support each other when unexpected deaths occur. The deaths of significant others are more likely to shake the belief systems held by people who view death as an anomaly, a taboo, or not in the nature of normal experience. The changing position of the place of death within life has consequences for both the bereaved and those who attempt to support them.

The work of Neimeyer, (2000c), Davis & Nolen-Hoeksema (2001) has emphasised the role of context, and the power of interaction with others in adjusting to bereavement. Those surrounding the bereaved person contribute to the emerging trajectory:

...processes in grieving cannot be understood as taking place within isolated subjectivities divorced from a larger social world. However private our grief, it is necessarily linked with the responses of others, each constraining and enabling the other (Neimeyer 2000:112).

The term “mourning” as introduced in chapter one, involves cultural and social rules around what is considered appropriate behaviour. The rules of mourning also include the element of time and a timeframe. For instance in the Diagnostic and Statistical Manual of Mental Disorders, (DSM-IV 1994) grief is said to move from “normal” to “pathological” when symptoms continue for longer than two to three months following the death of a significant other. Mourning practices and rules vary greatly between cultures (Rosenblatt 2001:293). Certain approaches may be more suited to particular people’s grieving styles, benefiting some whilst disadvantaging others (Doka 2002). Additionally certain people may be recognised as chief mourners in one culture, yet in another be ignored:

...grieving rules do differ between cultures. What is disenfranchised in one culture may be supported in another. In certain cultures, certain ways of grieving may be understood as valid expressions of grief whereas in other cultures the same behaviors may be disdained as excessive or inappropriate (Doka 2002:9).

The bereaved may feel supported by mourning rules which are in tune with the personality or grieving style of the individual person. Mourning rules may influence the way in which the bereaved construct meaning around loss (Klass & Goss 2003:791). For example, an individual’s meaning construction exists within a broader cultural narrative. The rules and beliefs held by the dominant culture may “limit the development of alternative narratives of an individual, a subculture or a less powerful culture” (Neimeyer & Levitt 2000:401).

In their study on the role of meaning making and sense of benefit in adjusting to bereavement, Davis and Nolen-Hoeksema argued that

“...meanings are tested and revised, at least subtly, in interactions with others” (2001:738). It is therefore possible that expectations of grief resolution placed onto the bereaved by surrounding “others” may inhibit adaptation. Expectation by well meaning friends, work colleagues etc. may leave the bereaved feeling further isolated for example, where the bereaved is told to remove possessions and reminders linked with the deceased person. This can also be the case when there is an expectation that socially sanctioned mourning time is over and questions are asked such as: “Why are you still moping?” In such cases support may be experienced as “drying up” (Doka 2002). The behaviours of others may turn from caring to frustrated, dismissing and/or hostile. It has been argued that a lack of support for bereaved people can increase their vulnerability to mental health difficulties:

High stress in unsupported individuals significantly increases the risk of psychiatric sequelae, whereas similar levels of stress in similar individuals who were concomitantly supported by helpful individuals or groups did not result in psychopathology... membership in a supportive group seems to protect against stress-induced damage to mental health (Caplan 1990:33).

Erich Lindemann (1944) worked extensively with bereaved survivors of a fire in a Boston nightclub that resulted in the deaths of many people. Lindemann developed theory and intervention programs for the bereaved believing that most people grieved adaptively. Whilst most survivors were viewed as responding adaptively, Lindemann noticed a minor group of people who showed

...a defensive refusal to suffer the pain of grieving; and this appeared to be linked with the emergence of psychopathology or psychosomatic disease (Caplan 1990:27).

From this point, Lindemann's work concentrated on developing interventions for bereaved people with the aim of assisting them "in such a way that there would be no deterioration in their mental health" (Caplan, 1990:28). It is significant that those in the bereaved's caregiving community context such as clergymen were accentuated as the most important and appropriate to provide support. Caplan, who came to work with Lindemann noted that in their work with people facing a crisis, that those directly affected "become temporarily more dependent on others and more open to their influence" (Caplan 1990:28) at that time. Whilst Lindemann is known primarily for his model on the process of grief, his work highlights the importance of context in shaping people's response to grief, and the potential for support to assist in the bereaved person's adaptation following exposure to the death of another.

Diagnosing what is "normal"

In the field of bereavement a multitude of psychometric scales have been developed to assess how people are coping with their grief. However, according to Neimeyer and Hogan these scales have tended to be generally related to psychiatric symptoms of distress (Neimeyer & Hogan 2001:91) rather than being specific to grief for example, the Beck Depression Inventory; and the Brief Symptom Inventory (BSI). An additional criticism of these scales is that they fail to take into account the psychosocial context of the bereaved, whilst also neglecting to acknowledge or incorporate

...theoretically and practically important outcomes such as processes of “meaning reconstruction” following loss or the “posttraumatic growth” evidenced by many bereaved individuals as a result of their encounter with personal tragedy (Neimeyer & Hogan 2001:91-92).

There is ongoing debate on where a so called “normal” grief reaction ends, and a “difficult” grief reaction begins (Stroebe et al. 2001:6). Diverse cultural belief around what constitutes “acceptable” mourning behaviour makes this task more complex (Stroebe et al. 2001:6). Much of the bereavement literature has concentrated on addressing problems associated with diagnostic issues in relation to the Diagnostic and Statistic Manual of Mental Disorders (DSM IV). However, the DSM does not include bereavement specific categories and places those who are experiencing symptoms into less bereavement specific diagnostic labels such as: Major depression, adjustment disorders, anxiety or trauma diagnoses such as “PTSD”. Efforts to introduce bereavement specific categories that are distinct from other diagnostic labels (in the up-coming DSM-V) are continuing (Boelen, Van Den Bout, De Keijser, Hoijtink 2003; Jacobs, Mazure Prigerson 2000; Prigerson & Jacobs 2001).

Prigerson & Jacobs, (2001) have worked toward delineating traumatic grief from other bereavement reactions such as bereavement related depression and bereavement related anxiety. In three separate studies of participants who were elderly and recently widowed, symptoms were identified in three separate and distinct symptom clusters: traumatic grief, depression, and anxiety. Boelen, van den Bout, and de Keijser, (2003) conducted a replication study with a different population of mainly self referred persons from an outpatient mental health setting, where types of

losses were varied (covering spousal, parental, child, and sibling losses) to check for the generalisability of results. Whilst the studies by Prigerson, et al. (1995) and Prigerson, & Jacobs (2001) had included only those losing a spouse from an illness, Boelen et al. (2003) included losses that occurred outside these parameters such as with accidental or sudden death. The findings of the replication study were in agreement with the work of Prigerson and Jacobs (2001). Boelen et al. (2003:1341) claim:

...results indicate that the complications of bereavement may include symptoms of traumatic grief that constitute a clinical entity distinct from bereavement-related depression and anxiety. This contrasts with DSM-IV, in which traumatic grief is not a separate clinical entity...Results suggest that different treatment methods may be required for the various syndromes that develop in people who fail to recover from bereavement.

Work on delineating “traumatic” grief from depression and anxiety has centred on discerning differences in symptomatology. The aim has been to expand current understanding so that treatment interventions can more effectively reduce suffering and promote adaptation. Recently Boelen, van den Hout, and van den Bout (2006) have asserted that three core processes are involved in a complicated grief response: a) failure to incorporate the loss into the survivor’s own story of themselves and memory; b) activating or reactivating negative beliefs about the world, the future and ones self; and c) relying on maladaptive strategies in order to avoid feeling or facing pain (Boelen et al. cited in Neimeyer 2006:141-142). In Boelen’s and colleagues’ model, three processes were identified which appear to be consistent with the “grief work” approaches emphasis on the maladaptive avoidance of emotion. However, the processes

presented are consistent with “post-modern” models that emphasise the activity of meaning making in (mal)adaptation.

As presented earlier, Neimeyer (2001) raises the issue of “meaning making” as forming an active and integral part of the journey toward accommodating loss. While attention has been paid to the role of meaning, few researchers have addressed the issue of spirituality as a potential component of the recovery process.

In their study exploring meaning making in the wake of bereavement, Davis and Nolen-Hoeksema (2001) hypothesised that family members indicating a presence of spiritual and religious beliefs (prior to the death of a loved one), would find it easier to make sense of their loss than those not possessing such beliefs. Their study affirmed the hypothesis, along with the assertion that the older the deceased, the more likely that bereaved loved ones would be able to also make sense of the loss (Davis & Nolen-Hoeksema, 2001). This research suggests a positive connection between spirituality, meaning making and adaptation after a loss. What is missing from bereavement research is a picture of process, ie. how such an adaptation may be experienced in the wake of a difficult bereavement experience.

Both constructivist and traditional theorists view identity development (defined as “self-narrative” in constructivist approaches) as being an important component of adaptation following bereavement. However, the

similarities end there, as the aim and nature of this identity development differs between the groups. Constructivist theorists believe that identity development occurs as the bereaved negotiate change in a unique non-prescriptive way. Engaging in the active process of meaning making may allow the bereaved to make choices:

...a meaning reconstruction view is based on the conviction that grieving persons are active agents in negotiating the course of their post-bereavement adjustment, whether such dimensions as culture, spirituality, and gender seem to facilitate or impede their attempts at reconstructing a life worth living (Neimeyer 2000:120).

There has been much ongoing debate concerning the human response to bereavement. The expectations and beliefs around what is “normal” or “acceptable” have gradually been shaped by the work of theorists, researchers and clinicians in the field (Neimeyer 2001a; 2005; Prigerson, Shear, Jacobs, Reynolds et al. 1999; Shuchter & Zisook 1993; Stroebe & Schut 1999) with many questions yet to be conclusively and consistently answered. Most research has been quantitative having measured the bereaved’s symptoms and distress over time (Neimeyer & Hogan 2001).

The work of Bowlby (1969; 1973; 1980), has been used to support the traditional “bond-breaking” approach. However, interpretations of Bowlby’s work have recently been challenged by post-modern theorists (Fraley & Shaver 1999). Fraley and Shaver (1999) argue that Bowlby (1980) not only allowed for the presence of continuing bonds, but saw their adaptive value in the bereaved’s struggle towards creating a life worth living. He asserts:

It seems likely that for many widows and widowers it is precisely because they are willing for their feelings of attachment to the dead spouse to persist that their sense of identity is preserved and they become able to reorganize their lives along lines they find meaningful (98).

The above quote illustrates that Bowlby was concerned with issues of personal meaning, and continuing attachment to the deceased.

Neimeyer's (2000b) has criticised the "grief work" approaches insistence that grief reaches an end point (resolution) and the presumption that patterns of emotional responses to grief are universal. Neimeyer's (2000), approach draws on constructivist theory that views people as active agents who are constantly in a meaning making process that involves the interpersonal context in which a person lives. Uniqueness replaces universality holding that no two persons' grief will be the same. Loss is viewed as "an event that can profoundly perturb one's taken-for-granted constructions about life, sometimes traumatically shaking the very foundations of one's assumptive world" (Neimeyer 2000:111).

While emotional aspects of loss are acknowledged, the emphasis in Neimeyer's approach is on continued connection and meaning making. Rather than emphasising "working to let go" Neimeyer (2001a) believes that the central process involved in grieving is the reconstruction of meaning. He also asserts that this central process involves cognition which in turn may significantly influence emotional processing. Another voice challenging the traditional grief paradigm is that of Thomas Attig (1996)

who claims that grief involves an active process of relearning how to adjust to an altered, disoriented world:

Bereavement jolts us off the path we have learned to follow in life and leaves our lives in disarray. As we learn our ways of being in the world, we identify, explore, test and ultimately appropriate new ways of going on (Attig 1996:19).

Attig believes that mourners have a variety of choices which they may grapple with in their experience of bereavement. Although we may have no choice in becoming bereaved, we do choose our response: "grieving is what we do in response to it...our coping is pervaded by choice" (1996:19). Thus grieving is seen as an active process involving choice in terms of meaning making. The central tenet of Attig's thesis is that grief involves "relearning our assumptive world". Relearning our assumptive world may involve relearning our connections with others including, but not limited to the deceased (Attig 1996). The goal of grief work from a constructivist post-modern perspective involves "a process whereby we effortfully and idiosyncratically reconstruct a world of meaning and restore coherence to our lives" (Stroebe & Schut 2000:69).

The post-modern approaches to grieving assert that there is no one "correct" or "right" way to grieve, and that grief may involve a variety of emotional states that include those that are positive. In their "dual process model of coping with loss: Pathways", Stroebe & Schut (2000) argue that there is a place for both confrontation and avoidance in the processing of grief.

A prominent theme in these newer models is their insistence that symptoms have significance, that the outward manifestations of distress associated with grieving can be understood only in terms of the struggle

of bereaved people and their social domain to accommodate to a changed (inter)personal reality resulting from the loss (Neimeyer 1998 cited in Neimeyer 2000:4).

Shaver and Tancredy (2001), argue that contemporary attachment researchers and theorists frame “unresolved grief” or a “difficult grief reaction” as the bereaved’s failing to develop a congruent story around their experience of loss and trauma as opposed to a failure of the bereaved to detach from the deceased (Shaver & Tancredy 2001:81). Defending the work of Bowlby, these authors draw attention to Bowlby’s final stage in his theory on attachment and loss being “reorganisation” which is conceptually different from detachment.

According to Klass and Goss (1999), humans have continued to maintain bonds to the deceased throughout history. These links have included ancestors and the sacred dead. The differences between the two involves the structure of the relationship. Connections with the sacred dead are asymmetrical, in that the living are not able to assist them, however there is the sense in which the sacred dead may help the living. With ancestors, the relationships have been situated in a way that care and responsibilities are reciprocal. Ancestors and the living are viewed as having the ability to help or hinder the other (Klass & Goss 1999:547). For example in Japanese culture the continuing connection between ancestors is “interactive, not ontological” whereby spirits are viewed as interacting with the living (Klass & Goss 1999:550). Some of the phenomena that has been identified as maintaining links to the dead include: a sense of the dead person’s presence; through objects linked to the deceased; through

memories; hallucinations; or identification with the deceased. These authors's argue that connections to the dead through the above means have been incorporated into many of the worlds' religious traditions such as Christianity and Japanese Buddhism.

In their critical review of bereavement research, Neimeyer and Hogan (2001) build a case for the necessary inclusion of qualitative research methods in the bereavement field. Qualitative methods are needed in bereavement study designs and have the potential of offering a "counterbalance to the often atheoretical, objectivistic, superficial, and decontextualized study of grieving that typifies conventional studies of bereavement (Neimeyer & Hogan 2001:106).

Conclusion

This chapter has presented a review of the grief and bereavement literature with an emphasis on defining and delineating approaches within the field beginning with the work of Freud. The traditional "grief work" approach that grew out of Freud's pioneering work has been explored. Challenges to the grief work approach have been detailed and explored and current gaps within the field around the bereaved's experiencing and adaptation following the death of a significant other has been foregrounded, highlighting the need for obtaining qualitative information on how people adapt and lead their lives following exposure to bereavement.

Even the study of “meaning making” and “distress” has so far tended to be investigated within a medically oriented “disease” framework. This has resulted in a narrowing of the focus of the research limiting the potential of studies to gain access to some of the subtler, more intricate aspects of the ways in which people grieve and adapt:

Most studies implicitly adopt a medical model in which meaning making is investigated as a possible “cure” for the “illness” of grief. From a constructivist point of view the process of grieving may have much more to teach us than how to avoid distress... future studies might investigate in greater depth the kind of benefits that are discovered, motives for finding them, and processes by which they are found (Gillies & Neimeyer 2006:47).

The current study is aimed at redressing some important gaps in the literature by utilizing a narrative technique through in-depth interviews. The qualitative interview data explores how people construct meaning around their experiences of loss and adaptation to bereavement following a difficult grief response. Klass and Goss (1999:548) argue that

At this time...scholarship has provided few concepts to understand how continuing bonds function in individual and family lives, or how continuing bonds express larger cultural meaning.

Narrative methodology has been seen as an optimal approach to researching the areas of grief and loss. For example, Gilbert (2002:237) states:

The richness of the loss and grief stories seen in narrative studies contributes to our understanding of the personal experience as well as the themes that transcend the individual stories. This approach may be uniquely well-suited to exploring the underlying meaning and evolving nature of the experiences of death, loss, and grief.

This project’s emphasis on the experiences of participants’ continuing connections with the deceased will create insights into the roles such bonds may or may not play. There are significant implications for the

creation of insights and understanding in the area of adaptation and continuing bonds. Increased knowledge will assist therapists and service providers to utilise appropriate and effective interventions in their work with bereaved individuals and their families whilst minimising the potential for counter-productive (or harmful) therapeutic applications.

Chapter 3

RESEARCH METHODOLOGY

Introduction

As indicated in Chapter 1, this research seeks to explore how people experience bereavement following the death of a significant other. Of particular concern is the place or presence of the deceased in the bereaved persons continued life. The project aims to capture how counselling is experienced, including generating insights into what aspects of counselling were experienced as beneficial. A major emphasis of the project is on understanding and discovering how the bereaved encounter continued life following a successful experience of counselling.

This chapter provides details about the narrative methodology chosen to answer the following research questions: a) How do people experience life following the death of a significant other; b) How is a positive counselling encounter experienced, and 3) How does such counselling facilitate the processes of living with bereavement. The narrative approach to research will be explained along with reasons for its selection justified. The second half of the chapter details how the research carried out and includes sampling, recruitment, data collection and analysis. Finally ethical considerations and limitations of the study are presented.

Rationale for selecting a Narrative approach

The research questions posed are focussed on gaining an understanding of how people construct meanings around their experience of loss and how this meaning changes over time. I will be looking for, and describing possible overarching patterns suggested by the data, as to how narratives shift or change as bereaved individuals encounter their experience of life following exposure to a significant other's death. Included in the analysis will be the bereaved's construction of their experience of counselling, and its role in their journey.

In order to achieve the aims of creating understanding into the lived experience of the bereaved it was necessary to choose a methodology that allowed the accessing of in-depth information. The methodology needed to be able to guide the accessing and exploration of issues of meaning connected with experience. The guiding theoretical orientation for this research project is Narrative (Bruner 1986; Lieblich, Tuval-Mashiach & Zilber 1998; Polkinghorne 1988, 1995; Riessman 1993). A narrative approach was chosen as it best fitted the projects aims of creating insights and understanding of "how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives" (Riessman 1993:2).

Narrative research has developed out of the epistemology of social constructionism (Crotty 1998). Constructionism is a post-positivistic approach that challenges the belief that truth is a singular objective reality

which is independent in and of itself. Constructionism asserts that “meaning is not discovered but constructed” (Crotty 1998:42), and that construction is a process that occurs within an interactive social context that is historically and culturally bound (Neimeyer & Mahoney 1995:16). Issues of power and privilege are acknowledged as forming part of the socio-economic and political context which shapes the way knowledge and experience are perceived and constructed (Riessman 1993:21).

In the positivist research tradition - researchers have tended to occupy positions hierarchical to those researched without acknowledging this positioning and the ways in which conclusions may have been influenced by this positioning. Recognising that people (including researchers) interact and construct their experience within a context that in turn shapes what they construct, (including what may be emphasised or overlooked) is central to constructionism (Clandinin & Connelly 2000; Polkinghorne 1988; Schafer 1992).

Narrative theorists and researchers argue that the act of story making forms a core part of what it means to be human (Mc Adams 1993). Stories are an active process that people naturally engage in, on a daily basis, functioning to both understand their lived experience and communicate with others (Lieblich et al. 1998:7). Within the narrative literature, many terms are used to explain narrative research. I will be using the word “narrative” and “story” interchangeably (Gilbert 2002). The goal of narrative research is to create insights and understanding into people’s

inner worlds through the stories they tell. “Narratives provide us with access to people’s identity and personality” (Lieblich et al. 1998:7).

Stories are the vehicle through which we come to understand the events around us. Narrative theorists argue that experience is not an object or thing, but a process which is ongoing (Polkinghorne 2000). Stories are concerned with meaning and help to create order out of the chaos, and randomness of human experience (Gilbert 2002; Polkinghorne 1995; Stuhlmiller 2001). In bereavement, the death of a significant other may represent exposure to heightened chaos and randomness. It has been increasingly argued that ‘complicated grief’ is the result of becoming stuck in the struggle to make sense out of the disorienting experience of bereavement (Neimeyer 2001). From this perspective, adapting to loss involves struggling with issues of meaning over time. In order to gain access to the ways in which the bereaved make sense of their ‘disoriented’ world, it is important to use an approach which embraces issues of interpretation and meaning making. Because people understand their world narratively, often responding to questions in storied forms (Mishler 1986), it makes sense to study their experiences using a narrative approach (Clandinin & Connelly 2000:17).

Other methodologies such as grounded theory (Glaser & Strauss 1967; Strauss & Corbin 1998) tend to fragment data into smaller constituent parts that may lead to the fracturing of the data from its context. In a process such as this, there is a risk of losing the threadlike connections

that are woven around events. It is through this linking that events come to be given their meanings. In the participant's story, meanings are constructed through the ways events are emplotted (Polkinghorne 1995). This emplotment in turn occurs in a particular context or situation.

Researchers have noted the construction of narratives as being central to both research and psychotherapy (Neimeyer & Mahoney 1995; Neimeyer & Stewart 1996). The early construction of stories around their experience following exposure to trauma and loss has been linked with more adaptive coping (Harvey, Stein & Scott cited in Gilbert 2002). In a study on the research participation experiences of bereaved parents, Dyregrov (2004) found that the structure of the in-depth interviews assisted participants in their reconstructing and re-ordering of meaning. Participants "stressed the importance of telling their story 'from the beginning to the end'" (Dyregrov 2004:397) which they experienced as beneficial. While this research was not aimed to facilitate adaptation to the experience of bereavement, it has been noted by narrative researchers that involvement with narrative research may have unexpected benefits (Stuhlmiller 2001:78). In narrative research the participant is given the space and time to develop coherent representations of their experience as they further develop their stories with each telling (Harvey, Stein & Scott 1995).

The interview gives the participant a place and time to explore meanings around the events in their lives, whilst allowing the researcher access to the layers of meaning contained through the story. Narrative research

methodology acknowledges the participants in interviews as being co-constructors of the narratives that come to be formed and told in the interview (DeVault; 1999; Riessman 2002). The researcher becomes the audience during the telling and therefore exerts some influence by way of their presence and responses to the participant. An example includes the researcher framing responses around certain material which may then come to be explored further, whilst other aspects may be ignored.

Both participant and interviewer work together as they dialogue, asserting the relational nature of the research endeavour (Riessman 2002). Each time a story is constructed, new meanings may surface for the teller as patterns and new awarenesses emerge. This process tends to be a circular, ongoing process that evolves with each telling:

The ongoing and evolving nature of personal narratives is openly acknowledged in narrative approaches to research....The process of telling one's story in an interview setting contributes to an altered understanding of that story for the teller. In effect participation in research influences the narrative of the research participant. The researcher then becomes a collaborator in the new and evolving story (Gilbert 2002:225).

Narrative methodology acknowledges that there is a temporal sequence (Mishler 1986; Riessman 1993) to the stories that people tell whilst noting that people do not always begin at the beginning, and may jump around moving back and forth in time when constructing their stories. For example spoken narratives may differ from those produced in formal socio-linguistic language where there is a clear chronological sequence comprised of a beginning, middle and end. Spoken narratives tend to be less formal, more flexible, and the chronological sequence may be disrupted, re-ordered,

disputed, with the emphasis shifting during the course of telling one's story (Ollerenshaw & Creswell 2002; Polkinghorne 1995).

Some narrative theorists such as Lieblich and colleagues (1998) have developed a model for organising the various approaches to narrative analysis. They divide the approaches into four categories that intersect along two dimensions. These are: a) holistic-content, b) categorical-content, c) holistic-form, and d) categorical-form. The holistic-content approach is used in life story research, where the story as a whole is the focal point with an emphasis on the content. In this approach the researcher reads the text over and over to see if patterns emerge, and to also obtain a "global" impression of the text. When exploring the data the researcher looks for indicators of significance that may indicate the presence of rich, meaningful material.

Potential indicators of significance include the teller's use of repetition (ie. the number of times an aspect of the story may be referred to or repeated). Other signifiers include the presence of contradictions in what is said, along with the way words are stated (ie. does the tone match the content) (Riessman 1993). The researcher examines the variations in the amount of detail in aspects of the story. Here the focus is on what is emphasised, compared with what may be understated or left out (Riessman 1993). The context surrounding the story and movements between story aspects are also attended to in the process of the analysis.

In a holistic-form approach to narrative analysis (Lieblich et al. 1998), emphasis is on the structure of the plots that the narrator constructs and how position(s) the teller takes may change over time. There are three basic plots which include the *progressive plot* such as the protagonist overcoming obstacles, the *regressive plot* which has also been named a “tragedy” involving a downward turn. The third plot type is a *steady narrative*, represented by an unchanging line; however, most narratives contain a combination of all three which unfold in a variety of ways (Lieblich et al. 1998). The holistic-form or *structural analysis* approach is also suited to life story work with its strength in framing and facilitating the understanding of transition. In this approach the researcher asks what stance the narrator takes in their construction. The researcher may construct a graph for participants plotting their structural movement over particular themes which can then be compared.

The form of the total life story is thus proposed as a key to understanding the personality of the teller than perhaps is deeper than the manifest contents and probably less given to falsification of different kinds (Lieblich et al. 1998:110).

While tellers may shape the content of their stories for their audience, they are less likely to shape the stances they take.

Categorical-content approaches to narrative analysis break the text into smaller parts (Manning & Callum-Swan 1994) which may then be analysed (Lieblich et al. 1998). This approach has been traditionally titled “content analysis”. The fourth approach: categorical-form involves the breaking down of the text from which certain parts may be analysed for their form. This approach is more interested in the way the teller

constructs their arguments, or point of view, than the actual content (Tetlock and Suedfeld 1988). The focus is on aspects of the text rather than the story as a whole.

One caveat the Lieblich and colleagues (1998) emphasise in their model delineating the approaches to narrative analysis, is that the dimensions described are not always clear cut and that content and form can be connected. Lieblich and colleagues (1998:169) advocate that some overlapping between the four approaches occurs when successful narrative analysis is employed.

The narrative approach I have selected draws from the work of the cognitive theorist and narrative architect Jerome Bruner. Bruner (1986) identifies two different ways of knowing. The first is titled: “paradigmatic type” which is based on the traditional scientific model in its emphasis on procedures for establishing formal and empirical proof. This form of thought is well known within the sciences and mathematics and involves issues of logic and timeless truths.

This second “narrative type” mode of thought is argued to be much lesser known than the first. The “narrative type” is concerned with human experience, human action and the construction of story, within the context of a situation. In differentiating the narrative mode from the paradigmatic Bruner states:

...[narrative] deals in human or human-like intention and action and the vicissitudes and consequences that mark their course. It strives to put its timeless miracles into the particulars of experience, and to locate the experience in time and place (1986:13).

The results produced by the narrative mode differ significantly to that of the “logico-scientific” paradigmatic mode. Narrative results lead us to “good stories, gripping drama, believable (though not necessarily ‘true’) historical accounts” (Bruner 1986:13). Good stories result from the way in which the teller arranges (and links) events and experiences into a coherent account. Within the narrative type there are two integral processes that operate together, yet are distinct which he calls “landscapes” (1986:14).

These “landscapes” are each constructed simultaneously, in relationship to the other (1986:14). The first “landscape” involves the unfolding of the events, and includes the characters, situation, aims and results of the story. The second is concerned with awareness and meaning. Included in the second “awareness” or “consciousness” landscape, is the story of what is felt and thought about the unfolding events by the characters and or narrator. Gaps in awareness such as what characters might overlook, or ignore are incorporated into this “landscape”. Contradictions that occur through the telling of the story are also examined.

Polkinghorne (1995) reconceptualises Bruner’s model by applying the two above listed cognitive modes to describe two approaches to analysis, each placed under the umbrella of “narrative research”. Polkinghorne (1995) asserts both types of narrative thought use stories provided by

participants to understand their life experiences. The paradigmatic approach to narrative research involves the analysis of stories provided with the aim of uncovering common attributes across the collected data with the eventuality of forming a system. Commonalities are grouped into categories, or typologies that maybe further reduced for computational analysis. Polkinghorne states:

Paradigmatic analysis provides a method to uncover the commonalities that exist across the stories that make up a study's database. It functions to generate general knowledge from a set of particular instances (Polkinghorne 1995:14).

The above approach appears to be limited by its seeking commonalities at the expense of varying individual experiences.

The second (also) lesser known group is the "Narrative-configurational" analysis type. Narrative analysis gathers events and happening as data to produce a descriptive story organised by a thematic thread or plot (Polkinghorne 1995). Emphasis is less on "truth" and more on meaning and believability. The outcome of narrative-configurational analysis is the production of a story.

I will be using Polkinghorne's approach to data analysis which focuses on synthesising the data to reveal connecting themes in the storyline (1988:177). The product of this approach to narrative analysis is a constructed story "which organizes the data elements into a coherent account" (1995:16). Polkinghorne uses the terms storyline and plot interchangeably describing the plot as the "glue that connects the parts

together” (1995:19). During the process of narrative analysis there is a continual recursive movement between the data and the re-constructed text to check the appropriateness of the fit between the two. When assessing the researcher’s reconfiguration Polkinghorne argues that:

The final story must fit the data while at the same time bringing an order and meaningfulness that is not apparent in the data themselves...In generating the story, the researcher needs to attend to the contextual features that give specific meaning to events so that their contributions to the plot can be understood (Polkinghorne 1995:16).

The focus in this approach is on how events are emplotted within the story – that is how the participant constructs meaning around the events and weaves them together. The result being that the researcher (re)constructs a story from the participants’ stories. Polkinghorne’s (1988) approach can be conceptualised within Lieblich and colleagues (1998) first “typology” titled: holistic content.

When narrative methodology was selected, the researcher was confronted by numerous choices. There is no one set way of carrying out the work of a narrative study (Gilbert 2002; Lieblich et al. 1998). However, Polkinghorne’s (1988; 1995) approach to narrative analysis provided a clearly defined framework for gaining access to the meanings participants construct around life events and happenings. As stated above, Polkinghorne’s approach foregrounds the ways in which participants’ link events into their story of experience (emplotment). This approach also foregrounds the context(s) surrounding the participants allowing the researcher access to meanings around why a story is told in a particular way (Riessman 1993:61).

One caveat in the use of a narrative approach is that much time is needed in order to gain access to the subtleties that may be present in the multi-layered texts (Mishler 1986; Riessman 1993). An often cited criticism of the narrative approach is that it is “long on theory and short on practice” (Minuchin 1991:47; Neimeyer & Stewart 1996). I found wading through the potential approaches to data analysis offered by theorists and researchers connected with these schools perplexing, and at times overwhelming. Most text on narrative focussed on theoretical orientations of approaches whilst relatively few texts examined the application of analysis.

Data collection

This section details the steps taken and approach used in sampling, recruiting participants and collecting the data. The interviews took place between January 2004 and October 2005. As presented in this chapter, I have used a narrative approach that allows for each participant to construct their experiences of bereavement through telling their story (Gilbert 2002). Each interview was recorded onto audio tape. Following each interview notes were taken by the researcher that recorded her impressions, and details of the interview. In one incident the final section of a tape failed to record and therefore hand written notes were relied upon with regard to this participant’s experience of counselling.

Sampling

In this study, purposive sampling was used (Llewellyn, Sullivan & Minichiello 1999:188). All participants in the study were identified by a bereavement therapist as having suffered a difficult grief reaction. The palliative care bereaved participants, had each been identified as being at risk of suffering from a difficult grief reaction around the time of death. Palliative care bereaved were given a high risk assessment prior to the commencement of counselling through the application of a “bereavement assessment risk factor tool” (BART). During a meeting in which deaths during the previous week are discussed, “BART” is employed to consider those who may be at a higher risk of an adverse bereavement outcome (Parkes 1972; Sanders 1993; Stroebe & Stroebe 1993).⁵

There are factors that limit BART’s effectiveness in its application. The most important of these concerns the varying amount of information that has been gathered by medical staff as they treat palliative care patients and families. The referral of patients into palliative care often varies in terms of the point at which referral occurs along the trajectory of the patient’s illness and death. It is not uncommon for patients to be referred just hours or days prior to their death. In these instances the palliative care team have highly limited access to the patient and family so that information gleaned that may assist in the application of BART is minimal.

⁵ BART” is comprised of 54 evidence based risk factors that are grouped in several clusters and have been created from an evidence based review of the risk factor literature. Each cluster emphasises an area of possible risk. Examples include: ill health in the bereaved, exposure to prior losses such as prior bereavement or divorce; history of mental health problems. The last section of “BART” considers the interpersonal context of the bereaved. The degree to which the bereaved is perceived to be isolated from a supportive context is considered. A copy of BART is provided in appendix 1.

The sample also included two participants whose significant other had died suddenly and unexpectedly. Since 2002, those suddenly bereaved have been included as recipients of therapeutic intervention by the Central Coast Bereavement Service. These bereaved enter the service through referral by GP's and hospital Social workers. Referral occurs when there is concern that the bereaved may be at elevated risk of a difficult grief outcome.

The participants had each attended at least six counselling sessions, and had been perceived by the nominating counsellor to have benefited from the experience through showing improvement. The term improvement was overtly stated, however not explicitly defined by the researcher. This was left to the assessment and discretion of the therapist. Implicit in this term is the sense that the bereaved may have displayed improvement by exhibiting fewer symptoms by the succession of counselling, including exhibiting lower levels of distress than were displayed when counselling began.

Recruitment

The researcher sent counsellors working within the Central Coast Area Health Bereavement Service a letter explaining the project. Counsellors were invited to locate completing clients who they believed had suffered a difficult grief reaction through exposure to the death of a significant other,

who had shown a positive response to counselling. The counsellors were provided with information sheets⁶ to pass on to those fitting within the above parameters. The information sheet for potential participants stated that the researcher did not have access to client's personal contact details, and that those wishing to be included in the study would need to contact the researcher. The researcher's contact details were provided in the information sheet. All who were invited to participate in the project accepted the offer with no person declining.

Potential participants were assured that their treating counsellor was independent of the research. Those deciding to accept the invitation to participate had the freedom to withdraw from the project at any time. The information letter explicitly stated that any decision to cease involvement in the project would be respected without question. Also included, was how to decline the invitation to participate from the outset. All that was required was for the invitation to be ignored and no further contact would ensue. The letter emphasised that declining the invitation would have no impact on future opportunities to gain access to counselling services.

The first contact with prospective participants occurred over the phone and involved talking through what was involved in the project. During this call each person was assured (for a second time) that they were free to change their mind and withdraw at any time. The aim was to create a relaxed atmosphere, so that by the time the interview took place,

⁶ Information sheets are provided in Appendix 2 of the thesis.

participants felt more at ease to tell their stories. I tried to make the interview as conversational as opposed to interrogative. Participants were assured that they could stop the interview at any time or refuse to answer questions. Participants were invited to choose their own pseudonym for themselves and the deceased.

Following telephone contact, an appointment was made with two participants (individually) to meet to discuss the study further, following which an interview appointment was scheduled. Others were happy to make an appointment for the interview without meeting beforehand. Each participant was offered choices as to where they would be interviewed with the majority opting to meet at one of the Bereavement Counselling Centres. Only one participant requested to be interviewed in their home.

Sample Characteristics

The sample comprises of five women and three men (a total of eight participants). These participants represented a range of experiences, from the sudden unexpected death of a young child, to the death of parents, and spouses through a palliative care setting. Two of the eight participants were exposed to the sudden/unexpected death of a loved one.

The length of time between diagnosis and death varied amongst those who died within a palliative care setting from 8 weeks to 17 years. Each participant who lost a spouse (five) had been in a long-term relationship,

with all being first marriages. At the time of the interview each of the spousal bereaved was still single with three participants (two women, and one man) speaking of being open to new partner relationships.

The length of the counselling relationship varied considerably ranging from six months to four years. The frequency and total number of sessions taking place over the length of this relationship also varied. Beginning sessions tended to occur at shorter, more frequent intervals (eg. weekly) in the beginning phase of treatment, with sessions being spread out further apart as time progressed (eg. monthly). Information on some of the study sample's characteristics is provided in the table 2 below.

Narrative Interviewing

The researcher adopted an interview approach consistent with a narrative framework. The Interview guide was organised temporally to invite participants to tell their stories. Interview questions were designed to follow the bereaved person's experience beginning prior to the diagnosis/onset of illness moving through to the experience of the death following on to the participants experiences of counselling, and of continuing life at the time of the interview.

The in-depth interviews ranged from one to one and a half hours per interview. Emphasis was placed on the style of the interview as conversational as opposed to interrogative. This approach was taken as an attempt to minimise the hierarchical power imbalance between the

researcher and participant (Riessman 2002) through giving choices where possible. An example of choices given to participants included explicit acknowledgment of their right to refuse to answer any question; to answer questions with as little or greater depth as wished; to stop the process/interview at any time without question; and to choose their own pseudonym for themselves, the deceased and others in their account.

Table 2. Participant Demographics
(Participants are listed in the order in which they were interviewed).

Alias	Relationship Of Deceased to bereaved	Length of time: since death (at time of interview)	Length of Counselling Relationship	Number of Sessions (approx)	Bereavement Circumstance (trajectory)
Helen	Spouse	6 years	24 months	20	Palliative Care – Long >12 Years Leukemia
Janice	Spouse	5 years	4 years	40	Palliative Care – Short <8 weeks
Brenda	Father	1 ½ years	12 months	40	Palliative Care – 12 Months
Vera	Spouse	2years	6 months	8	Palliative Care – Short <8 weeks
Fred	Both Parents	2 years	16 months	18	Palliative Care – Long + Extended
Peta	Child (son)	2 years	20 months	20	Sudden/Unexpected Death Cause– Unknown
Wilhelm	Spouse	9 months	8 months	18	Sudden/Unexpected Death
David	Spouse	12 months	8 months	14	Palliative Care – Cervical cancer

Participants were asked four open ended sequential questions. The first question opened up the topic, starting prior to the death: 1) Can you tell me how you came to experience the illness and death of (deceased’s name)? The second question followed on: 2) Can you tell me about your experience since (deceased’s name) death? The third question introduced the topic of the bereaved’s experience with counselling asking: 3) How did

you come to receive counselling? The final question asked participants to expand on their experience of counselling: 4) Can you tell me about your experience of counselling?⁷

I followed the above format, expecting that the interviews would flow through this logical, sequential order. However, I found that even though the questions were ordered, designed in such a way to facilitate the telling of the participant's story, what occurred during the process of the interview, was that the questions appeared to disrupt the flow of conversation resulting in a disjointed response from the participants. Participants tended to have answered part of the follow—on question, which left them, and myself ducking and weaving to fill in gaps. In some cases the participant had answered parts of several questions, so that the asking of follow-on questions left both of us with awkwardness whilst interrupting the process. The researchers attempt at adopting a sequential order to the generation of interview talk was imposing and not necessarily facilitating the participants exploration. This has been noted by narrative researchers in the field, including Riessman who states:

...I realized that participants were resisting our efforts to fragment their lived experience into thematic (code-able) categories—our attempts to control meaning...although participants resisted our efforts to contain their lengthy narratives, they were very aware of the rules of conversational storytelling (2002:695).

² At the bottom of the interview guide were four prompts aimed at stimulating further conversation aimed at facilitating the further exploration of the participants experiences. The prompts were: Have there been any important or significant points since the death?; How has the (deceased person's name) death impacted on you?; How do you see yourself now in terms of where you are at?; How do you experience your life now?

Narrative researchers note that in spite of the efforts of researchers to guide and focus their participants responses through artful questioning, and clever probes, participants often defy such moves, choosing their own (often lengthy) pathways in the answering of questions (Neimeyer 2001; Riessman 2002). Sometimes the above efforts block the flow of the story as opposed to facilitating its telling. This is consistent with what I experienced during the interviews. At times I found my responses appeared to disrupt the participant's thoughts obstructing the flow of the interview.

Finally, prior to the last interview I decided to print out the four open ended questions which I sent to the participant two to three days prior to the interview, giving them the opportunity to tell their story without imposed breaks. The participant was asked to cover the areas listed in the four questions, but was free to tell the story in their own way. The resulting flow was much improved in contrast to previous interviews. This format also gave control back to the participant – so that they were free to shape their constructions of their experience.

As stated earlier, the researcher influences what is constructed, through a multitude of factors from responsiveness, and warmth to body language, levels of confidence in what they are doing (Polkinghorne 1991), and timing. By communicating a “quiet enthusiasm” that embraced what participants said, it was hoped that this would result in less guarded responses:

The quality of the data developed in an interview is dependent on the skill of the interviewer, the reflective and recollecting capacities of the interviewee and the relationship that is developed. The interviewer has an effect on subjects and the level of description they produce. Positive interviewer effects are those that encourage subjects to overcome the propensity to give guarded and socially desired descriptions (Polkinghorne 1991:188).

The physical environment where interviews take place may contribute to the safety and respect participants experience (or conversely leave them feeling intimidated, or uncomfortable). Giving participants choice over the place of interview was an example of steps the researcher made in attempting to convey respect.

Narrative Analysis of the Data

Each of the interviews was tape recorded then transcribed by the researcher. As I transcribed, I noted words and statements which were emphasised with bold type, and notes. These included words which were stated loudly, quickly or alternately were whispered or stated slowly. I noted questions that I thought of as I transcribed in the “notes” column.

The gaps and contradictions in participants’ accounts were highlighted and underlined and considered for significance. Omissions from a story can signal the presence of important implicit themes – that contribute to the overall meanings that are part of the narrative. Other markers indicative of the possible presence of significant themes or issues concern the flow of speech (Gilbert 2002). Participants changing the pace, or pitch or intonation of their speech - may signal to a narrative researcher that there is possibly an area of significance being raised by the participant which deserves further consideration and analysis.

I experimented with arranging the texts to work at gaining access to the deeper meanings contained within them. Gee's (1986; 1991) approach was drawn upon, whereby the interviews were arranged into stanzas resembling poetry. In this approach certain aspects of the texts are excluded such as pauses and non-word utterances which can be distracting. The events contained in two participant's narratives were placed along time lines to look at the movement and structure of the plots including the stances the participants took in their story (Lieblich et al. 1998; Riessman 2002). Another way of analysing texts involved colour coding each temporally and thematically. The interviews were then reprinted in the reworked format to check for meanings. This method highlighted significant aspects of the text as repeated parts of the stories were easier to identify.

Whilst looking for connections in the collected data, I also paid attention to the uniqueness of each person's lived experiences, including how meaning was constructed, challenged, or struggled with. Both patterns and unique variations in the stories constructed were explored. I noted where diversions occurred, where a change in focus appeared to alter the direction of the story. This attention to diversion allowed me to access to subtleties in meaning that would have been missed through differing approaches.

Whilst analysing the transcripts, I returned again and again to the texts noting variations in the ways they might be read. Drawing conclusions tentatively whilst exploring alternate possible interpretations drawn from the texts was used to minimise the potential for narrative smoothing (Clandinin & Connelly 2000:181). Each participant's story was reconstructed and is presented in the following chapters of the thesis noting the uniqueness of their experience. Core themes identified through the analysis of the collected interviews where the experiences of participants overlapped and blended have been written up in chapter five on group storylines.

Introducing the researcher

Because constructionists reject the notion that research, and the researcher can be neutral, it is therefore important that the researcher openly disclose and acknowledge themselves as they form part of the surrounding context which impacts on the study (Clandinin & Connelly 2000:45).

I am a full time counsellor employed by The Northern Sydney Central Coast Area Health Service to provide bereavement counselling to those exposed to the death of a significant other. I have been working in this position since the beginning of 2003. Prior to this position, I worked as a counsellor in a non-government agency in the area of domestic violence. I also worked as a couple's counsellor during my time in this agency. In the

position of bereavement counsellor I work with adults and children (and families) exposed to bereavement.

I am in my late thirties, and was born in metropolitan Sydney, Australia. Over the years I have experienced loss from a distance and through vicarious means. A distant relative of mine died as an infant in tragic circumstances when I was five years of age. Others in the church community where I grew up died of cancer, old age, suicide and through motor vehicle accidents. This environment seemed to both support and yet place pressure on the bereaved to be at a place where they no longer displayed sadness, or spoke of the deceased.

Deaths were often avoided and not openly discussed following the funeral. The underlying motto for the bereaved was: do not wallow, do not talk too much, move on and get on with life. I had not really been aware of this attitude to bereavement until training as a counsellor, and beginning work with clients who were bereaved. Up until this point I had tacitly agreed with these values and underlying beliefs.

I am particularly interested and invested in the topic of bereavement. As a clinician in the field encountering grieving clients, I aim to work effectively with them, assisting their adaptation in ways that are safe, respectful and empowering. It is hoped that the results from this project will support the development of clinical work with the bereaved.

The experience of bereavement is highly personal, and at times highly emotive. Each of the stories I heard had tragic elements to them. Because of my full time work in this field, coupled with the research project being focussed on bereavement, I found I was being saturated with stories on grief. It was therefore important for me to consider the issues of self-care.

Gaining access to support – throughout the research process was imperative. This support occurred at a number of levels comprising of: 1) supervisors: both academic and clinical. Clinical supervision occurred monthly and became a context in which I was able to debrief following interviews with participants, as well as reporting on struggles encountered during the research process.

Collegial support has also been important. A colleague of mine who has completed a qualitative research project, and who is also a trained counsellor provided an important supportive role in debriefing. I was able to connect with her knowing that she was not affiliated with either the project or my work setting. This formed a less formal, but important resource which I was able to utilise when needed.

Finally, having time out with friends, and having fun with my son and family have been vital in keeping a sense of balance and perspective through the project. Balance has not always been easy as I have had my own health problems occurring at different points along the project trajectory.

As previously discussed, context forms an important part of a narrative research approach. Because “the construction of any work always bears the mark of the person who created it” (Riessman 1993:v) it is important to acknowledge the resulting interviews were influenced by the researcher’s responses, and the nature of their presence (Lieblich et al. 1998). The researcher’s presence is influenced by their own cultural context, personal history and values. Narrative researchers acknowledge that another researcher coming into the field may look at the same interviews and find their analysis of them yields differing interpretations. For example, Reissman (1993) argues that it is important that the researcher situate themselves, foregrounding the thoughts and concerns that have led to the development and shaping of the project in order to “open up these interpretive issues for readers to see” (Riessman 1993:61).

Ethical Considerations

Ethics approval was sought and gained from the ethics committee at the University of New England in 2003 (approval no. HE03/154) with minor modifications to the original application being required. Because this study has been carried out within the context of an area health setting, ethics approval (approval no. 03/42) was sought and gained by the area health service prior to the commencement of the study. No payments were offered to participants.

Because of the sensitive nature of the research topic, it was important to provide as many safeguards as possible to prevent and minimise potential distress caused to participants. The information sheet sent to potential participants was as informative as possible, outlining both the purpose of the research, and what was required in order to participate. It was noted in this letter that there was a possibility that the interview could cause distress to the participant, and that should it do so they were free to stop the interview, refuse to answer any questions and withdraw from the process at any time. The researcher offered to contact the participant within two days of conducting the interview to check on the participants level of comfort following the interview, with the aim of referring distressed participants onto appropriate supports. No participant reported feeling distressed as a result of the interview.

Additional contact numbers which participants could ring were placed in bold type on the first page of the information letter which all received prior to the interviews. The numbers listed included the Area Health's bereavement counselling service where counselling support could be obtained, and Lifeline's 24-hour telephone counselling service: 131144.

Unfortunately one of the participants died suddenly a year after being interviewed. At the time I had not fully analysed the transcript, during which I had planned to seek her response to the analysis for the purposes of accuracy.

A major ethical concern with all research that involves human participation is the safeguarding of anonymity. Several measures were taken to ensure that participants identity was protected. Firstly, participants' names have been changed along with any identifying information such as the names of places and other people. One of the participants was particularly concerned about protecting their anonymity, and so time was spent working with the participant about how best to mask aspects of the story that might lead to their identification.

A further step taken to safeguard the rights of participants was the explicit listing of the supervisor's phone numbers, and email addresses, along with that of the supervisory body overseeing the project. This was provided openly to the participants offering them a direct avenue if needed, to raise possible concerns or complaints regarding their involvement in the project.

Finally my number was listed along side an invitation for participants to contact me in the event of concerns or queries being raised regarding any aspect of the research. An annual report has been submitted updating the Area health's ethics committee on the progress of the research project.

Limitations

Narrative analysis is not a simple, prescriptive approach. "Narrative analysis assumes a multitude of theoretical forms, unfolds in a variety of

specific analytic practices, and is grounded in diverse disciplines” (Daiute & Lightfoot 2003:7), from literature to history, psychology and the social sciences. Narrative analysis is also time consuming, involving meticulous attention to the layered, implicit meanings that may be embedded in a text, and is not suited to be used with “large numbers of nameless, faceless subjects” (Riessman 1993:69). The impact of this methodological limitation was reduced by the design of the study which took small numbers of participants focusing in-depth on their experience.

Like other narrative studies, the sample size of the research has been small. The sample was not drawn from a representative pool, as a specific group of people were sort through use of purposive sampling. The results cannot be used to assert generalisations about how bereavement or counselling will be experienced because of the above reasons.

While acknowledging the above, narrative researchers draw attention to the fact that significant theories have been built from the “close observation of a few individuals...There is a long tradition in science of building inferences from cases” (Riessman 1993:70). The findings obtained have the capacity to inform the literature on the possibilities of what might be encountered or experienced through being bereaved.

Narrative researchers acknowledge that all texts are “plurivocal” (Rabinow & Sullivan cited in Reissman 1993) meaning that there are many ways to read a text. The significance of this is that another researcher interpreting

the recorded data in the study may form differing opinions, and reach alternate conclusions. Additionally the researcher's work is influenced by their particular social, historical and cultural context. While narrative theorists view the person as an agent interacting within their context (not just a product of their context), the influence of situation needs to be acknowledged as part of the lens through which the researcher constructs. In other words "there is no 'view from no where'" (Nagal cited in Riessman 1993:15). In order to minimise the impact of this limitation, I have foregrounded myself as the researcher to make my situatedness as transparent as possible.

The data collected for this study is cross-sectional, collected at a historically situated single point. However, peoples narratives as stated previously, are in a constant stage of movement as they are renegotiated, and reconstructed within their surrounding contexts. In this way the research is limited as the results represent a fixed point in time. An interview taken at a different time in the participants life would yield differing results.

This chapter has detailed and justified the approach taken to answer the question of how those exposed to a difficult bereavement move from their distress to adapting to their loss. The following two chapters present the findings from the research. Chapter four (the next chapter) focuses on presenting each individual participants story of their experience. Chapter

five presents the group storylines constructed from the overlapping individual stories.

Chapter 4

INDIVIDUAL STORIES

As discussed in the previous chapter, I have selected a narrative approach to this research because it most closely fits the aims of developing an understanding of people's lived experience of bereavement (Gilbert 2002). Personal narratives are arguably an important part of grieving because they "bring diverse elements of experience, thoughts and feeling together into a unified whole...creating order in disorder and establishing meaning in what can seem a meaningless situation" (Gilbert 2002:227).

In this chapter I want to honour the individual participant's story, paying attention to the way in which they weave and piece together the diverse, seemingly disparate aspects of their lives (Polkinghorne 1995). At the same time narrative approaches to research acknowledge that these stories are like "snapshots" of lived experience captured cross-sectionally at a particular moment in time, on a particular day with the researcher as the audience (Riessman 1993).

The participants are presented in the order in which they were interviewed. While I have tried to convey some of the essence of each interview by including my initial impressions about our meeting that day, I

have made efforts to allow them to tell their story from their perspective. This allowed stories to unfold chronologically beginning with their experience prior to the actual death, moving through to life following bereavement up to the point of the interview. I have tried to convey a sense of the participants' experience of their prior relationship with the deceased, as well as other significant relationships impacting on their experience. The participants' experience of counselling is also included as part of their narrative.

Helen

Helen was the first participant to be interviewed. I was fairly nervous and still learning how to use the recording equipment at the time. Helen was happy to be interviewed in one of the counselling rooms at the main centre of the Central Coast Palliative Care Service. Helen was aged around 60 at the time of the interview, and she presented as a confident and articulate woman. During the interview her voice frequently changed pitch from loud to soft as she emphasised parts of her story, capturing my attention. Helen was born in the UK and arrived in Australia around the age of nine. She had retained an English sounding accent, which had a regal quality to it, contrasting sharply with my local accent. I was not at all surprised when I later found out that Helen had been well educated.

Helen told me how she had lost her husband George 10 years previously in a palliative care setting. Her husband was diagnosed with cancer 17

years prior to his death. During the long illness Helen's husband had several brushes with death spending periods in intensive care where he was not expected to survive. George's illness intensified during the final three to four years of his life. Helen mentioned avoiding obtaining help or support from palliative care until George was at the end of his life saying: "because I was reluctant to have them in the first place" (Helen, 423). However, the reasons for this were not provided. The couple had two children who were teenagers around the time of their fathers' death, both of whom lived at home. Hearing the diagnosis left Helen feeling stunned:

The point of diagnosis was an absolute shock, one of panic...I had him dead, I walked around the house saying 'what am I gonna do'...it was like a real place of this is not happening, he's dead, he is gonna be dead, what am I going to do, panic (Helen, 47-63).

Over the years following diagnosis, Helen and George reduced contact with others in their social network particularly as the illness progressed. This was partly due to George's increasing vulnerability to infection, and partly because of decreasing energy for connecting with others:

He was ill for a long time. As a family, we had I think withdrawn a lot from social interaction. We didn't have a great deal of connection with people outside, a few friends, not a great number, but a few people. And as he got more and more ill, people came less and less, because they'd ring up and sort of say, oh we, you know so and so, he'd got a bit of a chill and we don't want...and that's fine. So people had begun to withdraw and we had begun to withdraw (Helen, 393-402).

During the final three to four years of George's life "things got more intense" and Helen and her children faced a movement back and forth between death, and life as George became critically ill on several occasions, during which he was not expected to live:

We've had the minister come, basically yes, at that point he would die (pause). And he came back (pause) and then he would die, and he came back. We had several; I think three or four of those occasions (Helen, 78-84).

As George's condition worsened, and he spent more time in hospital the family stopped engaging in activities. For example Helen and the kids no longer went on vacation:

The intensity of the focus...was so much on him...that everything else had moved out of vision, out of experience. This is where every moment of my thought and energy had been...as he got iller and iller...we'd actually lived at the hospital...our whole experience was just that...nothing else existed in our world (Helen, 228-242).

Helen's experience of her husband's death was complex and conflicted. Shortly before his death Helen was approached by the palliative care doctor who had noticed George was unsettled. The doctor indicated to Helen that her reassurance of it being okay to die might assist George to let go and die. Helen took the specialist's advice and gave her husband permission to die, whilst feeling inwardly torn about the decision: "words were spoken but...not heart felt[ly] so, cause that's not, none of us wanted this. But anyhow we said those words". Helen (and her children) were not ready for George to go. As I reflected on the interview, and pored over the transcript I wondered if Helen's avoidance of palliative care was connected with the difficulties she faced in accepting the reality of her husband dying. I wondered if her resistance allowed Helen to feel more in control of the situation.

Although George was in a hospital, the staff agreed to the family's wishes by allowing him to be wheeled out to the garden which became the place where he died:

Now, his actual dying moments, were beautiful moment...he was out in nature which he loved...it was a very beautiful moment. He sort of drifted slowly. And when he actually died, there was a real calmness...we were

all very calm. It was a funny thing because it was a nice experience. It was a really lovely experience (Helen, 99-105).

Helen and others close to the couple were allowed time with George in the garden following his death. This peaceful picture contrasts with Helen's later reaction to the death after George's body was returned to the hospital room and laid out for Helen and close others to view. After a while Helen decided it was time for people to leave so that she could say a final goodbye. When it was time to leave her deceased husband's side, Helen described hearing herself scream as though it were someone else:

...this huge NO came out of me, this Big Scream, came from somewhere, but it wasn't...it was there. The children in the corridor, my mother all those people they got worried, called the nurses, a couple of nurses came in, I was totally unaware of their presence. It was just this enormous, enormous noise. So they got the nurses, they came into the room and all of a sudden I thought: I can hear a noise, and it was my own noise (Helen, 135-147).

Helen found herself being comforted by the nursing staff who stood alongside her patting her arm. When Helen left the hospital and went home, she described feeling a sense of unreality and being enveloped by shock and fear. She described feeling disconnected from the world.

Following George's death Helen was faced with attending to practical tasks which included arranging the funeral and dealing with banks and other institutions. Pouring her energy into completing tasks allowed Helen a diversion from her emotional world:

The funeral stuff, all of that stuff was 'business had to be attended to'. And for me it felt like I locked into...things to be done. The practical, the practical, the practical...Somehow that was not emotional that was just practical (Helen, 263-271).

Helen did experience frustration when dealing with institutions. However, she found carrying out practical tasks:

...comfortable because it did take some of the pressure away. In a sense it took away the feeling of the loss because now I'm busy doing something (Helen, 292-296).

Helen felt she had "become a robot" (287), completing one task after another in a mechanical fashion stating: "Okay, [I] have to do this, have to do this, have to do this...And that, that, that, that, that" (Helen, 273-290) (said whilst pointing to a different place in the room with each word "this" and 'that'). The tasks gave Helen a purpose and focus that for her had its benefits in helping her avoid more painful feelings:

...And that became the focus of what I did then. It didn't feel hard for me. I don't remember it feeling difficult...In a sense it took away the feeling of the loss, because now I'm busy doing something, and being busy it was okay. Because it was also a way of avoiding, and not having to be aware of it (Helen, 276-331).

After the funeral, Helen said she experienced futility and angst. Helen's sense of self and sense of direction had merged with her relationship with George and her role in caring for him. With George gone Helen now faced issues of meaningless and disorientation. Who was she now and what was she to be? Helen's solution to her futility and purposelessness was to transfer her energies and focus to her two surviving children:

He was gone...I have no meaning!...Ah! I do I have kids! So now they became...a purpose for my living (Helen, 317-319).

Helen clung to her children and avoided leaving the house. On one occasion Helen and her children ventured out to pick out a frame for a photograph. The experience was uncomfortable and her senses seemed acute. The outside world felt foreign and unfriendly:

I remember feeling an overwhelming sense of intrusion. The noises were loud noises. The traffic was louder. The people were crowding...it was

like this overwhelming into the senses of stuff, and it was awful. So we got in the car, went home, shut the door, Oh, and felt relief (Helen, 205-212).

One strategy Helen used in coping with her grief was to maintain her focus on George through improving and maintaining the family home and garden. Helen and George had planned and completed the house together after purchasing the building when it was at a “preliminary” lock up stage many years earlier. Helen involved the children in this project which also gave them a focus.

Some time later Helen went back to work, and the children returned to school. Helen found the routine of work distracted her from the pain of grief. However, her senses felt somewhat deadened and over time she experienced increasing flatness. Feeling numb, Helen was trapped and felt herself closed off from growing and developing:

It's like I came back into the world of work, and the world or ordinary routine, and it sort of dulled in some way...it became a monotonous and an empty living. There was now an emptiness that I was very sensitive and aware of and work began to fill a void...or I used it, I used work. I used what I was doing to avoid in a sense maybe moving on with this opening up of great things (Helen, 595-609).

Helen sought counselling around this time following an exchange between her self and the palliative care doctor. This doctor had been the only medical person to ask Helen how she was going, offering to speak with her if she needed. Helen approached the doctor at the time, thinking to herself that she was coping fairly well. However, he told her she had issues with rage and that she would benefit from counselling. Helen was shocked because she believed that she was a calm person. Not completely convinced, Helen still decided to act on the recommendation

and saw the suggested counsellor. Helen recalled finding the experience of counselling transformative, openly expressing wonder and amazement at the level of the therapist's abilities.

Helen talked about the counsellor in highly favourable terms; however, she did not explicitly describe the therapist's personal qualities except to state that he was skilled. Helen explained: "I was aware that I needed to talk quite clearly...and something in me and something in him allowed me to trust him" (Helen, 490-493). The counselling helped Helen to reduce her levels of distress, including the "deadness" she felt within which had enveloped her following her return to work after George's death.

Helen stated that she was shocked by what counselling uncovered for her: "I went and saw him, and "boy" did I have rage!! And that was a really big help to me" (Helen, 454-459). I was impressed by how "in awe" of the therapist Helen was. It was as though this person possessed magical qualities that were activated during her encounters with him. Helen discovered and experienced energy and aspects of herself that had been so out of reach she did not realise they existed:

It was so powerful, the whole, 'the screaming', the physical energy that I got in contact with, and I beat up, I mean...he had me laying on there...we were talking about something or other and he said 'and what would you have said?', and I would have said 'oh...no', and he said: 'that's a pretty feeble no – Say it like you mean it!' and I said 'no', he said 'Oh I can barely hear that one' and he made me keep saying no until it came to this huge crescendo, and when that big one came out it was like it opened up this, like the plug came out (uses large hand gestures) and UHhhhhh (Helen, 538-555).

The images in Helen's description above are powerful, resembling lava escaping after having been compressed deep underneath the earth's

crust. An explosion of anger was released when the “plug” came out. Helen’s voice reached a crescendo when stating the word “UHhhhhh” conveying her contact with her own energy, which she experienced as freeing. For Helen the block came from the inside (472). I wondered what had been behind the “plug”, perhaps underneath Helen had felt compressed. The plug had developed some time ago, and releasing it “opened up enormous things that I had over many years of course carried” (Helen, 461-462). Helen does not specify when the plug formed but stated: “It wasn’t just to do with my husband’s death but it certainly was the catalyst” (Helen, 462-463).

Counselling marked the beginning of the process of change for Helen. During the first session the counsellor listened to Helen then confronted her “seeing through this facade” saying “you are your own worst enemy...there it is, all locked here” (Helen points to her diaphragm) (Helen, 505-511). Helen recognised that he was right: “I knew that minute he’d said it, I knew that” (Helen, 511). Helen was then invited to “do some work”. She was taken into a separate “sound proof” room which had a mattress on the floor, and numerous objects such as telephone books. The therapist encouraged the expression of feelings. Helen described therapeutic work in powerful terms stating:

It’s like the lid came off, it’s like a pressure cooker...there was still stuff, but it [was] sort of like, it wasn’t under the pressure now. but it sort of felt like okay...it. I got rid of the high pressure (611-617), and the skill of these people is brilliant (Helen, 533).

Helen described feeling more alive as a result of facing her anger and pain through counselling. Helen was able to make contact with feelings she

had avoided for a long time. During this process the intensity of her grief was reduced and Helen began to explore who she was as a person, separate from the others who she tended to support.

Helen was able to recall both positive and negative aspects of her relationship with George. She neither idealised him nor held him in contempt. Her recall of him and their relationship together seemed rounded constituting an ongoing activity where she expressed both appreciation for his strengths and acknowledgement of aspects of his personality that frustrated her, she stated:

I imagine him in the way we interacted...in the fun times we had, in the arguments that we had; in the frustration of how he was...when he wouldn't do things and his lack of wanting to get into a good argument with me...those things are real. My husband was a very passive man (Helen, 720-727).

At the time of the interview Helen was still single but expressed being open to another intimate relationship. Helen is now retired, and works part-time as a volunteer assisting in a nursing home setting. My interview with Helen finished on a lighter, more positive note as she summed up her journey drawing attention to the paradoxical nature of bereavement. Helen acknowledged her struggle to grow through bereavement finding the experience both:

The worst experience of my life, whilst it's also maybe been a catalyst for the best experience in my life...and maybe that's because I've allowed myself to look at myself and sort of take myself in hand" (Helen, 962-971).

Janice

I interviewed Janice early one morning. She was softly spoken; her voice conveyed a sense of warmth and vulnerability. Janice had a gentle motherly quality to her and I found myself feeling at ease in her presence. Janice had lost her husband Lewis to cancer five years prior to the interview. At the time of his death he was aged just 57. In contrast to the lingering illness of George, Lewis declined rapidly following a diagnosis of advanced cancer that had metastasised in the liver and lung. Janice said she had reacted with disbelief and shock to the news of her husband's terminal illness. Lewis died only eight weeks after being diagnosed.

For Janice, the relationship with her husband had been painful and rocky at times. I had the sense that theirs had been an ambivalence relationship as she spoke of having separated on several occasions, sometimes for months at a time. Janice also spoke of affairs that her husband had had throughout their marriage. Whilst she did give permission for this information to be included, it was shared with me after the tape had been turned off at the conclusion of the interview. Janice expressed feeling helpless about her husband moving in and out of her life, telling me he had instigated leaving each time for the same woman.

Janice's voice became teary and wavered as she spoke of Lewis moving out of the family home on the fourth occasion and as she spoke her voice was deeply sad. Janice had experienced periods of prolonged flatness

and spoke of struggling with her sense of self stating: "Because I, I for me, for most of my life I've felt so inadequate...I was always negative" (Janice, 807). During the interview Janice explained that this changed for her when Lewis was dying and she found she was able to support and care for him feeling strength from within herself:

...but then when I knew he was dying it was just something transformed within me. A strength that came that, I was there for him. He even told me I was his tower of strength and for him to tell me that meant more than anything. That I was his tower of strength. I was always negative, but this time near his death I was his tower of strength (Janice, 808-815).

Janice seemed to gain purpose and closeness with Lewis following the diagnosis. He valued her care for him and openly praised her. These loving words meant a great deal to Janice as he lay dying. She valued the fact that he needed her and as a result experienced a deeper level of closeness that she had been longing for.

At the time he was diagnosed, both Lewis and Janice had been close to retirement, having planned to travel around Australia together, which had been an important dream Janice had looked forward to. This represented a significant added loss for Janice, the loss of her expected and hoped for future with Lewis.

When Lewis died Janice struggled with the decision regarding his body. Should he be cremated or buried? It seemed that cremation was more difficult to consider and that burial was a way of holding onto Lewis:

And it's like we wanted to hang onto his body a bit longer...Burial, burial, we all agreed on burial. If we could just have his body in the ground rather than the ash (Janice, 2-6).

Following the funeral Janice's feelings threatened to completely overwhelm her, as if it would have been easier for her if she too had died:

I was totally alone. If the ground could have opened up and the house go in like an earthquake, I would have been happy for that to happen (Janice, 168-171).

Janice's sense of self seemed to unravel with Lewis's death. She experienced palpable distress relating to a loss of direction and purpose which she described at several points in the interview:

I just sat on his grave and I cried and I cried. And I didn't know what was gonna happen to me. I didn't know what was, where I was gonna be in my life. I felt too, I felt helpless, that there was no purpose in life anymore...I felt totally lost; Totally lost. I had no ambitions to know what I was going to do with my life, and I just sat there on the grave not knowing where I was going to turn or what I was going to do (Janice, 119-124; 135-138).

Janice paints a strong picture in the above quote, in which she is completely lost and disoriented. Janice did not know which way to move and was very fearful. I wondered whether Janice's idealising of Lewis and the status of being in a relationship, meant that Janice negated, and devalued herself, resulting in her experiencing heightened vulnerability and fear. Her sense of self and dreams for the future seemed to have been embodied in her relationship with Lewis. I pondered whether this might have been a longstanding pattern for Janice. I was also aware of an absence of supportive friends around her:

I didn't have the children around me, they were grown up and gone...and all I had was neighbours that stayed to themselves. I don't think they wanted to get involved (Janice, 132; 144-150).

When a neighbour did reach out to Janice she found the comments abrasive and inflammatory:

One elderly neighbour said to me 'it was time', straight away! And I immediately felt angry because I didn't want to hear about time. Cause it had only just happened. Her time was about twenty years prior with her

husband dying. Well mine wasn't twenty years; mine was just a matter of a week or so. Even then I just didn't know what I was going to do (Janice, 151-158).

In the months following Lewis's death Janice found it hard to believe that he had died, expecting him to suddenly appear: "I just in my heart still felt he was at the hospital and he would come home" (Janice, 180). Janice also needed to leave work, however, the reason for this was not explained. It is likely this could explain why there were fewer people around Janice to support her or distract her from the pain of her grief. This loss of her work added another layer to the losses Janice faced.

I wondered if the closeness that built up between the couple when Lewis was dying, meant Janice suffered even greater loss when he died as she had experienced what life could be like with Lewis. Lewis had affirmed her in ways she had not experienced during their married life.

Janice had four children, all of whom were of adult age. Each lived in different states (Queensland, South Australia & Northern Territory) pursuing careers and raising their own families. Telephone contact with her children was regular; however, the geographical distance left Janice feeling alone. Janice felt isolated, and robbed of the things that gave her life purpose and meaning.

As an attempt to deal with her pain, Janice began avoiding the house through going out to large shopping complexes where she could distract

herself and be anonymous, staying out until late. Whilst in the centres,

Janice avoided contact with others she knew:

...every day was traumatic (pause). To try and ease the feeling of being home alone I would go out in the car and I would go to the shopping centres that were open late at night, really late at night!, ten or eleven o'clock at night, cause I didn't want to be home by myself. I wasn't afraid, I just didn't like the loneliness of him not being there, not coming home anymore. I'd go home when I'd have to and all the neighbours would be asleep (Janice, 191-199).

Janice was contacted by the bereavement service, as she had been identified as being at possible high risk of a difficult grief outcome. Janice became teary during the interview when she referred to the phone call which she believed changed her life. She felt an instant rapport with the counsellor who contacted her sensing he was caring and warm:

...I just felt, by the tone of the phone call that there was something...could be something very special there for me and I said yes (Janice, 286-289).

Janice received weekly counselling sessions that became less frequent over time as she improved. Initially there was a tension in the way in which Janice experienced the counsellor. She felt something about him helped her to feel safe almost instantly; however, it also took time for her to trust the counsellor and know he wasn't going to reject or abandon her.

Counselling had been beneficial for Janice who found that her pain decreased over the course of counselling, and that "the loneliness is a little easier" (Janice, 538) now. At the time of the interview Janice told me that she still experienced a "hole" left by the death of her husband:

It's more than just a gap in my life; it's a deep hole in my life. It's trying to live and cope with that gap in my life, or that hole in my life, that is the biggest trial I am undertaking now, is to continue on and learn to live alone without the one's that died...to continue building on my life as a

single person in a big world, that is my biggest trial now (Janice, 525-532).

The interview concluded with Janice telling me in a bubbly voice about the work she engages in, in a voluntary capacity that has led to her forming connections with people who have given her a lot of joy. Janice also said that she was learning about herself and growing personally which she believed would continue:

I love all the people I mix with here in my work...every day at the moment; I'm learning to live now with more peace and harmony within myself. It's been a big transition for me. I see a tremendous growth in my own personal self. I think if I can see it hopefully others can, and they've told me so. Yes and that makes me feel so excited (Janice, 672-787).

Brenda

When I called to arrange the interview time, Brenda's voice seemed distant, and I wondered if I had called at a bad time, or if she was having second thoughts about being interviewed. The timing of the call was significant for her, which will be explained below. Brenda was a woman in her late thirties, whose beloved father Harold had died a year and a half prior to the interview. At the time of the interview Brenda was married to Peter; the couple did not have children. At the end of the interview when the tape was switched off Brenda told me that her relationship with her husband was not going very well, that they now lived very separate lives and had drifted apart. Brenda hinted that a possible separation might occur in the future.

I interviewed Brenda early one morning and noticed her tearing up from the moment she began to speak saying: “You better pass me the box of tissues” (Brenda, 7). As the tears ran down her face Brenda recounted receiving a telephone call from her father one morning telling her he had cancer. Brenda wiped her face several times as she explained how her father Harold died following ten months of battling with cancer, a disease Brenda had hoped and believed he would beat. Brenda’s father had been fit and well throughout life, making the diagnosis of cancer a shock for her. From the beginning diagnosis, Harold played down the seriousness of the illness including the extent of its threat to his life. He repeatedly reassured Brenda that he was going to overcome the disease, saying:

What I’m about to tell you, everything will be alright, everything’s going to be okay...I’ve got a treatable form of cancer...I’m going to have chemotherapy...and everything will be fine (Brenda, 10-11; 24; 31-33).

Brenda was the second eldest of three and the only girl. Brenda and her brothers had not experienced bereavement before except for an elderly grandparent who lived overseas and whom Brenda had never known. Brenda hinted that her lack of experience with death and bereavement left her feeling confused, and uncertain of what to do, such as how to respond to her father prior to his death when he refused to discuss his worsening condition. Harold’s continual hope seemed to prevent Brenda from being able to talk about his deteriorating health, leaving Brenda alone with her fears:

Dad held out hope to the last limit and so did we because we’ve never had...we’ve never had any death in the family, we’ve never had to deal with death (Brenda, 48-53).

Harold's pattern of insisting he was going to beat the disease continued on, even when it became obvious to Brenda that he was in the end stages of a terminal illness. Toward the end of her father's life Brenda attempted to raise the possibility of his not recovering, and facing his own death. Brenda recalled Harold refusing to discuss the issue with her.

At the time I telephoned Brenda to arrange the interview, she was stunned and upset following a conversation with her husband Peter. Peter had just disclosed (a year and a half after Harold's death) that on several occasions Harold had telephoned Brenda and on discovering she was out, had conversed with Peter about his deteriorating health and concerns for Brenda coping with his approaching death. It was a shock for Brenda to find that Harold had known what was happening to him; it was distressing that this information came at a time when it was too late for Brenda to act on it. Brenda had wanted and needed to have held these conversations with her father and I wondered about her feeling betrayed by the two who had kept this secret to themselves. I also wondered about the impact of this information on Brenda's relationship with Peter. Brenda made some sense of this information by recognising that her father had tried to shield her from the reality of his deteriorating health.

Brenda described her relationship with her father as having always been very close. She illustrated their bond by recalling her first day at school saying that it was her father who took time off from work to be with her for this event. Brenda's parents separated when she was ten years old and

Brenda explained that her mother Gwen left the family for another man. Brenda cried during the interview when she recalled her father's suffering in the months after the split. Following her parent's separation Harold pursued and won custody of the children:

He fought for us, he wanted us, and in those days it was a fairly radical thing, to have a court to, to give custody to the father...we all chose, we wanted to live with Dad, and then Dad got us. And I've just never forgiven my mother for leaving Dad, cause she left us...I've sort of protected Dad (Brenda, 87-90).

Brenda's relationship with her mother had continued to be strained, with Brenda refusing contact despite her mother's attempts. Unlike Brenda, her two brothers had regular contact with Gwen, having reconciled with her.

Brenda was proud of her father and described him as highly personable, likeable and a magnet to both adults and children around him:

He was like that honey pot for the bees. The kids would just climb onto him, because he did outrageous stupid things with them and they just loved him (Brenda, 143-145).

Harold had been actively involved in the community supporting children and parents in need, for which he was well loved. Brenda called him "king of the kids" (Brenda, 135) for his ability to draw others to him, with his sense of playfulness and fun. I sensed that Brenda was very proud of her father, as she recalled the words of a family friend who remembered Harold as "the lighthouse beacon, that everyone would just be drawn to him" (Brenda, 157-158).

Brenda's experience of her father's illness and death may have been made more difficult because of the greatly strained relationship between

Brenda and her stepmother Felicity. At the time Harold telephoned to inform Brenda of his diagnosis Brenda had been expecting very different news:

I really thought that he was getting divorced from his second wife, which was probably on the cards. Things hadn't been going too well there, and I would have been quite happy for that to have happened (Brenda, 16-21).

Harold's relationship with his wife Felicity was triangulated in that it involved people communicating through others rather than directly. An example of triangulated communication involved Felicity asking Brenda about Harold's will, angrily telling Brenda that he had lied. Attacking Harold seemed to reinforce resentment between the two women.

Brenda described Felicity as "a fairly pushy, forceful person" (Brenda, 292) whom she actively avoided over time: "I had to; I built this barrier between me and her. I...figure[d] the little I had to do with her the better" (Brenda, 320-21). When Brenda saw Felicity's car at the hospital she would wait until Felicity left, then go in and visit Harold. It is possible that power struggles emerged between the two over time resulting in increasing resentment and misunderstanding. Brenda recalled an instance of conflict between the two which arose after Felicity requested that Brenda accompany her to investigate a nearby hospice. Brenda refused out of a desire to protect her father:

(Because Dad) didn't want to go there, cause he said I wasn't, I'm not going to die...and I was sort of, no! not going. Dad didn't want to go there, I'm not going there. I'm not, she's just wanting me to go and have a look and I'm saying 'I'm not going' (Brenda, 234-235; 292-297).

This conflict later intensified when Harold accepted a place at the hospice after his condition worsened and a bed became available. Initially Harold refused the bed. However, some days earlier Brenda had visited the hospice after arriving at the hospital to find Felicity's car in the car park. Brenda drove around to the hospice in order to avoid Felicity and met with nursing staff who really impressed her. Harold had feared the hospice as a place where people just came to die, however, the nurses informed Brenda that the patients did have choices, and could choose to leave the facility. Brenda kept the visit to herself until staff informed Harold that a bed had again become available.

Brenda was able to persuade her father and within half an hour of their conversation, Brenda was packing up his belongings whilst Harold was moved by ambulance. Staff had unsuccessfully attempted to contact Felicity, who arrived at the hospital to discover the changes. Brenda said Felicity reacted angrily when she arrived. During the final weeks of Harold's life conflict further deepened between Brenda and Felicity around the issue of visitation. Brenda was spending large amounts of time with her father, staying overnight at the hospice to be near him. She resisted Felicity's attempts at a roster with Brenda stating, "That doesn't really suit me, I'm here to spend time with my Dad" (Brenda, 470). Tension continued to build between the pair, reaching a critical level for Brenda when on one occasion, she recalled turning up to the hospice to find her father crying:

Dad was sitting in his chair and he was crying, he was upset. I sat with him, I said 'What's wrong Dad?'. I'd never seen Dad cry, and...this is why

I'll never forgive her for having said this to my dad. Felicity had said to him: 'Brenda's spending too much time with you and I never get to come and see you, and apparently she said that she had told me that she wanted to spend that Sunday with Dad, this was the day I took Dad out and she had never said anything to me at all (Brenda, 566-578).

Felicity arrived at the hospital and Brenda confronted her stating: "Felicity you never told me that you wanted to spend this Sunday with Dad. I would have...you know, I wouldn't have come" (Brenda, 585-587). Words were spoken between them and became heated. A social worker became involved and attempted to assist the pair. Brenda said that the arguments took place in a separate room out of her father's view. Brenda explained that her visits were intended to protect her Dad: "I didn't want Dad to feel lonely and abandoned in this place where he had come to" (Brenda, 487-488).

Brenda was saddened when her father began asking her to leave around certain times when Felicity was expected to visit. Brenda argued that Felicity's visits were short and were not consistent with the actions of a loving wife. Brenda told me that she tried to give the couple space saying: "You know, when she did come, I'd leave and I thought well, you can spend time with Dad, it's not like I'm taking over" (Brenda, 479). In summing up her relationship with Felicity, Brenda explained:

...there was always conflict there...just her manner of a way that she did things or said things which I found really hard, to accept as her as a person (Brenda, 794-798).

Several days before his death, Brenda left the hospice and returned home to support her husband who was unwell. She planned to go back after a few days but was phoned by the hospice staff who informed her that

Harold's condition had deteriorated, and that she might return "just in the next day or so" (665). Feeling exhausted Brenda decided: "I'll get a good night's sleep and I'll head off in the morning" (675). On the morning Brenda was returning, just prior to leaving the house she received a phone call. Brenda felt a "sixth sense" about her father explaining:

Well that night, I don't know why, I don't know why (pause)...I thought Dad would die, and so I took some clothes in case I had to go to a funeral. And that morning, and it would probably have been about that time that I was packing, like we were nearly out the door, and I'm just getting a couple of things, I had a big thick rubber band...and I thought I'm gonna take that with me. And I got back and I put it in my bag...then my brother rang and he said 'is Peter there' and I said 'what do you want to talk to him for?' I could tell in his voice. I said 'he's gone hasn't he' and he said 'yes'. It was about the same time that I've had, was looking for this band was when he passed away (Brenda, 678-710).

Felicity also missed Harold's death, arriving at the hospice shortly after. Felicity became angry that she had not been present and blamed the hospice staff and the family for not contacting her. Brenda asserted both staff and family had tried to reach her. Brenda's elder brother supported Harold when he died.

I assumed that missing Harold's death would have been distressing for Brenda. However, she did not raise this aspect of his death as an issue. On hearing of his death Brenda recalled pleading: "please don't let them move Dad until I get there" (717). She found the four hour drive to the Hospice "was the longest drive ever...felt like it took forever" (714) but that seeing her father for the last time was important. When she arrived her brothers were there and Brenda took them aside saying: "I just want to be in here by myself with Dad" (727).

The experience of seeing her father was confronting for Brenda who said, "It will probably always stay with me, the way Dad was lying there" (752). In the few days since her last visit Harold had lost weight, his face had thinned, and his false teeth now sat awkwardly in his partially opened mouth. Most noticeable for Brenda was the sense of her father's absence: "It's just like Dad wasn't there. Like if his spirit had already left or something" (729-732). The coldness of his body when touched seemed to accentuate this experience. Brenda had spent just a short time with her father, when her elder brother stepped in the room telling her it was time to leave:

And I really regret not having said anything to my brother when he came in. Cause my brother came in and he said, 'Come on, you've got to come'. But I'd only been in there five, maybe ten minutes but I wanted to stay longer, wanted to stay longer with him. And he said, 'Come on. You've got to come out'. And I probably really resent, resent him doing that. And I look back and I think why? (Brenda, 739-747).

Brenda deeply regretted not having enough time with her father following his death. Her brother's insistence that she leave did not make sense to her although she tried to explain the motivation for his behaviour stating: "but I s'pose he's probably trying to protect me" (749).

A significant part of Brenda's story concerned a strong ongoing sense of connection with her father. Brenda came to represent this continuing bond by collecting rubber bands. This aspect of her experience is explored further in the next chapter on "Group Stories". My interview with Brenda finished with her showing me some of the rubber bands she had collected and which she stored in her handbag. Each were of differing widths and

sizes with some looking more tattered and worn than others. Brenda joked with me about the perception others might have of her when seeing her reach down in the street to pick up old rubber bands, making references to “bag ladies” and “homeless alcoholics”.

Unfortunately the final section of my interview with Brenda failed to record. I made notes following the interview, however, I did not know of the missing portion of the tape until days later when transcribing. The missing section of the interview had centred on Brenda’s experiences of counselling. All references to Brenda’s counselling experience are drawn from the notes made following the interview which are explored further in the “group narratives” chapter.

Vera

Early one afternoon I drove down to the retirement units where Vera lived. I found her standing outside, along the road, waiting for me to arrive. It was a cold day, and Vera did not seem to be bothered by the chill. At first I felt somewhat intimidated by her brusque manner. I was chatting to her just outside her front door when she turned to me and said “Well come on girl, get inside”. Inside the house the curtains were partly drawn and the lighting was dim. The sun was scarce that day, and I found myself fighting off the cold, surprised that Vera had not turned on any heating and seemed immune to the chill in the room.

Vera requested that I interview her in her home as she no longer drove. Once inside the house, we sat around her dining room table where I set up the audio recorder. Vera appeared eager to begin yet sensed my nervousness. She responded by instructing me to: “go on - be confident”. Vera was in her seventies and had lost her husband Gary to cancer two years earlier. The couple had had three sons, whom were now in their fifties. The eldest and youngest sons lived an hour and a half away from Vera by car, one north east the other south. Nothing was said about the other “middle” child, except that he had been sick as a baby and had kept her busy.

Gary and Vera were married for over fifty years, and had lived together in the retirement unit for eight years prior to Gary’s death. Gary began experiencing symptoms about two to three years prior to his death. However, the diagnosis of cancer did not come until it had metastasised and Gary died about four months after that. Gary had had multiple health issues including emphysema and prostate problems, and Vera said that the diagnosis of cancer did not come as a surprise: “I think we sort of said ‘well he’s had a good life’, he was 78 then...I don’t remember it, that being very traumatic” (Vera, 92-98).

Vera had suffered post-natal depression following the birth of her first baby in England. At the time she found there was an absence of support with no counselling or follow-up help being available, she said:

My experiences are probably different to other peoples because, I've got a tendency for depression, throughout my life. Well it started when my first baby was born...fifty years ago or so in England. And there wasn't any medication, no counselling, no nothing. Just grin and bare it, get on with it (Vera, 515-518).

Eighteen months after the birth of her third child Vera found herself immobilised by depression, suddenly unable to get out of bed one morning. On this occasion, her husband, whom she described as supportive, and caring, responded to her refusal to move by hitting her. She defended his action as being rare or a one off, claiming, "that he never hits me" (Vera, 541). Vera then scantily recalled being hospitalised for depression. She spoke in a matter of fact manner about receiving electro-convulsive therapy (ECT) "shock treatment" during her in-patient stay, and when asked if she found it helped stated dispassionately: "Well I s'pose it did...well yes, I was all quite alright when I came out so it must have been successful" (Vera, 547-551).

Vera said she had been okay after this point until retirement when depressive symptoms again entered her life. Vera's close and caring relationship with husband Gary had been a resource for her in coping with her "low" times. She recalled how he ritually took her out for meals, held and cuddled her when down, all of which she experienced as beneficial and supportive.

When Gary died, her main resource for dealing with the depressive symptoms which repeatedly featured in her life had gone. Vera missed her husband's companionship and talked of feeling lonely. Additionally,

other parts of her world were shrinking resulting from her advancing years which may have compounded her sense of isolation, and loneliness:

[In bereavement]...what you're missing is someone to talk to. You've lost your spouse, you talk, you know. And then when you're retired and you're in your seventies, you're not doing a great lot of things (Vera, 654-657).

There was literally less for Vera to do, less to distract herself from the pain of bereavement, and fewer others for her to seek support from. Over time Vera had found the village complex where she lived less able to meet her needs for social connection, whilst exposing her to multiple losses:

[What] I've possibly felt, um a bit depressed about is the fact that here everybody's over seventy more or less and they're um all going by the way side one by one, or dying or...and that's sort of a bit um panic, well not panicky but whereas I sort of feel that I need company away from the village...Just one by one they die, or move, or go to the hostel or go to the nursing home (Vera, 917-927; 942-943).

Vera wanted to be connected to a mixture of people that included those younger than herself. She seemed anxious about being surrounded by death and decline which was an issue facing many of her peers. In the ten years Vera had been at the village, she found the losses she observed in the village disheartening. Vera enjoyed seeing her son and grandchildren whom she would visit each month.

At the end of the interview Vera took out a piece of paper on which she had drawn a weekly timetable. This timetable represented a significant strategy that Vera had developed to help her survive the copious amounts of time she found herself facing. On each day there were several activities ranging from time alone, to coffee with a friend, volunteer committee meetings, line dancing lessons, interspersed with her ritual "5 o'clock

happy hour” during which Vera sat at home with a glass of wine and some cheese watching her favourite television shows. Each day had structure, a form of connection with others and a focus or purpose. The timetable gave Vera direction, and answered the question “What will I do today?” allowing Vera less time to flounder or ruminate.

With the death of her husband, Vera found she missed contact with men. At no point in the interview did Vera hint at being interested in the possibility of a new intimate relationship, rather that she enjoyed being around a mixture of people that included men. Vera had made the effort to join an organisation that had a majority of male members which she enjoyed. She expressed her dissatisfaction of being limited to female company stating:

Sometimes, you get a bit sick of the fact that, here there's a hundred and ten people and only like twenty men, and all the rest are women, and you go to [name's organisation] and they're all women (Vera, 698-702).

Vera did not discuss ongoing friendships with men whom may have been part of the couple's prior network. I wondered if that were a difficulty for her.

Vera said that certain parts of the day were easier for her than others, and that she had developed strategies for dealing with the more difficult morning hours. One of her strategies was to lay out her clothes the night before, so that she had fewer decisions to make, and “the minimum” to do the next morning when her energy levels and mood was likely to be at its lowest. Once dressed, Vera left the house and began carrying out the

activities listed on her timetable. Each morning began with an outing that required her to leave the unit. Vera said that she had developed her strategies “through trial and error” (661) discovering what worked best for her along the way.

I found Vera open, and forward in expressing her opinion. When expressing her frustration Vera’s voice often rose and her face became stern. Prior to bereavement counselling, she had sought help from a psychiatrist around the time she and Gary retired, prior to his diagnosis of cancer. Vera was dissatisfied with the care she received finding the psychiatrist’s manner and comments patronising, and inflammatory. Vera stated that at the time she was “very down” and illustrated her discontent by recalling an exchange between the two at the ending of an appointment in which the psychiatrist spoke to her like an adult might speak to a very young child with whom he has had a minor skirmish:

Psychiatrist: **Oh so you’re feeling a bit depressed are you!!**
(Emphasised in a sarcastic tone)...Oh well – ah, I’ll see you in two weeks time; you may feel better by then.

Vera: **Yeah, I might have committed suicide too**
(sounding angry) (Vera, 734-740).

During another part of the interview, when discussing her experience of this psychiatrist Vera illustrated her contempt toward him by stating:

...if I’ve ever nearly hit somebody, it was him. When I saw him the next time I was feeling better and I said, you know you really annoyed me last time. ‘Oh’ he said ‘Why?’ and I told him and he said: ‘Oh well, on your card I just wrote: depressed, angry’ that was that! (Vera, 754-759).

Vera did not equate feeling better with the treatment he provided and she decided never to return following this appointment. In the above exchange

recalled by Vera the therapist is painted as aloof, distant and uncaring. Vera had the strength to confront him about his seeming lack of concern for her yet again she was dismissed without her statement being validated or explored. Part of Vera's anger toward the psychiatrist was "because he didn't give me any clues" (Vera, 739) and she left the session without any additional understanding of what was happening to her or how to cope.

In contrast, Vera found her bereavement counselling experience to be beneficial. When invited to consider any aspects of counselling that may not have been helpful Vera said:

Oh no! the therapist has been marvellous. Ah, I'd praise him from the house tops...He's been very good, very helpful and he's seen me in all sorts of times (Vera: 765-768).

Vera's counsellor treated her depression as a separate although connected issue from her bereavement. He also referred her back to her GP for medication saying that the combination of medication and counselling would assist her. Finding a suitable antidepressant took some time as she experienced some unpleasant side effects including loss of balance resulting in falls of three separate occasions.

Counselling began some weeks after Gary's death when Vera was contacted by a counsellor from the bereavement service, by telephone offering her support through bereavement counselling. Vera would have been identified as being at high risk for a difficult grief reaction by the bereavement team. Vera spoke highly of the therapist, saying she

believed she had been helped by him. For Vera, the counsellor's manner, and responses contrasted dramatically with that of the psychiatrist.

During the interview Vera struggled to find words, stopping, becoming stuck several times. During these times she beckoned me to help her locate the words she was looking for however, I seldom guessed correctly. Vera's voice became quite loud and fast at times during the interview when emphasising parts of her story that were significant for her. Although she named difficulties that continued to be encountered in her ongoing life such as loneliness, Vera spoke of benefits she had discovered since her husband's death, such as the increased sense of independence she experienced in being able to make decisions without deferring to anyone:

And I was married for fifty two years, and you had somebody to consider all that time, and then all of a sudden now you can decide. I mean I can decide that I don't want to wash up after every meal, I'm going to leave it to once a day...and that's only a little thing, but I can decide that. [I'm a] bit more freed, yes, you make the decisions. And if you can't do it you get someone else who will come and help you (Vera, 1072-1091).

Toward the end of the interview, I was surprised to be asked to wait in the living room while Vera walked up the hallway returning with a large brown teddy bear that looked well loved. Vera wanted to know if I liked him and explained the story behind his purchase at a local fete. She had spotted the bear in a back room and thought he was beautiful, though Vera reprimanded herself saying: "Oh come on you big sook, what do you want to buy a teddy bear for" (Vera, 1115). After debating with herself she decided that she just had to have him. Vera called the bear Toby and told

me how he helped her whenever she felt sad or alone. She found that the bear was a comfort to her stating:

He's magnificent, and I cuddle [him] if I'm upset, and he sits on the bed with, with my um quilt and everything...So I think I'm going quite, slightly crazy but anyway he has been very helpful...Well I talk to him; well if I can't sleep or I roll over and turn over and cuddle him and get off to sleep again. He's been a special thing...something unusual that I wouldn't have expected you know (Vera, 123-128; 136-142).

I stood beside Vera admiring her bear, taking note of the hand made clothes he was wearing and felt touched that she had shared this very vulnerable and significant side of herself. Approximately a year after the interview Vera died suddenly after collapsing while visiting her family around Easter. She was in their company when she died.

Fred

The first thing that stood out when I met Fred was his size. As a woman who is scarcely above five feet in height, I felt minuscule standing next to him. Fred was tall and solid yet also quite nervous which seemed incongruent with his physical presence. He was aged in his mid thirties and had worked as a tradesman for many years. Fred had an eight year old daughter Skye from his first marriage with whom he shared a close relationship. His relationship with his first wife Jill was amicable and Fred looked upon her as a kind of friend.

Fred was the elder of two boys and regretted the increasing distance that had developed between them. Fred had been exposed to multiple deaths

in his family within a short period of time. Both of Fred's parents', an uncle and a grandmother had been lost to cancer. These deaths occurred within just a few years of each other. The focus of this interview was on the death and bereavement experience connected with Fred's mother and father.

Fred was highly family oriented and had been very close to both of his parents. He was profoundly affected by his mother's diagnosis saying: "[when] my mum was diagnosed in 1983, I was overseas, I came back and I heard that and my whole world changed" (Fred, 82-84). Fred followed his parent's relocations keeping close to them up until their deaths.

Fred's father Ted had a history of anxiety and depression and Fred felt that his father was not as strong as his mother Betty. However, on a positive note Fred described his dad as a "gentleman" whose personality and parenting style had contributed to Fred and his brother's identity which Fred proudly saw as being "different" from other men:

He was a gentle man, and that's why my brother and I are both. We're not men's men. We never have been...If you're brought up with it, with a bright gentle man then you will be, you know. We were never in trouble my brother and I. It wasn't important to be rough and ready and fighting and things like that (Fred, 159-161; 166-169).

Fred spoke of finding it easier to speak to women than men, saying that he did not easily connect with men in his male dominated workplace and he felt they had little in common:

...In my mind, a lot of men that I do know, especially work people are very different to me. Different aspects, different goals, different things that interest us. I suppose you don't really tell exactly what you want to say. The caring side's not there. Most men are pretty cut and dry...I'm, I'm not the same as other men, I know that (Fred, 341-348; 430).

Fred's lack of connection with men around him meant he was somewhat isolated in his bereavement experience. Fred spoke of needing to cry, however, he did not feel comfortable to do this in the presence of the men he knew.

Fred's mother Betty was diagnosed with cancer in 1986, seventeen years before her death in 2003. During her illness she had several remissions and relapses with the cancer spreading to other parts of her body and metastasising. Fred's father, Ted was diagnosed with cancer in 1998 (12 years after Betty's initial diagnosis). He died three years later, with Betty surviving him by another two years. In between their deaths Fred separated and divorced. For the first 12 months following diagnosis, Ted was able to keep relatively active. Initial attempts to de-bulk the cancer failed which Fred described as "quite tragic". During his final two years of life Ted lost vast amounts of weight becoming gaunt and frail and he increasingly withdrew from others.

During the interview Fred spoke of having suffered anxiety and panic attacks which began to develop prior to his parent's deaths. At that time he was promoted to a managerial position at his work place which he found highly stressful:

I took on a responsibility that was really too much for me, but I was driven by the dollar, it was because we needed the dollars when I was married, and I just couldn't handle it. I put too much into it every day and one day I just felt like getting off the train and just running and never coming back. I had to do something about it. It just got too much. I had this blanket and I couldn't get out (Fred, 507-517).

Fred was prescribed antidepressant medication which he found beneficial. He didn't like to give up and stayed on in the position for some time before resigning. Fred stated that he had suffered from both anxiety and depression throughout much of his life.

A significant part of Fred's story concerned the environmental context which Fred saw as having a potential role in what "caused" the cancer. Fred's parents and grandparents were from England and came to Australia in the mid 1960s when he was a young child. Fred's family had lived in a poor industrial area of England, where they were exposed to many environmental pollutants, including lead, asbestos and coal. Some family members fought in the First World War where they were exposed to mustard gas.

This story of contact with contamination seemed to be Fred's attempt to explain his family's relationship with cancer and the question of how and why so many of his relatives had succumbed to the disease. Reading between the lines, Fred was hopeful he might escape cancer in the future because he himself had not been exposed to these harmful carcinogens. This "environmental cancer story" created space for Fred to have a longer life, and one that may not have to be invaded by a cancerous disease.

Fred had grappled with a second cancer story which was not so optimistic, and concerned genetic heritability. This “genetic cancer story” was harder to escape leaving Fred the potential victim of a deadly disease that will one day claim his life. However, Fred seemed to have faced this possibility and alluded to moving from being fearful of the future to embracing the unknown:

If something happens to me, and I do, I mean the cancer, I don't know what they [the chances] are that I will have cancer eventually, I'm quite happy with the fact now that I accept it. I mean when I'm sick and I'm dying, I don't know if [I] could be different altogether (Fred, 459-464).

Fred's only surviving family in Australia was a younger brother, Grant, who became emotionally distant around the final months of their mother Betty's illness when conflict emerged regarding issues of care. Fred's brother wanted his mother to be cared for in a formal care facility whilst Fred wanted to care for his mother at home, with help from his brother Grant. At the time of the interview Fred had tried unsuccessfully to bring the two closer together stating:

Yeah my brother wasn't as close, he didn't you know, he obviously felt things but never showed it, and [was] very pigheaded in a lot of ways, especially when we were dividing the estate. I don't know whether he was scared or what, but he didn't want to participate and then he did want to participant...and then eventually like most families when it happens you end up fighting which didn't help...I have tried to make amends with him but it's, we're two different people now (Fred, 102-113).

Other family members were remote as they lived in England and were many years older. Fred lacked family support in his bereavement experience and felt sadness at the continuing distance between Grant and himself.

Fred nursed both his parents, taking a more active role in his mother's care. He was proud of his efforts and the results being that both were able to die at home as they wished. This was a feat considering the nature of the symptoms each experienced, and the level of care required in keeping each comfortable.

Following his mother's death Fred experienced heightened anxiety and was once again prescribed antidepressant medication. Because of the presence of risk factors such as: the recent death of his father, divorce from his wife, lack of family support, and a prior history of anxiousness, Fred would have been assessed as being at high risk of a difficult grief outcome. Fred and his parents had been in contact with a counsellor following their referral to Palliative Care, where they were identified as needing therapeutic support. Fred's counsellor had met both of Fred's parents which was important to him:

The counsellor actually knew my parents, so that made a difference too. You know I didn't go in just off the bat. She knew my parents, so she understood how I felt about how or who they were. Because the experience is there. If it was just someone I hadn't met a lot it would have been different to. And I think it was um, sharing a life not a death (Fred, 355-365).

When Fred was contacted by the bereavement counsellor he accepted an appointment. Fred's advice to people facing the illness and death of loved one's was to "get a relationship with them [the counsellor] so that you can carry on afterwards when someone's died" (Fred, 540). The counselling Fred received was connected to the Palliative Care service and was cost-free. Fred stated that if he had been required to pay for counselling, cost might have prevented him from firstly accessing the support he needed.

Secondly Fred may have terminated prematurely or missed sessions because of the financial pressure associated with having to pay.

Fred's experience of each of his parents' deaths differed. While both parents wasted away and had distressing symptoms at the end of their lives, Ted's suffering was great, and was coupled by cognitive impairment which developed in the last day or so prior to his death. Fred was almost thankful when he died:

Well my Dad, I was relieved when he died because he had such a hard time and it was just he was dragging himself to 'act' [on] occasions that we would have. And he'd be on his own, he was in so much pain and he just wanted to be quiet you know. So in a lot of ways I just wanted him to be out of his misery...it was a bit harder with my mum because you know, [it was] such a long time. With my dad he was just sick and then he died. Towards the end he was, I think it was about a day or two he didn't really know what was happening, where my mum had control right up to the time she died (Fred, 269-274; 279-284).

Fred recalled feeling very depressed following his mother's death, however, because of his awareness of his tendency toward depression, and his attentiveness to the symptoms, Fred knew when he needed help and was able to accept counselling when it was offered to him. Prior to receiving counselling Fred stated that he had moments when he'd "lay there for hours in a daze" (Fred, 410). Counselling provided Fred with a place where he was free to express his feelings without embarrassment. An important resource for Fred concerned his daughter Skye. Skye gave Fred direction and meaning in his life: "if I didn't have her I think it would have been different, you know I had something to strive at".

At the time of the interview Fred had recently remarried and reported feeling better suited to his second wife, describing her as highly family oriented. Maria had migrated to Australia, and brought with her strong values that emphasised the centrality of family life. Fred eagerly embraced her and the security the relationship gave him stating: "I'm back in a family environment now which is what I really missed, I really missed that family" (Fred, 445-447).

Peta

Out of all of the accounts of living with loss that I recorded, and responded to, Peta's story touched me the most. Peta was close to my age, and I felt an instant connection with her. I found her manner to be very down to earth. I sensed she was generous in her openness throughout the interview, in spite of the pain this raised as she talked about the experience of suddenly losing her first born son, Tristan at the age of two. Peta directly chose pseudonyms for herself, and each of the family members she discussed. She adamantly requested though, that the name of her son be used without substitution. Out of respect for her, his first name is used. Peta turned up to our first meeting with her two young surviving children, Colby and Johanna. Peta's second born child, Colby, had been just 6 months of age at the time of Tristan's death. Johanna had been born since the death.

Peter shared with me that the young family was returning by car from a holiday with close friends and family when she noticed that Tristan was having a fit in his seat. They were within five minutes of their holiday destination when the fitting began. This was traumatic for Peta and her husband Scott who were powerless to stop Tristan's attack. They were in a remote area where mobile phone coverage was poor:

...And we didn't know what to do, so we turned around and went back to the people that we'd been with, cause we knew some of them had first aid experience...it was a pretty emotional situation, because it was my brother and my sister in-law who were there and other very close friends so, it was really difficult for them to kind of separate emotionally. So we calmed down a little bit, and we couldn't get him really to stop fitting. He did eventually stop fitting but he was still altered, in an altered state (Peta, 19-27).

The couple drove to higher ground where they were able to receive a mobile signal. They were told by the emergency services personnel, that it would be quicker and better for them to drive Tristan to hospital as they were an hour's drive from an acute care hospital. On the way to the hospital Tristan's fitting ceased. Peta managed to contain her own anxiety whilst attempting to soothe her ailing son:

And I was talking to him the whole time and keeping him calm and just trying to say 'it's okay, Mummy and Daddy are here', and try and keep everything nice and calm just because I've heard in different points that they can still hear you, and so you want to keep them calm because they're kind of trapped in there and not able to do anything (Peta, 39-43).

By the time the family arrived at the hospital traces of the ordeal Tristan and the family had been through had vanished with Tristan seeming relatively unaffected.

This event had been completely unexpected as Tristan had been a healthy child up to this point. Other complications in the story emerged

with regard to the care Tristan received at the hospital. A significant gap in Peta's account concerns the couple's dissatisfaction with treatment at the hospital and questions around culpability and Tristan's death. Tristan was found to have only a minor infection, which was linked to the fitting. After a sleep at the hospital Tristan appeared well. Peta and Scott had been informed by the treating doctor at the hospital that he would return to check on Tristan:

It was a small regional hospital so the doctor wasn't there all the time, he went home to his family again. And he was supposed to come back and check us out again, and he didn't (Peta: 58-61).

Peta recalled Tristan being discharged by an insistent nurse saying "we just have to go home" (Peta, 62) whilst being told that it was unlikely that the fitting would reoccur if Tristan's temperature was kept down with medication.

Later that night the family went out for dinner and Tristan was playing and appeared well. After bathing the children Peta put them to bed. Another complicating factor involved Peta having to get up for Colby during the night whom she breast fed and put in bed with her. At the time she picked him up, she was so tired she did not check on Tristan. As Scott got ready for work, the next morning he noticed Tristan did not arise as usual to play with him. When he went to check, Scott found his son dead in his bed. Tristan had been dead for several hours and "There was nothing we could do...There was nothing to be done" (Peta, 116; 136).

The distress the couple experienced on waking to this harrowing discovery was palpably described in Peta's account. She began her story of the experience by describing the relational bonds between Tristan and Scott. The two ritually spent time together playing each morning as Scott prepared for work. Normally Tristan awoke at the sound of Scott moving around the house, while on this particular morning he didn't:

...Tristan and Scott were very, very close and so he [Scott] wanted to see him. So he went to check on him and he was dead in his bed (becoming teary). And he went in and he found him, and I can still remember hearing him calling like they do in the movies: no, No, NO!! (voice raising). And I just left Colby on the bed and raced out. And he was holding him in his arms, No, he was dead, and he was quite obviously dead. He'd been dead for a couple of hours...We didn't know what to do. We'd never dealt with this before (Peta, 88-95).

The distressing nature of the event is reflected in the responses of those close to Tristan, including the immediate reactions of extended family. When Scott telephoned his mother-in-law to inform her, for several seconds she believed she was receiving a prank phone call saying: "what's going on...what are you talking about, that's ridiculous" (Peta, 104). Shortly after the discovery, Scott went outside and began punching bricks on the walls of the house with his bare hands. Scott later insisted that Tristan's body be wrapped in a blanket because of him being so cold. Peta sat on the lounge "just holding my little boy" (133) as others close to the couple began to arrive to show support.

The heightened pain and shock Scott and Peta faced that day is also indicated through Peta's reaction to a room at the hospital. Peta spoke of how she had taken Tristan to the hospital some three months earlier fearing that he had meningococcal symptoms. Staff at the hospital had

taken Peta into a smaller room for her to change his nappy. Following Tristan's death, on reaching the hospital by ambulance, staff attempted to direct Peta to take Tristan's body into this same room. Peta adamantly refused and another location was arranged.

The news of Tristan's death circulated and people began arriving at the house that morning. Peta explained that she was from a large family and she found the company of people around her comforting at the time of Tristan's death.

When asked about how she experienced the presence of others around her on the day of Tristan's death Peta indicated that while her memory of the day was somewhat blurred, the responses of others in the form of their company, served to assist her in reinforcing that the event had happened, and that she was valued and cared for:

You know having people there makes you realise that it is a reality, that it is actually happening; but [having] somebody's actually there and they care about you, and they want to make sure that you're okay (Peta, 171-173).

There were numerous ways in which the support of others was expressed and experienced. People came to the house when they learned of the tragedy. Attending the funeral was also important to Peta. Some friends brought around meals, whilst others invited the family around for dinner. Peta felt positive support from her sister-in-law who brought her young baby with her, and was able to sit with Peta and Scott. People did not have to have "the right words" to be experienced as supportive:

And it, it's surprising how many people, they don't know what to say, but they know that there's nothing to be said, so like my sister in law just stayed on the lounge. She didn't try and make conversation; she just stayed there because she knew that we needed to have somebody there (Peta, 194-198).

Friends helped to buffer the couple through being present and available to listen to each partner separately so that the couple did not overload each other:

Sometimes you need to, like it's very difficult for two parents because you want to be selfish in your grief, but you want to look after your mate as well; so to have somebody else there helps you to be able to go to that person and be really selfish, and just be upset for yourself and not worry about upsetting your mate (Peta, 205-209).

The presence and absence of friends and family during that time has had further reaching consequences: "He died and we buried him, and it was just, we kind of found who our friends are and who they aren't" (Peta, 275-276). The structure and closeness/distance of the relationships between Peta, Scott and others has changed with Peta reporting that she cut off emotionally from those who withdrew or failed to attend the funeral.

...people who didn't come around have actually severed relationships, and I don't know whether that's just because of us, but yeah, it's damaged relationships because they didn't come around (Peta, 186-190).

Stronger bonds have developed however, between Peta and others who did reach out and offer support

I found myself pondering "what if" questions such as: what if Tristan had been retained at the hospital and was monitored? Would his deterioration have been picked up and treated in such a way that his death may have been prevented? What about the promises of the return visit that for Tristan and his parents had been broken? As I contemplated these questions I was convinced that these were some of the questions that

Peta and her husband had been grappling with, and would likely have contributed to heightened feelings of anger and injustice both individually and as a couple.

The interview took place in the building where Peta and her husband Scott had received much of their counselling. In the interview Peta openly revealed that I was sitting in the very place where the counsellor normally sat. Peta and her husband were referred for bereavement counselling by their local GP, who monitored and supported the family following the death. Peta and Scott's experience of counselling was problematic in the beginning as Scott had been highly dissatisfied with the counsellor's failure to recall significant details such as the names of places connected with their son's burial and death. The counselling relationship did substantially improve with trust building over the course of the therapeutic relationship. This aspect of their bereavement experience is explored more fully in the next chapter.

Peta reported that the intensity of her grief had lessened over time, and that she felt able to experience joy in her life once more. Her connection with Tristan was still an important part of her life and she spoke of herself as the mother of three children, not just two:

I think I'm in a good spot now with our two children, well our three children, but our two living with us. And you know everyday brings a new experience you know. I was just getting used to having a child over two and a half, which I've never had it before and it's really difficult (laughs) (Peta, 799-805).

The interview closed with Peta talking about the meanings surrounding Tristan's death, about her sensing Tristan's presence, and about the mystery of life:

Like it really does feel like he's here. Like he's a little angel on our shoulder around all the time. And even though he's not physically here, which you know [is] not nice, he's still, he's around...I mean obviously I wouldn't recommend it to anybody, but it's amazing how you can go through such an experience...And so I think everything happens for a reason. An even though we don't necessarily like the reason. I don't know the reason, but things happen for a reason (Peta, 992-996; 1004-1014).

Peta spoke with me as she left the interview room, about her hope of being able to help others through participating in this interview. She stated that this had been a motivating factor in her decision to be involved with the research. At the time of the interview Peta was balancing her role as a mother to her children with voluntary work that she'd recently begun in the community. As she left I had the sense that Tristan's ongoing sensed presence was a source of comfort, support and hope to her in her continuing life.

Wilhelm

I met Wilhelm for the first time on the day of the interview following telephone conversations. Wilhelm was eager to be interviewed and have the chance to tell his story. The first thing that struck me was Wilhelm's rich Dutch accent which I enjoyed listening to, although I found myself straining to understand him at times during the interview. Wilhelm was aged in his mid 50s having been born in Holland where he was raised and

began his career. At the time of the interview he had spent more than two decades in Australia where he and his wife Ann (also from Holland) raised their family. The couple had three children who were each now in their late twenties and early thirties. Wilhelm was a university graduate, and had worked in managerial roles within a highly specialised industry.

Wilhelm's wife Ann had died 13 months prior to the interview, from a rare condition that escalated suddenly, and unexpectedly. Although Ann had suffered for many years, Wilhelm said he was shocked the condition took his wife's life. There had been a great deal of confusion surrounding Ann's condition as doctors and specialists had disagreed over the nature of her illness and the reasons for her death. Wilhelm was aware Ann's condition caused her suffering, restricted her movement and had been worsening over time. He was completely unaware however, that there was a possibility that she might die. At the time of the interview Wilhelm was still at a loss as to what led to his wife's death, with little prospect of this changing in the future:

Wilhelm: At the end of the day she just died, had a massive bleeding, a haemorrhage and it was coming out of her artery, coming from the veins which is something we didn't know until after the post mortem results. The doctors wanted a post mortem because they wanted to see if there was any underlying cause because they couldn't find any...

Interviewer: So did they come up with an explanation?

Wilhelm: No they can't...most of the time they don't know, they have no idea of what's causing it. If you can't, you don't know what's causing it [then] you can't treat it (Wilhelm, 47-53; 73-77).

During the interview it became apparent that Wilhelm was beset by numerous unrelenting and ongoing stressors. As he spoke Wilhelm continually returned to issues he felt passionate about that connected with

his experiences and beliefs. These issues included deep dissatisfaction and frustration with: mental health departments and mental health departmental policies, the current elected federal government; and Centrelink. Wilhelm experienced unresolved struggles and felt oppressed following interactions with some of the above named organisations.

A significant ongoing stressor for Wilhelm concerned his daughter Chloe who was disabled by severe schizophrenia. Wilhelm spoke of being repeatedly faced with the task of gaining court orders to keep her medicated. Without the orders, Chloe was able to refuse medication and had come to grief in situations which threatened both her safety and the safety of others. Wilhelm also expressed his frustration at the medical/psychiatric and legal system which he believed were inept and out of touch with the reality of life for families of severe schizophrenic sufferers. When talking about this issue Wilhelm stated:

...the mental health people...They don't understand that...you're not treating an individual you're treating a family, because the moment the patient goes off the rails, it's the family that has to pick up the pieces...and that happens all the time (Wilhelm, 326-333).

Since Ann's death, Wilhelm had faced the ongoing demands of caring for his daughter, and attempting to seek treatment for her alone. Prior to Ann's death the couple had shared this responsibility.

Wilhelm spoke highly of his deceased wife, whom he described as being intelligent, academic and caring. He seemed to be struggling with the loneliness of life without her, and was seeking to make a follow-up appointment with his counsellor at the time of the interview. He talked

about the void left by Ann's death, because she had shared so much with him, including his passionate political views, and outlook on life Wilhelm stated:

I can't get used to that I've got nobody to talk to that's...what we normally would talk about or laugh about and things like that (Wilhelm, 247-249).

Wilhelm craved contact with others with similar passions, including sharing a love of literature and intellectual argument and discussion all of which he had shared intimately with his wife Ann.

Wilhelm was also exposed to further stress and grief due to his mother Ida's steady decline. Ida was in a nursing home at the time of the interview, and had caused embarrassment to Wilhelm through her racially abusive comments, which he stated were the result of damage to her frontal lobes due to advancing dementia. Just a few months after being placed in a nursing home, Ida's house had flooded causing extensive damage making it uninhabitable. The insurance agency refused to pay and Wilhelm was struggling to have the matter resolved.

Wilhelm was referred for bereavement counselling by the social worker in intensive care who was at the hospital around the time Ann died. The social worker advised Wilhelm to wait until after the funeral before contacting the counsellor to make an appointment. Wilhelm reported finding counselling beneficial, however, he experienced the first session with the counsellor as distressing and difficult stating:

The first session that I had with the counsellor was probably actually the worst; It really was, was like being pulled apart. That's it in a nutshell. I

think if something's going to be successful (small laugh), you, it's in all probability going to be along the same lines that is it's going to be really bad (Wilhelm, 90-98).

When asked about what the counsellor was like, and what stood out Wilhelm was not able to describe or list anything specific, instead he noted:

I suppose the more skilful you are the less noticeable what it is, what you're doing, you know, certainly, nothing really stands out "hey this is the technique he's using" it's, it's...um, and he gets results. I s'pose that if it hadn't been for David I most probably would have gone off my rocker myself (Wilhelm, 627-637).

Wilhelm stated he felt safe with the counsellor who treated him in a caring way. The counsellor was interested in what he had to say and listened carefully. To illustrate the counsellor's style he contrasted the approach with medical people he'd experienced in intensive care saying:

...even though they communicate well...there's still um, it gives the impression of being talked to. And that is never the case with the counsellor. It is always: we are having a conversation. It's not a lecture, and it's not 'Oh I'm donating my time' (Wilhelm, 743-747).

Wilhelm describes the counsellor as "having a calming effect on people...he's so professional" (Wilhelm, 730) which contrasted sharply to the images Wilhelm painted of other health professionals and personnel he had interacted with.

Wilhelm spoke of being in continuing struggles and disagreements with workers in large organisations that held considerable power, and did not listen to him. These included: doctor's caring for his mother, a psychiatrist/mental health worker treating his daughter, insurance agents, and Centrelink workers. Wilhelm felt that he had been continually given the brush off, and that staff were at times rude and offensive:

You know I'm dealing with public servants; I'm dealing with organisations that basically don't want to know you. And if at all possible they try and fob you off. And a lot of them are in fact ah...they are no longer courteous, they're downright rude. You know, I must be a non-person by now...and they're aggressive; they are so aggressive (Wilhelm, 643-652).

Wilhelm felt abandoned by friends he and Ann interacted with prior to her death and experienced them as stepping away from him following the funeral:

Well a lot of people don't want to talk to you, um I think they try and avoid you. With our, we used to invite each other around for dinner, and I mean, that stopped (Wilhelm, 315-317).

The counsellor normalised Wilhelm's symptoms and reactions to Ann's death explaining "certain things are normal". During counselling Wilhelm had the space to talk about a range of subjects, both in and outside of Ann's death, he stated: "I talk about a lot of things with David, about all the stupid things...It's the only time I get a reasonable sort of conversation" (Wilhelm, 530). At the time of the interview Wilhelm was experiencing continuing loneliness, and ongoing struggles, stating "right now I live in a world that is like Kafka" (Wilhelm, 641) and I had the sense that the counsellor's work with Wilhelm was not finished.

Wilhelm was continuing to seek work, and felt discriminated against because of his age. He applied for jobs via the internet, and had met with conflict from Centrelink staff over his methods of application:

In my industry for example, there are very few jobs that are advertised in the papers, very few, cause it's all on the internet. You know they didn't recognise the fact that you can apply for jobs online...that didn't fit their idea of y' know you actually need to send one in by mail, or you need to go in there and crash'. And that's another thing in my industry, you do not go in unsolicited, that's really bad, and that's what they encourage you to do (Wilhelm, 680-693).

In the above quote Wilhelm is feeling pressured to go against the “employment seeking rules” (etiquette) of his industry, to fulfil government requirements so that his pension is not cut off. His voice became louder to emphasise how unacceptable the demands were. Another aspect of Wilhelm’s unemployment woes concerned his seeking appropriate work within his area of expertise. Wilhelm stated that he had explained to the employment agencies that work was not advertised in his industry over Christmas and was met with the response: “well you shouldn’t be so picky, there’s plenty of labourers” (696) jobs available. Wilhelm described feeling insulted and that the department had “lost the plot” (704).

Wilhelm was seeking work, not just to satisfy government requirements but as a way of reducing the loneliness he was experiencing as a widower:

Well I feel pretty useless right now, but I don't know, um, it's really hard going to sleep when there's no one beside you. It's still really difficult, um, after all this time, not being able to talk to anyone really (Wilhelm, 491-497).

Wilhelm had a need for engaging with people who were able to converse around subjects he was passionate about. Ann’s death had left him in a vacuum, as he no longer had her beside him to engage with about the things that mattered, along with her companionship which he missed:

Suppose I'm looking for work so that I can actually have some intelligent conversation. I would join the bridge club there but there's no intelligent conversation there. I mean I drop around to my son's and they quite often come to us, but it's all baby talk (Wilhelm, 507-517).

I experienced Wilhelm’s desire for conversation at several points during the interview as he ducked and weaved around questions, diverting my

attention to such topics as the local roads, immigration policy, and his disgust at (what he saw as) the totalitarian approach of the current federal government. As he spoke about his beliefs about the government's treatment of "the common citizen" it seemed that Wilhelm was expressing part of his experience of others since Ann's death, particularly the multitude of organisations that he had and was required to continue interacting with. Wilhelm argued:

The policy is 'use a big stick'. Right, you make a mistake, we're going to clobber you. You don't go 'Oh what's the problem' No, no no! Hit em first, hit em hard, then hit em again. And if they still speak, hit em again, cause they don't want to listen to what you're trying to say!! (Wilhelm:663-668).

Counselling appeared to be a kind of antidote to Wilhelm's experience of being invalidated and ignored by institutional representatives occupying positions hierarchical to him. Underlying his frustrations was a palpable sense of anger. Wilhelm had once occupied a place of influence with regard to those he was now required to acquiesce to.

As the interview came to a close Wilhelm described the kind of "library crawl" events which he and his wife shared together, and which he now continued solo. The couple would travel from one library to another searching out books for their grandchildren, and for themselves spending hours at a time revelling in books, searching out everything from classic novels to biographies and documentaries. Wilhelm informed me of the strengths and limitations of each library with regard to topics of interest including: who had the most up to date contemporary writers and which library stocked a more thorough range of classic fiction.

The interview concluded with Wilhelm talking to me about some of the executive positions he'd held in organisations where he had creatively engineered money saving strategies that were now commonly used by corporations in their dealings with the public. As he spoke I had the sense that he was proud of his innovative work and the knowledge that other companies had taken up his ideas. I also had the sense that his identity had been challenged by the multiple losses he had been exposed to.

David

David was ready and waiting for the interview before I arrived. He was positioned in a chair in a far corner when I arrived. David had been let in and was quietly waiting. When I suggested we move to a different part of the room, because of noise and laughter from a gathering in an adjoining room he smiled and said, "I wondered what you were going to do about that". David accepted a glass of water that I offered him. He was a highly trained engineer who had held managerial positions where he trained and mentored others moving upward in the field. David was articulate and generously open (something I came to increasingly appreciate as the interview continued).

David had lost his wife Stephanie to cervical cancer 12 months prior to the interview. They had been married for 38 years and David described them

as “soul mates”. David came to rely heavily on Stephanie following a stroke he suffered a decade earlier. The stroke was sudden, occurring without any prior warnings, and to David seemed unfair as he had been a health conscious man. David’s sustained impairment meant he was forced to leave his job and abandon a successful and lucrative career, which he had ambitiously cultivated over many years up until the point of the attack.

Following the stroke David battled unsuccessfully to find work. Like the previous participant Wilhelm, the stressors had been multiple and were continuing for David at the time of the interview. He was engaged in a continuing financial dispute which linked back to a housing investment that had failed long before Stephanie’s death. As the interviewer I felt a strong sense of injustice as David spoke of the struggles had faced and would continue to face long after the interview was completed.

An impression I had following our conversation was that David’s career had formed a significant part of his identity, and that his greatest source of (longstanding) support had come from his wife. Her efforts had enabled him to pursue career development opportunities. She had stood by him when this vital part of his life collapsed. It seemed an understatement to say that David had suffered multiple losses.

David had been receiving counselling for a period of 12 months at the time of the interview. David sought counselling after exploring internet literature on grief which was developmentally and traditionally based. David was

distressed that his own grief experience did not conform to the prescriptive linear stage models he was reading:

I was getting disturbed by the fact that I didn't seem to be fitting in with the models...and I tried to do what the models had said and it wasn't working for me...And I thought 'there's something wrong here' (David, 591-594).

While he connected with parts of the models, David's experience of grief did not conform to the delineated categories and processes, particularly in terms of how they were structured and sequenced:

And one of the reasons I went to the counsellor was I downloaded stuff off the internet about grieving and how to handle it, and it was all based on stages of grieving. And I found that what I was doing didn't fit the stages. I'm not fitting the model. I'm some of parts, stage one, I'm some of stage two, some of stage three, some of stage four (David, 580-584).

The traditional "grief" models and accompanying information that David had accessed over the internet heightened his fears and undermined his confidence in himself as opposed to supporting him in his grief or allaying his distress. The counsellor openly challenged the information he had accessed stating: "We've dropped the idea now of [the] stages of grieving, and we've got more of an holistic approach" (David, 589).

David found counselling supportive in validating his experiences. During counselling, the therapist was able to reassure and assist David in several ways. The counsellor offered David information that broadened his ideas of what constituted legitimate grieving. David was challenged to include processes such as the bereaved's struggle with issues of meaning and meaning making, and to value his own sense of what was happening (and what was important) as legitimate. The therapist used visual diagrams and images to represent and explore David's struggles which further validated

his experiences of grief. David said, "This helped me to understand what was happening to me" (David, 591-592). David was able to explore his grief, which became focussed on struggles with meanings and meaning making. Fears around the validity and normality of his ways of experiencing and processing grief were lessened.

The counsellor was empathically attuned to David assisting him in clarifying important meanings, whilst reflecting a deep respect for David and his relationship he had shared with Stephanie. David described an important part of a session that illustrates the counsellor's empathic approach:

Last week we talked about my loneliness and he said, 'Well you've lost your soul mate', and that was the word that I hadn't been able to find. (David, 595-597).

One of the central issues foregrounded during counselling concerned the complex relationship that existed between David and his deceased wife. The relationship between Stephanie and David prior to her death was significant in its impact upon David's grief. Several months before she was diagnosed with cervical cancer Stephanie began to experience episodes of "parasomnia" which David referred to as "sleep sex". David recalled how, several evenings each week, around midnight Stephanie would begin to groan and make noises resembling her involvement in sexual intercourse. David stated that she was fully asleep each time this occurred, and that her voice became louder and louder as she appeared to approach orgasm. This was distressing for David who described feeling like a "voyeur" (732) as he lay next to his wife.

A significant blow for David occurred one night toward the end of an “episode” whereby Stephanie requested the imagined “sleep sex” partner to stay on top of her following the “sleep sex”. She then laughed calling out, “Don’t worry about David, Fuck David” (204). This represented a critical moment for David in several ways. Up until this point David had presumed that he was the partner in Stephanie’s “sleep sex” episodes. Suddenly he was aware that this was probably not the case. Secondly, in their sexual relationship together Stephanie did not like David staying on top of her at the end of sexual intercourse. Stephanie would tell David he was too heavy, and that he needed to move. David was a light framed man, and while he accepted Stephanie’s wishes, the “sleep sex” incident where Stephanie requested the “imagined” partner to stay on top, left him feeling confused and deeply hurt. However “unreal”, or “innocent” the episodes were, this particular aspect of the incident connected with a reality in their sexual life together which left David feeling rejected. David was left with doubts about Stephanie’s love for him, and the fear of her covering up a deep attraction to another man.

From this point forward, David suddenly became impotent, and was not able to sustain an erection without medical intervention. He felt betrayed, and angry:

I mean, I was very angry about it. What happened as a consequence of that was that whenever I tried to have sex with her again I couldn’t. I’d just, I’d have no erection it’d just go limp...I just couldn’t do it (David, 234-238).

For David, it was as though he was in another man's territory. Although he held the belief that the "sleep sex" episodes were "a total unconscious thing (where) there's no moral thing in it, (with it being) the same as sleep walking" (268); David was inwardly torn and subconsciously no longer trusted Stephanie.

In an attempt to make sense of the episodes of parasomnia David took Stephanie to specialists one of whom ordered a sleep test. On the day of the sleep test Stephanie took in too much caffeine, and was unable to fall asleep. David believed that Stephanie had sabotaged the sleep test in order to avoid disclosing information, which added to his confusion and sense of being betrayed.

This was perplexing for David as he had believed that he and Stephanie were exceptionally close, and intimately connected. She was his soul mate and "this was totally out of character" (211) for Stephanie. Adding to the distress was David's discovery that he was no longer impotent following Stephanie's death and this confronted him with guilt.

Through counselling David was able to explore the paradoxes of his feelings and relationship with Stephanie, including the belief that they were "soul mates" being challenged by the "sleep sex" episodes. Understandably, David felt a lack of trust toward Stephanie following the development of the sleep disorder. At some level David felt suspicious. David began his expressive writing just prior to beginning counselling.

David was able to express and explore the complexity of his grief through story writing which he centred round fictional characters. There was a strong parallel link between the main characters in the stories, and the experiences of David and his feelings toward his deceased wife Stephanie:

I was writing about Stephanie...I mean there was anger, but I've also got [the lead character] with a mixture of, anger and joy, and elation but also a hatred, and a great love of God and all this sort of stuff, um, so all of my emotions which have been pretty mixed over the last twelve months, all of my emotions, I'm bringing out into this, and as I write them down, and as I finesse them, I feel better...I think I've cured that. You know when I finish doing something. I think that's a load off my shoulder (David, 878-890).

David presented much of his writing to his counsellor. The counsellor affirmed his agency, and creativity, respecting the writing as a legitimate way of exploring and expressing his grief. David felt encouraged by the counsellor who celebrated the uniqueness of David's approach; he recalled the counsellor stating:

...well I have never seen anybody else grieving through their writing like that...you know taking that form and working at it, and putting it into written form and expressing your anger as well as your grief as well as your hope and these things in a written form. So he supported me in that (David, 826-830).

David admitted that the counsellor had the power to shape the way he grieved in that, had the counsellor denounced the validity of his writing, he probably would have ceased it. The counsellor's opinion mattered, and could have silenced this creative response to grief.

David also experienced a heightened sense of loneliness which pervaded his grief and explored his loneliness through his writing. In the final story, issues of trust, betrayal and intimacy were explored through the

characters' interactions with one another. David's writing was a fruitful vehicle for the expressions of the myriad of feelings and conflicts in his grief, including struggles with issues of spirituality raised by Stephanie's death. He said:

And so I've done my bleeding through my writing and I've done my crying through my writing and I've done my ah, reinforced my faith through my writing and it's just been my way of doing it (David, 420-424).

One paradox of David's writing concerns his knowledge that without Stephanie's death, the writing would never have been generated. David's writing formed both a process and product which contained layers of meaning. Through his writing David was able to explore many aspects of his grief and this assisted him in understanding the depths of his feelings and thoughts.

The expression of grief through writing allowed David to ventilate difficult feelings such as anger and rage, as well as to explore disappointments. Writing had facilitated David's struggle with his spirituality which was significantly challenged by Stephanie's death. At one point during Stephanie's illness, it was believed that she had been cured. Both Stephanie and David had been active and strong in their beliefs and religious practice and it seemed an answer to their prayers that Stephanie had been made well. The sudden recurrence of the cancer left David feeling desperate. He prayed earnestly to those he knew well and who had already died that they might act on Stephanie's behalf and attempt to intervene with God to save her life:

I said for God's sake, do something, intercede, go and talk, get, do something to save her life because she's not going to make it if you don't do something...for God's sake go (David, 353-357).

Later, when it was evident she was going to die, David felt betrayed by those he had called upon. I wondered if he also felt spiritually betrayed by a God who appeared uncaring and punitive.

David felt deep anger towards these family members, whom he perceived to have let Stephanie and himself down by failing to intervene on their behalf with God. David felt so betrayed by the inaction that he stopped visiting a sacred "memorial" place positioned in bush land, which he had devoutly tended over many years.

I felt disastrously let down, when Stephanie died. I didn't lose my faith; I just lost my faith in those people. I just thought they'd taken their eye off the game (David, 428-431).

Stephanie's movement from remission to terminal illness was spiritually painful, throwing into question aspects of David's "assumptive world" (Attig 1996). David's wrestling with God is mirrored by a key character in one of his written accounts who argues with God over the injustice of the death of a young adolescent girl. Counselling and writing offered opportunities to explore meanings around spirituality. Implicit in David's experience of counselling, was the presence of a counsellor who was sensitive and skilled in assisting David's exploration and struggle with issues of spirituality and meaning. During the interview it was clear that David's spirituality had moved from challenged and disoriented to an enabling resource allowing him to have hope in the face of the despair of grief.

David had a strong spiritual framework and believed in the existence of life after death. He was a member of a Christian church believing that God provides a spiritual home for those who are faithful. David experienced hope and some anxiety over this belief. On the one side, David had no hesitation in the confidence that Stephanie was in Heaven. He saw her as faithful to God, and as having enough spiritual integrity to ensure a place there. However, David was concerned about his own worthiness, (and that of his children who he stated were not religious). Part of David's spiritual practice involved visiting her grave and whilst there saying prayers for her, himself and his children. David also regularly attended services. David stated that his ongoing connection with Stephanie through memories, and visits to her grave brought him comfort forming an uplifting part of his journey toward hope:

When I leave Stephanie at the cemetery, I seldom leave with tears in my eyes. I usually drive home with a smile on my face because I've thought of something we did, or with joy in my heart, because I know...she's one of the one's whose gone straight to heaven. And I say well I can't take any bloody chances. I've got to keep on going to mass for her, and I've got to keep on saying the rosary for her, and for myself also (David, 780-787).

As stated earlier, David's writing was part of the counseling process. The counsellor used visual methods drawing images on butcher's paper, and on a white board to help connect and explore meanings with David.

Following counselling David stated that he continued to feel pain; however, the nature of his pain had changed:

I'm up and down less often, and...I'm taking each day as it comes...mostly I'm good, things trigger me...trigger tears. I'll hear a song that we used to dance to or something (David, 796-799).

David's efforts were agentic and in line with a particular Christian perspective which formed his spiritual and religious context. His hope was to ultimately be reunited with his deceased wife. David spoke of the role that his writing had, had in facilitating his movement through grief, and the processing of spiritual issues:

...all the writing that I've been writing effectively has been part of my rehabilitation; What is it? It's been part of my grieving to get this anger out, and to get my feelings out and get my, get my, my, my belief out there that I'll be with Stephanie again sometime (David, 553-556).

David also actively involved himself in continuing his connection with Stephanie through the use of spiritual symbols such as lighting candles, and working on a memorial garden for his wife in which he designed the layout including a memorial stone for her. David's spirituality and continuing connection with Stephanie also included phenomena he experienced directly. For example, on a visit to Stephanie's grave as David prayed, clouds opened up to reveal personally significant stars. For David this represented a combination of a mixture of two spiritual and religious traditions, both of which he was deeply connected to. David reflected during the interview that he had needed to grieve in "my own way" and it seemed that the counsellor had assisted him in being authentic staying true to his own experiences.

Toward the end of the interview David talked about the future and the possibility of being in an intimate relationship. David envisaged that perhaps this might one day happen. However, his connections with Stephanie would continue to be important and present:

I don't want to live like an isolated lonely existence, like I've seen so many of the women that I know living since their husband's died, and so

many of the men that I've known whose wives have died. And they live in isolation and they stay desolate and I don't want to do that. I want to get back to the joy of life with Stephanie being part of my joyful life (David, 918-925).

David concluded the interview by discussing his mixed thoughts and feelings about the possibility of a future relationship explaining on the one hand how it might assist him in feeling less lonely, whilst on the other hand being daunted by trying to adapt to another person after so many years living in a certain way with Stephanie. David sadly described how he had been "hit on" by a friend of Stephanie's shortly following her death and how this had left him cold reflecting that "I was hurt by it...I just felt this good friend of Stephanie's was not such a good friend of Stephanie's" (958-959).

I left the interview with the sense that David was optimistic about the future, whilst being cautious and that whatever happened, his continuing bond with Stephanie was going to accompany him.

Summary

In this chapter I have tried to preserve the individuality of each of the participants' narratives. Each interview contained experiences that were uniquely felt and uniquely storied. The relationship between each participant and the loved one who died was also unique, as was the meaning around the loved one's illness and death. Whilst participants all responded to the loss, individual responses were unique. For example

Peta sought out companionship, whilst Helen retreated. Additionally the loss raised unique issues of meaning for each of the participants.

The next chapter focuses on the shared narratives that have been constructed from the individual stories presented in this chapter. Effort has been made to respect the tension between the overlap of “collective” experience and the individual’s own “unique” sensing and emplotting of their experience.

Chapter 5

GROUP STORIES

Introduction

The previous chapter presented the individual storylines which were temporally ordered and centred on each participant's unique experience of bereavement. This chapter presents the group storylines and common themes which have emerged from these individual storylines. As I analysed each of the participant's stories I paid attention to the way participants linked their stories together, looking for patterns and overlap within the way bereaved participants wove their stories together (Polkinghorne 1988). I colour coded sections of the transcripts where links and overlapping were present, looking for the threads which connected these multiple stories together. This involved stepping back from the individual narratives to assemble collective voices and find ways to present and construct these collective storylines. This required a process of moving from the group storylines back to individual transcripts to check for the fit between them.

I moved from part to whole, re-reading and reviewing transcripts in their totality in order to check for the presence of collective plotlines and to avoid fragmenting the texts, separating them from their broader contexts. I

paid attention to the sub-text within the narratives of what was hinted at or implied. As the researcher taking a narrative approach I have influenced what has emerged, through what has captured my attention, and conversely what has perhaps gone unnoticed (Riessman 1993). I have made efforts to keep close to the data. However, the group narratives are essentially my re-storying of the participants stories.

Group Narratives

Each “group narrative” has been listed separately. However, it is important to note that each is connected with the other group narratives, sometimes with considerable overlap. It is also important to recognise that each participant’s own emplotment of the “group narrative” was unique. The “group stories” presented in this chapter include:

1. The evolving relationship between the bereaved and deceased
2. Loneliness at the heart of bereavement
3. The paradox of bereavement
4. The experience of counselling

The first group narrative “The evolving relationship between the bereaved and deceased: included the nature of this relationship from prior to diagnosis, through illness and death and during bereavement. This narrative focuses upon the changes that took place in the relationship and includes the experiences of an ongoing connection with the deceased that was storied by several participants. The second group narrative is centred

on the bereaved survivor's profound experiences of loneliness. The impact of the bereaved person's surrounding social contexts on their experiences of loneliness in bereavement is examined. The third group story concerns the issue of the "self" of the bereaved which was disrupted and shaped by the death of the loved one. The bereaved faced challenges around adapting their "self" as they faced altered circumstances, and altered lives. This issue was intricately linked to meaning and meaning making. This group narrative suggests the paradox of the experience of bereavement and looks at the tension between growth and distress. The final theme brings into focus the counselling narrative exploring those aspects of counselling that were identified as supportive and helpful in assisting the bereaved to adapt. In this discussion the place of counselling as a "grief enabling" context in the bereaved's journey is examined.

The evolving relationship between the bereaved and deceased

The relationship between the participants and the person who died was at the heart of each story told. Each relationship was complex, and dynamic. Experiences in this relationship prior to the death appeared linked with participants' distress following the death. Some of the ingredients impacting on their experience of grief included the a) degree of sensed closeness (or distance) between the two; b) the history and trajectory of the relationship and its place in the bereaved's life prior to the death, and the degree to which the deceased was connected and embedded in the bereaved's sense of self. For example, a history of significant struggles

(such as conflicts and cut-offs) within this relationship appeared to intensify the survivor's experience of distress during bereavement. Sometimes conflict had led the participant to question their sense of self-worth or the worth and integrity of the relationship. These struggles continued on into bereavement in ways that seemed to threaten the bereaved, undermining their coping efforts whilst simultaneously heightening experienced distress.

Relationships are not static, and consist of a multitude of interactions occurring across time. While it is important to distinguish between issues that predated the diagnosis of illness, and those that seemed to arise as a consequence of the illness, there is obviously some continuity in relationship patterns. These patterns are historically situated with prior interactions and issues impacting upon successive ones. Degrees of distance and closeness develop over time between people in relationships as they each experience one another. In the literature the ways people relate to each other, have been referred to as "interactional patterns" (Greenberg & Johnson 1988; Johnson 1996). Interactional patterns can bring people together with a deepening of intimacy and connection or conversely lead to strain, ambivalence and rupturing of the bonds between them. Sometimes bonds may be unevenly shared with one party more invested in the relationship than the other.

The circumstances around the diagnosis, including the nature of the illness, formed a context which influenced interactions between the patient

and carer, shaping the distance/closeness in the relationship. As indicated in the previous chapter, for several participants, the carer and patient's relationship became more insular, as they narrowed their connections to others without consciously meaning to restrict their social world. This pattern continued between the diagnosis through the trajectory of the illness and death so that the social and interpersonal worlds of the bereaved had shrunk in ways that increased their vulnerability to isolation after the death:

Our whole existence focussed here (emphasised)...yeah and that sort of maintained, and that's why going out was just overwhelming. [I] don't like this, [I'm] not going out (Helen, 250-253).

For example, much of Fred's interpersonal world revolved around his parents who were both dying. As his mother became increasingly ill her needs for care increased. Fred was determined to support his mother's choice to die at home and so he increasingly became involved in her care, whilst also trying to give her as normal a life as possible:

It was very hard, but I just took every day at a time. I used to take her out as much as I could. In all that time she wanted to travel, and she couldn't in the end. I was in control when my mum died. I mean she just got sicker and sicker (Fred, 208-210; 223-228).

At the same time a reduction in interpersonal connecting space resulted in an intensification of the relationship between the dying person and the carer, heightening the disorienting nature of grief. When asked about his grief Fred's stated: "Well (pause) I just felt so depressed...I felt like I needed help...I'd lay there for hours just in a daze" (Fred, 308; 410) Fred seemed to move between intense panic and periods of flatness.

There seemed to be a connection between the centrality of the relationship prior to the death, and the heightened nature of grief following death. The participants described their relationship with the deceased as comprising a central part of their interpersonal and emotional world. The presence of complex inter-dependence was characteristic in many relationships.

Sometimes one party relied on the other in order to function in ways that brought increasing closeness between them. For example, David's dependence on his wife had taken place over a long period. She acted as his memory, and the emotional grounding force that enabled him to manage many situations. David described her as: "the rock of the house, the heart and soul of the family" (David, 28). The place of the deceased had been immense, leaving an overwhelming gap in the bereaved's life when death occurred. This gap was connected to the place and space the deceased had occupied in the bereaved's life prior to their death.

This relationship could be central to the bereaved prior to the death, even when conflicted. Although their relationship was ambivalent, Janice still depended on her connection with her husband. She had been caught in a cycle or pattern of attempting to pursue closeness over many years. While the closeness and distance in the relationship seemed to oscillate, the place of this relationship in the bereaved's life, and its connection to her sense of self remained central. She seemed to lose her bearings in her experience of grief:

I was just bewildered, I was beside myself...I just didn't know what I was going to do. My life was just so upheaved. I couldn't see sense nor reason in any of it (Janice, 186; 159-160)

The merging of the bereaved's sense of self with the deceased (prior to the death) was not limited to spousal relationships. A parent's sense of self can be closely connected with their children, whilst the connection between children to their parent may also be central. Two of the participants were adult children losing a parent. Both participants had been very close to their dying parents, where each had formed a large and central position in their interpersonal world. For example, when Brenda was asked if she had been close to her father she responded:

...yeah especially Dad and I, after Mum and Dad had separated years ago, um, and to this day I don't talk to my mother. so yeah, Dad and I we've been always close...from day one (Brenda, 61-67).

As explored in the individual chapter, Brenda's sense of closeness seemed to intensify following her parent's divorce.

Hidden stories within relationships

The presence of gaps in participants' stories between what was said and what remained unacknowledged and unexpressed in the relationship with the deceased appeared to remain significant in their experience of bereavement, potentially snagging the bereaved in their adjusting to loss. For two of the participants, the gap concerned the presence of anger that was difficult to express in their relationship. For example, Janice was so fearful of Lewis abandoning her that she did not express her anger over many years. Her anger was disowned and over-regulated (Greenberg &

Bolger 2001) and Janice described herself as being depressed throughout the relationship saying: “because he knew I was always depressed” (Janice, 818).

Avoiding contact with negative feelings (such as anger, fear etc) prior to the loved one’s death was a strategy that did not necessarily resolve the issues or situation confronting the carer. Following the death the issues and anger returned seeming to heighten the bereaved’s experiences of pain. David’s subconscious distrust of his wife and feelings of betrayal left him feeling insecure in the relationship and battling impotence prior to her death, then guilt in bereavement when his sexual functioning returned. For Brenda the gap concerned the nature of her father’s illness and she faced pain and regret over not having had conversations around the issue of him dying. A major barrier to open communication was the presence of fear. This fear was linked to concerns such as offending or hurting the other’s feelings, or negatively impacting on them in such a way as to be detrimental to their health such as speeding up the illness. In the literature unresolved issues between the dying person and the carer(s) have been termed “unfinished business” (Rando 1984:356), which has been linked with difficulties in the bereaved navigating through the tasks, stages or phases of grief. Brenda’s fear of distressing her father kept her from discussing many issues with him, which she later regretted.

The experience of death

There are several studies in the literature (Ball 1977; Lundin 1984a, 1984b; Parkes 1972, 1975; Sanders 1983; Stroebe, Stroebe & Domittner 1988) which suggest that exposure to sudden death tends to be more traumatic, raising the bereaved's vulnerability to poor health outcomes. Participants in this study who had warning of an impending death did not necessarily feel sheltered by the extra time afforded them.

Whether it was sudden or long and protracted, each of the participants found aspects of the illness and death of their loved one traumatic. Trauma was experienced in a variety of settings, from the shock of a diagnosis or onset of acute disease to the situation and way that death and dying unfolded. For example David's wife Stephanie experienced significant pain and discomfort necessitating the use of a syringe driver⁸ in the days before her death. The pair fought in the hospital when Stephanie was at the "end of life" (EOL) stage. David found he had to leave the hospital as he could not reason with Stephanie who was agitated, and he became overwhelmed. When David returned he noted that she appeared sedated. David believed his wife's death was being hastened by the palliative medicines she was being administered. He stated:

Her death wasn't easy, and I feel robbed of those last couple of days when she was on what I reckoned was too much morphine. I just thought they'd given her more than what was needed to take away the discomfort of this, this thing...I do think that they overdosed her, that she had too much, that's a burning difficulty with me (David, 115-119; 123-125).

⁸ A syringe driver is a device used to carefully, and precisely administer medications, such as morphine for pain relief. A syringe driver is often used in end of life (EOL) care when oral medications are no longer tolerated or sufficiently effective for the dying patient.

Difficulties with communication between David and the medical staff may have heightened his exposure to trauma, whilst the fight and also the sight of his wife in an agitated state may have added to his distress and sense of powerlessness. The “out of control” nature of the situation was experienced as traumatic. That Stephanie’s palliative treatment appeared to be hastening her death and the process of her illness (as opposed to gaining control through reducing her pain and additional symptoms), would have risked heightening his experience of trauma.

Communication difficulties were also highlighted by Wilhelm, whose wife died unexpectedly within a hospital setting. Wilhelm felt that the hospital doctors and specialists dismissed him, failing to communicate effectively:

They are...they just don't know how to speak in plain English. They have no idea. And in fact some of them said 'What you want to know for anyhow?' (Wilhelm, 145-147).

On the other hand, Janice felt a sense of peace when communication with the palliative care specialist assisted her husband in settling, moving from terminal agitation to an experience of peace:

...the loving caring specialist at palliative care at the time, gave him a peace in his heart...that I knew that there was something that he'd connected with the director. I could never get through to him with spiritual conversations. So when I saw the peace within him, I found a peace within me, to think that he was dying peacefully for some beautiful spiritual thoughts had been put into his mind (Janice, 831-840).

For Janice, her husband’s actual death had been calm however, her experience of watching him deteriorate during his illness had been devastating for her:

Anticipating someone to die is the most... was for me – so cruel, and so traumatic. Anticipatory grief is a terrible thing to be happening to you. Not knowing what day, what moment it's going to happen (Janice, 762-767).

The calmness of his death paled against the backdrop of pain that constituted Janice's life with Lewis, and her journey with him toward death. Other factors could contribute to the ways in which bereavement was experienced. For example, the experience of prior mental health problems seemed to heighten the bereaved's personal sense of vulnerability. Several participants had experienced a history of depression and anxiety which recurred following the deaths making their experience of bereavement more complex and overwhelming. For Fred however, having experienced depression before meant he understood that process and what was happening to him. His awareness guided him in his coping efforts.

I have suffered from depression probably most of my life. In a lot of different ways... so I know when I start getting the symptoms, I know that I've got to get up and do things (Fred, 290-294).

For some participants the experience of prior anxiety and/or depression seemed to leave them more vulnerable to a successive recurrence which exacerbated their grief:

Scott was on medication because he found it very difficult ...and he's a bit anxious to begin with. He has an anxious personality so it (the death) just kind of exploded it (Peta 236-237; 247-248).

The age of the bereaved contributed to their experience of distress, as age had the capacity to either buffer or complicate grief. For example, living in a constraining context such as one where those in the bereaved's interpersonal world were becoming elderly and less able to live independently (facing physical and mental decline), made the exposure to successive loss more likely. Two of the participants had lost friends within the previous 18 months. For example, Vera was in her mid seventies and

was living in a small unit in a retirement village. She lamented watching the demise of others around her, describing this as “depressing”. Advancing age also placed the bereaved at a disadvantage in terms of having opportunities for accessing social support through traditional avenues such as employment. Two male participants were in their mid to late fifties and had been struggling for months to find employment, which both perceived as connected to their age. Age seemed to form a formidable barrier to their gaining work. In the above circumstances the age of the bereaved was experienced as a disadvantage and a potential context disabling force.

However, age was sometimes perceived to be protective. Peta reflected on the loss of her son, seeing her age as an advantage. She had been trying to have a child for several years prior to her deceased son Tristan’s birth. She asserted that her increased age, at the time of his death, meant she had a higher level of maturity and greater resources to draw upon. She stated:

...the fact that we didn’t fall pregnant for like three years before he was born. I think about people now and you hear about, you know, nineteen year olds having babies, and I’m thinking ‘Oh my god If I had of had this little boy at nineteen...and lost him at twenty one, I don’t know where I would be now?’ (Peta, 1008-1011).

The bereaved’s age was experienced as either constraining or enabling depending upon how the survivor’s age, combined with other factors such as health and employment opportunities, to facilitate or constrain social contact with others. The bereaved’s sense of how their age impacted upon them was integral to their interpretation of their experience.

Renegotiating the relationship and reprocessing bonds

The presence of continuing connections with the deceased were described and reported by most of the bereaved participants during the interviews. Variations extended from the types of connections that were experienced, to the degree of importance and place the continuing bonds occupied in the participants' ongoing life. It is important to note that not all participants reported having an active continuing connection with their deceased loved one, whilst others spent substantial time and effort in maintaining a continuing bond that was open ended.

The ways in which a connection with the deceased were continued included a) dedicating time and effort into projects that had been valued by the deceased prior to their death, including preventing deterioration of things that were perceived to have mattered to the deceased; b) experiences of the spiritual presence of the deceased such as a sense of their being around in spirit; c) incorporating positive qualities of the deceased into their sense of self; d) holding onto symbolic, or significant objects that were owned or given as presents by the deceased; e) gaining direction or guidance through remembering the deceased, such as incorporating the values held by the deceased in the decisions and direction the bereaved's life took; f) keeping conversations about the deceased open and continuing; g) maintaining the sense of benefit of having had the deceased in their lives.

Continuing connection helped to direct and orient the bereaved in their actions in daily life. For Peta and her husband this included working on their relationship, and making efforts to keep their family together because she and her husband believed that their son “Tristan” would not have wanted his death to result in the dissolution of their marriage. In this way continuing connection motivated the couple to value their relationship with each other and tend to it as a way of honouring their son.

The strengthening or loosening of bonds with the deceased seemed to be connected to the prior relationship that the bereaved had with the deceased. Where the relationship had constricted the participant’s sense of self prior to the death, the adaptation to bereavement involved the loosening of these bonds and connections. At the same time, as bonds to the deceased were loosened, there was an increase in development of the bereaved’s relationship with their self, along with a broadening of the bereaved’s supportive interpersonal base. For example, Janice seemed to have significantly loosened her grip on the connections between herself and her husband which had previously consumed her. Her attention was now firmly focused on the present:

But I don’t go back too much now, into past things. I concentrate more on my life now...the happy things, the beautiful people that are all round me with my work (Janice, 669-672).

For other participants however, their connection with the deceased was an integral part of their ongoing life. These connections seemed to assist them in maintaining and increasing a sense of hope, and a positive sense

of self. The angst present in their initial experiences of grief where they were experiencing acute pain, had been transformed into more positive reflections and experiences of an “altered” ongoing connection with the lost person. This did require an ongoing investment of energy:

I go and pray with Stephanie, I go and talk to her each day um all these things help me and they help to keep the relationship with Stephanie going, although it's a different relationship (David, 575-578).

Half of the participants spoke of a hope of being reunited with their loved one. Their desire for reunion did not appear to be constraining or constricting their life in the present. Rather a sense of their loved one's ongoing “altered” existence seemed to support the bereaved helping them to maintain hope and meaning in their life. For example, David was clearly planning for the future at the time of the interview. In the literature a continuing bond with the deceased has been conceptualised as resulting in the withholding of an investment of energy into other relationships or endeavors. However, participants' holding of ties did not block their considering other connections such as the possibility of an intimate relationship for those who had lost a spouse:

I don't know how, and I don't know when, and I don't know if ever, but if it happens it'll happen, Know what I mean? But I'm not cutting it out...I'm I guess, hoping it will (happen) cause it will make me feel better (David, 927-933).

I accept that fact that if something very special happens for me that's okay, and if it doesn't that's okay (Janice, 588-591; 599-601).

Several participants expressed an awareness and appreciation of how the deceased had shaped their values and beliefs throughout their lives, and how in death they continued to influence the bereaved. For example, Helen stated: “because of him I have grown in this way”. Janice's

continuing link was less focussed on her husband's presence in her daily life, and more connected to keeping a promise that she made to him as he was dying to "do my very best in life" (Janice, 820). In the examples above the continuing connections involved meaning and direction, facilitating pathways forward.

Connection with the deceased appeared to occur along a continuum with the loosening of connections at one end, where the deceased was distanced occupying a passive place in the bereaved's ongoing world, while at the other end of the continuum the deceased was kept close to the bereaved to enable them to feel a greater sense of security. However, rather than holding the bereaved back, the deceased seemed to represent a secure base from which the bereaved were able to step out and get on with life. While it was common for participants to refer to the hope of becoming once again reconnected with the deceased, this desire for reunification did not seem to impede the bereaved's investment in their continuing life. Instead this desire seemed to assist the bereaved in enriching their lives with meaning in the present.

A sense of mystery pervaded the participants' stories of continuing connections and sensed presence. Harold's promise to Brenda of connecting them together in death through gathering a great rubber band that would stretch down from Heaven connecting them both was an important metaphor of hope to Brenda in her continuing life. Her collection of rubber bands served as a symbolic reminder of Harold's ongoing bond

with her that went beyond death. This continuing connection seemed to buffer her from the loneliness of facing life without his physical presence, whilst assisting her to face the other stressors in her life.

For one participant there had been an absence of spiritual “sensing experiences” which he found disappointing. Fred had expected to find signs of his deceased mother’s presence around him, particularly as she had had many “sensing” experiences involving her own parents. She had experienced them as nearby following their deaths. Fred felt that he had missed out on anything resembling a spiritual presence around him. This seemed to add to his feelings of loneliness and loss.

However, Fred’s experience contrasted with that of others who had multiple experiences of the continuing presence of the deceased in their lives. For instance Scott felt his son’s presence on the back of his motor bike when riding. Scott’s wife Peta sensed her deceased son as a kind of angel looking out for her, and watching over the family. These experiences of continuing connection were a source of comfort to both:

To me there were lots of little signs that were telling me that he was around...saying ‘Hi Mum I’m here’ and there’s other little things even just recently – out of the corner of my eye every now and again I can swear I can see a four year old running around our house. And I mean I’ve never had a four year old so I don’t, it’s just every now and again. I’ll often think that it’s Colby but it’s not. Because I know where he is and I’ll often think that it’s him and I’ll go looking for him, and it’s not him. When I talk about it now I think – how can a four year old help me? But he does (Peta, 877-878).

The above experiences of connection illustrate how the deceased continued to be part of their lives, albeit in a different capacity. This ongoing connection appeared to assist the bereaved in gaining a sense of

security, and of moving toward experiencing the world as a safer place again. Sensed connection seemed to make grief less of a burden. Continuing bonds varied widely for participants with some experiencing multiple types of ongoing connection to the deceased.

Not all bonds involved spiritual “sensing” experiences. Being able to continue to talk openly about the deceased formed a continuing bond that required the participation of others to be successful. Not all participants expressed the need to continue talking about the deceased. However, for the bereaved who did want to continue talking, it was sometimes difficult for them to find others who were willing to speak openly about the deceased.

In clinical practice it is common for bereaved clients to report that their attempts to hold conversation around the person who has died are met with a range of unhelpful responses, including awkward silences, the abrupt changing of topics by the non bereaved, or their beginning to talk about seemingly minor issues of their own as a way to divert the conversation. Peta said she needed to be able to continue talking about her son in the presence of friends. She needed to be able to mention his name in normal conversations.

Wilhelm had few opportunities to talk about his deceased wife because of the withdrawal of friends with whom he had previously been close. Brenda found her brothers unreceptive, and the conflict between herself and her

step-mother prevented opportunities for discussing her father. Friends and family who distanced themselves from the bereaved (following the death) may have increased participants' wariness about holding conversations regarding their own experiences of bereavement or about the deceased. For example, Janice responded to the hurtful statements of a neighbour by keeping her feelings and thoughts within herself and avoiding others. An environment of safety seemed to be an important requirement for bereaved participants to be able to share their thoughts and feelings around the deceased, and their experiences of bereavement.

Loneliness at the heart of grief

For many participants loneliness formed the most painful and disabling part of their bereavement experience. A sense of loneliness formed an overarching story that was shared and named by most of the participants. Loneliness was a multifaceted experience that included (but was not limited to) the following: being confronted by the physical absence of the person in environments they had previously inhabited; missing the psychological and emotional energy that had existed between the bereaved and deceased that was now gone; the loss of meaning in life and feelings of being alone in trying to develop new meaning. The bereaved also experienced loneliness when they received support from others which was "out of tune". Isolation and loneliness were also the result of the gaps encountered in the bereaved's social and interpersonal world that occurred when previously supportive friends withdrew or cut off

from the bereaved. The presence of caring people did provide comfort that was invaluable; however, the presence of others was not sufficient to erase the emotional loneliness experienced by the death of their loved one.

The first aspect of loneliness was connected with the “separation anxiety” (Parkes 1972) of death. For example, the deceased no longer inhabited the places and spaces they frequented and were part of before. The bereaved faced the profound enormity of physical absence of their loved one. Suddenly and repeatedly the bereaved were confronted with places and spaces that had been previously inhabited by the other that were now loudly absent. This absence and silence were overwhelming:

It was the most hardest thing to do, was to walk into that empty home. [With him] not there, knowing he'd never be back again (Janice, 138-139).

At times loneliness was experienced as isolation. The bonds between the self and others around were likewise breached. The bereaved could feel profoundly alone even when physically situated in the company of a group of friends:

I just feel so lonely, I feel lonely in a crowd, I can be with a group of people, I can be with my family and I am devastatingly lonely. I'm just absolutely lonely...and that's the worst thing I've got, the worst thing it's the bloody loneliness (David, 445-448;485).

The loneliness experienced by the bereaved was linked to the uniqueness of the relationship experienced with the deceased. This uniqueness included a constellation of aspects of the prior relationship such as the roles each had played in the other's life, which were now disrupted; the

nature of the prior relationship, such as the qualities of interactions between the survivor and the deceased prior to the death. The physical absence of the deceased was experienced as a void: “there was now an emptiness that I was very sensitive and aware of, there’s still this void thing;” (Helen, 606). For Janice the experience of loneliness came suddenly:

And horror and shock hit me. I thought ‘what do I do now?’...I suddenly felt all alone. I knew there was nobody at home...my life was empty (Janice, 112; 132).

The rupturing of the bereaved’s world sometimes raised a kind of loneliness that company with others could not fill. Attempts to reduce loneliness through seeking out the company of others could sometimes even heighten the bereaved person’s sense of loneliness. Wilhelm had tried strategies such as visiting his son and grandchildren however, he found the conversations frustrating in that they all centred on baby talk.

Company with others may bring into sharp relief what is missing and heighten grief. It is that which does not arise in the company of others that would have arisen in exchanges with the deceased that is so sorely missed. These aspects of the self that arose in interactions with the loved one were now absent. For example, Janice stated:

It’s a loneliness of missing my husband in my life. People have said to me, If you’re lonely contact me, phone me, but they’re not understanding my loneliness (Janice, 545-548).

So while loneliness involved missing and longing for the other, there could also be a sense of losing (and longing for the) parts of the self which no longer seem to arise or be experienced as they had been. Loneliness

appeared to possess a unique shape. The void of loneliness cannot be erased or reversed through company, or the substitute of another, rather loneliness is far more complex. Loneliness overlaps with the “sense of self” of the bereaved. This is considered further in the narrative exploring the impact of grief on the changing sense of self.

Missing the psychological and emotional energy and interaction which the deceased once co-created with the bereaved, formed a key part of loneliness. For example, Wilhelm had strong political views and interests in local issues from business to the environment. His wife had had a sharp mind and shared his passions and his views, which they frequently and energetically discussed. Wilhelm faced the vacuum of his days now emptied of this energy. It was the way in which the two discussed issues and interacted that Wilhelm so sorely missed. At one point in the interview he stated:

I can't get used to that I've got nobody to talk to that's...what we normally would talk about or laugh about and things like that...the antics of that idiot called Howard (Wilhelm, 247-249).

Loneliness was part of the commonly reported experience of extreme pain. For some participants there was a strong pull to give in, give up and join the deceased. There were times when the pain of bereavement was so overwhelming that it would have been easier to have joined the other in death:

The loneliness, the emptiness...I was just bewildered. I was beside myself. I just didn't know what I was going to do. Everyday was just a new day of horror to me (Janice, 178-182).

The above quotation highlights the confusion, and disorientation felt by the bereaved. The word “horror” captures a sense of inescapable angst in which the bereaved experiences a sense of profound powerlessness and pain. Part of the pain involved chaos which was experienced as engulfing. Many bereaved participants attempted to minimise their feelings of loneliness by reactively throwing themselves into activity. This is explored further in the section on coping efforts.

Barriers to connection

These stories provided some significant clues about obstacles to receiving support. The recesses and gaps of the stories held obscured barriers that existed between the bereaved and those who might support them. It is not always easy to respond to those who are deeply hurt. Attempting to provide support to the wounded may confront the helper with several obstacles. The first concerns the supporter being faced with the enormity of trauma and the pain of the “death” event. For instance, losing a child is perhaps the most feared loss that any parent (whatever the age of the child) could face. To sit alongside a bereaved parent is to be exposed to the reality that such a shocking death does occur, confronting supportive others with the vulnerability of being mortal and human (Worden 1984). For example, when Peta’s son Tristan died, there were friends and extended family members who were unable to remain in contact with her. A friend who had a child the same age as Tristan, refrained from attending the funeral or keeping in contact.

Exposure to death may shatter people's long held beliefs and assumptions (Janoff-Bulman 1992; Parkes 1996) regarding the issue of control over their lives and sensed invulnerability. Those attempting to support a bereaved person, face both the distress of the bereaved, and their own reactions to the death. They may feel placed in a path of distress that is overwhelming and disorienting. Wilhelm lamented that many of the friends he had been in contact with had stepped away from him. Dinners and visits that were once part of his life seemed to cease. Supporters may attempt to try and get the bereaved to "look on the bright side" to impart the message that all is not lost. Fear of the bereaved irreparably worsening may drive supporters to attempt to pull the bereaved upward. Brenda asserted that her husband found it difficult to listen to her, and that she could not talk to him about her grief, or show distress in his company. She no longer seemed to confide in him, and he was experienced as distant.

Feelings of loneliness increased because people distanced themselves, or those that were available seemed to be out of tune with the bereaved. Those who distance themselves may do so because they are overwhelmed by their own issues of loss or do not know how to respond to the bereaved. This may result in a reluctance to continue supporting or approaching the bereaved person, or stepping away and avoiding the bereaved (whose pain and suffering is awkward to be around). The bereaved are sometimes acutely sensitised and may acutely feel the

removal of aspects of interpersonal support. Even though many people surrounded her following her son's tragic death, Peta noticed the absence of a prior friend of hers who'd she'd met in a mother's group. This woman had issues of loss and avoided attending the funeral:

...it got back to me that she said that she couldn't come because she felt it was too traumatic. And in my opinion, I've not spoken to that woman since because, how dare she not come to my son's funeral because it would be too traumatic for her (Peta, 408-412).

The friend's absence was experienced as a deep betrayal by Peta which irrevocably ruptured their bond. Perhaps this friend's own grief (she had suffered a loss) had been triggered (or heightened) by Tristan's death in a way that was made attending the funeral overwhelming for her. The "would be supporter" may face recurring pain from their own losses in addition to being exposed to the pain of the other who is grieving.

Others' fear and discomfort may contribute to un-synchronised responses which bring additional pain (rather than comfort) to the bereaved adding to the load they carry, thereby heightening their distress. For example: Peta recalled being approached by would be supporters who stated words to the effect of: "I know exactly how you feel". This added to her sense of isolation. For Wilhelm it was as if there wasn't anyone available who really knew how he felt, or even worse, cared. It is important to note that the bereaved did not always find the words offered by those seeking to comfort them particularly helpful. Certain comments whilst well meaning, actually heightened feelings of anger.

A significant additional obstacle may present itself in the responses that the bereaved give to those offering support such as the angry feelings which were stirred up for Peta when another survivor of child loss stated: "It will be okay, you know; you know you'll get there at some point". Peta took exception to the words chosen and retorted:

I'm like -You don't know what I'm doing, You don't know what I'm going through, You don't know me!...and maybe time will heal, but I don't need to hear that (Peta, 480-484).

Sometimes the words or actions of others presented the bereaved with a target for their frustration and anger:

Yeah, sometimes the negative were experiences that were good because they helped me focus my anger...or whatever on that person instead of being angry at Tristan, or myself or Scott (Peta, 490-494).

The experience of pain could be engulfing for the bereaved. At the height of her pain she and Scott considered escaping their ordeal through suicide. Peta's relationship with her six month old surviving son Colby served to support her struggle to survive:

I didn't say it but I thought it. And we discussed it later. But we actually considered how easy it would be to just drive into a tree and end it all, and not have to deal with...how dreadfully painful it is...We did have difficulties, but we had Colby. Had we not had Colby – I don't know!; We're not really negative thinking people but had we not had Colby? This is really traumatic (Peta, 342-348).

Participants tended to feel misunderstood, and dismissed by people who attempted to push their own meanings or beliefs on to them. For example Peta argued: "You don't know my exact experience you might have lost a child, but you haven't been through my exact experience" (Peta, 378-381). Comments asserting knowledge of this kind were experienced as dismissive, and out of tune. Support that was experienced as beneficial

tended to be more tentative, leaving space for the bereaved to be the definer and author of their own grief. Those responding in this way were able to separate their own experiences of loss from the participant's. They expressed their own sadness at the loss, and the pain the bereaved was facing however, they did not attempt to speak for the bereaved. This group "tended to be a little bit more understanding" and were felt to be more supportive.

Sometimes beneficial support came from those who had never experienced the bereaved's particular type of loss. These people were able to:

Just grieve for us, and they were very supportive and they were very, very important in those early days to have contact with those people and be able to talk about Tristan (Peta, 387-390).

Another obstacle to providing support for the bereaved concerned the changing nature of what was needed. For instance, at some points the bereaved sought to distance themselves from others like Janice who avoided contact with friends. She avoided friends she saw at the shops, including other couples whom she and Lewis had socialised with. Seeing couples holding hands left her feeling resentful and envious. Avoidance sometimes allowed the bereaved space from uncomfortable feelings.

At other times the bereaved may feel a desire or need for company. Just as no two people's experience of grief is identical, so too the needs of each person will vary. People's needs change over time, and this may be hard for significant others in the bereaved's context to keep up with. This

may be particularly so if the “supporter” senses they have made a mistake or have had a previously awkward interchange where their attempt to help has fallen flat or been met with criticism and/or rejection.

Is time a healer?

A significant challenge facing many of the bereaved concerned the dimension of time. Time prior to the death was often filled with caring for the dying patient. Suddenly the carer is plunged into a different world where time is too plentiful and is experienced as engulfing, overwhelming and exacerbates the bereaved’s sense of loneliness and isolation. When life is experienced as a struggle moment by moment, the concept of looking ahead to years in the future is unfathomable. Time seemed to intensify pain and was an aspect of ongoing life that needed to be coped with.

Traditionally time has been linked to the healing of wounds and the amelioration of pain. In supportive contexts where people are able to tell and retell their story, time assists the processing of meanings along with the other multi-dimensional aspects of their grief which are touched upon as they tell and retell (such as emotion, schemas, spiritual beliefs etc). However, time may allow the bereaved to ruminate, and in through such a process time allows pain to increase. Time is part of the constellation of factors that impact and shape grief. Time is not independent or unconnected to the above aspects and cannot act alone in a healing

capacity against other significant constraining contextual factors. One of the bereaved participants developed a strategy for dealing with time. Vera created a “timetable” which she had hand written that assisted her in dealing with time constructively. As described in the individual chapter, Vera balanced her time alone, with time spent in the company of others, and time spent volunteering. Vera’s “timetable” assisted her by creating a focus, direction, and purpose, for each day.

Impact of wider social context on bereavement

It has been noted in the literature that experiencing the death of a significant other is perhaps one of the most stressful and overwhelming experiences that a person may ever have to face (Parkes 1972; Stroebe & Hansson 1993). The experience of bereavement can involve such high levels of pain that it threatens to overwhelm the bereaved on multiple levels including emotional, cognitive, interpersonal, and meaning making (spiritual) levels. Most of the participants experienced levels of pain that at times literally threatened the viability of continuing with life. As the bereaved struggled to find meaning and purpose in life they were sometimes confronted with the pain of meaninglessness.

Those struggling with pain the most, had the fewest “in tune” relational and social resources, at a time when they were grappling with extra stressors in their lives, some of which had intensified since the death. Some of the extra stressors faced included the illness of others in the

family who needed support. For instance, Wilhelm's father's health had deteriorated whilst Wilhelm's daughter suffered from a debilitating mental illness that included frequent psychotic episodes during which she would refuse treatment. Wilhelm was also out of work, having cared for his wife and his daughter. Wilhelm's and his wife Ann's friends had been supportive. However, following Ann's sudden and unexpected death from a chronic condition which became acute, Wilhelm found himself alone. Friends withdrew, whilst Wilhelm faced an escalating set of issues. His experiences with government and non government agencies left him feeling further squashed disheartened and alone:

I'm trying to get um, back into the workforce and that is getting very difficult. I had to take some time off five years ago because our eldest daughter suffers from a mental illness...It's very hard to treat and because she won't take her medication. Anyway, she can be done with a community treatment order. But the mental health people don't understand...every time she'd get a community treatment order, it would last for say three or five months and then at the end of it, you know they don't continue it, it stops – and then you're back to square one again (Wilhelm, 319-327; 349-351).

Wilhelm had also attended two other funerals in less than 12 months since the death of his wife. He did not feel heard and seemed especially vulnerable to the treatment he received from people in organisations who appeared to hold power over him. Organisations appeared to form a disabling broader social context that negatively impacted upon his struggle to adapt to bereavement, complicating Wilhelm's experience of grief.

Friends and family may struggle with the question of how much, and what type of support to provide for the bereaved including the question of "for how long?" The bereaved themselves may find it difficult to ask for support, yet feel acute pain when significant others do not respond as

hoped, (however unspoken these expectations or hopes may be). The sudden or gradual cessation of supportive interactions from friends and family were experienced as rejection, and as hurtful. Bereavement seemed to be an acid test that sorted out deeper friendships from superficial acquaintances. Part of the experience of bereavement involved adjusting to the changing (sometimes significantly reduced) interpersonal world. The bereaved were not easily able to predict who in their realm of contact would step back or cease contact from those who would take up the challenge and remain in contact with the bereaved as they journeyed through their angst and uncertainty. For example, Peta spoke at length about relatives and friends who avoided her, whilst others in her husband's workplace had embraced the couple forging closer ties. Fred was surprised to find that his manager was caring and flexible. Fred's respect and regard for Jeff deepened, whilst his connection to his brother waned.

It was striking how participants who struggled the most with their grief, had the greatest difficulties in their wider social context. This context ranged from immediate family, friends in the community and work settings, to the broader context of government authorities and corporate organisations. These participants had had their sense of trust in the world and in others breached.

Two participants were involved in long-standing struggles with government and corporate organisations that impacted negatively upon their grief.

Feeling unheard, and powerless in interactions with these organisations, these participants seemed to have experienced further pain through their attempts to have matters sorted, having their efforts to gain assistance thwarted. Whilst ordinarily these struggles would have been difficult, the added complication of bereavement compounded the frustration, distress and sense of powerlessness that was experienced. These sorts of interchanges seemed to further invalidate and isolate the bereaved leaving them vulnerable to beliefs about the social world as unresponsive and uncaring. For example, Wilhelm argued:

I've never been treated so rudely in my life...they don't want to listen to what you're trying to say...you think about anything that deals with the public...anything that deals with the common citizen the policy is use a big stick (Wilhelm, 715; 660-663).

Wilhelm seemed to have lost faith in the capacity of (staff in) organisations to respond fairly and respectfully to either himself, or others who were vulnerable.

The Paradox of Grief

This group narrative is focussed around the tension between growth and distress that characterised many of the experiences described by the bereaved. The meanings people attach to the events around them impacts upon their experiencing those events (Neimeyer 1995:17). For many participants, the meanings which had given direction and purpose to their life were challenged. Life did not seem as certain as it had before. Even when a sense of purpose and meaning was redeveloped, that which was regained was somehow different. A sense of absence was experienced

before, purpose and meaning were rebuilt. The daily intimacies and behaviours that sustained meaning had disappeared:

When you mention the word intimate things, all that goes. Everything goes!! In death it's all gone. Everything's gone. And you're just, you're just there... but you feel like everything's been stripped from you, totally alone! Everything's taken from you. No, no hugs no noth[ing], everything's just stripped and taken from you and then you're left alone (Janice, 614-616; 620-623).

A significant part of processing grief for participants involved examining the (sometimes multifaceted) purposes which their lives had been guided by and based upon. Examining issues of meaning and purpose seemed to be a bit by bit process. Synthesising the old with the new involved a tension between finding renewed purpose in living for now and the future, with exploring and extracting sustaining meanings of the past. Helen believed she had developed into the kind of person she was because of the shaping nature of her relationship with her husband. This included traits of compassion and kindness. As Helen progressed she began to engage in making choices around how she would define herself and live her life. One of those choices involved volunteer work at a nursing home which she wholeheartedly immersed herself in. Rather than reactively erasing the caring qualities that had defined her in her role as carer for George, Helen re-synthesised them, opening herself up to “new and great things” outside of her previously more narrowly defined self.

However, Helen's exploration was not immediate. Like other participants her initial responses tended to be reactive attempts aimed at self protection. These efforts were aimed at solving the problem of overwhelming pain and with time there was a movement toward a more

altruistic focus. It is normal to want to minimise and avoid pain and distress. As stated in the literature review, bereavement is one of the most distressing and painful life experiences a person can be confronted with.

The participants described and alluded to using various strategies as attempts to cope with their distress and ameliorate pain. Some of these strategies seemed initially adaptive bringing comfort for a time yet seemed to increase the vulnerability of the survivor as time went on. These initial coping efforts appeared to be reactive attempts to self-protect. They began without the bereaved having an opportunity to reflect on the possible consequences of their actions as they were in “survival mode”.

Difficulties with coping strategies involved: these being too narrow and over-relied upon, such as constricted coping strategies/patterns the survivor had used in the past. For instance, Janice’s chief coping mechanism was avoidance which initially served to assist her in dealing with exposure to the out of tune comments of others. However, this same coping mechanism served to isolate her from others, adding to her experience of isolation and loneliness.

Other coping efforts involved attempts to regain direction and meaning through activities. The coping efforts Helen used saw her transfer her energy and sense of purpose from her husband to that of her children (who were in their teenage years). This allowed her to distract herself from her pain, which was of some benefit to her. In the short term it gave her a

sense of control and direction. However, it did not address the underlying existential issue of “Who am I now? Now that I no longer am the carer for George”.

For other participants like Janice there was a shift from rumination and constant crying to processing and synthesising their relationship with the deceased, and finding a sense of self. For example, as Janice progressed in her grief, she deepened her own ties with herself, caring for herself in a more loving way, loosening ties with the deceased. The longing for him and for relationship had not completely evaporated. However, she had deepened her capacity to experience and feel a wider range of affect. Her view of herself has changed to incorporate a more active positive self-image. Her efforts moved from automatic, unconsidered responses to those which seemed to transform her as she connected with others, and became involved with meaningful endeavours such as her work as a volunteer. The ties with her husband seemed to have bound her, constricted her when her husband was alive, limiting her even before his illness and death. Janice seems to have been somewhat liberated by the loosening of ties to her husband, which has formed a central part of her adapting to bereavement.

As David grew, so did his confidence in his own creative coping efforts. He moved from self-doubt and fear to an embracement of his “own way of doing things”. His uniqueness was no longer threatening, instead this came to be connected to growth. David’s growth and adaptation to

bereavement resulted in him continuing a strong and meaningful bond with Stephanie. The security of this continuing tie seemed to support his openness to a new intimate relationship. David explicitly stated that a new relationship would not sever his ties to Stephanie, instead these ties would continue and travel with him into the new relationship (where they would hopefully be embraced by the new partner). His hope for the future involved both a new intimate relationship and the continuing bond with Stephanie.

The paradox of pain

One of the core group narratives concerned the presence of pain that did not end in a finite way. Each bereaved participant continued to encounter pain in one form or another. Little attention has been paid in the literature concerning the normality of continuing pain for the bereaved, and there is the assumption that pain diminishes to the point where it no longer significantly impacts upon the survivor. However, this study challenges this assumption suggesting that one of the ongoing experiences that the bereaved encounters is a continuing experience and relationship with pain (Gilbert cited in Bryant 2003). Participants' experiences were open ended, suggesting that grief did not resolve as stage theories suggest. Ongoing pain was a continuing aspect of living, although somehow transformed or altered from its original state and in some cases liberating the person to an expanded sense of self as has been discussed above in the case of Janice, (along with others such as Helen and David).

There was a paradox existing between participant's experiences of growth, and experiences of pain and suffering. Sometimes the presence of pain was experienced quite intensely. In discussing the term "healing" Helen talked about the ongoing unrest she experienced and the ambivalence she has about her life in the present. Helen took exception to the term "healing" stating:

In terms of how did it heal...I can't even say that healing has fully happened. I have managed, I think, to have established a way of living (pause) which is from where I sit (pause) not really satisfactory (Helen, 626-629).

Helen continues to miss her husband and the positive aspects of her life with him which were not replaceable. Her answer to suffering is through personal growth and self-development:

There is still this void thing, there is the loss there. Now that loss is connection with him, which I found fulfilling and rewarding and enhancing. Trying now to find, It's...like the only way I can find those things is within myself. And there is, the struggle continues (Helen, 639-648).

I wondered about Helen's (and other participants) possible future experiences of grief such as finding themselves experiencing "secondary losses" (Parkes 1972a). Secondary losses may accompany positive life events such as the birth of grandchildren. While the prospect of grandchildren may be positive (this issue was never raised with her), it could be suggested that when or if this occurred the bereaved may find themselves facing losses not ever anticipated, such as missing the presence of the deceased who would have shared celebrating the event. Alternately I wondered if Helen may find herself able to face these

challenges fostered by the deepening of ties she was building within herself, as she found the resources needed “within”.

Janice still experienced ongoing exposure to pain and loneliness at the time of the interview. For Janice this was ongoing, taxing at times and involved struggle and continued learning and personal growth. She stated:

The biggest trial I am undertaking now, is to continue on and learn to live alone...and to...continue building on my life as a single person; in a big world (Janice, 528-532).

Janice struggled with being single, in a couple dominated world. However, she felt there was meaning in her remaining single. She seemed philosophical about whether this might change in the future:

There's no good me wasting my...I've wasted tears and tears and tears, longing for a person to come into my life. It hasn't happened. So there's obviously a reason for that. And I'm trying to accept that fact that if something very special happens for me that's okay and if it doesn't that's okay (Janice, 595-601).

So Janice finds consolation in accepting there is a reason behind her experiences, and that the direction her life takes is linked to a larger sense of purpose and meaning.

When I met with Janice to obtain feedback on her individual storyline she described finding the story accurate, expressing surprise at seeing her experiences articulated clearly. She brought in examples of poetry for me to see which she had written expressing and exploring her experiences of loneliness. Janice gave permission for these to be used, explaining that the only person ever to see her work had been her therapist. One of the examples was titled: “through happiness – I bear great pain” which

expressed the grief she has carried inside, behind a mask of cheerfulness, she wrote:

I carefully hide my heartache, so that people cannot see
That deep space of hurt that is inside of me
I bear it alone Oh! Yes, I seem so bright
My black hole of loneliness is out of sight (Janice).

Janice wrote these lines in the midst of deep grief. She stated that this poem, along with many others were now no longer so important to her. They were now stored in a cupboard which she seldom opened, whereas at the time they were written, Janice spent long hours writing and poring over her words. Now however, Janice asserted that she no longer felt the need to revisit or focus on this part of her life.

Janice continues to struggle with a desire for an intimate relationship, yet feels unsure about seeking male company. She expressed fear at being hurt or taken advantage of by men. One of the ongoing issues for Janice seems to involve trust. Her few contacts with men have been discouraging. Janice recalled being approached by a dishevelled intoxicated man in a local car park where he attempted to persuade her to become involved with him. Janice further illustrated her disappointments by recalling a date, where she found herself attracted to the man she was paired with. When the encounter did not blossom into a romance she felt seriously let down. Janice found herself being drawn back into the heightened pain of bereavement, feeling a deep sadness and loneliness about the gap left in her life. Disappointments in the present seemed to reactivate the pain of bereavement.

However, Janice has progressed. Improvement for Janice meant being able to go from “moment to moment” to looking further and further ahead. Gradually her fear of the future has dissipated. Improvement has also meant self discovery, a sense of growth and possibilities for the future:

I've discovered within myself, something greater than I've ever experienced within myself. And if I can just...build on and continue of the way I am, learning and feeling now. I feel that's going to be great for me to just continue ahead with the way I am now and just see what presents itself and what comes my way (Janice, 747-753).

Helen's journey with grief has involved her exploring issues of her “identity” and discovering her “self”. This has been and continues to be an ongoing process:

I have, I've still got so much of finding out who I really am, as separate from the wife and the mother who I had been. And that I'd lost myself in that identity thing. So I think in terms of healing, healing from the loss of my husband is kind of like, it's okay (Helen, 631-637).

Helen's quest to discover and deepen her understanding and connections to herself is an ambivalent one. It has been a quest arising out of suffering and the need to survive. The experience of pain was non-finite for participants who expressed a sense of adapting to bereavement, yet who also experienced ongoing pain. Growth seemed to be intermingled with pain in the bereaved's story of their experiences and both were described as open ended (refer also to the story of David).

The experience of counselling

The counselling relationship is very different from other social and familial relationships. The uniqueness of the relationship served to assist

bereaved participants in numerous ways, beginning with the issue of safety. The counselling relationship was experienced as safe because of the therapist's separateness from others known to participants. The bereaved felt protected by confidentiality so that personal information would go no further than the counsellor's office. The asymmetrical structure of the relationship meant that the counsellor was there to assist the bereaved, and this was not a reciprocal relationship. In counselling, the bereaved client's obligations were to themselves, not to investing and providing support for the therapist. These qualities offered participants freedom, safety and space to be authentic in their grief as, participants did not have to prove or justify their experiences of grief or feel pressured to provide returned care:

I said yes because with somebody that I'd never met before, I didn't have to, I felt really good about that. To be able to speak to someone that I didn't know that I didn't feel obligated to this or that however I felt or didn't feel (Janice, 312-316).

Important qualities for the counsellor to possess included an ability to be accepting and non-judgemental in both their presence and work with the bereaved. Bereaved people may feel the need to minimise or cover their distress with others such as family, for fear of being judged or misunderstood. In counselling the bereaved could be open and found they were accepted and heard in ways that they had not experienced prior to this point in other relationships:

For once in my life there was a person listening to what I was saying. I was always used to people not listening to what I was saying, going in one ear as they say and out the other. This person I could tell, apart from being professional, seemed to be genuinely interested. And I'd never experienced that with people (Janice, 330-335).

There was a sensed benefit in talking to a trained person whose role was to be separate and unbiased in a way that others connected to the bereaved could not be. The counsellor could be depended upon to be there for the next appointment regardless of what was said, unlike instances where anger or heightened distress were expressed, to relatives of friends and had the effect of overwhelming them or frightening them. The confidential nature of the counselling relationship protected the bereaved from having to face any possibility of information being passed on to others in the bereaved's social world. Counselling assisted the bereaved to explore and cope with additional losses that in the literature have been termed "secondary losses" (Parkes, 1972) such as the altered social world the bereaved found themselves in following the death. For instance, several participants talked about how previously close friends, relatives and significant others distanced themselves (or cut themselves off from the bereaved) in the months following the death. Withdrawal and the cutting off of contact sometimes began around the time of the death.

For example, Peta stated:

I've got an uncle who chose not to come to the funeral. And when I was a child he was actually my favourite uncle...And over the last couple of years for whatever reason...his relationship has deteriorated with my father...But for him to not come to the funeral, because he just didn't come! His wife came and she was lovely, but he didn't ring. He didn't come. And since then I've seen him a couple of times out, at shopping centres, and I go out of my way to go away from him, I won't talk to him. He didn't help me in any way, shape or form. If one of his children had died, I would have gone to him (Peta, 446-468).

Peta experienced her uncle's non-attendance at Tristan's funeral as a kind of betrayal. She interpreted his absence as a lack of care or support. Contact with this uncle is now difficult because of the pain this raises for Peta who uses avoidance as a way to protect herself. Unfortunately

breeches in contact and communication seemed to leave Peta holding onto her resentment and anger.

The counsellor needed to have relationship counselling skills with the ability to work with families (and family systems). Peta found that the counsellor was able to assist her and Scott to be open with each other, facilitating communication:

to have...good communication that sometimes needs a third person and we've always been firm believers that you shouldn't involve your family, because if you involve say my mother, she's automatically on my side, so she can't be objective; so it's nice to have that objective party to be able to listen and just help you through and know that they're going to be there in a fortnight's time (Peta, 618-626).

The process of forming of a relationship between the therapist and the participant varied. Not all clients felt an immediate bond, or warm connection with their counsellor. For example, Peta and Scott's beginning was tense and conflicted. Scott "knew he didn't want to be there...he's not the counselling type". During the first session the counsellor made mistakes with names and places, (such as the place where their two year old son had been buried, and the place the couple lived) that riled Scott. He confronted the counsellor expressing how angry he felt "because Len had forgotten some pretty big details". Instead of refuting the charges or defending himself as others connected to the couple may have done (when attacked), the therapist remained calm, non-defensive and validated Scott's feelings and experience of him:

He didn't get defensive or anything like that. He just, he didn't even get into excuses. He just said: 'I'm sorry, that wasn't my intention'...I remember him being very calm and I remember thinking he didn't defend himself like most men normally would like if a man attacks another man which is essentially how it almost seemed...Normally another man would just put his back up...whereas Len didn't do that, he was very calm. He

understood that this is an extreme situation and he just kind of said: 'I'm sorry'...I'm trying to get it all, I'm sorry' (Peta, 691-709).

As Peta explicitly stated, the counsellor's position in the conflict ran counter-cultural in that the usual behavioural response to conflict is attack back or defend. The counsellor's behaviour was of critical importance, and it is doubtful that a beneficial counselling experience would have followed had a more reactive course of action been taken. The counsellor did not need to be perfect, but genuineness and the creation of safety where each partner felt heard were important for the developing of a therapeutic alliance:

And so we decided to come again, and then we came again, and we came again, and there were still little things here and there that, you know the second time I think there might have been another mistake. But it didn't bother my husband as much that time. It's easy for us, we know our story. And you were going to be able to cry if you needed to. And there wasn't gong to be any judgements. ..It was really beneficial to be able to come here and know that Len was gonna listen (Peta, 589-611).

The development of trust tended to be a gradual process even when the bereaved had a strong sense of the therapist being worthy, skilled and professional.

Counselling could be preventive in supporting the bereaved as they interacted with others in their social world. For Peta and Scott, counselling enabled them to head off arguments before they became deeply hurtful. The counsellor assisted the couple to communicate respectfully with each other about issues that they were not adequately resourced to deal with at the time. These issues had the potential to escalate, potentially overwhelming them or wounding them further:

...you know, sometimes things get brought up in arguments and that ends up hurting the other person because you've said something in the heat of the moment, whereas in counselling it's slightly different...I guess because you get to air before you get to an argument. It's not quite so attacking (Peta, 647-657).

Many of the participants struggled to put into words specific aspects of counselling that they experienced as beneficial. Comments and descriptions tended to be of a general nature with warmth being important:

I just personally find him really easy to talk to. This is a good environment, and we come here in an evening and there's nobody here, it's just the three of us...and it just seems to work. We talk and it's always a nice warm environment. I think it's a personal thing. I personally find Len really easy to talk with (Peta, 666-672).

Peta's ease in being able to talk increased over time and was not present at the beginning of counselling. Peta said she initially found it easier to sit back and allow her husband to speak whilst taking a passive role. The counsellor was able to build a relationship with both Peta and Scott who were both experiencing a myriad of emotions such as anger, hurt and with ambivalence regarding attending in the first place.

The death of a child can put an enormous stress on a couple's relationship resulting in many couples separating following the death. An important aspect of counselling for Peta and Scott concerned the buffering role it served in their relationship:

So that's very freeing for you, so you can say whatever and it's almost, the environment itself is almost like a little cocoon where you can come in say whatever and then you can leave or it has been our experience. You can leave and whatever you've said actually stays in the room. So it doesn't actually damage our relationship, like it doesn't damage Scott and my relationship. It helped us to be able to air our feelings without have to worry about hurting the other one's feelings because it was kind of almost a bit of a level ground to start with (Peta, 637-644).

In the quotation above Peta uses the metaphor of a “cocoon” to describe the sense of safety she experienced in counselling, which enabled her to “say whatever” she needed to say. The words: “a bit of a level ground” suggests that there was a sense of equality present, where each person was going to be treated fairly. The structure of the counselling relationship appeared to create safety for the couple so that they were able to broach difficult issues.

Several of the participants required the combined support of counselling and medication and this led to an interdisciplinary approach. Sometimes this was identified by the therapist in the case of Wilhelm who was referred back to his GP following the first session: “Well the first thing that came out of counselling was that I really needed some antidepressants” (David, 113). In other instances the need for medication was identified by the GP. For Peta and Scott, their GP was their first point of contact following their child’s death and she suggested they maintain close contact with her. The GP assessed and monitored the family, prescribing antidepressant medication for Scott whilst referring both partners for bereavement counselling. The counsellor formed a segment of an interdisciplinary professional supportive context. This broad based framework of support was experienced by the bereaved as containing and beneficial:

...like the system really worked...Even though I’d made the appointment for Colby, it was part of her (the doctor’s) job to make sure that I was okay for him too. And so we discussed it for a few minutes and she told me that there were things that we could do that there was medication both of us could have and that we should come back and see her.... We ended up keeping in close contact with her and she said that I think you should have counselling (Peta, 517-536).

It was important that those providing medical and professional support be able to work together. When Vera approached her GP about her symptoms requesting help through medication she was dismissed. The GP argued: “No, you’ve just got to grin and bear it, or you know, work through it”. Vera experienced his comments as unsupportive and not fitting with her needs. She felt angry and decided to seek help through seeing a different doctor. Vera also saw an unsympathetic psychiatrist whose manner Vera experienced as inflammatory and dismissive. Instead of experiencing support she experienced empathic failure.

Vera’s counsellor instead supported her by validating her reports of depressive symptoms, assisting her to place these in a perspective in which her depression and bereavement were separated out. The counsellor aided Vera’s construction of meaning around her experience whilst encouraging her to take the steps she needed to. The therapist was also optimistic:

The main thing I kept saying is: ‘How can I prevent the downs, you know, what can I do?’, and there really isn’t an answer, or I don’t remember him telling me that. The only thing he did say, and this I think was right, he said: ‘You’ve got a depression problem, which is nothing to do with the bereavement although it’s connected, and I think you should go back to your doctor and see what they do’, and then he said, ‘You know, what with the medication correct’, he said ‘I think you’ll come good’ (Vera, 772-787).

At times the use of antidepressant medication was not straightforward. Two participants in particular found the search for a suitable medication problematic. Wilhelm reported that: “the first lot was useless” referring to his first attempt to find a suitable antidepressant. Medication was not

without its hazards. Vera felt dizzy and faint when she finally began taking antidepressant medication. She fell three times in three weeks, with one fall occurring on an escalator in a shopping centre where she narrowly escaped serious injury. After consulting a third GP she found a medication that worked for her.

Many bereaved are challenged to make sense not only of the death of their loved one, but to make sense of the loved one's life, death and the relationship (its interaction, positive and negative parts); their challenge is to make sense of the whole. Grief counselling that focuses only on the death may miss crucial components such as the multiple meanings connected to each of the above aspects shared between the deceased and the bereaved.

At the time counselling commenced several of the participants were experiencing escalating distress that from a traditional "stage" framework would be labelled as "complicated grief" (as opposed to "uncomplicated grief" where distress steadily declines). In "complicated grief" Patterns of escalating distress are said to persist and even worsen over time (Boerner et al. 2005). However the intensifying distress is not viewed as occurring within an influential context.

Counselling resulted in lessening the degree of experienced pain over time. However, the pain people felt tended to be intensified in the beginning of counselling as the bereaved approached and explored their

experiences (including pain). Over the course of counselling the pain began to be ameliorated with participants describing change as feeling more hopeful, and having fewer “down” or “dark” days. This reduction in experienced distress was challenged at times by the tendency for participants to experience instances of profound pain which could be triggered unexpectedly. For Janice the pain tended to be triggered by the appearance of Christmas decorations being placed in shopping centres which marked the anniversary of the diagnosis and death of her husband.

David was greatly assisted by a combination of counselling and writing. He began to write short stories in which he explored and expressed his grief with the support and encouragement of the therapist. Writing formed a significant active process, which he was still undertaking at the time of the interview. David utilised writing to express and grapple with the many issues and aspects of his experiences of grief. Sometimes writing occurred in the most unusual of places, such as outside the house whilst undertaking chores:

When you're doing something like that your mind is turned off, and that's when good writing comes into your mind. You know you're thinking on a particular theme and then your mind sort of creates a line around that. And then I stop the mower, get the card out of my pocket and write, write that story bit and put it back in my pocket and then I might go another 50 yards, and turn it off again and start and write a bit more. I mean...at the end of the day I might have read it and say 'that's crap' but it's helpful, but remember that all the story writing that I've been writing has effectively been part of my, um no rehabilitation, what's it? It's been part of my grieving (David, 543-554).

In grief there is a need for pain to be processed, to be felt and expressed. However, the context in which pain is expressed and felt is important, shaping the continuing experiencing and understanding of grief and pain.

These participants were able to process and explore their pain in a safe space allowing them to examine the meanings around their pain. As they processed their pain they seemed to access beliefs around their sense of self. For example, Janice's negative beliefs about herself changed and she had room to consider other less constraining, more positive beliefs about herself.

Counselling formed a safe context in which people could unload their pain, and when their pain was unloaded, there was space for other feelings, and an opening up of the self. When the self is carrying considerable pain and the interpretations/beliefs about the self are negative, the experience for the bereaved is an – increasingly negative and constricted environment where time leads to a worsening of symptoms as opposed to improvement. Withdrawing from others is a reactive coping strategy that at first leads to the experience of relief. However, this narrowing social context leaves people alone with their potentially negative beliefs, and their painful feelings where meanings and the experiencing of self is not open up to new possibilities. It seems that in this narrower space the bereaved are more vulnerable to negative rumination.

The counsellor encouraged the bereaved to process meaning in between sessions. For instance counselling assisted Janice's move from reactive coping where she avoided others and appeared to be immobilised, in a constricted "depressed" state, to becoming more active in her grief, and able to reprocess her pain in ways that incorporated creativity. During the

most difficult hours she created picture albums and wrote poetry, where her feelings, reflections and experiences of loss came together with the exploration of meaning. David found that he was able to express and reprocess his pain through writing at seemingly inopportune moments, such as when mowing the lawn. He would stop and write down his ideas, sometimes recording them onto a dictaphone. David found processing and “finessing” his writing helped him to emotionally unload, saying: “by writing it down, I’ve taken some of the pressure off me, you get it? I’ve taken some of the pressure off me”. (David, 861-863).

During counselling Helen explored and expanded the way she defined herself during her husband’s illness and after his death. Paradoxically, she found that this experience both reduced and expanded her sense of self. Helen’s world and sense of self narrowed as George became increasingly unwell, thereby constraining her.

Helen experienced success as a carer and was confident about this aspect of her life. Additionally, she described being positively influenced by George’s values and his way of being with her in the relationship (including his beliefs) which helped Helen to grow. Helen’s relationship with George was a rich source of meaning and purpose in her life, and it has been important for her that he is still involved in meaning and purpose in her life.

For some participant's there was a changing sense of self. For example, Helen moved from a place where she had been dependent ("When my husband was alive then somehow or other my life had meaning because it was connected to him") to an immediate reactive transferring of her energy and purpose across to her children following George's death. She explained with the statement: "(be)cause my own life never seemed to have significance for itself" (321); Helen has moved to a more considered interdependent sense of self where her connection to others is balanced with an investment in self-discovery.

For Janice the process of change began gradually. Change was connected with her developing confidence within herself that had been previously lacking:

I was confident in my counsellor, very much so but I had to build up the confidence in myself...It just took a little while to build the confidence for myself to be able to say, and then by about the middle of the year...I started to feel a lot better...I still didn't know where my life was going to take me, but I was starting to feel that there was sunshine. There was happy things starting to surround me (Janice, 436-441; 327).

With growing confidence Janice was able to reach out and try new things, and this helped her to redefine herself from dependent and depressed to being confident and able to explore new horizons. Her perceptions of her surroundings seemed to lighten:

I could see hope, hope around me that I even decided, what I'd never done before was to take a long, long train trip. A twenty four hour train trip to Queensland...at the time and that was a big thing for me...I felt very happy and proud of myself to be able to, in the few months, to get to this stage that I could do that (Janice, 443-449).

Janice's sense of change also involved the development of a new social network which was connected to a volunteer organisation she became

involved with. Janice made new friends, and engaged in unpaid work which she experienced as meaningful. She felt deeply connected to others in the organisation and seemed to be battling less with her internal world. Janice had finished receiving counselling prior to the interview. However, her quest to learn more about herself was continuing: "I'm learning to live now with more peace and harmony within myself".

The experience of Tristan's life and death, have profoundly shaped Peta and Scott's lives which Peta recognised as both costly but beneficial. Peta stated:

He helped me when he was here. His life has changed my life so much that yeah, I think he's here all the time (914-921).

Tristan is still a continuing part of the family's life, a dimension which involves his sensed continuing spiritual presence. Tristan's continuing presence represents hope for both his parents. Both are hopeful to one day see their son again, to be reunited, just as David's hope of being reunited in heaven with Stephanie one day, helped to motivate him. Tristan is still very much part of his mother's life. When I emailed Peta I noticed how she defined herself by her relationships to her immediate family: Peta: "Wife of Scott, Mother to: Tristan (date of birth & date of death), Colby, and Johanna". Tristan's place in the family has not been erased, nor has he been replaced through the birth of other children.

Summary

This chapter has explored the group narratives that were constructed from the individual stories. The group stories presented in this chapter included: the relationship between the bereaved and deceased which transformed following the death. Several participants developed continuing close bonds with the deceased whilst others loosened ties. Another group narrative explored the central place of loneliness in the bereaved's experience of their grief which was linked to the physical absence of the deceased and the unique qualities of the relationship. The impact of the bereaved's surrounding social context on the trajectory of their grief formed a significant group story. The paradoxical nature of pain and growth in the bereaved's experience of their continuing life was also presented with findings indicating pain was non-finite. Finally the bereaved's experience of counselling formed an important narrative where counselling formed a context enabling relationship that compensated for empathic failure by others, whilst assisting the bereaved to experience pain, process meaning and work with issues of identity.

The next chapter will examine the significance from the findings of both the individual and group story chapters, with a focus on the insights from these stories being used to develop further understandings of the bereaved's experiences of grief. Implications for practice with bereaved clients and policy development for providers of care will be examined along with a consideration of how the study contributes to the literature on grief and bereavement.

Chapter 6

DISCUSSION

This project has sought to deepen the understandings of how people experience their lives following exposure to bereavement. It has aimed in particular to gain insights into the ways in which the bereaved move to cope and adapt. The project has also sought to answer the question of how counselling assisted the bereaved to adapt with an emphasis on uncovering aspects of therapeutic work which have been experienced as beneficial.

This chapter discusses the findings from both the group narratives and individual stories presented in chapters four and five. The contributions made by this research are detailed and examined within the context of the bereavement literature. Amongst the contributions are findings that: increasing insularity between the carer/patient prior to the death intensified the bereaved's distress following the death; the experience of emotional loneliness is multidimensional and not limited to spousal loss; an experienced "loss of self" is not uncommon and is connected to the uniqueness of the relationship (which allowed aspects of the self to emerge, not arising in connections with others). Other key findings include: the capacity for the broader social context surrounding the bereaved to intensify the bereaved's distress through empathic failure; and that the nature of continuing bonds with the deceased is linked to the nature of the

prior relationship and the identity of the bereaved. A significant finding concerned the way counselling supported the bereaved's journey to adaptation. Therapists collaborated with the bereaved to construct of a "context enabling" relationship where "empathic attunement" compensated for "empathic failure".

The implications of the findings, for therapeutic practice in providing support and assistance to the bereaved are addressed in this chapter, including recommendations for policy and service development. The chapter begins with a reflection on the selected methodology and considers both the strengths and limitations of the approach chosen. This chapter includes further questions raised through the process of the project that went beyond the scope of the study. Recommendations have been made on directions for further research.

Reflections on the methodology

During the course of the study I have become aware of a potential anomaly with regard to the research design. Participants selected for the study were drawn from therapists who used the tool BART. This tool reflects a "normative" approach to bereavement based upon the traditional understanding of grief and loss. By using a narrative constructivist approach to collecting and analysing the data, I have been working to deconstruct these traditional approaches. I am also deconstructing terms like "complicated" and "uncomplicated" grief with their normative

connotations, to look at the particularities of the individual participant's story. I am not necessarily claiming that traditional approaches do not serve an important function in providing maps of the bereavement journey but that they can be problematic if imposed on people.

I have selected a methodology that attends to the ways in which people construct meaning. Narrative methods allowed for greater understanding of people's experiences following bereavement (Lieblich et al 1998; Riessman 1993). Narrative analysis was useful in directing attention to the ways in which people link their stories together to create meaning (Polkinghorne 1988). The experience of adapting to bereavement involved complex issues of meaning and narrative analysis formed a lens enabling the foregrounding of how people experience their loss.

However, there were some limitations to the study. One of the limitations concerned the lack of information available about the specific interventions utilised by treating therapists. However, recent research has indicated that the therapeutic relationship and what the client does accounts for 70% of the outcome, while techniques only account for 15% (Orlinsky & Howard 1995). Unfortunately it was beyond the scope of this project to have the therapists provide direct information about their sessions. This would have raised considerable ethical dilemmas with regard to confidentiality, and may have undermined the freedom of bereaved participants to remain anonymous, and report openly, on aspects such as their negative experiences. Having stated this, attempts by researchers to prove the

superiority of individual psychotherapeutic approaches have found that when differences in effectiveness have been noted, “such differences as were found could usually be explained more plausibly in terms of circumstances having to do with research methodology” (Orlinsky & Howard 1995:4).

Another limitation concerns the cross-sectional design of the study. The data collected from the study capture the bereaved at a particular point in time. However, as discussed in chapter three, people are continuously engaged in a process of (re)constructing their experience. It is likely that successive interviews conducted in the future might lead to different results. For example, aspects of the bereaved’s stories would have changed as some experiences may be viewed as increasingly significant whilst other aspects are deemed less important.

Narrative analysis is a methodology which by its nature is time consuming requiring small sample sizes (Riessman 1993). In the present study the sampling methods targeted a specific group of those experiencing bereavement, limiting participants to those identified with a “normative tool” as having had a difficult reaction to grief. It may be argued that the results arising from the project are therefore not applicable for others who are bereaved. However, it is important to remember that “there is a long tradition in science of building inferences from cases” (Riessman 1993:70). As stated in chapter three, findings from narrative research are judged on their plausibility, and trustworthiness (Riessman 1993:65).

Findings are considered persuasive and convincing “when theoretical claims are supported from informants’ accounts and when alternative interpretations of the data are considered” (Riessman 1993:65).

The relationship between the deceased and bereaved

As explained in chapter five, the findings in this study involve issues that overlap in multiple and complex ways. One key finding concerned the relationship between the deceased and bereaved prior to the death and into bereavement. According to many of the participants, this relationship became increasingly insular through the trajectory of the illness. The potential for this relationship to become closer as the illness progresses has been noted by Parkes & Weiss (cited in Rando 1984:356). Results from the current study show that the quality and intensity of attachment between the carer and patient contributed to the carer’s experience of bereavement having the capacity to intensify distress.

This study has used attachment theory to explore the experience of bereavement (Bowlby 1980; Fraley & Shaver 1999 Mikulincer & Shaver 2005). As presented in the literature review (chapter two), from an attachment perspective relationships are either secure, or anxious in the ways that partners (or significant others such as parents/children etc) are connected to each other (Feeney 1999; Hazen & Shaver 1987; Shaver & Hazen 1988). In securely attached relationships, the other is experienced as responsive, available and dependable. When threat or pain is

encountered, comfort and reassurance is sought. However, insecure relationships are characterised by people behaving in dismissive and/or attacking ways, reacting with fear or hostility to closeness or perceived abandonment (Ainsworth & Bowlby 1991; Bowlby 1977). Consequently, anxiously attached relationships tend to be more reactive, and may negatively impact upon the self esteem of partners.

As stated in the literature review, the status of a person's attachment has been linked to the experience of grief following bereavement (Bowlby 1973, 1980; Horowitz, Bonanno & Holen 1993; Parkes & Weiss 1983), with anxiously attached people theorised as being more vulnerable to complicated grief. For example, anxious "preoccupied" persons are more likely to display higher levels of distress and ruminate negatively (Stroebe & Schut 2001:356). However, not all who are anxiously attached are at risk of chronic or difficult grief responses. For example, those who are anxious and "dismissing" may adapt well to bereavement because of their tendency to use avoidant coping efforts and downplay the importance of emotional closeness in relationships (Fraley, Fazzari, Bonanno & Dekel 2006).

Findings from the current study showed there was a tendency for participants with an anxious "preoccupied" attachment style to use reactive forms of avoidance. For example, avoiding those in their interpersonal world increased the bereaved's vulnerability through increasing their isolation (refer to the narratives of Helen and Janice). Also significant was

the finding that no bereaved participant appeared to have had a relationship with the deceased characterised by an anxious “dismissing” attachment, supporting Fraley and colleagues (2006) above argument.

Findings from the current study show that the presence of dependence, ambivalence and conflict in the relationship (between the bereaved and deceased) was found to be connected to heightened distress (refer to the narratives of Janice, Helen and David). These participants seemed to struggle intensely with issues of meaning which raised their distress causing protracted pain in their bereavement experience. These findings support the literature linking ambivalence and/or dependence in the relationship prior to the death with problematic grief experiences for bereaved survivors (Parkes 1986; Parkes & Weiss 1983).

Findings from this project suggest that the greater the place, and centrality of the relationship in the bereaved’s life (or “self story”) the greater the challenge it was to adapt in bereavement. Where the bereaved’s sense of self overlapped (or was highly aligned) with the deceased prior to the death, the bereaved was confronted with a loss of “sense of self” and loss of purpose. The structure of the relationship and presence of the other that had permeated much of the bereaved’s life was now palpably experienced as missing, causing “separation distress” and loneliness (Bowlby 1980; Kobak 1999). A loss of “self” has been named as an indicator of complicated grief within traditional models (Parkes 1972; Parkes & Weiss 1983). This experience of missing the other was linked with emotional

loneliness raising the bereaved's sense of personal vulnerability. Increased levels of distress have also been linked to personality factors and ambivalence in the relationship between the bereaved and deceased (Parkes & Weiss 1983; Vachon, Rogers, Lyall et al. 1982).

However, not all participants experiencing a central overlapping relationship with the deceased appeared to suffer a loss of self. For example, in spite of her relationship with husband Gary being central, Vera did not experience her husband's death as something that seemed to challenge her sense of self. However, Vera grappled with facing loss of support. She was now alone in managing the sadness and depression that Gary had assisted her with in their life together. For Vera, adaptation involved developing strategies, such as finding ways to self-soothe (such as hugging her teddy bear) in her bereavement experience.

Anticipation, death and distress

Findings from this study suggest that an anticipated death can also be traumatic. For the carer, the approaching death was experienced as distressing, involving feelings of powerlessness and anticipatory grief (Glick, Weiss & Parkes 1974; Knott & Wild 1986; Rando 2000). As discussed in the literature review (see chapter two), the debate over whether sudden unanticipated death is more traumatic for survivors than anticipated death has yielded mixed results (Stroebe & Schut 2001:354).

For the majority of participants, distress prior to the death was connected with heightened distress following the death. The worsening condition of a significant other appeared to raise stress levels that remained elevated. However, these results challenge the view that sudden death is experienced as more traumatic for the bereaved (Ball 1977; Lundin 1984a; Sanders 1983). However, findings are consistent with other literature where heightened levels of distress (for the carer) prior to the death have been linked with elevated distress (and difficult grief) over an extended period of time during bereavement (Boerner, Wortman & Bonanno 2005). Hence, trauma can be experienced in slow progressing illnesses and still involves issues of powerlessness for the carer/bereaved. Heightened distress during the trajectory of the illness appears to elevate the bereaved's vulnerability.

Continuing bonds with the deceased

A key focus in the study concerned the presence of continuing bonds between the bereaved and deceased (Conant 1996). In this study the majority of participants experienced continuing bonds that were ongoing and open ended at the time of the interview.

As presented in the group narrative chapter, continuing bonds were multidimensional and included: a) sensing the presence of the deceased, b) maintaining conversations about the deceased person with others significant to the deceased/bereaved, c) maintaining connection through objects that had been significant to the deceased, d) being involved in or

continuing activities that were important to the deceased prior to their death, e) being mindful of the deceased's wishes and values in making decisions in ongoing life, f) maintaining connection through actively recalling memories of life with the deceased and pondering/replaying these aspects of shared experiences and g) integrating qualities/values from the deceased into the "self" of the bereaved that held meaning (refer to the story of Helen).

The above pathways of maintaining connections with the deceased were most adaptive when they brought comfort to the bereaved. A unique contribution made by this research is the finding that continuing connections helped to direct the bereaved's actions whilst assisting the bereaved (re)gaining access to aspects of their sense of "self" that had been shared with the deceased in life.

This study shows that some forms of continuing connection with the deceased require the interaction of others within the bereaved's social context. Thus, there were both interpersonal and private ways in which continuing bonds operated. For example, the need for bereaved participants to talk about the deceased in everyday conversations represented an interpersonal way of holding on and continuing bonds. Alternately, replaying memories could be intensely private and reflective (such as Helen) or shared interpersonally (see story of Peta) through conversation. In the literature there has been a focus on the intrapsychic nature of continuing bonds with the deceased (Silverman & Klass 1996;

Neimeyer, Balwin & Gillies 2006). The above finding supports recent movement in the field where the impact of culture and political environments on the bereaved's continuing bonds with the deceased have been highlighted (Klass 2006; Klass & Goss 2003).

For several participants, continuing bonds included sensing the actual presence of the deceased. Findings suggest that spiritual sensing experiences are common, forming a potentially important aspect of the bereaved's experiences. This is consistent with Richards' (2001) findings where a majority of participants reported sensing phenomena that were felt to be positive. Only a small minority from Richards (2001) study found these experiences unsettling or troubling. In the current study all participants describing "sensing" or "continuing bond" experiences with the deceased described these in positive terms. The deceased was viewed as assisting the bereaved (as described earlier), through providing them (the bereaved) with direction and/or support as they made decisions in ongoing life. The deceased helped to maintain the survivors' sense of purpose and meaning in the present through the hope of reunification in the future.

As discussed in the literature review, experiences involving bereaved survivors sensing the presence of the deceased have been traditionally viewed as aberrations of what is normal. Sensing experiences have been referred to as "hallucinations" or "illusions" (Parkes 1986:78-79). These terms reflect the values held by the medical model which conceptualises sensed connection with the dead as a product of defensive processes

(Baethge 2002; Kersting 2004). These aspects of the bereaved persons experiences and beliefs are viewed as controversial and have been largely dismissed by theorists and researchers advocating a “traditional” approach to grief (Baethge 2002; Kersting 2004; Parkes 1972). At best such experiences are viewed as “novel” responses that may be “normal” provided they are transient, occurring during the initial aftermath following the death (American Psychiatric Association 1994). As stated in the literature review, the ongoing presence of sensing experiences has been used to diagnose complicated grief. In the current study “sensing experiences” were open ended and continuing at the time of the interviews. These findings challenge the “traditional” view that sensing experiences should be transient.

These results show that sensing experiences are a normal aspect of bereavement for many. Findings support Rees’ (1971) research investigating the presence of “sensing phenomena”⁹ in a conjugally bereaved sample. For example, Brenda’s sense of her father being connected to her from a new spiritual place, from which he watched over her, which brought her comfort and hope. Peta sensed her son’s presence amongst the family, whilst her husband Scott sensed Tristan was being cared for by his (Scott’s) mother who had died several years earlier. Tristan was experienced as being safe, remaining spiritually present and amongst his family.

⁹ Rees (1971:37) referred to “sensing experiences” as “hallucinations” in keeping with the medical language.

Consistent with Rees' research was the tendency for participants to withhold sharing "sensing experiences" from others in their interpersonal world. Rees (1971) did not explore the reasons why people kept their continuing bonds private. However, the current study suggests that the bereaved maintain privacy around their experiences for reasons of self-protection. Being labelled negatively (as abnormal) would increase the stress experienced by the bereaved whilst potentially negating an important source of comfort and hope that was felt through the deceased's continuing presence.

The processed (re)connection of ties to the deceased allowed the bereaved to step out and engage more fully in their life, increasing their interpersonal life space. To optimally reprocess the relationship with the deceased, people need to be in connection with others in an environment that is perceived to be supportive and available. Neimeyer and Jordan (2002) have emphasised the need for the social environment to be attuned and available to support those who are grieving. However, in western culture it appears there are few easy ways to discuss and share the ways the deceased remain connected or continued in ongoing life, in an open-ended way.

Loosening ties

A significant finding from the study indicates that the need for keeping hold of or loosening connection with the deceased is complex and connected to the nature of the relationship prior to the death. A need for close

continuing bonds with the deceased was not evident for all participants. The nature of continuing bonds appears to occur along a continuum from highly connected at one end to disengaged/loosened at the other.

Findings showed that the movement to seek distance or continue bonds with the deceased involved the continuing sense of self of the bereaved. Where relationships had been constraining or constricting the bereaved appeared to loosen (and/or realign) ties with this process being facilitated through counselling. As discussed in chapter five, two participants distanced themselves from connections with the deceased in their journey of adapting to bereavement. Those who loosened ties appeared to support the traditional model's emphasis on the relinquishment of ties (Sanders 1989; Worden 1991). However, there were multiple paths to adapting to bereavement.

The issue of identity has been named in the "grief work" approach as being integral to adaptation to bereavement (Parkes & Weiss 1983). However, the traditional approach has viewed identity development as involving the relinquishment of ties. The findings from this project support the importance of identity development, with the caveat that identity work does not require distancing from the deceased. Findings support the post-modernist approach emphasising meaning making and uniqueness (as opposed to universality) (Neimeyer 2001) by conceptualising individual meaning making as being intricately connected to each person's relationship to the deceased. This approach leaves room for continuing

bonds and/or relinquishment with each being tied to the bereaved's identity (re)development.

Certain aspects surrounding the bereaved impacted upon the path they took. For example the presence of additional stressors surrounding the bereaved left them with less energy to (re)process their bonds with their loved one. Another key factor involved the amount of, and quality of support available to the bereaved. For example, Brenda faced limited support from friends and family. Her processing of the bonds with her father and her sensing experiences were private and not shared. Whilst she did continue her bonds with her father, it seemed that the counsellor played a key role in affirming and supporting these efforts. Empathic failure/support appeared to have a role in the paths individuals took.

A significant finding from this project suggests that the death of a significant other has the potential to disconnect people from those around them just as it disrupts and permanently alters their connections with the one who has died (refer to the narratives of: Helen, Janice and Wilhelm). A profound aspect of the disruption between the bereaved and others who care about them is the survivors' experience of deep loneliness (Costello 1999; Stroebe et al. 1996). Findings suggest that the experience of loneliness is linked to a loss of intimacy with the deceased and the result of experienced trauma where the bereaved feels that their world has been turned upside down (Attig 1996; Janoff-Bulman 1992).

In adapting to bereavement participants struggled to incorporate their experience of loss into their “story of self”. This was a dynamic process that involved meaning and meaning making. These findings challenge the traditional model’s emphasis on the bereaved’s need to work toward accepting the reality of the loss (Worden 1982; 1991). For the majority of participants a significant aspect of their struggle to adapt involved their moving from an utter sense of having lost the deceased, and a loss of “self” to a place where the deceased was (re)incorporated into their lives. This reframing of the path of adaptation to bereavement supports Walter’s autobiographical account of his own response and adaptation following his father’s death (Walter 1996). For the majority of participants, adaptation involved re-finding the deceased so that the deceased could be (re)integrated into the bereaved’s ongoing “self” story. In (re)finding the deceased, participants acknowledged the altered nature of the relationship suggesting that (re)finding is not incongruent with “acknowledging” or “knowing” the loss has taken place (Worden 1991).

As stated above, from a traditional “grief work” perspective, the need for the bereaved to take in the reality that the other is missing has been viewed as essential to adaptation (Parkes & Weiss 1983; Sanders 1989; Worden 1982; 1991). The assumption is that denial of the loss needs to be worked through both emotionally and cognitively before acceptance can take place (Worden 1991). However, findings suggest that the path of adaptation is linked to meaning making and that acceptance may not form a significant issue for all who are bereaved. For example David did not

appear to struggle with accepting the reality that his wife had died. However, he struggled intensely with meaning around his relationship with her, which permeated his struggle to adapt in bereavement. For David, adaptation involved him incorporating his experience of loss (including his relationship with his deceased wife) into his “sense of self”.

Rather than prescribing a stage like path that the bereaved must traverse, post-modern theorists and researchers such as McCabe (2003) have suggested that denial and acceptance of the loss occur along a continuum where bereaved persons move between the above two opposing points, taking up positions somewhere between. Movement is open-ended where it may be normal to have feelings of disbelief years down the track following loss. From this perspective an element of denial is conceptualised as normal. From McCabe’s (2003) perspective “acceptance” is no longer a goal but a dynamic process that is open ended. It seems more fruitful to allow for diverse responses to loss, understanding that the issues people face will not always be universal. A problem with the “acceptance” task is that it conceptualises all who are grieving as needing to overcome a hurdle, and do so in a prescribed way. This leaves the bereaved as either “passing” or “failing”, and does not include a view of the context surrounding the bereaved. From this perspective it is easier to pathologise the bereaved, however, a continuum approach does not (McCabe 2003). A continuing approach allows for a more holistic perspective.

Findings from the current study extend McCabe's (2003) conceptualisation to include an additional continuum. This continuum would have "an utter sense of having lost the deceased" at one end, with "(re)finding/(re)connecting with the deceased" at the other end. Also consistent with McCabe (2003) is the sense that any position taken is open-ended and that movement is normal.

Findings from the current study showed that connections with the dead provide support to the living by offering them a sense of comfort and support. These results are consistent with Klass & Goss (1999:553), who found that continuing bonds occurred within a context of the "private sphere", where they were not shared publicly with others. They stated

...the roles deceased play in their lives as supporting their being better persons, making better decisions about their lives, or personifying important values...The dead do return, it seems...They come in unseen presence, communicate in silent words, and influence our lives by siding with our better selves. The living can do nothing for the dead although the dead can help the living to be better persons (Klass & Goss 1999:564).

For the majority of participants in the current study, keeping hold and (re)incorporating the deceased formed a significant part of their adapting to bereavement. Klass and Goss (1999) have argued that in modern western cultures continuing bonds tend to operate asymmetrically (with the dead being able to help the living but the living being unable to assist the dead). However, this model did not fit with the experiences of all participants in the current study. For example, at the time of the interview David was still lighting candles for his deceased wife, and saying prayers for her and his remaining family. His continuing connections were symmetrical, and mutually supportive. Other participants' connections

were asymmetrical, and consistent with Klass and Goss's (1999) view such as Peta and her husband Scott who felt they were being assisted by their son's ongoing presence in their daily lives.

The deceased was experienced as having a vested interest in the bereaved's well-being possessing the potential capacity to assist the survivor. Most examples of continuing bonds tended to be asymmetrical. However, the structure and perceived beneficence to either party was connected to the beliefs (sometimes tacitly) held by the bereaved, which have links to the bereaved's cultural or spiritual context (Klass & Goss 2003:807-808). Their connections with the deceased were based around personal meanings and were unique as opposed to prescriptive (Neimeyer 2001). Hence the structure and nature of bonds will vary between bereaved persons.

As noted previously, the presence of bonds was not reported by all participants. The interview guide did not elicit information directly about the sensed presence of, or the continuing bonds with the deceased. In a study by Richards (2001) spiritual "sensing" phenomena arose without the topic being elicited through direct questioning (Richards 2001:176; Richards cited in Gillies & Neimeyer 2006:39). Klass (1996) found that parents sensing experiences of their deceased child were normal and that

a

...belief in the child's continuing active influence on thoughts or events, or a conscious incorporation of the characteristics or virtues of the child into the self – are no longer occasions for the parents' concern about their

own sanity, The phenomena are accepted as a positive part of everyday living (Klass 1996:214)

Consistent with Richards (2001) findings, participants in the current project felt their “sensing” experiences and continuing connections with the deceased were helpful.

An important result of this study suggest if others in the bereaved’s network dispute or are not in tune with the bereaved’s ongoing connections to the deceased, there is a possibility that empathic failure (Neimeyer & Jordan 2002) may result leaving the bereaved to grapple with issues of meaning around these bonds in isolation. Since analysing the participants’ narratives I have noticed how bereaved clients tentatively report sensing experiences because the phenomena does not readily fit within the “usual” or “normal” confines of experience. It appears that the bereaved person watches vigilantly for possible criticism or rejection of the validity of their experienced phenomenon (refer to the story of Brenda).

It is important to note that not all recalled “sensing” experiences were connected with people who were religious. Only one participant described being affiliated with a religious tradition. In Australia, people are less likely to regularly attend religious services or report being part of a religious organisation than those in the United States (Black 1990). Another participant (Fred) had attempted to reconnect with his religious roots by attending services. However, he found the experience disappointing as the services had changed and bore little resemblance to those he had attended in the past with his mother. Fred’s experience illustrates that not

all efforts to seek comfort or connection with the deceased will be fruitful. Sometimes efforts may leave the bereaved feeling deflated.

However, findings show that being non-religious does not equate to a lack of spirituality or sensed connection with the deceased (refer to the stories of Peta and Brenda). It may be that spiritual “sensing” experiences transcend religiosity. For example Peta stated that her husband Scott strongly disliked God, and was not religious. However, Scott had continuing experiences where he sensed his son Tristan’s presence. Questions remain as to whether religiosity (or absence of this) contributes to bereaved survivors making sense of their experiences and integrating these into their lives. Religion may place sufferers within a context that affirms “the commonality of suffering” (McFarlane & Van Der Kolk 1996:25) providing meaningful support. However, suffering may threaten the bereaved’s attempts at meaning making resulting in “loneliness and a disintegration of belief” (McFarlane & Van Der Kolk 1996:26). In the literature however, having a connection to some kind of higher power has been linked with higher resilience and adaptive responses to stress (Seligman 2006; Stroebe & Schut 2001:358).

Grief and the social world

The results from this research support the view that the interpersonal context surrounding the bereaved significantly impacts upon their grief experience (Doka 2002; Neimeyer & Jordan 2002). For the participants in

this study, their social context included others who may also have been grieving, such as immediate and extended family members (Nadeau 2001), friends, and colleagues. It also included staff in private and government organisations whom the bereaved had encountered as they attended to (practical/financial etc) matters connected with the death. Participants experiencing the most constraining social and relational contexts appeared to be struggling the most at the time of interview.

These findings are consistent with Caplan (1990:28) who asserted that the bereaved are temporarily more influenced by the behaviour of others whom they are in close proximity with. Findings from the current project advance these assertions further by incorporating the broader social context as an influential environment having the capacity to impact upon the bereaved.

Findings from the current study suggest that the potential for the broader social environment to negatively impact upon the bereaved is linked to the constellation of factors which the bereaved is encountering. The bereaved appear more vulnerable to negative social interactions at an organisational level when support from those close to the bereaved fails. When these factors (such as the withdrawal or absence of family and friends) combined with other aspects (such as financial difficulties and negative interactions with organisations) the results were more damaging and constraining potentially magnifying grief (Cook & Oltjenbrun 1998). As noted earlier, the issue of empathic failure has been named in the

literature as impacting upon the trajectory of the bereaved (Neimeyer & Jordan 2002). Findings from the current project emphasise the multidimensional nature of grief where diverse factors form a “constellation” which impact upon the bereaved. Included in this constellation of factors is the bereaved’s own storying of these factors (see figure 1).

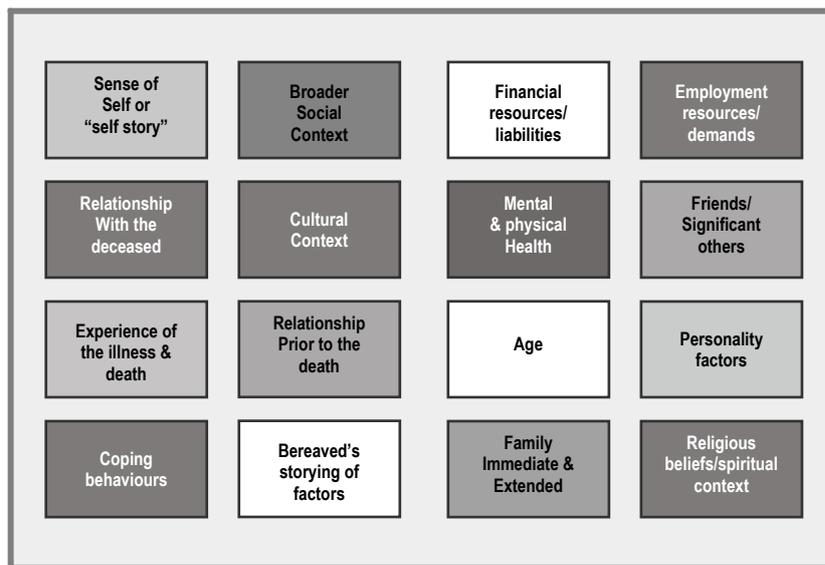


Figure 1. A constellation of factors: Contributions to a bereavement journey¹⁰

In the literature the results of research focusing on the buffering effects of social support have been mixed (Stroebe et al 1996). However, findings from this project are consistent with the work of Stroebe and colleagues (2005) who found social support reduced the experiences of social loneliness (for all people including the bereaved). Stroebe and colleagues (2005) found that heightened social loneliness was linked with increased suicidal ideation. Emotional loneliness was also linked to heightened

¹⁰ This is an original figure arising from themes in the study.

distress (Stroebe et al. 2005). However, they cautioned that social support did not reduce the pain of emotional loneliness.

Support

Findings from the project suggest that the bereaved need open ended, ongoing support from those significant to them. A perceived lack of responses from others was experienced and storied negatively by participants and appeared connected to elevated levels of distress. Findings suggest that support needs to be balanced between practical support such as cooking meals, watching over children or helping with chores and the provision of emotional support such as the support of a quiet presence. Those providing emotional support did not have to have the “right” words, in fact sometimes it was important to use few or no words. What was needed depended on where the bereaved was at, at any given time. Beneficial support was synchronised (“in tune”) with the needs of the bereaved. The concept of “supportive effort” is consistent with Martin and Doka’s (2000) model on coping styles and grief. However, the above authors concentrated on the bereaved’s own coping styles which (as stated in the literature review) fall between emotional “intuitive” coping and practical “instrumental” coping (Doka & Martin 1998; Martin & Doka 2000). This study suggests that the same model can be applied to conceptualise support efforts offered by friends/family who attempt to assist the bereaved (Nadeau 2001).

As identified and discussed in the literature review, a gap has existed in the literature with regard to the intricate qualitative aspects of social support (Davis et al. 1998). Findings from this research project suggest that support is experienced when those significant to the bereaved: a) keep a consistent connection with the bereaved, b) are prepared to allow the bereaved to speak without placing expectations on them to disclose/respond; c) have awareness that the needs of the bereaved change over time for example, a silent presence may be required one day, and practical help another; d) that supporters take initiative being mindful that those who are bereaved may not ask directly for what they need. It is significant that only one of the bereaved participants spoke of actively recruiting support from those around her, and this involved appealing to her immediate family for practical support in the days surrounding the death. There is a paucity of information in the literature with regard to the bereaved's ability or tendency to elicit support from those around them. Traditional models focus on intrapsychic processes, overlooking interpersonal engagement (Averill 1968; Engel 1964; Lindemann 1944; Sanders 1989). The current study found it was important that support was instigated by friends/significant others who took steps to engage the bereaved whilst simultaneously making offers of support invitational respecting the bereaved's wishes.

As stated earlier, interpersonal support is complex and it has been argued that existing models have lacked attention to the complex and changing nature of social support (Bernal Maldonado-Molina & del Rio 2003; Davis

2001:139). Support needs to change across time in response to the needs of the bereaved:

...one's social support (and presumably also coping) requirements ebb and flow, then our attention needs to be drawn to the specific issues that drive these changes in coping behaviour. As long as an inordinate amount of researchers' attention is focused on coping, and not on the underlying and changing issues with which one is coping, their understanding of the coping process will remain conceptually fuzzy and incomplete, and findings are likely to continue to be inconsistent (Davis 2001:139).

Findings from the current project suggest that there is uniqueness to the specific actions required by the bereaved from one day or week to another. Support is optimal when communication between parties is open so that what is needed can be discussed and negotiated.

Obstacles to finding support

The findings from the study include the identification of obstacles that existed blocking others, significant to the bereaved from providing support to them. Several obstacles were identified and included: helplessness, confusion and a lack of confidence by the helper and the (sometimes baffling) behaviour of the bereaved. Because the situation of bereavement cannot be undone (Attig 1996), the supporter could be confronted with overwhelming feelings of helplessness, and ineptness. Family, friends, and colleagues of the bereaved experienced a profound sense of powerlessness as they attempted to support the bereaved in their grief (Fleming & Bélanger 2001).

A significant obstacle preventing supporters from engaging with the bereaved involved their confusion regarding how to interpret the bereaved's behaviour. It is likely that avoidance and withdrawal signals to those within the bereaved's social world that contact is not wanted or needed and that inquiries or offers of help are unwelcome. Displays of anger sometimes hurt or discouraged supporters. Those in the bereaved's network may lack knowledge and/or confidence in knowing what to say and how to behave around people in distress (refer to Peta's story).

Another obstacle concerned the increasing levels of pain that the supporter faced as they make efforts to support the bereaved over time. Beneficial support may lead the bereaved to share more of their pain. Because of supporters lack of knowledge of what grief entails, the supporter may sense that the situation is worsening when the bereaved shares more of their distress. This may lead the supporter to doubt the effectiveness of their support, interpreting the bereaved's openness as a sign that support is failing. This obstacle connects with social and cultural beliefs people inherit and unconsciously absorb such as: grief must be resolved (it should lessen in intensity in a period of weeks/months); that continuing distress is a sign of disease and abnormality on the part of the bereaved who has failed to grieve properly (Neimeyer 2001b). Both of these strategies are from a post-modern perspective that allows for a diversity of experience which contrasts with the "prescriptive" nature of traditional approaches.

Coping strategies

As presented in the chapter on group stories, a number of coping efforts were utilised by the bereaved in the aftermath of the death. An overarching coping effort employed by survivors involved avoidance (Bonanno et al. 1995; Fraley & Bonanno 2004). Avoidance was a multidimensional strategy where the bereaved distracted themselves from emotional pain through intrapersonal and interpersonal diversion. For example, engaging in practical tasks, such as: gardening, cleaning, and employment. While not all of these activities were instigated to avoid pain, bereaved participants found they were able to distance themselves from emotional pain through their use (refer to Helen's narrative). Interpersonal avoidance reduced (triggering) distress through minimising the bereaved's exposure to situations that triggered pain, such as, Janice's avoidance of socialising with couples. Sometimes avoidance was used by both the bereaved and those in their interpersonal world. For example, Janice stated the neighbours kept to themselves and had reduced their contact with her following her husband's death. However, she also actively avoided potential contact situations by avoiding her own house. Avoidance strategies that obstruct the bereaved from receiving support appear counterproductive. Traditional "grief work" theorists would view such actions as providing support to the hypothesis that avoidance behaviours are maladaptive.

However, efforts to cope with pain are complex. Findings suggest that distraction from the emotional pain of grief offered the bereaved ways to

channel energy and gain a sense of control whilst granting the bereaved temporary respite by reducing the intensity of emotional pain.

The practical, the practical, the practical. Somehow that was not emotional that was just practical (Helen, 271).

Redirecting energy towards practical tasks allowed the bereaved to switch their awareness, foregrounding other parts of life that were less emotionally charged. In the literature cutting off from pain has been referred to as “emotional dissociation” (Bonanno et al. 1995). Whilst becoming involved in activities that are absorbing, where the persons sense of self vanishes is referred to as experiencing “flow” (Seligman 2002:116).

The findings from this study show that both approaching and avoiding pain occur along a continuum, and that the bereaved move between these two points through their experiences. The bereaved’s place along the continuum at any given time is influenced by the responses (or absence of response) from others significant to them and the type of support they receive. Findings show that the bereaved are caught between what happens within them (intrapsychic) and without (context), and that adapting requires the bereaved to manage pain as they make sense of complex issues and experiences. This is consistent with Neimeyer’s argument that adapting to grief involves grappling with issues of meaning, within a social context that impacts upon the bereaved (Neimeyer 2002).

Findings from the present study support arguments made by Bonanno and colleagues (1995) asserting that the use of avoidance strategies can be

beneficial for the bereaved assisting them to cope and reduce their levels of distress. As explained in the literature review, the traditional grief work approach has conceptualised coping efforts as activities or efforts directed at confronting the loss and facing pain. In “post-modern” approaches such as the dual process model (Stroebe & Schut 2001; 1999), the emphasis is on oscillation from a loss state to a restorative one.

Findings from the current study show that avoidance is not always adaptive. Avoidance coping efforts were sometimes too narrow and over relied upon arising as a beginning response to the (dis)stress of loss. Sometimes the bereaved did not have the resources to reflect on the impact of their coping behaviours, lacking awareness that avoidance of others to might lead to isolation and increased vulnerability. Frequently coping efforts needed to expand to include a range of behaviours that included seeking company. Participants’ use of constricted coping efforts did not appear to change until after counselling had commenced. Following the beginning of counselling, five participants broadened their strategies to encompass multiple ways of approaching pain and the creation of space where the bereaved could have time out from pain. For instance, Janice began expressing herself through poetry which allowed her an adaptive avenue for exploring meanings around her pain and enabled her to manage difficult late night hours.

These findings are consistent with the literature on trauma and its impact on the body. During trauma the body’s autonomic nervous system is

highly activated (Van Der Kolk 1996). Avoidance can be conceptualised as the bereaved's attempt to dampen their arousal and self-soothe. Movement between the states of connection and self-protection (avoidance) afford the bereaved a sense of control over an otherwise uncontrollable situation. Stage theorists have paid attention to an end point of resolution where the bereaved experience "healing" and invest in new relationships. They have however, failed to address the processes in between of relating and retreating from the social (and internal) world not recognising the potential adaptiveness of both activities.

This study suggests that coping strategies need to be varied with participants utilising a variety of coping strategies that are fluid and responsive. Adaptive coping efforts sometimes included the bereaved holding on to areas of life that held purpose for them, such as caring for children (refer to the narratives of Fred, Peta and Helen). Whilst caring could be experienced as a demand, the presence of dependent children helped to motivate bereaved participants.

Findings from this project add detail to Stroebe and Schut's (1999; 2001) dual process model suggesting that movement between the loss and restoration states is complex and multidimensional. Little attention has been placed upon the way people may reactively or more adaptively move from one state to the other. Emphasis has been on keeping the momentum going with the idea that becoming stuck at either end of the continuum is maladaptive and that grievers need to eventually move from

the earlier intense focus on loss to restorative coping efforts over time (Stroebe & Schut 1999; 2001). However, findings suggest that the qualities of the movements people make are equally important as the maintenance of movement between the states. A key focus for clinicians concerns the monitoring of the clients movements with the focus being on the “quality of the coping efforts used”. It is not so much the movement back and forward as the constellation of movements between the self, the deceased and one’s social world. The underlying question is: Is whether such movement is serving to deepen support for the self or are efforts deepening the bereaved’s experience of isolation and disconnection within themselves and in their connections to others? (see the story of Janice). Adaptively experiencing pain involved the bereaved integrating thought and feeling, ultimately processing issues of meaning.

The challenge of bereavement involves the bereaved adapting to the complex and multiple ways in which life has been disrupted and fractured. What has not been highlighted in the literature is the way in which the bereaved experiences dislocation and disruption in their relationships with others. Adapting to bereavement also involved creativity. The old paradigm stated that one must replace what is lost, gradually pulling away the remnants of the past relationship, replacing these with connections to the living (Engel 1964; Pollock 1961; Sanders 1989; Worden 1991).

However, in the current study adaptation to bereavement involved the bereaved processing three core relationships areas: the bereaved’s

relationship to: 1) the deceased, 2) themselves and 3) significant others to (re)ground themselves rather than as a function of relinquishing ties to the deceased. Furthermore, processing these relationships was an activity that occurred throughout their journey and as the bereaved (re)processed these three core relationships they employed coping efforts. The results suggest that coping efforts need to be conceptualised more broadly extending Martin and Doka's (2000) "intuitive" and "instrumental" continuum, by placing a second intersecting continuum comprised of "intrapersonal" and "interpersonal" coping efforts (see figure 2). This extension allows the bereaved's coping efforts to be conceptualised more comprehensively allowing therapists to collaborate with the bereaved to monitor and assess coping efforts.

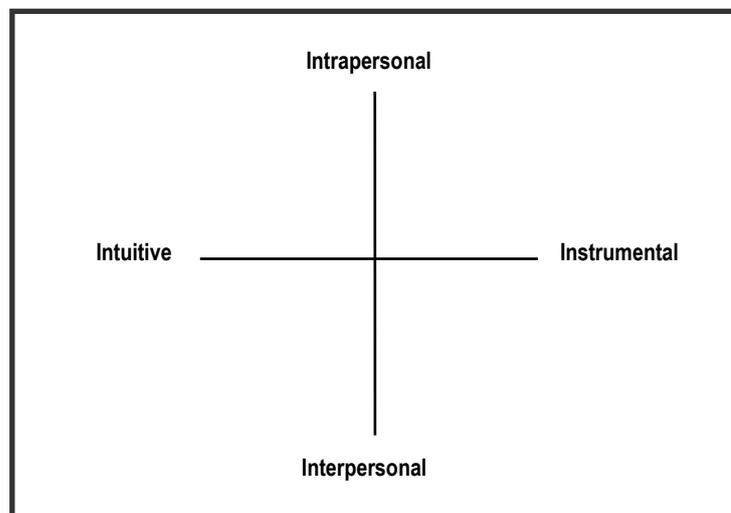


Figure 2. Grief Coping Efforts figure adapted from Martin & Doka 2000.

The complex pain of loneliness

The results of the study showed that loneliness formed a significant and central part of the bereaved's existential pain. As stated in chapter two, in

the bereavement literature loneliness has only received intermittent attention with an emphasis placed on reducing loneliness through social support (Stroebe et al. 1996). As reported earlier, findings have been inconsistent with significant gaps being present in the literature around understandings of “emotional loneliness” (Davis, Morris Kraus 1998; Stroebe et al 2006). An important contribution made by this research is to identify the issue of loneliness as a central, normal experience of bereavement that could also increase the bereaved’s vulnerability.

A shortcoming in the literature on loneliness involves findings being exclusively drawn from those who are conjugally bereaved (Costello 1999; Stroebe et al 1996; Van Baarsen 2002). However, this project suggests that loneliness is experienced with other losses such as the death of a parent or child. Emotional loneliness involved the loss of aspects of the self that were uniquely connected to the relationship between the deceased and the bereaved. Because relationships are unique, it is normal for parts of the self to remain hidden in interactions with others, but which were evident in the relationship with the deceased, leaving the bereaved feeling incomplete. In this regard, it appears normal that aspects of the self are experienced as missing. Hence “loneliness” and “loss of self” are interconnected. These findings extend the attachment approach to loneliness (Stroebe et al. 1996; Stroebe et al. 2005; Weiss 1975) by showing that a sense of “loss of self” was both common, and connected to the experience of emotional loneliness. In the literature a sense of “loss of self” is viewed as a sign of complicated or pathological grief (Stroebe

1992). Findings from the current study challenge traditional normative approaches suggesting that both experiences are normal. However, both have the capacity to complicate grief.

As stated in the literature review, loneliness can be broken into two linked but distinct aspects: social loneliness, and emotional loneliness. Results showed that both aspects of loneliness were intensified through lack of support or mismatched care from others. A context of poor interpersonal support negatively impacted upon the bereaved's grief, making their efforts to adapt more difficult (refer to the story of Wilhelm). As stated earlier, this has been referred to as "empathic failure" (Neimeyer & Jordan 2002). However, emotional loneliness could not be erased solely through the company of others. An absence of support, however, resulted in the bereaved being faced with copious amounts of time that appeared to increase their opportunities for rumination that heightened their experience of emotional pain (refer to the stories of Janice and Wilhelm). Findings from the current study are consistent with Stroebe and colleagues (2005) who found that social support did not decrease the distress of emotional loneliness. However, the current project suggests that emotional loneliness can be ameliorated through counselling and empathic attunement.

The paradox of bereavement

Research findings suggest that adapting to bereavement involves a tension between growth and distress. Participants struggled to gain a sense of distance from their pain. However, they still had recurring experiences where pain could be reactivated (sometimes unexpectedly) causing them to feel intense distress as though little time had lapsed. For one participant, resurfacing pain was predictable coinciding with festive decorations being placed in shop windows (refer to the story of Janice). For another the trigger of pain occurred unexpectedly (refer to the story of Peta). The intensity of recurring pain was still difficult for participants.

However, their fear of pain had reduced. Four participants spoke openly about feeling that they had grown and developed through the experience of adapting to bereavement (Schaefer & Moos 2001). Whilst bereavement had been the worst experience of their lives, adaptation to bereavement had led to personal growth and change that would not have otherwise occurred. As Helen stated: "it's been both the worst experience and yet the best". Sometimes the bereaved had changed in unforeseen ways that were surprising (refer to the narratives of Peter, David, and Helen). In each case, the experience of counselling appeared to be a catalyst that facilitated participants' growth.

Findings showed that the bereaved do not reach an end point where pain ceases. It is normal for pain to be encountered in an ongoing, albeit less debilitating way (McCabe 2003; Neimeyer 2001). However, participants'

relationship with pain had changed. Participants developed resources to cope with (re)surfacing pain. Significant improvements took place, enabling the bereaved to engage more fully with their social world, sometimes building new connections with others. The reprocessed relationship with the deceased helped ameliorate the pain of loss.

People have a need for relationships. Findings suggest that it is not so much replacing what is lost but extending relationships so that aspects of the self can be created and (re)found, a compensation model therefore is too simplistic. Growth did involve building/developing intrapersonal and interpersonal bonds however, the bond with the deceased did not end.

Growth was linked to meaning and meaning making. In the literature questions have been raised about the nature of the activity of meaning making stating:

...it is not clear whether the need to make sense, what Frankl called 'the will to meaning', is an enduring trait within people throughout their lives, or a state that arises at certain critical points (Gillies & Neimeyer 2006:46).

This study found that participants remained engaged in the process of meaning making at the time of interview. Meaning making was an ongoing activity with participants' stories being open ended. Many were explicitly continuing their development of their identity, for example Helen's story of continuing self-discovery:

I have, I've still got so much of finding out who I really am as separate from the wife and the mother who I've been...It's like the only way I can find those things is within myself (Helen, 631-648).

These findings challenge the traditional approaches assertion that grief is a linear process that has an end.

The experience of counselling

When counselling began each participant was experiencing significant distress. The history or prior experience of psychiatric illness such as anxiety or depression has been linked in the literature to a heightened risk of depression (Stroebe & Schut 2001). Several of the participants had experienced depression and were having recurring symptoms in their bereavement experiences. Four had been treated with antidepressant or anti-anxiety medications. Counselling led to reduced distress whilst facilitating growth and the development of adaptive coping efforts.

Findings showed that counselling supported the bereaved in adapting to bereavement through a number of means. A key aspect of counselling involved the creation of a safe and secure therapeutic relationship (Orlinsky & Howard 1995). This relationship was unique and supported by professional boundaries. Boundaries, such as the non-reciprocal nature of the relationship (described in chapter five) enabled trust to develop. Counselling assisted the bereaved to grapple with issues of their identity which often went beyond the immediate situation of bereavement and sometimes touched on past issues. Gaining access to emotion in counselling was freeing, allowing participants to experience (and define) themselves in new ways.

In the literature a secure bond between the therapist and client has been highlighted and related to positive outcomes in the treatment of a range of issues and problems (Bordin 1994; Horvath & Luborsky 1993; Horvath & Symonds 1991). However, the client's self-reports of the status of the alliance have more accurately predicted the success of treatment than has the reports of therapists (Horvath & Symonds 1991 cited in Murray & Baxter 1997:615). In the current study the counsellor's warmth, genuineness and regard for the participants formed an important aspect of the experiences of all participants' experiences.

Findings show that counselling assisted those struggling with complex circumstances to reprocess their experiences and relationships with the deceased, themselves and others in their social context. Through counselling participants deepened their self-awareness and increased opportunities to make choices about their life and future:

The counsellor's been exceptionally helpful, he's helped me to understand...and help me to make sense of what was happening to me. Because I was getting disturbed by the fact that I didn't seem to be fitting in with the models, you know, and I tried to do what the models had said, and it wasn't working for me (David, 590-594).

At times this meant providing information that validated the bereaved's experience when other sources undermined the bereaved's confidence in themselves (refer to the narrative of David). When facing a significant degree of empathic failure in one's social world, counselling may be indicated. Findings show that counselling helped to combat empathic failure. Instead of imposing stage or task based models on the bereaved, the therapist collaborates with the bereaved to locate themselves and

deepen their insights and understandings into their own experience, supporting their efforts when others were not able to do so.

A key aspect of four participants' stories concerned the presence of unfinished business. "Unfinished business" is the term used in the literature to refer to issues between the bereaved and deceased (Rando 1986) that have not been openly discussed or resolved. Part of the therapist's work was to help the bereaved in addressing "unfinished business" that had not been attended to prior to the death. The avoidance of issues prior to the death of the loved one sometimes took place in order to protect that person (refer to the story of Brenda). The therapist needed to be skilled in relationship/family counselling, to be able to work with issues that occurred between people, such as the deceased, family members, and (non)supportive others (Walsh & McGoldrick 1991).

The study found that therapists were able to draw upon a variety of means such as use of visual diagrams and creative/expressive exercises to deepen the bereaved's understanding of themselves:

I've gone to the counsellor and I've had substantial problems and I've told him the problems and he's been able to put up a diagram, that sort of show me where everything fits and where I'm at, at this time. And that has made sense to me. I think diagrammatically, visually. And so looking through a graph or a diagram like that,..that made a lot of sense (David, 817-825).

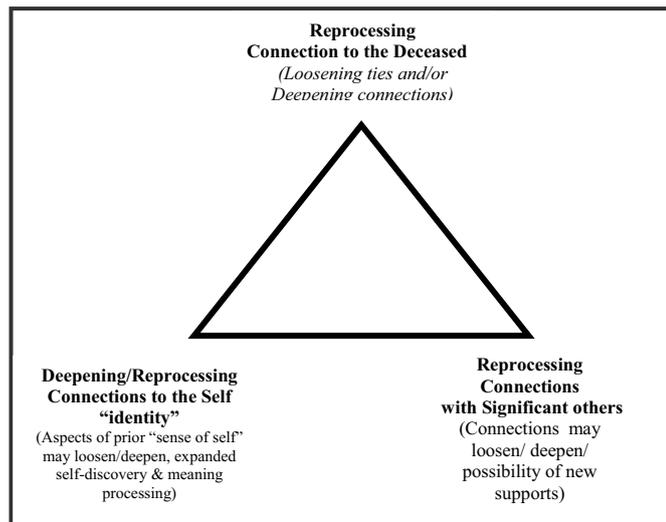


Figure 3 Adaptation to bereavement: Reprocessing 3 core relationships¹¹

Empathic failure and counselling

As stated earlier in this chapter, the social withdrawal of others significant to the bereaved (and deceased) constituted an area of significant empathic failure. Empathic failure was experienced as further loss amplifying the bereaved's loneliness and distress. The therapeutic relationship formed a secure base from which the bereaved could explore their pain.

Findings from this study suggest that the solidity of the therapeutic relationship is critical in bereavement counselling. Building a trusting relationship with the therapist took time, particularly when the bereaved had experienced isolation and/or abandonment of multiple significant others.

¹¹ This is an original figure arising from the study

Findings showed that in counselling experiences (that were felt to beneficial), the therapist's position was supportive and containing allowing the bereaved to express themselves without fear of being abandoned or judged. In counselling, the therapist temporarily joined the client becoming part of their supportive interpersonal context. An important task for therapists was to counteract "empathic failure" (Neimeyer & Jordan 2002) through empathic attunement. Though separate from others in the bereaved's interpersonal world, the therapist was connected through hearing the stories that were told. The participants' counselling experiences varied in length of time however, none reported therapy as being brief.

Findings suggest that people deepen their understandings of themselves and their loss through having their pain listened to and understood. Expressing pain however, involves more than the mere venting of emotion. Participants' expression of pain led them to explore meanings around the death, and their experience of bereavement. Those appearing the most confident had deepened connections with significant others (who in turn were understanding and responsive), and with themselves (see figure 3) and had redefined their relationship with the deceased. In this study the presence of complex issues around the three core relationships (named above) formed obstacles to adaptation.

Findings suggest that the bereaved did not link their counselling experience with loosening or keeping hold of ties to the deceased. Rather

the changing in connection/ties with the deceased appeared to result from the processing of their pain and exploration of issues of meaning connected with their experiences. In the current study participants used creative methods involving both “instrumental” and “intuitive” processes (Doka & Martin 1998:149). For example, David expressed himself through writing stories whilst Janice created poems. The therapists supported and affirmed their efforts sometimes incorporating the bereaved’s creative work in sessions. The bereaved needed choices in how they explored and expressed their grief that respected their personality style, yet challenged and/or invited them to develop understandings of the issues they faced. Creative methods may assist the bereaved who are stuck in emotional pain to both “dose” their pain, and have time out (Stroebe & Schut 1999; 2000) whilst facilitating clients exploration of issues of meaning connected to their experiences. Meaning and pain were interconnected and beneficial counselling explored the (sometimes multiple) meanings connected to pain.

Findings from the present study show that counselling contributes to participant’s personal growth. Participants seemed to re-evaluate their priorities and values as a result of their growth. Four of the participants made choices to work within volunteer or self-help organisations, developing themselves altruistically. This work placed them within a rich social context reducing their isolation. The building of parts of a new social network may be necessitated following bereavement where relationships between the bereaved and those in their former social world become

constrictively altered. Findings affirm the therapists' role of assisting the bereaved in rebuilding and re-negotiating their interpersonal and social world.

Traditional models have argued that the bereaved need to express their grief and work through their pain with the aim of relinquishing ties to the deceased (Lindemann 1944; Worden 1991). This research suggests people run into difficulties when their interpersonal contexts restrict their being free or safe to be authentic in their grief. The role of counselling is to serve as a kind of "holding space" granting the bereaved opportunities to encounter themselves and their grief in a way that is authentic. The therapist's role here was to: a) create safety for the bereaved through empathic attunement b) be able to comfortably tolerate the expression of distress and venting of emotion; c) facilitate the bereaved telling their story and d) process meanings connected with their story and experiences. Counselling experiences empowered the bereaved to make choices about themselves ("self story"), their connections with the deceased, their relationships with others and future direction. The bereaved deepened their understandings with regard to these three core relationships. The bereaved's sense of "self" or "self story" was explored and (re)structured as a result of their adapting to bereavement.

In reprocessing the relationship to the deceased, therapists need to be sensitive and respectful around the bereaved's spiritual beliefs and "sensing experiences". The bereaved may lack confidence to disclose

their experiences openly, or feel hurt if no such “sensing phenomena” are experienced (refer to the story of Fred). Therapists need to be aware of their own beliefs around spirituality and continuing bonds and hold them in check so that the bereaved are free to raise and explore meaning around such issues if needed without the therapist invading or unduly influencing their efforts.

Recommendations for professional practice

Organisational

As stated earlier, the results of this research suggest that organisations have the capacity to negatively impact upon the bereaved through “organisational empathic failure”. Two participants described being dismissed and rudely treated by staff in organisations. There has been limited consideration of the impact of broader social bodies on the bereaved in current literature. Organisations form part of a wider community context that the bereaved may need to deal with particularly around the time of their loved one’s death. Issues such as wills, pensions and the changing of banking details all involve interpersonal transactions with staff from government or corporate organisations. Those most vulnerable to the effects of negative encounters may be facing multiple difficulties such as financial hardship and/or a paucity of close interpersonal support.

There is a need for community organisations (such as welfare and financial institutions etc) to have policies in place to reduce the likelihood of “organisational empathic failure”. Where possible policies should ensure the bereaved are dealt with in a case-like manner providing opportunities for building rapport with staff to minimise the risks associated with organisational empathic failure. Policy would include training requirements for staff in face to face (or direct telephone/electronic) communication with their clients. Services need to equip staff with the skills to communicate respectfully and patiently. A significant aspect of these skills involves the ability of staff to listen empathically. Training for workers would address the potential impact of interactions with the bereaved on their grief trajectories. It would also aim to foster greater understanding of significant issues that bereaved people face, and stress the importance of respect and sensitivity to reduce the risk of secondary traumatisation (Herman 1992).

Since writing the group chapter I have heard a number of complaints whereby bereaved clients have felt deeply hurt through their interactions with staff in organisations. Recently a client handed me a photocopy of a letter in which they had written “I am tonight considering suicide due to the cruelty shown by [names organisation]. I can no longer face this attack on me”¹². It seems the effects of experienced “organisational empathic failure” can (in certain circumstances) lead to overwhelming experiences of distress.

¹² Permission was granted by the author to include this excerpt.

There were several issues raised by the study that have implications for health and community work with the patient/carer/bereaved through the illness death and bereavement trajectory. The issues raised included: a) communication, with difficulties occurring around clarity and negotiation between clients and health workers, b) the need for assessment and monitoring of the carer/bereaved to extend beyond the immediate situation and symptomatology of the patient and c) need for education that equips health workers to work with carers and patients around the issue of social support and constriction. The issue of communication was raised by four participants who described experiencing difficulties with health practitioners in various settings, (refer to the narratives of Vera, Wilhelm and David). There is a need for health practitioners such as: GPs, specialists and others treating the patient/family to monitor and provide support and information/referral where social constriction is identified as an issue or risk. Local medical practitioners need to keep in close contact with patients and their carers throughout the illness trajectory. Care needs to be taken in order to engage both the carer and patient and to assess and monitor communication. GPs would be well placed to identify escalating distress and refer clients for counselling support.

Clinical Practice

The use of BART helped to identify bereaved individuals who faced multiple obstacles in their bereavement journey. Whilst BART is based on

a medicalised “normative tool”, it plays a significant role in identifying those who may be struggling because of the complex constellation of factors they are facing within multiple contexts (see appendix 1).

One of the key recommendations resulting from the study involves an emphasis being placed on therapists empathic attunement in their work with bereaved clients. Empathic attunement serves as an “antidote” to empathic failure in the client’s interpersonal context. A key goal of therapy involves the creation of a “context enabling” therapeutic relationship.

Therapists guided by the prevailing models risk “empathically failing” their clients by believing for instance, that grief has an end, or subtly dismissing possible sensing experiences reported by their bereaved clients. Terms such as “illusion” or “hallucination” pathologise sensed presence. In attempting to foreground therapists’ (sometimes tacitly held) beliefs that negatively impede our work with the bereaved McCabe (2003:189) states that clinicians and researchers need

to focus on how our perceptions and attitudes towards death and grief affect our treatment of clients in order to prevent us from denying bereaved clients’ realities and from labelling them as pathological to make it easier to deal with their pain.

A connected recommendation concerns the need for therapists to work collaboratively with clients. Beneficial therapeutic work resulted when therapists respectfully collaborated with clients to deepen the client’s awareness of their experiences and the issues that they were confronted with.

An additional recommendation concerns applying the “coping strategies” model to reflect, assess and monitor client’s coping efforts. This model extends Martin and Doka’s (2000) “grieving style continuum” by intersecting the “intuitive and instrumental continuum” with a second “intrapersonal and interpersonal continuum”. Therapists can assist clients by raising their awareness of the coping mechanisms they are using, checking these out for their appropriateness of fit, and with the bereaved assess, challenge and where necessary facilitate the broadening of coping strategies. This model can assist clients in identifying their preferred coping styles whilst identifying areas where coping behaviours/efforts are constricted or under utilised. This model is congruent with Stroebe and Schut’s (1998;1999) “dual process model”, in that the coping efforts can be used to both approach/tend to and avoid/take time out from the pain of grief.

As therapists listen to their bereaved clients’ stories, they need to observe the movements the bereaved make between the three core relationships (which have been referred to throughout the chapter, see figure 3). A key area for intervention concerns supporting and challenging the bereaved to develop and reprocess ties to the three core areas that foster resilience. Additionally, the therapist can work with the client to understand how significant others are moving toward/supporting or undermining the bereaved’s own coping efforts. Therapists can use this information to guide their interventions, for instance when a client is facing significant

empathic failure, they may require increased empathic support and a focus on shoring up their own connections to themselves to reduce further traumatisation (Rothschild 2000).

Consistent with constructivist psychotherapy models (Neimeyer 2001) is the recommendation that therapists assist clients in naming how their struggles occur within a multidimensional context (that shapes their experience of bereavement). Such an approach depathologises the bereaved and their grief.

Therapists also have a role in assisting clients to understand and reduce their level of emotional loneliness. An important recommendation is for therapists to be alert to helping clients identify emotional loneliness whilst normalising this aspect of their pain/experience.

A significant implication arising from the study concerns the issue of clinical service provision and cost. Each participant in the study received counselling free of charge. One participant explicitly stated that had he been required to pay for services it is likely he would not have been able to attend sessions as often or for as long as needed. Several of the participants were experiencing financial difficulties at the time of interview. Three faced long term unemployment. Financial stress was part of the constellation of disabling factors that participants faced. If bereavement counselling was only provided to those able to pay then the bereaved that are most vulnerable are likely to miss out. The Central Coast bereavement

service is unique in providing free counselling and bereavement support to carers and family members of the deceased. In other parts of the state bereavement services are under resourced or non-existent. Those struggling with their grief must pay for private services or go without. There is a need to ensure the provision of bereavement counselling departments within all area health service settings. This study suggests bereavement services should be extended to others areas within the state and country, so that those who are vulnerable receive the support and treatment they need.

This study shows that bereavement counselling formed a catalyst for adaptation resulting in personal growth and reduced distress. These services need to be available for those who are financially disadvantaged.

Educational

There is a need for education to target all in the community about the interpersonal constriction faced by those experiencing life-threatening illness, death and bereavement. Education would focus on raising awareness of the risks of social isolation, whilst encouraging friends/family etc. to be active in maintaining their involvement and connections with family's/individuals affected. There is a need for health workers to provide education for patients experiencing life-threatening and chronic illness and their carers about the potential for family members to become socially isolated and constricted. Findings from this study suggest that isolation

increases the carer's vulnerability both prior to death and in bereavement. Education/support groups may assist family members through raising their awareness of these issues whilst helping to combat isolation through prevention. Education would address the fears people carry regarding how to talk to and support those who are bereaved.

There is a need for education on the unique and personal nature of adapting to grief, to empower the bereaved to be able to make choices (Attig 1996). Because of the impact of the interpersonal context on the bereaved, education needs to target both the bereaved and others of significance connected to them. Education would provide information that normalises the bereaved's symptoms such their experience of emotional loneliness. Information that depathologises the bereaved's experience will serve to reassure the bereaved and reduce fear.

Since analysing the findings the Central Coast bereavement service has piloted a bereavement education seminar that invited bereaved family/carers of palliative care patients who had died to a two hour presentation on bereavement. Emphasis has been placed on the importance of interpersonal support and the broadening coping efforts. Other aspects of the evening involved presenting information on continuing bonds and the open ended nature of grief. Responses to this educational evening were overwhelmingly positive. Volunteer bereavement support workers were integrally involved meeting and greeting those who arrived.

Directions for further research

Further research is needed to explore possible links between the bereaved's sensing experiences and the influence of others (through their (non)receptivity to such phenomena) on the bereaved's adaptation. Additionally there is a need for longitudinal research to further explore the relationship between the bereaved and deceased. It is important to obtain a longitudinal picture of how continuing bonds shift over varying time frames. For example, would those who developed close bonds to the deceased in adapting, continue to maintain these connections in the years to come? Further exploration is needed to uncover the varied and intricate ways in which continuing bonds alter over time. Future research should explore the extent to which organisational behaviour/contexts impact upon the bereaved.

During the process of adapting to loss the majority of the bereaved transformed their connections to others often developing new relationships. A question raised by the study concerns the nature and meaning around interpersonal change. For instance, was it that the bereaved's changing "self story" led participants away from some and drawn to others?

This study has also raised the issue of the vulnerability that bereaved survivors feel around sharing their "sensing experiences" with others.

Further research is needed to uncover factors influencing the disclosure of “sensing” experiences to others in the bereaved’s interpersonal world.

The factors influencing people’s behaviour toward the patient and carer/bereaved deserve further exploration. In the literature focus has centred on the behaviour/distress of the bereaved. Few studies have explored support people’s “coping better” or “assisting” the bereaved in more effective ways. Findings from this project suggest further research is warranted to uncover the “restraints” that exist (whether internal or external) to providing effective/beneficial support.

Supportive action has the capacity to significantly impact upon the grief experiences of the bereaved. Deepening understandings of barriers to providing support will enable the development of approaches for minimising the impact and dealing with barriers to supporting the bereaved from an individual to a community and society level. The movements of those within the bereaved’s interpersonal world between withdrawing and engaging the bereaved have not been the focus of research.

Conclusion

This study has explored the journeys of participants who struggled to adapt following a difficult bereavement experience. Findings from the study indicate that key relationships impact upon the bereaved in their adaptation to bereavement. These relationships involve: the relationship

between the bereaved and deceased (and its history); the relationships between the bereaved and others significant to them, and the relationship between the bereaved and the “self”. Relationships between the bereaved and their broader social environment have increased significance particularly where other “close linked” relationships are constrained.

A key assumption underlying the “grief work” paradigm is that “identity work” (which I have termed) and “deepening ties to the self” requires a corresponding need to loosen ties with the deceased. However, results from this project indicate that this is not the case for all people. Bereaved survivors reformulate or reprocess their ties to the deceased rather than mechanistically disengaging or letting go. Just as people connect to each other in differing ways in relationships in life, so to their connections in death are not uniform. The deceased can still form an anchor point for the living that grounds them and imparts meaning to their lives, in addition to forming an impetus for growth.

Participants who developed confident, secure ties to the deceased, seemed to have moved from withdrawing from the world around them to more fully engaging with those in their social context. As stated earlier, the sense of utter loss and desperation that had characterised the bereaved’s (lack of) connection to the deceased had significantly shifted. In continuing connection, there is a process of transition (or adjustment) where the bereaved moves from fearful reactive clinging and a sense of losing all (Karen 1994:383) to where the deceased becomes a kind of “secure base”

(Ainsworth 1967:345) for the bereaved, albeit an altered “secure base”. In the literature a secure base has been tied to relationships between the living. However, this research suggests that the concepts of a “secure base” (Ainsworth 1967) can be applied to relational connections between the living and a significant other who has died.

For some participants the place of the deceased assisted them to live more fully, acting as a catalyst for growth and personal development. One perspective is that this processed connection may be adaptive in continuing into the future (Klass & Goss, 1999; Klass, Silverman & Nickman 1996). The findings from this current study suggest that adaptation involves movement from reactive connection that results from the pain and terror of separation distress, to a processed continuing connection that is meaningful, not founded on reactive feelings, rather an exploring of meaning which helps to enrich life. Reactive pain appeared integral to the earlier experiences of bereavement, constituting part of the journey of grief. However, adaptation involved participants moving beyond reactive coping efforts.

This study has found that adapting to bereavement involves a constellation of the above factors. Counselling has the capacity to compensate for empathic failure in the bereaved’s interpersonal world. Counselling assists adaptation through facilitating the bereaved’s (re)processing of three distinct core relationships between the bereaved and: “the self” the “deceased” and “significant others”.

Importantly findings show that adaptation involves exploring meanings and identity around these core relationships and that loosening ties or keeping hold was unique for each person. Movement regarding the closeness – distance in this core relationship unfolded as a result of processing issues of meaning. Healthy connections with the deceased (whether loosened or held close) support the bereaved's engagement with the "self" and their interpersonal world.

The journey of adaptation to bereavement is connected with the journeys of others, and adaptation involves the interweaving of many paths:

the mining of life lessons from the vein of grief is by no means a certain outcome, and when it occurs, it is likely dependent on a host of maturational, personal and social resources (Neimeyer 2002:50).

Results from the project suggest that the bereaved have choices regarding what is to be retrieved and reprocessed with the lost person such as connecting with them in a range of ways, as life is re-storied and re-emplotted. This project also suggests that other parts of the process of re-storying may be affected, where the bereaved's world interfaces with the world of others. Adaptation to bereavement involves the bereaved processing issues of meaning around these core relationships. The question has moved from the global (mal)adaptiveness of bonds with the deceased, to a more unique consideration of how such bonds (or absence of bonds) are serving the bereaved in their journey to adapt. Ultimately the health or (mal)adaptiveness of continuing bonds are reflected in the

bereaved's own relationship to themselves, their connections with those significant to them as they experience continuing life.

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Appendix 1
Bereavement Assessment Risk Factor Tool
(BART)

Central Coast Bereavement Service Bereavement Assessment Risk Factor Tool (BART)

Name of Patient:		Age:	<i>Office Use Only:</i> BART Assessment Referral Date: _____ High Risk <input type="checkbox"/> Low Risk <input type="checkbox"/> Follow up High Risk Letter (2/52)= C.Phone (4/52)= Low Risk Letter (6/52)= V.Phone (10/52)= Letter 3 Required <input type="checkbox"/> Assessed by: _____ Counsellor/Volunteer Following up: _____
1. Name of Bereaved:			
Address:			
Phone No:	Relationship:		
2. Name of Bereaved:			
Address:			
Phone No:	Relationship:		
3. Name of Bereaved:			
Address:			
Phone No:	Relationship:		
Date of Death:	MRN:		

**The illness, care and death of the Patient:
As Perceived by the Bereaved**

	1	2	3
<p>Trajectory</p> <p>1. Time a significant Issue (highly drawn out or sudden)</p> <p>2. Perception of not being in control</p>			
<p>Patient's Suffering</p> <p>3. Distressing physical pain</p> <p>4. Patient spiritual angst (crisis in meaning)</p>			
<p>Difficulties in Care</p> <p>5. Patient was demanding</p> <p>6. Carer highly fearful/anxious</p>			
<p>Impact of Illness</p> <p>7. Problem of acceptance (eg. diagnosis unfair/unjust)</p> <p>8. Physical disfiguration: patient difficult to look at</p> <p>9. Stigmatised / shame issues (dignity compromised)</p>			

Experience of Death

- 10. Death not talked about (closed communication)
- 11. Sudden decline/ Timing of death unexpected
- 12. Traumatic Death (eg. Massive bleed/distressing)
- 13. Bereaved has issues with missing death

Characteristics of the Bereaved:

Stage of Life of the Bereaved:

- 14. Child/Adolescent (losing parent)
- 15. Spouse young
- 16. Parent losing child/adolescent
- 17. Single parent of child
- 18. Spouse – long relationship
- 19. Bereaved Elderly

Multiple Losses:

- 20. Recent death of a significant other
- 21. Other significant loss (eg. divorce)
- 22. Past evident loss (eg. death, miscarriage in past)

Concurrent Other Stressors:

- 23. Dissatisfaction with care giving (medical etc)
- 24. Substance reliant/abuse issues
- 25. Low socio- economic experienced prior to the death. (financial hardship)
- 26. Financial hardship (increase to be faced: post-death)

Physical and Mental Health:

- 27. History of depressive episodes
- 28. Current symptoms of depression
- 29. Anxiety symptoms (panic)
- 30. Post traumatic Stress
- 31. Bereaved has dementia
- 32. Bereaved has health issues

Emotional Distress and Coping resources:

- 33. Hostility (anger) evident (can be with/without crying)
- 34. High pre-death distress (eg. constant crying)
- 35. Fear of the future
- 36. Neglect of self care
- 37. Inability or refusal to process grief (eg. Difficulty communicating with staff)

Interpersonal & Contextual Resources:

- 38. Geographical isolation
- 39. Lack of social support (friends/church/club)
- 40. Lack of family support (absence of family or family unsupportive).
- Conflict/cut-offs** 41. Family chaotic/reactive
- Abuse within Family** 42. Indicators of abuse in family: history or presence of (eg. physical/emotional/verbal)
- Spiritual** 43. Lack of a spiritual framework
- Cultural** 44. Cultural issues complicating

Relationship with the Deceased:

- 45. Tension evident in relationship
- 46. Dependent or fused relationship with deceased
- 47. Ambivalent relationship with deceased

Characteristics of Deceased:

- Age of Deceased** 48. Deceased a child/ adolescent
- 49. Perceived premature death
- 50. Deceased elderly
- 51. Deceased had dementia
- Indicators of Abuse** 52. Deceased perceived to be an abuser
- 53. Deceased controlling (eg. Carer/ family not able to exercise decision making)
- 54. Deceased substance abuse issues

Narrative:

May include protective/resilience factors

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Email: mdavis@nscchahs.health.nsw.gov.au

Appendix 2

Information Package Inviting Participants

Invitation to participate in a research project:

Project Title: Recovering After Bereavement.

I wish to invite you to take part in a research project on the topic of: **how people recover after suffering bereavement.** I am a bereavement counsellor currently undertaking a Master of Counselling (Honours) at the University of New England, Armidale. The focus of this research project has arisen out of my work with bereaved clients. The project will be used to inform future work in this area.

What are the Aims of this Project?

- To increase understanding of how people suffering bereavement begin to cope and heal in the aftermath of their loss, and how coping is experienced.
- To assist counsellors and other professionals working with bereaved clients – through increasing knowledge on recovery, including what helps/hinders recovery, and what your needs are.

If I Participate, what is Involved?

- Participation in the project involves agreeing to be interviewed for approximately an hour, on the topic of your experience of being bereaved. During the interview you will be invited to tell your story, of what it has been like, and what you have experienced over this time.
- In order for the researcher to get an accurate picture of what has been said, interviews will be audiotaped. Participants will be able to stop the interview at any time or refuse to answer questions that do not feel comfortable.
- If you agree to participate, all information will be treated as confidential.
- Any reports written that draw on collected information, will be put together in a way as that preserves the anonymity of participants.
- The topic of recovering from bereavement is a sensitive one. It is possible that talking about your experiences will raise sad feelings. You will be treated with care throughout the interview. However, if you do find yourself feeling upset or distressed, you will be able to access support through the Area Bereavement Service. To receive counselling support contact the **Area Bereavement Service on: 4336 7777.**
- Alternately you can contact **Lifeline 24 hour telephone counselling on: 131144.**

How Did I come to Receive this Invitation?

The student researcher – Gerlinde Davis, has approached counsellors asking them to identify people who have received bereavement counselling. Your counsellor was then provided with a number of invitation leaflets to pass on to those identified. Please note that no information has been passed on to the researcher by counsellors.

IMPORTANT NOTE:

Your decision to either decline or accept the invitation to participate will not impact upon further access to counselling treatment. The researcher will keep confidential, the name of any responding participants. Information will not be passed back to nominating counsellors.

What if I do not wish to be included?

- *Simply ignore this letter. You will not be contacted any further.*

How do I volunteer to become a Participant?

- To become a participant in this research project you will need to:
- Be over the age of 18
- Have suffered bereavement and received some counselling.
- Agree to be interviewed by the researcher for around one hour
- Be willing to talk about your experience of being bereaved.

Contact the Researcher (Gerlinde) on: 0414 192200 or 4336 7777

Unless the researcher is contacted, it will be assumed you have declined the invitation to participate.

What if I say yes and then Change my Mind?

- You are free to change your mind and withdraw from the project at any point. If you withdraw, any information that has been collected will be destroyed.

Where Will It Happen?

- The interview will take place somewhere that is convenient for you and the interviewer. Possible interview sites include: your home, the bereavement office rooms at Long Jetty, Woy Woy, or Wyongah; or somewhere else of your choosing. It is important that you feel comfortable, and that the setting is private so you can feel free to talk.

Who Sees the Information:

- The issue of confidentiality is important. Only the interviewer will know the names and identifying details of those participating. All identifying information will be changed on written materials in order to protect anonymity.
- No other person will have access to identifiable information.
- The Researcher's University Supervisor (Dr Margot Schofield) will be the only other person to have access to written information. Written material sent to Dr Schofield will **not** contain identifying information.

What happens to the Information and How long is it Kept for?

- The information you provide will be grouped with that from other participants and written up in my Master of Counselling (Honours) degree. It may also be published. No identifying information will be included.
- The project will be completed by Feb 2006.
- It is required that information be kept for 5 years. After this point it will be destroyed by the researcher.

What if I have Questions or Concerns?

- Please feel free to contact the researcher or research supervisor should you have any questions or concerns regarding the project.
- **Gerlinde Davis** can be contacted on: **02 4336 7777**
- **Research Supervisor: Dr Margot Schofield** on: **03 94158252 or 0417 402 954**

Should you have any questions or complaints about the way in which this research is being conducted, please contact the:

Research ethics officer, Research Services, University of New England, Armidale, NSW 2351; Phone: 67733543; E-mail: ethics@metz.une.edu.au

Thanking you

Gerlinde Davis

Mob: 0414 192 200

Appendix 3

Consent Form

Project Title: **Recovering After Bereavement.**

Participation Consent Form

I acknowledge that I have read all the information provided to me outlining what is required to participate in this research project.

I understand and agree to the researcher and their supervisor as the only people who will have my contact details and that all information gathered in the interview(s) and at any time in between will be coded so that I am not identifiable.

I agree that in becoming involved in this project I will take part in an interview, which will be audiotaped by the researcher. I understand that I may withdraw my involvement at any time and that should I wish to do this, my decision will be respected.

I consent to participating in this research Project

Please Circle one:

I AGREE

I DO NOT AGREE

I consent to the use of an audiotape recording of my interview with the researcher.

Please Circle one:

I AGREE

I DO NOT AGREE

Signed by participant:

_____ **Date** _____

Name of participant: (please print)

Phone Number:

Appendix 4
Interview Guide

Research Project:

The Experience of Bereavement

Student: Gerlinde Davis

Interview Guide:

1. Can you tell me how you came to experience the illness and death of (deceased's name)?
2. Can you tell me about your experience since (deceased's name) death?
3. How did you come to receive counselling?
4. Can you tell me about your experience of counselling?

Possible Prompts:

Have there been any important or significant points since the death?

How has the (deceased person's name) death impacted on you?

How do you see yourself now in terms of where you are at?

How do you experience your life now?

Appendix 5
UNE

Human Resource Ethics Committee (HREC)

Approval Letter

Dear A/P M Schofield and Ms G Davis

HREC has given approval for the following.

How is Recovery/Coping Experienced: Developing a picture of experienced coping/recovery from those who have suffered a complicated grief reaction.

Your HREC approval number is: HE03/154valid to 20/03/2006

The Human Research Ethics Committee may grant approval for up to a maximum of three years.

For approval periods greater than 12 months, researchers are required to submit an application for renewal at each twelve-month period. All researchers are required to submit a Final Report at the completion of their project. The Renewal/Final Report Form is available at the following web

address: <http://rs-nt-10.une.edu.au/~/Home/V21/ecforms.html>

The NHMRC National Statement on Ethical Conduct in Research Involving Humans requires that researchers must report immediately to the Human Research Ethics Committee anything that might affect ethical acceptance of the protocol. This includes adverse reactions of participants, proposed changes in the protocol, and any other unforeseen events that might affect the continued ethical acceptability of the project.

In issuing this approval number, it is required that all data and consent forms are stored in a secure location for a minimum period of five years.

These documents may be required for compliance audit processes during that time. If the location at which data and documentation are retained is changed within that five year period, the Research Ethics Officer should be advised of the new location.

Best Wishes,
Belinda

~~~~~

Belinda Ackling  
Acting Research Ethics Officer  
Researcher Services  
University of New England  
Armidale NSW 2351

Ph: 02 6773 3449

Fax:02 6773 3543

Email: [Ethics@une.edu.au](mailto:Ethics@une.edu.au)

## ***Appendix 6***

**Northern Sydney Central Coast Area Health Service  
(NSCCAHS)**

**Coast Human Research Committee (CHRC)**

***Approval Letter***

Ms Vicki Ross  
Ethics & Research Officer  
Area Executive Unit  
Northern Sydney Central Coast Health  
P O Box 361  
GOSFORD, NSW 2250  
Tel: (02) 4320 3070  
Email: [vlross@nsccha.health.nsw.gov.au](mailto:vlross@nsccha.health.nsw.gov.au)

**Area Office**  
Locked Bag 2915  
Central Coast Business Centre  
NSW 2252  
Telephone 02 4320 2333  
Facsimile 02 4320 2477

6 October 2005

Ms Gerlinde Davis  
Area Palliative Care Service  
Central Coast Health  
P O Box 6088  
LONG JETTY NSW 2261

Dear Ms Davis

**Project Title: 03/42 How is Recovery/Coping Experienced?: Developing a picture of experienced coping/recovery for those who have suffered a complicated grief reaction (Approved by the Coast Human Research Ethics Committee on 10/09/2003)**

The *National Statement on Ethical Conduct in Research Involving Humans*, (1999), which the Coast Human Research Ethics Committee is obliged to adhere to, includes the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfil this function, it requires:

1. A report on the progress of the project submitted annually
2. A final report submitted at the completion of the research

A proforma for the annual report is attached for you to complete and return. An electronic copy can be emailed upon request.

If for some reason the above study did not commence or has since concluded, please inform me so I can close the file.

If you have any enquires please contact me, as per my contact details at the top of the page.

Yours sincerely



Vicki Ross  
Ethics & Research Officer  
Coast Human Research Ethics Committee