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Exploring the concept of receptivity to bereavement support: Implications for palliative care services in rural, regional and remote Western Australia

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Chapter 5: Existential Diaspora

Introduction

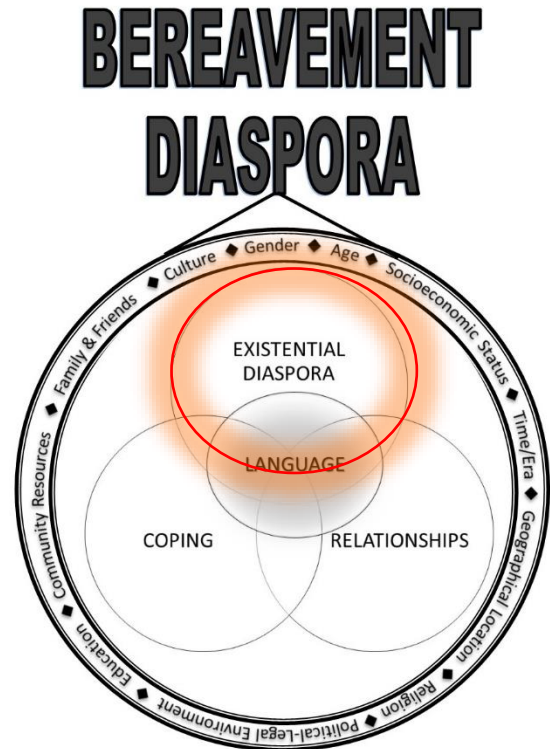
The previous chapter outlined the main concept that emerged from the data, diaspora, and discussed its transformation from findings to concept, *bereavement diaspora*. This chapter begins the presentation of the findings with a focus on *existential diaspora* in bereavement.

This chapter will discuss common concepts from the diaspora discourse and link them with bereavement and existential tenets. How diaspora transformed from a finding to a concept, which culminated in the overarching theme *existential diaspora*, will be demonstrated through linking the findings of this study to diaspora and existential concepts, specifically as it relates to bereaved individuals.

The final section of this chapter will discuss issues of receptivity and *existential diaspora*.

Subthemes that emerged from the data in this study reflect elements from the existential and diaspora literature. Although the bereavement literature is saturated with the psychological, emotional, social and spiritual impact of bereavement, the diaspora discourse provides concepts that can frame understanding through a different lens. Bereavement viewed through a diasporic-existential lens can provide a different perspective of the lived experience of bereavement.

Figure 18: Bereavement Diaspora: Existential Diaspora



Existentialism, Diaspora and Bereavement

Viktor Frankl (2006, p.100) in his book *Man's Search for Meaning*, described the term 'existential' as having three applications: i) *existence* itself, that is, the human mode of being; ii) the *meaning* of existence; and iii) the striving to find a concrete meaning in personal existence. In bereavement, how individuals make meaning of their experiences is based on this existential situatedness. Existentialism has much to contribute to understanding bereavement as it recognises that experience does not exist in a vacuum, individuals view their world through a reality that is socially constructed (Stephenson & Murphy, 1986; Kominkiewicz, 2006; Tomer & Eliason, 2008; Lewis & Staehler, 2010; "Existentialism", 2016).

The existential literature refers to the perception that *existence precedes essence*, a concept introduced by Jean Paul Sartre in the 20th century. This perspective suggests that we are born (existence) and shaped by the influences of the world in which we live (essence). This concept indicates human beings have choices and the freedom of the 'will' to decide who they want to be. In the existential discourse, *angst* and dread are concepts imbued with the realisation that an individual is responsible for their own actions and decisions and that in order to live an *authentic* life, a person must live a life consistent with their own values and be true to themselves. When an individual is confronted with a life changing event - such as the death of a loved one, whether it is expected or unexpected - they experience an existential struggle that challenges their choices, values and understanding, as they try to make meaning out of the experience. As a result, strategies used in the past to provide a frame of reference for understanding the world, and their place in it, may no longer work for the individual. Existential discourse refers to the concept of *absurdity* where the world has become meaningless and individuals strive to make meaning and sense of the world. Furthermore, there is an associated sense of despair at how absurd the world is and a profoundness in the loneliness one can experience. The existential discourse recognises that there is an associated *angst* with the realisation by individuals that they are alone in the world. Angst is not only a realisation about the inevitability of death, a sense of loss of innocence and a sense of foreboding, but is also

an awareness of the paradoxical implications of human freedom whereby individuals must make their own choices. The responsibility of making these choices can evoke a sense of angst (Stephenson & Murphy, 1986; Younger 1995; van Deurzen, & Kenward, 2005; Kominkiewicz, 2006; Tomer, & Eliason, 2008; Lewis & Staehler, 2010). As Heidegger (1927a, p.186, cited in van Deurzen & Kenward, 2005, p.6) states "...'angst' does not know what it is about for which it is anxious..."

Factors which influence the way we make meaning and shape the *essence* of who we are, is known as *facticity* in the existential discourse. Facticity suggests we evolve into the individuals we are, shaped by external socio-cultural and historical forces (Stephenson & Murphy, 1986; Kominkiewicz, 2006; Tomer & Eliason, 2008; Lewis & Staehler, 2010; "Existentialism", 2016). Similar to the existential concept of *facticity*, Marat (2016) highlights that diaspora identity is developed within a social, psychological, religious and cultural framework. These factors influence the way an individual makes sense of their world, and the events that occur within it.

When examining the diaspora literature, meaning-making is engendered with existential elements and describe the psychological and emotional processes that diasporics engage in to modulate existential distress. Likewise, in the bereavement discourse, how people cope with the existential aspects in bereavement is contemporaneously referred to as 'meaning-making', which is often confined to the intrapersonal level. Nadeau (2011, p.514) recognises the impact of internal and external factors on meaning making in bereavement and defined meaning as:

cognitive representations, held in the minds of family members, constructed in the context of the family, that symbolically represent various elements of reality. Meanings are products of interactions with others and are influenced by society, cultural and historical time

The death of a significant person is a traumatic event and can disrupt and displace the bereaved into a world that is unfamiliar. The philosophical foundations of diaspora and

existentialism can provide a framework for examining *existential diaspora* in bereavement.

Diaspora Findings to Concept: *Existential Diaspora*

The diaspora literature refers to concepts such as *hybridity*, *double consciousness* and *lived tensions* to reflect how people have choices in who they want to be, how they make sense of the world and the factors that influence this. Events that happen which lead to a *disruption* in peoples' lives and *displaces* them from all that is familiar creates a crisis in *identity* (Forinda & Norberg, 2010). The discussion of *existential diaspora* will be informed by the following diaspora concepts:

- a) Existential Shock: a new world
- b) Disruption: Violence to the psyche: Lived tensions
- c) Hybridity: Identity
- d) Displacement: Yearning and Nostalgia
- d) Embodied Diaspora and Transcendence
- e) Diaspora Deathscapes

a) Existential shock: A new world

When an event creates a crisis that causes a significant disturbance in the psyche, and a shattering of world views for an individual, this often creates an existential crisis. The individual reconsiders their worldview, assumptions and core values and re-authors their life narrative (Wong, 2008a; Neimeyer, Gillies & Milman, 2016). Robert Solomon (2005, p. xi, cited in Lieb, 2016, p.133) stated that "...the existential attitude begins with a disoriented individual facing a confused world that he cannot accept..." Many participants in this study described their sense of feeling lost, confused and disconnected as a result of the death of their loved one. Their experiences propelled them into foreign territory, a world in which they no longer had a sense of grounding. The death of a loved one

confronted individuals with their own mortality, and left them feeling alone and lonely. As participants struggled to reconcile their loss, their grief became a private world. However, some participants also identified that as time went on, they felt a sense of hope and even of freedom.

Participants described what the diasporic *existential world* was like for them and how it created a sense of disorientation, confusion and despair. This new world of *existential diaspora* is characterised by participants' narratives depicted in the table below:

| <i>Subtheme</i> | <i>Participant Statements</i> |
|------------------------|---|
| 'in foreign territory' | <p data-bbox="537 764 1328 800">“...I was just shattered and I was in total foreign territory...”</p> <p data-bbox="537 816 938 852">ID: B: 3371: F; 77; Sp; 7-9; R2</p> <p data-bbox="537 926 1424 1125">“...it’s like being lost on an unfriendly sea. You don’t know which way to turn. You have no sense of direction especially in those first few days. That is when you are at your most vulnerable...” ID: B: 3725: M; 63; Sp; 7-9; R1</p> <p data-bbox="537 1220 1424 1310">“...it’s hard to describe - some of the feelings that you have are very hard to describe...” ID: B: 3113: F; 61; Sp; 19-24; R3</p> |
| 'feeling lost' | <p data-bbox="537 1331 1424 1421">“...I’ve kind of really got no focus...there’s no direction, and I am all over the place often too...” ID: B: 3180: F; 70; Sp; 0-3; R3</p> <p data-bbox="537 1514 1424 1713">“I don’t know where to go from here. I don’t know the rules of grieving. Nobody tells anybody - everybody says, ‘but there’s no rules’ I don’t know the rules to this game, it’s all new...” ID: B: 3398: M; 67; Sp; 10-12; R3</p> |

| | |
|----------------------------------|---|
| | <p><i>“...after a death, if you haven't experienced a death before, you're completely lost. What do I do?”</i> ID: B: 3073: F; 87; Sp; 6-9; R3</p> <p><i>“...I don't know what direction to go in...”</i> ID: B: 3369: F; 53; Sp; 13-18; R1</p> <p><i>“A couple of times I've just broken down, I just said, "I just don't know what to do. I don't know where I am...”</i> ID: B: 3386: F; 53; Sp; 19-24; R1</p> <p><i>“...I'm still trying to turn my life around but I just don't see which way to turn...”</i> ID: B: 3725: M; 63; Sp; 7-9; R1</p> |
| <p><i>'feeling confused'</i></p> | <p><i>“...you're in a state of confusion, grief really does create confusion in your mind...”</i> ID: B: 3725: M; 63; Sp; 7-9; R1</p> <p><i>“...I don't understand this. I honestly do not understand how a person as large as life, as beautiful, soft features, big heart with that much love in it, can just disappear off the face of the earth into a little urn. I just don't understand it...”</i> ID: B: 3398: M; 67; Sp; 10-12; R3</p> <p><i>“...there's no guidelines when you're grieving and I guess it's very frightening because you don't really know what to expect or how to be and for me - it was scary; I'm thinking – ‘am I going mad or something? Is this how other people are, or am I the only one like this?’ And so because there's no guidelines you're really on your own and you don't know what to expect... when you're kind of grieving on your own, there's no guidebook, and you don't know how you're going to feel from one day to the next in many ways.”</i> ID: B: 3180: F; 70; Sp; 0-3; R3</p> |

| | |
|--|--|
| | <p>“...I was wrecked - I didn't understand why...” ID: B: 3369: F; 53; Sp; 13-18; R1</p> |
|--|--|

There is a sense of loss of hope, and loss of identifying qualities of one's self or identity. This existential world was not only unfamiliar to the bereaved, but the bereaved became unfamiliar to themselves, feeling a sense of being ‘*disconnected from themselves and others*’ as demonstrated in the following participant quotes:

“...it's sort of like you're in two people. One must be this practical person and the other person is more or less thinking 'what are you doing it for?’”

ID: B: 3073: F; 87; Sp; 6-9; R3

“...you feel as if there's a glass wall between you and everybody else - not a glass wall between you and others - but between you, your emotions and other people...” ID: B: 3073: F; 87; Sp; 6-9; R3

“...It's like you're watching...it was like, you're right on the outside, everything's happening; you're involved in it, but it's like you're just watching everything happen. As time went on it was like you come closer and bang! You were back into it again. But it was like you were right away watching it. And even though you were doing it, I think back now and I think how did I do it? I really don't know how I did it...” ID: B: 3386: F; 53; Sp; 19-24; R1

Despair is an existential concept that refers to a person feeling like a stranger in their own life and a stranger in the world. In other words, there is a real sense of alienation amongst previously familiar surrounds. Likewise, the diaspora discourse describes the impact from displacement and disruption and the sense of alienation this brings from self, others and the world they once knew (Bakare-Yusuf, 2008; Hua, 2013; Kaur, 2015). Participants in this study described a sense of disconnect from their world as they previously knew it, a

sense of ‘*having no anchor*’ and ‘*hopelessness*’ as portrayed in the following participant quotes:

| <i>Subtheme</i> | <i>Participant Statements</i> |
|-----------------------------|---|
| ‘ <i>having no anchor</i> ’ | “...I wouldn't have acknowledged that I was feeling hopeless. I used to describe it as having no anchor. No rudder...” ID: B: 3371: F; 77; Sp; 7-9; R2 |
| ‘ <i>hopelessness</i> ’ | <p>“...that’s something else that I remember about the depths of grief. You can’t look forward... you feel there is nothing to look forward to. So instead you just begin sinking into a morass of guilt, grief, sadness - everything all at once... What’s that old line? ‘I was down so far that bottom looked like up. I couldn’t see anything ahead of me at all’. Even now I’m having trouble seeing a rosy tomorrow because oh I’m out of work and worried about money...” ID: B: 3725: M; 63; Sp; 7-9; R1</p> <p>“...now all those plans, everything's just gone; everything. Everything we'd planned to do has just gone out the window and I just feel empty. There's no plans, there's no future where I had a future before...” ID: B: 3386: F; 53; Sp; 19-24; R1</p> <p>“...she was the motivator. ‘Come on darling, we have to go and do this; come on darling, we’ve got to get the crop in; come on, I’ve got to go to a dog show, can you do such and such while I'm gone?’ ...she was the motivator. Now I sit here and I look out there and I think, ‘well I’ve got to go and do that,’ and then I think to myself, ‘what the hell does it matter? It doesn’t matter anymore... you don’t have anybody to do it for anymore, that’s a big problem...” ID: B: 3398: M; 67; Sp; 10-12; R3</p> |

Many participants portrayed how the now deceased had provided a central locus in their life. To use a metaphor used by the participant above, the deceased provided the living with a metaphorical ‘anchor’, a safe base with which to explore the world (Voicu, 2013). This metaphorical anchor provided the bereaved with a frame of reference for their own existence and meaning of their life. The deceased represent this anchor and the bereaved diasporic individual no longer has an ‘anchor’ where they feel secure and safe. Bowlby’s (1969/1980) attachment theory provides an understanding of this metaphorical anchor in which the “...attachment system is a motivational system that regulates the proximity to attachment figures...who provide protection, support and care...” (Zech & Arnold, 2011, p.23). The deceased, the metaphorical anchor, represented the ‘attachment system’ which is imbued with the individuals’ self-esteem and self-worth. When the attachment figure is no longer around, it can induce feelings of existential loneliness. These concepts of attachment system, self-worth and self-esteem are demonstrated in the following participant statements under the subtheme, *‘irreplaceable loss of significant relationship’*:

“I had a good life before, we had a happy life, we were lucky that we had a really good marriage and I actually say to people that I may not have had [G] as long as I wanted him, but I am so lucky that I did have such a good man, and I was loved, I was so loved, and some people go through their whole life never, ever experiencing that...” ID: B: 3386: F; 53; Sp; 19-24; R1

“...when my marriage broke up, I was absolutely beside myself when that happened...I was so incredibly lonely and so much weaker then...I felt worthless, whereas I don’t feel worthless this time around, it’s different. But I did feel worthless when my marriage broke up, my husband decided he didn’t want me anymore and that was it.... with [N] (deceased) you had to be far more independent, because he was a different kind of a person, and so that made me much, much stronger... So our relationship made me a much stronger person...I don’t feel worthless...” ID: B: 3180: F; 70; Sp; 0-3; R3

Despite drawing comfort from the sense of self-worth participants felt in connection with their relationship with the deceased, participants also spoke of the profound loneliness they have experienced since the death of their loved one. Existential loneliness has been identified as an innate experience of all human beings at some time in their lives (Younger, 1995) and becomes pronounced in bereavement loss (Ogbuagu, 2012). With the deceased now absent from the world, participants talked about the existential ‘*loneliness*’:

“It was just the loneliness or the emptiness that's basically what it amounts to...Loneliness. Being by myself. Doing things by myself instead of sharing it...” ID: B: 3400: M; 70; Sp; 13-18; R3

“...it was just loneliness. You look for the person...” ID: B: 3398: M; 67; Sp; 10-12; R3

“I felt so lonely...” ID: B: 3388: F; 69; Sp; 13-18; R3

According to Younger (1995, n.p.), “...loneliness is the feeling of being alone ...” The concept of existential aloneness emanates from an awareness that human existence is finite, that death is an inevitability and that it is the destiny of the human condition to be alone and to be aware of it (Younger, 1995). The following participant ID: B: 3725: M; 63; Sp; 7-9; R1 talked about feeling a sense of existential ‘*aloneness*’ stating, “...*I have never felt so alone...*” and “...*the aloneness of grief is, has a unique, cruel side to it...*” When some participants described ‘*getting used to being in the world again*’, they often recounted experiences which amplified their sense of aloneness, “...*when you go out, everyone else has got their wife or husband there...*” ID: B: 3372: F; 75; Sp; 4-6; R3. Participants also described the challenges of going out in public in the early days’ post death and the anxiety this would often evoke:

“The hardest part was actually facing people again. Like the first reaction, are they going to cry, or do they expect me to cry, or - just the first meeting

with each person that was close to us, that probably was the biggest impact for me...” ID: B: 3109: F; 64; Sp; 10-12; R3

I guess the first couple of days when I was sort of going out and you had to go to these places, I sort of thought, ‘oh, gosh, I hope I don't meet anybody I know,’ you know – ‘what am I going to say?, what am I going to do?’ ID: B: 3373: F; 64; Sp; 13-18; R1

“...it's a bit hard at first because you didn't know if you'd get, you know, tearful or anything like that...” ID: B: 3370: M; 73; Sp; 10-12; R2

Younger (1995, n.p.) states that in response to suffering, ‘people retreat into themselves for perceived safety and regrouping, trying to make sense of what has happened and that this inward turning’ is an almost universal response. Some participants talked about how grief became a ‘*private world*’, which compounded the sense of existential isolation:

“...you have your private moments...there was a lot of grieving. I didn't want to grieve publicly...” ID: B: 2875: F; 81; Sp; 13-18; Rem1

“I found I really can't talk to a lot of people about how I miss him and I wish he was here you know?” ID: B: 3110: F; 61; Sp; 19-24; R3

“I found it very hard to talk to people about what I was dealing ...I didn't want them to know how bad I was really doing...if I was here by myself I was a mess...” ID: B: 3386: F; 53; Sp; 19-24; R1

“I guess it really is a private thing and it's only really people that are close to you [that you talk to] ...” ID: B: 3407: F; 44; Child; 7-9; M2

The sense of existential aloneness portrayed by participants highlight that when the deceased were alive, they helped the bereaved to forget they are alone in the world. The death of a loved one brings to the forefront the fragility of life, as individuals are confronted with their own mortality. Participant's reflected on '*mortality*' as part of the meaning-making process (Neimeyer, Harris, Winokuer & Thornton, 2011; Neimeyer & Sands, 2011), as demonstrated in the quote below:

“...*death is random. Life is not fair, you know, it is fragile at any time...*” ID:
B: 3433: F; 60; Child; 13-18; R1

Participants in this study reflected on the randomness of death which resonates with the notion of *absurdity*, a tenet in the existential literature. *Absurdity* takes the position that there's no meaning in the world beyond the meaning that we ascribe. The bereaved try to make sense and seek meaning from the death in order to try and create some order, and find something to 'anchor' them in the world again (Stephenson & Murphy, 1986; Kominkiewicz, 2006; Lewis & Staehler, 2010; “Existentialism”, 2016). Many participants described their '*struggle with reconciling the loss*' and trying to make meaning out of an unfair death that did not make sense to them as depicted in the following participant statements:

“...*learning to deal with it, and learning to live with it when you don't want to...*” ID: B: 3386: F; 53; Sp; 19-24; R1

“...*it's something you have to get used to. You have to get used to getting up of a morning, walking outside with your coffee and walking back inside with nobody...*” ID: B: 3398: M; 67; Sp; 10-12; R3

“...*acceptance of the finality of death is perhaps the hardest thing of all...*”
ID: B: 3725: M; 63; Sp; 7-9; R1

The death of a significant person in someone's life can result in an existential shock, where people have to adjust to a new world without the deceased. Feelings of disorientation and confusion compel the bereaved to try and re-orient themselves as they are confronted with the fragility of life, where an event can change one's life in an instant, or that a person's life could be extinguished in an instant. The bereaved wish to escape 'being condemned to this frightening state' of being on their own (Mayers & Svarberg, 2001, p.542) and experience an assault to their psyche as they try to make sense of their loss.

b) Disruption: Violence to the psyche

The diaspora discourse refers to concepts of *disruption* and *displacement* and Chen (2015) proposes that an existential state in which there is emotional and psychic disruption, characterise an existential diaspora. Disruption and displacement are often associated with *violence* in the diaspora literature as people are forced to leave their homeland, often under war time conditions (Anthias, 1998). Many participants in this study described the assault to their psyche as they struggled with the psychological and emotional impact. Participants described feelings of shock, trauma, torment, anger, abandonment, guilt, embarrassment, fear of being judged and of being under the microscope of others so felt they had to hide their thoughts and feelings. Stories from the bereaved participants in this study describe a violence to the existential self, a violent disruption of psychological and emotional trauma. The following participant statements provide some insight into this trauma and were drawn from the subthemes '*psychological and emotional ambushes*';

“...it just comes out of the blue when you suddenly get these jolts, or the hollow gut days...” ID: B: 3113: F; 61; Sp; 19-24; R3

“...sometimes I can feel almost normal and then all of a sudden, it'll hit me just out of the blue, and it's like, 'oh', and it kind of takes you back...” ID: B: 3180: F; 70; Sp; 0-3; R3

'Shock' was a term commonly used by many participants feeling overwhelmed by their grief. Despite having an awareness that death was inevitable, participants still experienced shock, as demonstrated from the following participant statements from the subtheme '*the shock factor*';

"I always thought I would be able to cope really well. The shock was... death is so final - even after illness..." ID: B: 3371: F; 77; Sp; 7-9; R2

"You know that the inevitable is going to happen but it's still a heck of a shock when it happens...you have that knowledge that it's going to happen, and even though when it happens, you're still in shock..." ID: B: 3113: F; 61; Sp; 19-24; R3

"...he'd been a part of their lives for so long and it was just a big shock for everyone..." ID: B: 3372: F; 75; Sp; 4-6; R3

"I can see very clearly now that me, being me, I "toughed" it out - it's in the genes - when inside I was in shock, I was sad, I was frightened..." ID: B: 3388: F; 69; Sp; 13-18; R3

However, shock was not a feeling reported by all bereaved participants as the following participant expressed that as it was an expected death, he did not feel a sense of shock that a sudden death would cause:

"...there are times I almost wish that [B's] life had been taken like a snap of the fingers because then, okay, there is shock and grief, but I think the shock would wear off and actually pave the way for deeper grief, whereas I didn't have a shock." ID: B: 3725: M: 63; Sp; 7-9; R1

The language of shock and trauma was identified by Sanderson et al. (2013) who conducted qualitative research exploring post-traumatic stress disorder (PTSD) symptoms in bereaved caregivers of women who died of ovarian cancer. Despite the deaths being expected, they found the language used by participants was words such as ‘shocked’, ‘traumatic’ and ‘surreal’ (Sanderson, et al., 2013) and are echoed by participants in this study. The presence of PTSD in bereaved caregivers is emergent research in the current palliative care bereavement literature (Elklit, et al., 2010; Kristensen, Elklit & Karstoft, 2012; Sanderson et al., 2013; Kristensen, Elklit, Karstoft & Palic, 2014). One participant described her experience and related it to ‘PTSD’, as memory loss manifesting as the significant psychological impact in her grief:

“I lost my memory for three months - that’s why I had people to take me out. That’s why I had to go with someone else. I would see somebody and I forget who they were. Forget their name - I had three diaries around the house - wrote everything down because I would forget everything. I had short term memory loss - I kept saying, “what’s going on, what’s going on?” So my daughter [who was working for mental health in Perth and working with psychiatrists and psychologists] talked to one of the psychiatrists and they said, ‘post- traumatic stress disorder where you are stressed for so long and then something has to shut down’. So even though I was putting on this brave face and going and jumping off buildings and everything else, really, inside, I had all this stress and it came out not so much maybe in the grief side of it - maybe in...’oh well, we’ll just away the memory...’ which is the worst thing for me. And it took three months - probably six months...” ID: B: 3369; F; 53; Sp; 13-18; R1

The impact on memory and recall was reported by other participants. Saketopoulou (2015, p.281) uses the term ‘attacks on linking’ where psychic disorganisation occurs where there is lapses in thinking, ability to problem solve and string thoughts together as demonstrated in participant comments from the subtheme ‘difficult remembering’:

“...all the cards from the funeral director, the hundreds of cards that we were sent in the mail, I read them just after the funeral - not the same day - but a couple of days later, and it didn't sort of sink in. Then like a couple of months later I was going 'Oh my God, they were there...'” ID: B: 3109: F; 64; Sp; 10-12; R3

“...at first I found it very hard to remember anything, we couldn't remember things that had happened earlier on. I suppose because you're in shock and everything you've gone through, I couldn't remember before [G]got sick... I remembered the wake but I could not remember any of the funeral. As time went on it slowly come back...” ID: B: 3386: F; 53; Sp; 19-24; R1

“...I still cannot - in the darkness - see her face. I could picture my father, he died when I was 12; I'm 67 years old now. I can picture my mother, I can picture my daughter that got killed when she was 10, I can - any face - but I can't pull her face out of the darkness for some reason, I don't know...” ID: B: 3398: M; 67; Sp; 10-12; R3

Disruption from bereavement causes trauma which impacts on cognitive functioning. Forinder and Norberg (2010) highlight that when individuals are unable to accommodate existential crisis in a positive way, it can lead to PTSD. The trauma of bereaved participants is underscored by intrusive or distressing images and potential missed opportunities¹⁸ if they perceived they did not feel adequately prepared. Participants described the struggle they experienced in their grieving from feeling ‘*tormented by images*’ as portrayed in the following participant statement;

“...I still go through the business of seeing [B]’s eyes with the desperation in

them as I'm going through the door - I just had this feeling - his eyes were saying 'you're leaving me,' you know? I think back and I keep thinking 'oh, if only I'd pressed the red button and stayed there', you know? I suppose because he was so on the point of death really, and he'd been in that sort of moribund state for so long... was he conscious? Was he? But that was the first time his eyes were open, his eyes were wide open, you know?" ID: B: 3073: F; 87; Sp; 6-9; R3

Participants also described feeling haunted by the missed opportunities and doubts as reflected in vignettes under the subtheme 'what if's':

"...Sometimes I wake up every two hours 'cause I've been dreaming or thinking of something, or thinking of one of these things that happened here - could we have done it better? Should we have picked it up? Because there were a few signs beforehand, but we didn't..." ID: B: 3372: F; 75; Sp; 4-6; R3

"The only thing that really concerned me was that weeks and weeks and weeks later after my father died, I got a letter. He did have a chest infection. I had to call a doctor in after she'd finished her surgery. She put him on to some antibiotics - weeks later I got a letter claiming he had MRSA, which I was really shattered about because he had obviously been on the wrong antibiotics and the sputum specimen had been sent off way before. I never got the results on them. Obviously the doctor didn't either. The doctor that normally would look after my father was unavailable, so I had to get another one in after she'd finished work - surgery - during the night. So I never discovered this and my father had already died. So that was pretty shattering..." ID: B: 3399: F; 65; Child; 13-18; R3

"...on the morning of the 5th when she wanted me to stay and I stayed until I thought she was asleep. The fact that I'd helped her to the toilet 3 times and they found her collapsed on the toilet. Hello guilt trip! I still can't get that out of my

head. All the right things have been said to me of course, that it might have made no difference at all. It could have happened when I was there or not; but all I knew was that 3 hours later they considered her breathing too bad so they did a code blue. Rightly or wrongly, I still feel a sense of guilt at the fact that, although I'd said I would stay all night, I gave up at about 4:30 thinking that she'd settled. She hadn't. So that's one very painful part that I guess I just have to live with...." ID: B: 3725: M; 63; Sp; 7-9; R1

One participant described the psychological impact in terms of thoughts that go through their mind soon after death as reflected in the subtheme '*thoughts like a metronome*':

"... that was the hardest drive I have ever done. A drive that [B] and I had done together so many times, but that day - that day after - was when it was really hitting like a thunder clap inside my head every 5 minutes. She's gone. She's gone. She's gone..." ID: B: 3725: M; 63; Sp; 7-9; R1

Thinking repetitively and recurrently is identified in the bereavement literature as rumination and is a common feature, particularly in early bereavement. Rumination about causes and consequences of negative life events, or causes and consequences of one's negative emotions, has been linked to psychopathology and general distress following loss (Eisma et al., 2015).

In the period after death, there continues to be distress and there is also a "...conjoining of identities from historical and contemporary consciousness..." which can be intense and not easily resolved (Clarke, 2010, p.233). The person can feel like they are going crazy and thus *existential diaspora* can have significant mental health implications. This was evidenced by some of the participant narratives in this study who reported a PTSD diagnosis. The following participant experienced a significant amount of psychological '*trauma*' from the impact of caring for his spouse, witnessing her death and then in his bereavement:

“...all I could see was her suffering. All the bad memories from those 9 months in [hospital] took over. They still spring back - usually with no warning at all...It was an ambush, like an ambush. I just had no expectation and hearing it [code blue call over the phone]; it just threw me right back into the daze of confusion and pain...There is nothing subtle about grief. Nothing subtle at all. It is raw, brutal, cruel...” ID: B: 3725: M: 63; Sp; 7-9; R1

The participant was diagnosed with ‘PTSD’ several months following the death of his wife and he describes events leading up to how he received help:

“...the first few weeks after she died I have never felt so alone and then one day I got a call from... [palliative care social worker] ... in [town] and of course, we’d had no contact with them really. And she said, “we just wanted to check on how you’re going.” I found out later that ... a social worker [at hospital where wife died] had asked them to check on me... we got about 90 seconds into the phone conversation and I started to lose it, and she said, ‘stop, put the kettle on I’ll see you soon’ ...click...she was on the doorstep in less than 10 minutes...kept me talking for about an hour and a half and said, ‘right who’s your doctor, yes, I’ve got his email address I’ll send him a report and you’ve got to make an appointment with him.’ And I’m saying, ‘but why? What’s wrong?’ and she said, ‘you’ve got fully blown post-traumatic stress disorder.’ Which I couldn’t get my head around. I said to her, ‘look I’ve got an uncle who is only 7 years older than me and he had PTSD after either his 1st or 2nd tour of duty in Vietnam; it’s a front line thing.’ - and it was very clever of her - and she said, ‘yes, and you’ve been on the front line with your wife for 9 months.’ She had just nailed it for me! Suddenly, at least I understood why I was feeling what I was...I was beginning to doubt my own sanity...” ID: B: 3725: M: 63; Sp; 7-9; R1

Research in PTSD in bereaved individuals who had a loved one die from cancer has only been explored in the past decade. A study by Kristensen, Elklit, Karstoft and Palic (2014) found that 30% of bereaved caregivers had clinical PTSD one-month post death with a further 26% reaching a subclinical PTSD level. A follow-up study six months' post-death showed 21% of bereaved caregivers continued to show clinical PTSD. Predictors of risk for PTSD have been identified including place of death, negative affectivity, intake of medicine after the loss, not having a close intimate other and A2 criterion in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* which specifies that the initial response to the traumatic event invoked feelings of fear, hopelessness or horror (Elklit, Reinholt, Nielsen, Blum & Lasgaard, 2010; Kristensen, Elklit, Karstoft, 2012; Sanderson, et al., 2013; Kristensen, Elklit, Karstoft & Palic, 2014).

Although contemporary discourse looks at resilience and strengths perspectives (Pomeroy & Garcia, 2009; Bonanno, 2010), there needs to be recognition that PTSD can occur even with expected deaths, along with other psychosocial morbidity such as depression (Assareh, Sharpley, McFarlane & Sachdev, 2015). However, identification by palliative care services of those at risk of adverse psychological outcomes remain challenging due to multifaceted and complex issues including assessment skills of clinicians, resources in services and the variety of instruments and measures (Sealey, Breen, O'Connor & Aoun, 2015). One of the health professional participants recognised the level of '*the trauma of death*' one client was experiencing and responded through getting urgent psychological support:

"... there's been a couple of people that very much start talking suicidal ideation, start hopping into the alcohol a bit too much, just start to lose the thread of life and the will to live, and so probably with the social work skill, you come in on that, and start to really tease that out and see where this person's safety is...there's been a couple of cases where - quite literally - I've walked them to the mental health clinic and we've seen the triage nurse, and then seen the psychiatrist, and gone through that process of firming up

their safety and giving them the immediate support that they need... ID: HP: 3334: F; 43; R1

Significant psychological trauma in bereavement following the death of a loved one is poignantly portrayed in the participants' story below, when he talked about his '*struggle with losing the will to live*' and what stopped him from following through on any suicidal ideations:

"...Who was going to find me, my daughters? I've seen what happens when you pull the trigger, it's just not a little pop and everything goes black. Everything goes up the walls, all over the bed, all over the floor; who's going to clean that up, my daughter? That's the thing that stopped me...If I could've done it without making a mess and putting my young [daughter] into trauma I probably would've...and I still have the pills, I've never been a pill person, so the only way was to pull the trigger. Now that's okay, pull the trigger but everybody else around you then has to cope, clean up, cope, get everything done - like deal with the police, deal with this one, deal with that one. It's just not a bang and it's all over, it goes on for the rest of their lives then...I went to the extreme where I was going to shoot every animal on the property, shut the place down and just walk away. So the person who is at the stage I was, has to have a clear mind, has to understand that it's never going to be over - but you can, and you will, get past it. You have to get used to that, if you don't, if you can't get past that, then you do pull the trigger..." ID: B: 3398: M; 67; Sp; 10-12; R3

The desire for the living to die with their dead "...runs as deep in human nature as both love and the death drive...making grief one of the most dangerous and potentially self-destructive psychic crises..." (Harrison, 2003, p.55 cited by Baptist, 2010, p.298). The bereavement literature that has explored suicidal ideation of intimate others with individuals who died from an expected death from illness found there was a direct correlation of suicidal ideation and bereavement. Rosengard and Folkman (1997) found

the incidence was higher in gay primary caregivers of a loved one who died of HIV and caregivers who perceived their loved one had a poorer quality of life at end of life (Abbott, Prigerson & Maciejewski, 2013). Other studies of the incidence of suicide following the death of a spouse found that suicidal ideation was higher among widowed people with limited social support and reported a heightened sense of loneliness (Stroebe, Stroebe & Abakoumkin, 2005), and that there were higher suicide rates in the first week of bereavement and the incidence was higher among young widowed persons (Ring, Bopp, Gutzwiller & Rossler, 2008). The diaspora discourse often discusses the tensions and struggles of the diasporic agent. In this study, participant narratives reflected that there is a desire to be with the deceased, but also a need to remain.

The holding of two contradictory emotions and thoughts simultaneously is referred to in the psychological literature as dialectical perspectives. Dialectical thinking refers to "...the tolerance of apparently contradictory or ambivalent beliefs..." (Hui, Fok & Bond, 2009, p.493). Cheng (2009) reinforces this notion and refers to Hegel's thesis-antithesis-synthesis perspective: that individuals accept that contradicting propositions can exist simultaneously. Dialectal stances reflect the dynamic tensions that occur with the diasporic agent, a concept referred to as *lived tensions*, where difference and sameness co-exist in one space, *lived tensions* (Gilroy, 1993 cited in Anthias, 1998, p.568). Applying concepts of dialectical thinking and *lived tensions* can contribute to understanding the potential for suicidal ideation in the bereaved, where polarised thoughts are held at the same time ie. the bereaved want to be 'here' but want to be 'there' at the same time (Clifford, 1994).

The early stage of bereavement is recognised as a time betwixt two worlds. The diaspora literature refers to as the condition of being *in* one place (the 'existential now') and *of* another (the 'existential before'), as a *double consciousness* of existential states. *Double consciousness* reflects identity fragmentation in which there are fractures of memory and a sense of '*inward twoness*' (Kaur, 2015). Although *double consciousness* has its origins in the Black Diaspora, it represents "...the existential experience of two souls, two

thoughts, two unreconciled strivings, two warring ideals in one body and mind...” (Voicu, 2013, p.172). This condition of *double consciousness* is fraught with psychic danger to a person’s mental and emotional wellbeing (Clarke, 2010; Pittman, 2016). The participant statement below depicts the *lived tensions* he experienced while struggling with the will to live and reconcile his loss. The process of *double consciousness* where two thoughts and unreconciled strivings co-existed simultaneously:

“... there were a couple of times where I thought maybe I would be better off with you sweetheart. Because we were married for 41 years - I have read that there are a disturbing number of suicides shortly after bereavement - I can understand why, because you are in such a state of confusion and pain...I found myself thinking probably a couple of times, maybe I should join you – [thoughts of] my daughter [stopped me] - because I can imagine nothing worse for her after losing the mother she loved so much, to then lose her father? No that would be most unfair on her...that literally stopped me from thinking any further of ending it all, taking my own life because knowing the pain that [B]’s death had caused to [L] as well as me, ...so it was my darling daughter who caused me to abandon those thoughts each time...” ID: B: 3725: M; 63; Sp; 7-9; R1

Cognitive and emotional dialectical positionings are intrinsic to the bereavement experience. Participants in this study described the challenge of holding two conflicting emotions at the same time, emotional dissonance. Bakare-Yusuf (2008) discusses the emotional impact of *disruption*, where people in the diaspora are uprooted, rooted and re-rooted which leads to mixed emotions and responses. The notion of emotional dissonance is evidenced in the following participant statements from the subthemes ‘*feeling guilty*’ and ‘*mixed relief*’ which are common phenomenon in grief (Worden, 2010):

“...rightly or wrongly there’s a feeling a guilt that no, I can’t enjoy myself because she’s not here with me. I can’t do that, I can’t do this, because she’s not here to share it....” ID: B: 3725: M; 63; Sp; 7-9; R1

“...you feel guilt because you're feeling relief too... I had this overwhelming feeling of relief, it was a mixed relief, it was a relief for him. Then you feel guilt because you're feeling relief too. You're feeling relief that it's all over for you as well as him, and perhaps you shouldn't feel that way...” ID: B: 3073: F; 87; Sp; 6-9; R3

“...in some respects it was a relief because I'd been on a certain level for 18 months, different levels of intensity in terms of what I needed to do for mum. So it was a relief in some respects. Obviously in other ways – emotionally - it was pretty bloody hard, because mum and I were very close...” ID: B: 3076: M; 52; Child; 4-6; R1

A nuance to the bereavement experience is the influence of living in rural communities. For those participants living in rural areas, there was the additional challenge of people knowing what had happened and there is a lack of privacy and confidentiality. Some participants also described a sense of ‘*assumed familiarity*’ by people in the community who would approach them to offer comfort, or acknowledge the death. This assumed familiarity did not allow the bereaved the opportunity of ‘*getting used to being in the world*’ at their own pace. The following participant described her perspective of experiencing death in a rural community and in the broader context of her narrative, the challenges of being bereaved in a community where ‘*everybody knows everyone*’:

“...in the country, you're not a statistic...you can walk down the street in the city when your husband's died the day before, and no-one knows a thing. No-one has a clue. But you walk down the main street in your town and...that's why I know a lot of people who have lost partners in town. You don't see them for a very long time because people have to say something to you. They have to give you a hug and say they're sorry...you can't get away with much in a rural community...”
ID: B: 3072: F; 52; Sp; 6-9; R3

“...I felt people were coming at me and making it more of a reality every day...”
ID: B: 3369: F; 53; Sp; 13-18; R1

This can lead to participants developing a social anxiety and wanting to avoid public areas. Specifically, participants *‘felt under the microscope’* as the experience of living in rural towns is where everybody knows everyone, as portrayed in the participant statements below:

“...you feel like you, you're being watched in a way. When you make a move that might not be in the norm of bereavement process, but there isn't a real norm in my book...” ID: B: 3072: F; 52; Sp; 6-9; R3

“Everyone knows everything. Everyone knows what's happened.” ID: B: 3111: F; 68; Friend; 13-18; R3

Participants expressed a reluctance to utilise formal or professional support if there is a sense of lack of privacy in the local town. However, one participant stated it would be easier to see a stranger than utilise her informal networks for support:

“...I think it's a sign of weakness [to cry in front of people I know] somebody did ask me, and I thought about it and thought ‘why do I cry easy in front of strangers?’ Why do I run away so that I don't have to cry?’ [it's] because the strangers don't know my story. I don't show weakness, because everyone thinks I'm strong. A stranger doesn't know me and won't ever see me again...” ID: B: 3369: F; 53; Sp; 13-18; R1

As a means of managing the psychological and emotional impact, the bereaved may use professional support as the preferred option if individuals feel they do not have an emotional investment in the person. Participants also expressed concerns that they would

be judged for not experiencing bereavement according to social norms. As depicted by the participant below, he expressed ‘*embarrassment*’ about not feeling a significant emotional impact from the death of his spouse:

“...*I feel embarrassed to say this, but I was fine... It's a bit of an upset for a couple of days, or a week really...*” ID: B: 3370: M; 73; Sp; 10-12; R2

Bereavement, like diaspora, has inherent in its condition, existential crises and angst. When participants in this study discussed their ‘*struggle in grief*’, many of them reported that the hardest aspect was that their loved one was no longer there to talk with, for companionship, to share experiences combined with the sense of being alone.

The disruption to the psyche that occurs as a result of the death of a loved one can lead to an existential crisis in which the bereaved often experience the holding of contradictory thoughts, or emotions, simultaneously, known as *lived tensions* in the diaspora literature (Voicu, 2013). The struggle with trying to cope with the assault on their psyche can lead the bereaved to experience PTSD. In bereavement, the bereaved balance the desire to return to their old life with having to survive in their new world without their loved one (Canagarajah & Silberstein, 2010). There are many ways the bereaved try to make sense of their new world and a part of how the bereaved negotiate these crises and *lived tensions*, is through reorienting and renegotiating their identity

c) Hybridity: Identity

Bereavement ruptures the meaning of our existence and the bereaved are propelled into a ‘diasporic existential space’. The diasporic condition is constituted in conceptions of pluralities, of dissonant identities, in which people can produce and reproduce themselves through the notion of hybridity (Clarke, 2010).

The diaspora experience as I intend it here, is defined, not by essence or purity, but by the recognition of a necessary heterogeneity and diversity,

by a conception of 'identity' which lives with and through, not despite, difference, by hybridity. Diaspora identities are those which are constantly producing and reproducing themselves anew, through transformation and difference.

(Hall,1990, p.235, cited in Anthias, 1998, p.560).

Historically, hybridity referred to transcultural formations, a cross between two separate cultures or races. For example, African slaves introduced to the USA in the 18th and 19th centuries have influenced music, food, art, and national identity in America. Contemporary self-definition is shaped through transglobal forces from technologies, influencing political, religious, linguistic and social identities. The experience of bereavement is a catalyst of hybridity. For example, a person shows a different side to themselves when in the company of others to when they are in the company of 'intimate' others, a person who was part of a family unit and is now part of a different or changed family unit, or, a person who had certain characteristics, now incorporates new characteristics developed as a result of their experience (Zezeza, 2010; Canagarajah & Silberstein, 2012; Kaur, 2015). The notion of *hybridity* in the diaspora literature refers to dynamic identity deconstruction and re-formation (Anthias, 1998; Voicu, 2013; Kaur, 2015). Bereaved individuals revisit their self-narrative of who they were, are now, and who they are going to be in the future (Neimeyer & Sands, 2011; Neimeyer & Cacciatore, 2016) as portrayed in the following participant's narrative:

"I've felt that I had to find out who I was again. That was the strange part because I'm a great one for...getting the most out of my life...they always ask, 'Who are you? Are you daughter, or wife?' I had to find out who I was and where I now fitted in life...and what ambitions I had that hadn't been fulfilled..." ID: B: 3371: F; 77; Sp; 7-9; R2

An individual has to 'create oneself' and the elements of past, present and future co-constitute and re-constitute one's identity. This re-negotiating or reconstructing a new

identity and finding renewal is a common theme in the bereavement discourse (Neimeyer, 2016). The diasporic existential body has a crisis of self-image and displacement creates alienation of vision for the future (Kaur, 2015). Participants reflected on the uncertainty of their future, and of how the ‘*world profoundly changed*’ for them and how they tried to reconcile past, present and future:

“I remember sitting in here and saying "Ok, this is the first day of the rest of my life...I've done that." I was kind of leading up from his death to that point and having that holiday and then coming back and, and thinking 'ok, I'm going to go back to work now.' I've done all that, now I've got to plan, what's my future past that point..." ID: B: 3072; F; 52; Sp; 6-9; R3

The work of Okpewho and Nzegwu (2016) describes diaspora as a condition where an individual’s state of being is a process of becoming, negotiating multiple spatial and social identities drawn from the interstices of ‘here’ (present) and ‘there’ (past and future). Being torn between the world that was before and the world that is now, the bereaved oscillate between “...being at home, and being not at home, to a non-linear temporal form of being in the world...” (Bakare-Yusuf, 2008, p.153). The [bereaved] diasporic individual draws on the past, the present and the imagined future and reconciles their identity through a process of finding a ‘different rhythm of living and being’, a term referred to in the diaspora literature as ‘*syncopated temporality*’ (Clifford, 1994). This is a temporal disjunction where a sense of rupture in time (as a result of the death and envisioned future) leads the individual to experience a different sense of time, “...you’re never quite on the beat. Sometimes you’re ahead and sometimes you’re behind...” (Gilroy, 1993a: 281 cited in Clifford, 1994, p. 318). The bereaved have a ‘here’ and ‘there’ *lived tension*, where they find they are living a completely different temporality to what they envisioned. That is, they still feel an attachment to the person and the life prior to their loved one’s death, but now have to face the reality of the present and the future. This sense of syncopated temporality is depicted in the following participant quote when she was discussing her ‘*struggle with reconciling the loss*’ and ‘*getting used to a changed reality*’:

“...it’s sort of like coming into town was like a past life - that was [P] and the kids, but now I’m coming here but they aren’t here. It’s not him anymore - he’s not here - that life is no longer that we had...and it’s a really weird feeling because I am coming back into that life, but it’s no longer and it’s a very, very strange feeling that I get...and I get it every time I drive into town when I have been away for a while.... Maybe it’s a feeling I will gradually lose but it’s just coming into the house and feeling them. I guess I feel him here, and I feel the life that we had before, and I haven’t got that - life is so different now to the life I had before. So when I walk in I feel that old life, and it’s very difficult to walk in and feel this life now...there’s that old life - I feel him, I feel all the same feelings that have been in here for 35 years, and that’s the part that I’ve just got to deal with now. If I’m going to stay here in this house I have to figure out just exactly what that is - and I haven’t quite figured it out yet...” ID: B: 3113; F; 61; Sp; 19-24; R3

The bereaved experience an identity reformation, a process of finding new identities that can potentially co-exist, known as *hybridity* (Bakare-Yusuf, 2008; Canagarajah & Silberstein, 2012; Johnson, 2012; Kaur, 2015). One participant talked about the different elements that constituted her identity and who she was now as the result of the death of her husband:

“I was a farmer’s daughter and a farmer’s wife but I never drove a tractor like some wives do because there was five of us and my older brothers, they drove... then when I moved down here, [A] was in partnership with his brother so there was no reason for me to...then [S] and [A] got into a partnership. And now I think, why didn't you show me how to do that? ...so now I'm sort of, I'm the helper...” ID: B: 3110; F; 61; Sp; 19-24; R3

The notion of hybridity was evidenced in the data in this study where participants described feeling a sense of connection with others, whilst simultaneously feeling

separate. The following participant quote depicts this sense of feeling connected but separate in *'public-private worlds'*;

"I do have a very close-knit group of friends, I'm with the [Name] Group and ... they were really good people, but I found, I didn't want to talk to them. I didn't want them to know how I was feeling... if I was here by myself I was a mess. When [people] saw me out, they couldn't believe how well I was coping, but it really was just a front because inside I was not doing really well at all..."

ID: B: 3386: F; 53; Sp; 19-24; R1

There is a sense of belonging but non-belonging. Hentz (2002) highlights the paradox of the need by the bereaved to connect and distance themselves from others. This is particularly salient when the bereaved want to share memories of the deceased which may create a need to distance oneself from others who have difficulty dealing with the distress of the loss.

The *'existential condition'* of diaspora emphasises the connections and meaning we make between memory, place, and displacement and memory plays a key role in how people negotiate the diaspora (Chen, 2015). Diaspora is thus not just a physical situatedness where there is a disruption of the connection to *'community'* either real or imagined, but diaspora is also a disruption to the psyche, enmeshed with memory (Chen, 2015). The diaspora discourse highlights the importance of time and memory as key factors relevant to identity re-constitution as depicted in the participant statement below:

"...but as the time goes along, you're six months into your bereavement and it seems that - you're in a bubble - and it seems that everybody else has moved on, and you sort of feel alone all the time...nobody to talk to and your mind goes back to all the memories" ID: B: 3398: M; 67; Sp; 10-12; R3

Time highlighted the pain of anniversaries and emphasised the expectation that the grief from loss will be enduring as reflected in participant narratives in this study. The role of memory is reflected in the following quotes from the *'pain of anniversaries'*, a poignant subtheme from the data as anniversaries bring memories to the forefront of the psyche:

"...on the 18th of every month, it's not a good time for me. I thought it'd be every twelve months but it's not, it's every month on the eighteenth at twenty past twelve in the morning is a really bad time..." ID: B: 3398: M; 67; Sp; 10-12; R3

"...on those days, I think about what we did on those days you know, the day we were married, the day we emigrated out here. It's sort of, although it's always upsetting and it's emotional and you probably cry, there's some really good memories there and I think that's how you get through..." ID: B: 3373: F; 64; Sp; 13-18; R1

The 're' constructions of the 'self' are a product of reconciling past, present and future but are influenced by the deceased in shaping personal attributes, behaviours and attitudes of the bereaved. 'Re'-constructions of the self can occur through the complex intertwining of emotional and psychological schemas. New ways of thinking about the locus (deceased) which previously provided the point of reference for a person's life, are often reflected on, as depicted in the participant quotes from the subtheme *'legacy items and leaving footprints'*:

"...you know I like to think that maybe it's the stubbornness I get from my father, that I like to think that I can handle everything myself.... the strength that I get from my father..." ID: B: 3407: F; 44; Child; 7-9; M

"[B] taught me that it was fine to show affection because in our family, we're a long time Irish family, you shook hands over the Holden, that was the

affection...[we] always held hands, always. Every night he slept with his arm over me. He was always protective. He wanted to be with me... ID: B: 3388: F; 69; Sp; 13-18; R3

There were also some reflections by participants on how their bereavement experience has made them metamorphose into *'a changed person'*

"...I'm no longer that person. I said it took losing a husband to make me a different person and I have this awful sense that I've got so much I want to do, but I'll be 70 next year, how am I going to fit it all in...." ID: B: 3388: F; 69; Sp; 13-18; R3

An individual's understanding of their existence is often shaped by the social environment they are in. When they engage in their social environment, individuals assign emotional effort to areas they believe are significant such as relationships with others (Kominkiewicz, 2006). Where once there were real encounters between two people, there is a transition of that dialogue from the flesh-and-blood interaction in the real world, to a transformative symbolic and creative relationship. For many bereaved, the relationship with the deceased transforms from a corporeal one to an internal, spiritual realm, creating a lasting and ongoing relationship (Ogbuagu, 2012). Maintaining this connection with the deceased through a transcendent relationship can evoke a melancholic nostalgia, which is linked to connection to a bygone past. This can lead to a cycle of yearning and nostalgia as grieving and bereavement is a developmental process that occurs throughout the lifespan (Bakare-Yusuf, 2008; Neimeyer, 2016; Chen, 2015).

d) Displacement: Yearning and Nostalgia

Although yearning is pathologised in the bereavement discourse regarding complicated grief (Shear, 2015), nonetheless it is seen as a natural and enduring condition in diaspora.

Displacement in the diaspora literature is linked with a desire to return to the world that once was. *Displacement* actually gives rise to yearning and nostalgia, a desire for life prior, an idealised image is constructed and self-esteem and self-worth are situated within this ‘life’ (Clarke, 2010; Chen, 2015; Jain, 2015). The deceased provides a ‘locus of significance’ in which the bereaved have framed their identity, and displacement from this locus can lead to feeling disconnected. There is no longer a familiarity and an ‘anchor’ which grounds their identity and gives meaning (Bakare-Yusuf, 2008). This ‘*loss of irreplaceable relationship*’ is reflected in the following quote:

“*I just feel like a little girl. I'm 61 years old and I feel like a little girl... you know, having to go through all this again, you know, make decisions... he was the one that did everything, made the decisions... I always assumed he'd be looking after me...*” ID: B: 3110; F; 61; Sp; 19-24; R3

This participant expressed feeling overwhelmed at being on her own and being responsible for making her own decisions. The following participant described the angst that was created when she realised she had full responsibility for her own existence which reflects the existential themes of *angst* and *dread*. This participant angst was related to the position of ‘*making decisions*’:

“*...I think just this sense that you are now responsible for things by yourself...things that come up and you haven't got anybody to talk to right here, and you have to make the decision about what you're going to do....if there's two of you, you don't feel, not vulnerable - that's not the word - but even if you make the wrong decision there's still two of you...*” ID: B: 3391; F; 69; Sp; 13-18; R3

Displacement propels the person into a world where they are alone and responsible for themselves which engenders nostalgia for the life that was. The diasporic condition is a journey of relocation and localisation, where there remains a wish for reconnection

(Clarke, 2010; Chen, 2015). The bereaved wish for reconnection with the deceased and a yearning that endures as the person travels through their life journey. The yearning is reflected through participant narratives under in the following table:

| <i>Subtheme</i> | <i>Participant Statements</i> |
|--|---|
| <p><i>‘world profoundly changed forever’</i></p> | <p><i>“I had a future before... I was so loved...I was so lucky that I did have that, but I want it back too; I wasn't ready to let it go.” ID: B: 3386: F; 53; Sp; 19-24; R1</i></p> <p><i>“...all those sorts of things I miss. Along with just every day - I go into the shed he's not there anymore. His tools. I go out to do some gardening because I'm trying to sort of keep things together but it's lonely, because we used to garden together or we would kind of talk about our day...” ID: B: 3180: F; 70; Sp; 0-3; R3</i></p> |
| <p><i>‘irreplaceable loss of significant relationship’</i></p> | <p><i>“I found I really can't talk to a lot of people about how I miss him and I wish he was here, you know? Without him by my side anymore...the decision making, you know?...he was my first love and my only love... I met him at 16, married him at 20 and he died on me at 59...” ID: B: 3110: F; 61; Sp; 19-24; R3</i></p> <p><i>“...every time somebody dies, you lose something. I still miss some of my friends who have died...” ID: B: 3111: F; 68; Friend; 13-18; R3</i></p> |
| <p><i>‘missing the deceased’</i></p> | <p><i>“...I just wish you could just come here for a few seconds, wrap your arms around me, tell me that you love me again...” ID: B: 3386: F; 53; Sp; 19-24; R1</i></p> |

Yearning can transform the relationship with the deceased to a transcendent one. The grief and bereavement literature refer to this as ‘relocating the deceased’ (Field & Wogrin, 2011). Anthias (1988) discusses continued attachments and continuing affective bonds.

These bonds are constructed from the shared dreams and shared identity with the deceased. Diaspora is the constant reference point that maintains a sense of continuity that a bereaved individual returns to. This has led to some of the participants feeling ‘*cheated*’:

“I’d describe it as being cheated, having to do it all by myself. Not being able to share what I’m enjoying with [C]. The fact that I can go out and enjoy myself, I can go out to dinner, I can go out and do things but she’s never there with me and that’s, that’s the part that hurts and I know she’s never going to get there with me either. So I think, to me, that’s probably the hardest part of my grief... I just feel cheated that she’s not there to share it all with us...if anything, that’s probably my grief at the moment is being cheated out of what should have been...” ID: B: 3400: M; 70; Sp; 13-18; R3

“...the plans we had for growing old together didn’t quite work out... this wasn’t to be expected. This wasn’t the way the fairy tale was supposed to play out. We were going to grow old together walking hand in hand. It just didn’t figure out...” ID: B: 3725: M; 63; Sp; 7-9; R1

“I do get very angry with him at times, I think how could you do this to me. I feel so ripped off at times, because he only had another 10 or so years working, we planned to work and then we wanted to travel around Australia, we wanted to get the caravan and go and enjoy ourselves.....everything we’d planned to do has just gone out the window ... there’s no future where I had a future before...” ID: B: 3386: F; 53; Sp; 19-24; R1

The role of memory in the ongoing human agency of a bereaved individual brings renewed painful yearning (Clifford, 1994; Chen, 2015). However, *displacement* may not always lead to negative experience. Death had changed participant attitudes and this was often

viewed by participants as a positive aspect from the bereavement experience. Forinder and Norberg (2010) highlight that traumatic events can promote growth and this notion is found in the existential literature, referenced by terms such as ‘adversarial growth’, posttraumatic growth’ and ‘stress related growth’. Forinder and Norberg (2010) highlight the positive accommodation that can occur demonstrating transformative post traumatic growth. Some participants talked about a renewed investment in life as demonstrated in the following subthemes:

| <i>Subtheme</i> | <i>Participant statement</i> |
|--|--|
| <p><i>‘continuing with living’</i></p> | <p><i>“Actually, I feel that I should put it away now. I don't think that it's something you should cling to. I want to get on with life...I just want to get on with living... That's my attitude. I want to get on with living and I want to do it healthy [sic]. I don't think I should dwell on it anymore. That's why I've agreed to talk to you and I thought, this must be the final bit. I've written about the illness...” ID: B: 2875: F; 81; Sp; 13-18; Rem1</i></p> <p><i>“you need to think about making a life for yourself - I don't wallow, nothing can bring [G] back, but I need to move forward. I definitely don't want another man, I'm not going through that again, like nursing somebody and then they leave you...” ID: B: 3109: F; 64; Sp; 10-12; R3</i></p> |
| <p><i>‘changed attitudes’</i></p> | <p><i>“...there's no point in beating around the bush about anything in life. Life's reality. You don't get a second go at this...I honestly do not worry about anything. I am nowhere near that person that I used to be...” ID: B: 3388: F; 69; Sp; 13-18; R3</i></p> <p><i>“...we added up ten [deaths] in that year of something - with neighbours and close friends and relatives. So I did go through this big thing of, why plan for a future when there may not be one? Then it was a big realisation and a big you know thing about really what is important in life...” ID: B: 3433: F; 60; Child; 13-18; R1</i></p> |

| | |
|------------------------------------|--|
| | <p><i>“I reckon I've become more patient. It gives me a different perspective on life. Yeah things still rile me, get me uptight, but I suppose it takes - giving you a different perspective on life, when you've dealt with someone passing away, what is there left but death, and when someone pisses you off at work, or you face a particular challenge in your life you think, 'okay, what can I do about this? Can I change it? Yes? Okay go ahead and try and change it. Is it within my circle of influence? No? Have you done everything you can? Yes, right let it go, move on.' And I try and do that as much as I possibly can...”</i> ID: B: 3076: M; 52; Child; 4-6; R1</p> <p><i>“Look, I'm always prepared to accept what comes is meant to be, and you must learn lessons from it. Don't take any negativity in the next step in life so, I have no regrets...”</i> ID: B: 3371: F; 77; Sp; 7-9; R2</p> |
| <p><i>‘positive attitudes’</i></p> | <p><i>“There's a lot of life left in me yet and I'm going to enjoy it. I know that's what [C] would want, you know, type of thing...”</i> ID: B: 3400: M; 70; Sp; 13-18; R3</p> |

Diaspora recognises the retention of allegiances and connectedness and although this has been applied to geographical displacement (Ben-Rafael, 2013), this can apply to bereavement, where the bereaved maintain connection to the deceased via a ‘transcendent’ relationship. Maintaining ongoing relationships with a homeland is a key feature in the Diaspora literature (Ben-Rafael, 2013) but when applied to bereavement from a psychological discourse perspective, this ongoing relationship applies to the continuing bonds with the deceased (Klass, Silverman & Nickman, 1996). Continuing bonds is often linked with emotional and psychological ‘relocation’ of the deceased within the context of a continuing relationship.

e) *Embodied diaspora and Transcendence*

Emotional and psychological relocation of the deceased is challenging when the bereaved continue living in the domestic space that was a shared environment in which day to day interactions and rituals are embodied. The bereaved person's internal model of 'shared space' now is to be negotiated as a single person or family with a member missing (Hockey, Penhale & Sibley, 2001). Maddrell (2015, p.166) highlights how grief and remembrance are "...embodied-psychological spaces of the interdependent and co-producing body-mind..." Ben-Rafael (2013) describes a sense of 'dual home-ness' in diaspora where individuals exist in the present setting, or home, whilst retaining loyalty, or connection, to the past 'home space' in which the deceased dwelt. Homes constitute social and spatial environments in which bereaved have lived with the deceased and their relationships - marked by 'synergy' - are embedded in the everyday corporal intimacy of life. Death interrupts this synergy (Hockey, Penhale & Sibley, 2001; Baptist, 2010) as depicted in the quotes below *absence-presence of deceased* and '*getting used to a changed reality*':

"...quite often when I'm here by myself and night times I find are the worst. At first I found like mealtimes were really bad because we always sat at the table, we always ate together, always talked..." ID: B: 3386: F; 53; Sp; 19-24; R1

"...you walk into the house and you walk into the bedroom where I spent so much time looking after her..." ID: B: 3076: M; 52; Child; 4-6; R1

"...you look for the person, where she would be at that time of day, by walking up the street at about four thirty in the afternoon, walking up the steps over the veranda with the eggs or out in the paddock feeding a lamb and she's not there...I always walk out of a morning and she's not at the sink, she's not bringing the eggs in, she's not feeding a lamb, she's not - and that's the

thing...where is she? ...and I miss her, and I miss her... ID: B: 3398: M; 67; Sp; 10-12; R3

Bakare-Yusuf (2008) refers to “...embodied beings and bodily practices which have been...’rooted’ in a place...” This reflects behavioural habits that occurred with the deceased, and is referred to as spatialised experiences. Hockey, Penhale and Sibley (2001) highlight that memories are bound in the material spaces of home and locality. Embodied diaspora thus refers to ‘relational habits’. Baptist (2010, p.298) cites Tanner (2006, n.p.) who “...situates grief as an embodied entity that haunts the bereaved with shocking corporeal solidity...” The bereaved can witness and experience the loss repeatedly as their minds construct the absent-presences of bodies that can no longer be touched or held, but are vivid in the images or memories that remain.

Experiencing loss as a spatial embodied grief experience, has received little attention in the literature. Diasporicity can relate to a temporal or embodied connection to a bygone past and can include habitual behaviours of communicating and interacting. This phenomenon emerged from the data in this study as demonstrated in the following quotes:

“...I'd see something and I'd say "Oh, [B], look". You know and it wasn't old [B], it was [P]. So I still do that if I see something...” ID: B: 3073: F; 87; Sp; 6-9; R3

“...you find yourself thinking, ‘oh I must tell [R] that....I can see that that will go on just forever because you’ve been together for so long...” ID: B: 3391: F; 69; Sp; 13-18; R3

Earlier research by Hentz (2002) explored embodied grief and highlighted the body memory experiences of bereaved individuals around anniversaries and how this was experienced either as a conscious process with awareness, or as an unconscious

phenomenon that seemed confusing. Chow's (2010) article on anticipatory anniversary effects in bereavement highlights the bodily responses during the time preceding an anniversary, as being more notable than on the anniversary *per se*. The concept of 'temporality as cycles' in which re-grieving occurred was identified in research by Hentz (2002). Anniversaries and time was not recognised as calendar days or months, but how the body perceived the time, such as the season, or certain characteristics of the weather that was similar to the day a loved one died (Hentz, 2002).

Grief exaggerates the spatial isolation of one body from another. The bereaved can have pre-set embodied sensations from when they interacted with the deceased. The bereaved can also experience haunting memories or a spectral presence that can be experienced in dreams or in the real world and can sometimes in fact be welcomed. The bereaved can thus sense the lingering presence of the deceased in body, imagination and in vision (Baptist, 2010). The following participant described her experience of a *transcendental presence*:

"...in bed at night, oh, it's terrible, even now.... after he died, he came into my bedroom one night. It was just...he was there, I mean I didn't feel frightened or anything, he was there. It was just the outline of him... I wish it would happen every night..." ID: B: 3110; F: 61; Sp: 19-24; R3

Other transcendental experiences are described by participants in this study. The following participant described receiving *transcendental signs* after asking her deceased spouse to confirm he was still around:

"...10:43. So we've only just noticed [the clock stopped] that the last month because I kept asking [S] for a sign - 10:43 - and the second hand is still trying to go so the battery is not flat. It [the clock] just stopped at 10:43..." 3369: F: 53; Sp: 13-18; R1

Participants talked about the *ongoing presence of deceased*, that they were very active in taking care of their families, even though they were no longer corporeally present:

“...that would be dads’ way...I honestly believe he saved [T] from a car accident. I swear my dad put his hands over her, because I said to her, ‘grandfather did that’...the young policeman that pulled her out - and everybody that saw that car - cannot believe all she had was a bruise from the seatbelt, couldn't believe it, could not believe it...” ID: B: 3109: F; 64; Sp; 10-12; R3

In addition, many participants found comfort in the thought of a transcendental progression through having a *belief in the afterlife*:

“...I believe that he's somewhere, he's, it's not just puff gone. And the body's just a body. But I always sort of believed in the spirit...” ID: B: 3109: F; 64; Sp; 10-12; R3

“...I can't see [B] as dying, he's gone somewhere and he's still learning, he's still progressing...” ID: B: 3073: F; 87; Sp; 6-9; R3

When the relationship with the deceased transforms from a corporeal to an internal, spiritual realm (Ogbuagu, 2012), the bereaved can continue to feel the influence of their loved one in their lives as demonstrated in the subtheme *the voice of the deceased* in the following participant quotes:

“I find it so hard without him. I'm like, ‘what would he think, what would he do? Am I making the right decision love? And love, am I doing the right thing?’ You know?” ID: B: 3110: F; 61; Sp; 19-24; R3

“...I come back here and I can sit around and think of her. I know what she’s saying, she’s saying, ‘Oh darling, you’ve got to get out there on the tractor and plough’...” ID: B: 3398: M; 67; Sp; 10-12; R3

If the experiences of the bereaved do not fit within expected norms, they can become silent and keep their grief hidden, particularly with sharing transcendent experiences. Hentz (2002) found that anniversary effects on the deceased went beyond what was considered as socially acceptable timeframes for ‘uncomplicated grieving’. Many of the participants experienced ‘body memory’ following a loss, experiencing a ‘physical knowing’ that was non-cognitive and non-rational where the past became ‘sedimented in [the] habitual body’ (Merleau-Ponty, 1989, p.33, cited in Hentz, 2002, p. 162). The bereaved believe others would not understand, compounding their sense of aloneness in the world (Hentz, 2002).

Many bereaved people have dreams of deceased loved ones, that can leave them feeling confused and like they were going mad. However, studies have found that such dreams can provide an alternate, ephemeral landscape which provides comfort (Baptist, 2010). Dreams are important and provide a meeting place between the realms of the living and the deceased, this enables the bereaved to feel that loved ones continue to exist, which is an important part of accommodating grief and maintaining continuing bonds (Baptist, 2010). As well as having a transcendental ongoing relationship with the deceased, the bereavement literature acknowledges continuing bonds occur through ritual and ‘sacred spaces’ or places of memorialisation (Henning, 2016). These spaces are referred to in the Diasporic discourse as ‘*deathscapes*’.

f) Diaspora Deathscapes

In bereavement, adjustment to the absence of a corporeal body (the deceased), leads to a change in relationship with the deceased. The bereaved continue a relationship with the deceased through transcendental and physical means such as the creation of *deathscapes*. *Deathscapes* are defined by Teather (2001, p.185) as “...the material expression in the

landscape of practices relating to death...” and include cemeteries, places where ashes are interred, shrines or other sites where the living situate a ‘spatial fix’ for memorialisation and grief, such as roadside memorials for road accident victims or virtual online communities (Teather, 2001; Baptist, 2010; Maddrell, 2012; Hunter, 2016).

Deathscapes provide a material or tangible forum for expressing grief relating to the death of a significant person. These deathscapes provide sacred spaces that are constituted by the meanings attributed to them by the living. These spatial sites embody grief, memorialisation, honouring, acknowledgement, love and connection (Hunter, 2016). Cemeteries are regarded as one of the main ‘deathscapes’ to commemorate the deceased. Participants had varying views and attitudes in relation to ‘*cemetery visits*’:

“...I have an old friend in town, his wife died recently too and he's always up at the cemetery and he'll tell me if a flowers fallen out, or 'it's about time, you know, you haven't been there for a little while [G]...(laughs).”
ID: B: 3110: F; 61; Sp; 19-24; R3

“...I don't want to go out to the...I don't need to go out there, it's purely a place to get rid of a body...” ID: B: 3388: F; 69; Sp; 13-18; R3

Participants in this study created also ‘*sacred spaces*’, either individually or with the community, such as the participants in the following:

“...I play corporate bowls so every time I go to the bowling club, I used to go through the back door of the bowling club I now go through the front gate because his ashes are just by the front gate...” ID: B: 3373: F; 64; Sp; 13-18; R1

“...I have my little shrine set up...” ID: B: 3369: F; 53; Sp; 13-18; R1

Although ritual activities related to these sites trigger waves of grief, the ritual activity gives meaning and structure to errant psychological and emotional energies (Baptist, 2010). *Deathscapes* can provide a space for the bereaved to channel the emotive depth of the existential condition of the diasporic experience (Chen, 2015). *Deathscapes* provide the medium through which mourning, grief and celebration can be expressed.

Despite the existential crises that can result from death of a significant person, there is also the potential for transformation through self-discovery and personal growth (Wong, 2008b; Neimeyer, Harris, Winokuer & Thornton, 2011). The Diaspora discourse recognises and acknowledges the existential crises and potential for transformative growth. Within the constitutive suffering, there coexists strengths in adaptation and renewal (Clifford, 1994; Bakare-Yusuf, 2008; Hua, 2013). When reflecting on this journey of ‘*reconciling the loss*’, one participant recalled the moment she found ‘*hope*’:

“...then six months down the track I woke up one day and I thought "I actually feel hopeful of the future" and it was kind of like - somebody wrote "you don't know that you've got no hope until you find it"- Isn't that fabulous?... When you're not even looking for it [*hope*]. It just raises its delightful smiling face (laughs)..." ID: B: 3371: F; 77; Sp; 7-9; R2

Loss and hope are a constant *lived tension* in the diaspora consciousness (Clifford, 1994; Clarke, 2010). Neimeyer and Sands (2011, p.11) state that “...loss does not inevitably decimate survivors’ self-narratives and mandate a revision or reappraisal of life meanings...” This is reflected by a participant who felt a sense of ‘*freedom*’ from the death of their spouse and that they felt released from the possessiveness of the relationship:

“...quite frankly, life is much easier now he's not here – emotionally - because his health was getting worse, and worse, and worse, and he was afraid of what was happening to him. This was going over about 10 years. He was frightened of what was happening, and he was very reluctant for me

to go off and have my own life. He became extremely possessive. So, you know, it was kind of a bit of a freedom for me..." ID: B: 3371: F; 77; Sp; 7-9; R2

Dutton and Zisook (2005) found that although bereaved individuals enjoyed the freedom of being a separate individual, however this only seemed to occur with the passage of time. There is an association between increased sense of self-mastery and independence with freedom. (Dutton & Zisook, 2005).

The death of a significant person can result in an existential shock, where people have to adjust to a new world without the deceased. Feelings of disorientation and confusion compel the bereaved to try and re-orient themselves as they are confronted with the fragility of life. Although there is an assault to the psyche that can traumatise the bereaved, as time goes on, there is the potential for transformative growth. A focus on *existential diaspora* is the starting point to discussing *bereavement diaspora* as a new contribution to the diaspora and bereavement discourse.

Receptivity and Existential Diaspora

Exploring receptivity through an *existential diaspora* lens can provide some insights into the provision and planning of bereavement support services. The narratives of the private world of grief highlight that grief is so personal and private that participants struggle to share their grief with their loved ones. The experience of *existential diaspora* seems too profound to let people into this private world, but also to open oneself up to others. Seeing their vulnerability at a time when they are experiencing heightened vulnerability themselves, has implications for receptivity to bereavement support. For example, the following participant demonstrated their reticence to let people into this *existential diaspora*;

“...you’re in a bubble and it seems that everybody else has moved on and you sort of feel alone all the time...the bubble is hard to get out of, once you’re in it, you’re looking for somebody who feels the same as you. You’re looking for somebody who loved this person as much as you did and is grieving as much as you are. You’re not going to find that person.” ID: B: 3398; M; 67; Sp; 10-12; R3

This participant felt that no-one could understand his ‘*private world of grief*’ and this may be a factor that would influence receptivity to seeking support. Another participant shared a similar viewpoint that one’s ‘*private world of grief*’ could not really be understood, or that she did not want others to impose what she should be thinking or feeling about her inner world;

“...but of course there is still certain things that you can’t really share with anybody that you don’t - no one can probably tell you how to feel or what to think. You just have to work that out yourself...” ID: B: 3072; F; 52; Sp; 6-9; R3

At the crux of participants in this study and their receptivity to seeking and utilising professional support, was the feeling that others would not fully understand their inner world, that they did not want people to impose meaning into their inner world and that they did not want to expose their vulnerability to others. Pascal, Johnson, Dickson-Swift, McGrath and Dangerfield (2016) identified that vulnerability created embarrassment and shame and similar sentiments were echoed by participants in this study:

“You want to ask for help but you’re too, you’re too proud or, or you don’t, you just don’t want to do it, you know, so you just sort of push through...”
ID: B: 3072; F; 52; Sp; 6-9; R3

“You either need help or you feel you don't need help or you don't feel worthy of asking for it. Too complex to give a yes-no answer to that one....” ID: B: 3371: F; 77; Sp; 7-9; R2

Hooghe, Neimeyer and Rober (2011) assert that there is an ongoing tension in a bereaved individual where they struggle between the wish to be open and share with others, and the desire to keep feelings and thoughts private. As demonstrated in this research, the *existential diaspora* featured dialectical stances and *lived tensions*, which the bereaved constantly try to balance as they reconcile their loss and get used to their new world. Being open to others and others being open, or receptive, to the bereaved person's *existential diaspora* invokes the concept of reciprocity, which plays a role in receptivity (Pascal et al., 2016). The presence of a pre-existing therapeutic relationship has also been shown to influence receptivity to professional support (Milberg, et al., 2008). However, bereaved participants described trying to make sense of their new world and did not wish to have others impose their thoughts, ideas and judgements. This indicates the need for the bereaved to try and ‘do it on their own first’ before they may be open to seeking support. Some bereaved described a sense of feeling like they were going crazy and this is another mitigating factor influencing receptivity – that someone else may think they are crazy too because of the thoughts and feelings they were experiencing. Central to a reticence to seek support, is fear of embarrassment, shame and of being judged.

Expressions of fear, of being embarrassed and of being judged, indicated concerns about overtly showing one's vulnerability, and this may be a confounding factor influencing receptivity. Brown (2006) posits that when a person has insight into their own personal vulnerabilities and emotional makeup, they may possess higher shame resilience. Shame resilience may be a confounding factor in receptivity as it encompasses:

- a) the ability to recognise and accept personal vulnerability,*
- b) the level of critical awareness regarding social/cultural expectations;*
- c) the ability to form mutually empathic relationships that facilitate reaching out to others; and*

d) the ability to 'speak shame' or possess the language and emotional competence to discuss and deconstruct shame.

Brown (2006) found that strategies to deal with shame were too diverse to be able to identify one effective tool. Likewise, in this research, the experiences described in the *existential diaspora* are too diverse, with many confounding factors interweaving to influence the intrapsychic concepts of will, judgement and perception. Strategies that may enhance receptivity to support include being with, or talking to, others who have shared similar experiences. Psychotherapy or counselling in itself is an inherently shame-inducing relationship hence reticence by individual's to utilising professional support (Brown (2006). Intrinsic in the findings from this research is the need for professionals to be open to the non-dominant discourse and the differences in *existential diaspora* experiences, in a non-judgemental and open way, with a focus on the bereaved person's metaphors to describe their own world.

McGrath et al. (2000) identified the 'independence factor' in which asking for help was associated with weakness and a perceived threat to one's ability to cope independently. Pascal, Johnson, Dickson-Swift, McGrath and Dangerfield (2016) found that strategies including will and determination, and minimisation influenced receptivity to allowing others to inner thoughts and feelings. Minimisation was a strategy used by participants to reduce anxiety, enhance hope and conform to socially acceptable norms. The notion of self-determination to facilitate emotional and social independence identified by Pascal et al. (2016) has implications for receptivity to support in bereavement, however cannot be viewed in isolation. As McGrath (2013) stated, an individual's *desire* or *ability* is influenced by many factors. Receptivity is more than just a person's will, determination and intrapsychic phenomenon. Nouel (2008) describes the process of bereavement as profoundly symbolic and social, reflecting intrapersonal, interpersonal and linguistic dimensions of human life. Dialogue with others who co-create a narrative of the deceased, along with dialogue with those who are deceased, foster continued bonds and thus ongoing relationship with the deceased. Language connects the inner, outer and transcendent

worlds and was a feature of participant narratives in this study. Participants described ongoing dialogue with the deceased and how the words of others either encouraged, or discouraged, them to talk about their bereavement. The interdependence of all these factors need to be considered, hence *bereavement diaspora* provides a different perspective to explore receptivity. Analysis of receptivity issues as they relate to specific diaspora concepts is helpful to explore factors that can inform service design and delivery.

a) Existential Shock: a new world

The deceased provided a metaphorical anchor for the bereaved. The bereavement discourse describes the impact of loss where assumptions about the safety and predictability of the world are shattered and individuals thus lose their sense of connection, security and a sense of purpose (Neimeyer, Harris, Winokuer & Thornton, 2011). This existential ‘black hole’ leaves people feeling dazed, confused and alone and this has implications for receptivity to support, particularly in the early period following death. Neimeyer and Cacciatore (2016) describe the sense of emotional anaesthesia that occurs in the bereaved where they may experience difficulties with self-care, physical health, emotional regulation, cognition, interpersonal relationships and social transactions. There is a *lived tension* of connection versus isolation and the bereaved may withdraw at this time. In terms of receptivity to support, the sense of emotional amnesia can create a block to utilising support as the bereaved endeavour to make sense of their new world and turn into themselves, seeking safety. This however, can compound a sense of isolation.

The early period post loss is a time when the bereaved feel lost and the bereavement discourse highlights the benefits at this time of trying to provide a safe ‘holding environment’ for psychological and emotional expression, or having professional support services available such as counsellors or support groups (Neimeyer & Cacciatore, 2016). However, an individual’s receptivity to support remains central to whether this support is utilised. As every individual is unique, this poses a challenge to developing support targeted at psychological or emotional issues. If the bereaved are having difficulty making

sense of their world, perhaps they feel others could not help them to make sense of it either?

b) Disruption: Violence to the psyche

The empirical literature in relation to palliative care bereavement highlights the importance of the therapeutic relationship during the caring period and in bereavement (Milberg, et al., 2008; Trevino, Maciejewski, Epstein & Prigerson, 2015). The bereavement literature identifies that it is important that health professionals who had known and cared for a loved one, provided support in bereavement. If the health professionals were known to the family, and if there was a positive therapeutic relationship, this fosters a sense of security and trust which are important factors influencing receptivity to support (Milberg, et al., 2008).

What is of interest is what makes an individual receptive to letting people into their inner world, even if they feel they may “make a fool of themselves”, get embarrassed or are judged as being a fool. This indicates receptivity is contingent not only on an individual being open to others, but in others being open to the individual (Hinchman, 2009; Hooghe, Neimeyer & Rober, 2011; Lewandowski, Ciarocco, Pattenato & Stephan, 2012). Pascal et al., (2016) identified the notion of reciprocity where participants did not wish to burden others and cause emotional or cognitive stress, so wanted to protect informal networks from how they were feeling and coping, and to keep their own self agency intact.

c) Hybridity: Double Consciousness, Lived Tension and Identity

The role of memory plays a significant role in how the deceased reconcile the loss. The subjective sense of an ongoing connection in which the deceased maintains a background presence provides much comfort to the bereaved (Field, 2011). Although psychotherapeutic approaches have been developed to facilitate the use of memory to foster continuing bonds and thus transform the relationship to the deceased to a transcendent, incorporeal one, receptivity to sharing the inner world with another still

remains challenging. There remains a heightened sense of existential *angst*, particularly in the early period post death. Fear of being judged, feeling embarrassed or ashamed are factors that influence receptivity.

d) Displacement: Yearning and Nostalgia

The notion that yearning seems to be a normative feature for participants in this research is somewhat at odds with the current bereavement discourse. Indeed, yearning and nostalgia are intrinsic in the diaspora discourse. Participants who articulated a yearning for deceased loved ones in this study range from 0 up to 24 months' post death, indicating yearning may be an enduring feature, and the presence of such does not necessarily indicate a psychopathology of complicated grief. This has implications for professionals who use complicated grief as an assessment framework for bereaved individuals post death. For example, Shear (2015, p.155) advocates the following provisional proposed guidelines for the diagnosis of Prolonged Grief Disorder in the *International Classification of Diseases, 11th Revision*:

A grief response that has persisted for an abnormally long period of time after the loss, clearly exceeding expected social, cultural, or religious norms; this category excludes grief responses within 6 months after the death and for longer periods in some cultural contexts

As participants were still experiencing a level of yearning for the deceased up to 24 months' post death, this may impact on an individual's receptivity to support, because they may be made to feel there is something abnormal or maladaptive about feeling a sense of yearning and don't want to have the stigma of having a diagnosed mental illness. Likewise, they may feel that yearning is a normal feature of bereavement and thus would be reluctant, or less receptive to support, if they feel others do not understand that for them, this is a normative experience in bereavement.

e) Embodied Diaspora and Transcendence

As there is a dearth in the literature in relation to embodied habits and bereavement, this has implications for receptivity. An absence in the literature means there is less awareness that this is an experience of bereavement and therefore may lead to a belief of psychopathology in professionals. As this is not a dominant discourse, the bereaved may also 'feel like they are going crazy'. People may be more, or less, receptive to using psychological support if they feel this is not a common feature of bereavement. This phenomenon is worthy of further exploration.

f) Diaspora: Deathscapes

Deathscapes have implications for receptivity as the bereaved may benefit from ritual and memorialisation that fosters their connection with the deceased. Some bereaved may not be receptive to support or to let people into their private world for fear of being criticised for creating a sacred 'shrine' dedicated to the deceased, or that they leave the deceased person's belongings, or room, where they are. Hunter (2016) highlights that deathscapes are places and sites of contestation, based on individual and socio-cultural influences. However, the creation of 'virtual' deathscapes may open the bereaved person's receptivity to engaging in a 'virtual bereaved community'.

Social networking sites (SNS) play an increasing role in an individuals' and community's bereavement. Walter et al. (2011-2012) look at cyber sociology and whether SNS's produce social isolation or enhance community. They posit that the dead continue as social actors in the online community, that research participants have reported a sense that the deceased can see or listen to the virtual domains (Pitsillides, 2011; Walter et al., 2011-2012; Roberts, 2012) and this has contributed to increased disclosure online, whereby a 'psychological community' is highly valued, more so than face to face, group participation. Furthermore, participants reported that there was no embarrassment about speaking to the deceased through posting comments, even though a public audience would be privy to such thoughts (Walter et al., 2011-2012). The internet is changing the way

individuals and communities mourn and SNS allows grief in the private and public sphere to interface, where the deceased has an ongoing presence socially and privately (Walter et al., 2011-2012). Likewise, receptivity to support with things technology related would also be worthy of further examination.

Conclusion

Theorizing diaspora to bereavement contexts can open up the ‘discursive space’ to provide new insights and perspectives to understanding the existential dimensions of bereavement. This chapter discussed key concepts from the diaspora literature to articulate a link between the diaspora discourse and existential elements of bereavement. *Existential diaspora* provides a new language and ontological and phenomenological lens through which the bereavement experience can be examined. Bereavement can induce a profound emotional and psychological response, through *disruption* leading to a violence of the psyche and the yearning and nostalgia that come from their *displacement* in the new world. The bereaved negotiate their new foreign world, or *existential diaspora*, through balancing *hybrid* identities, double consciousness and lived tensions. They negotiate and relearn new *embodied* habits that form through sharing space, spatialised embodied inter-relational habits that are acquired through having lived with the deceased. The bereaved maintain their connection through memory, keeping the deceased as a part of their life and taking them into their future. The relationship is thus transformed from a physical one, to a transcendent one where *deathscapes* are created to memorialise the deceased. *Existential diaspora* in bereavement encompasses psychological, social, emotional and spiritual components and provides a new diasporic identity to add the broader diaspora discourse.

Although there is an abundance of empirical literature in the bereavement discourse regarding the psychological, social, emotional and spiritual impacts in bereavement, there were some experiences in this research in which there is little or emergent evidence in the empirical literature. Some features, particularly a sense of freedom and feelings of embarrassment in bereavement, embodied diaspora and spatialised habits, along with the incidence of PTSD in loved ones who experienced an expected death, are relatively new

or uncommon concepts to the palliative care bereavement discourse. Exploration of *existential diaspora* has reinforced the complexity of receptivity to bereavement support and should not be examined in isolation of the broader social and systemic issues which will be discussed in the following chapters.

The focus of this chapter was on discussing the findings as they apply to an *existential diaspora*, a concept that forms part of the broader experience of *bereavement diaspora*, a new concept to the bereavement and diaspora discourse. The next chapter will discuss individual ways of coping by the bereaved that aims to mediate the existential crises that bereavement can bring.