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

Pippa Blackburn

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Chapter 6: Coping in the bereavement diaspora

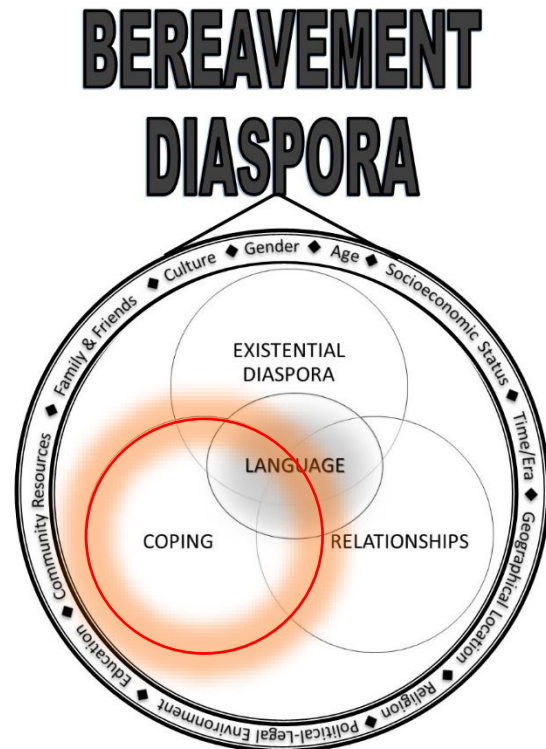
Introduction

The previous chapter set the context for how *existential diaspora* can shape our understanding of the lived experience of bereavement. Diaspora as an existential concept, has only clearly been articulated in the extant literature in the last two years (Chen, 2015). The existential impact, along with broader situational issues, emerged from the data in this study and echoed themes from the diaspora discourse. *Bereavement Diaspora* was thus conceptualised as incorporating *existential diaspora* along with individual and broader socio-cultural features.

This chapter will begin with a discussion on the ways people cope in bereavement using a contemporary model to explain common characteristics of the way the bereaved cope. Concepts from the diaspora literature will frame the discussion on the experience of *bereavement diaspora*, the experience of being-in-the-world as a bereaved person. The final section of this chapter will discuss issues of receptivity and *bereavement diaspora*.

Although the bereavement literature is saturated with the different ways of coping in bereavement, nonetheless the diaspora discourse provides concepts that can frame understanding through a different lens. This chapter aligns the diaspora concepts with the narratives of participants in this study to frame the situatedness of being-in-the-world in the *bereavement diaspora*. What the diaspora discourse contributes is the socio-political

Figure 19: *Bereavement Diaspora: Coping*



influences in bereavement. A significant narrative by participants in this study was recounting the stress of dealing with macrosystems to address practical matters related to the death. There is a dearth of empirical literature in relation to the impact that dealing with practical matters has on the bereavement experience.

Contemporary Theories of Coping in Bereavement

Coping in bereavement has historically focused on ‘grief work’ where individuals are encouraged to engage in confrontation strategies and relinquish, or relocate, their bond to the deceased. There have been inconsistencies identified in the empirical literature around the efficacy of these traditional interventions, and this has led to the development of process models that incorporate confrontation and avoidant ways of coping with loss (Zech & Arnold, 2011).

An awareness of the different styles of grieving have provided supplementary understanding of the possible reasons for the differences in grieving between men and women and the way they cope with loss. Instrumental ways of grieving have historically been attributed to male grief, where cognitive and problem focussed strategies, or physical activity, are the dominant ways of coping in grief. Often the use of activity is a means of exploring or accessing affect, for example using activity for ventilation of emotions such as sadness and anger (Martin & Doka, 2011). Intuitive ways of grieving have commonly been attributed to female grief, where more energy is converted into the affective domain and less in the cognitive. Ways of coping are generally through expressing emotions, or talking about experiences (Martin & Doka, 2011). Although instrumental and intuitive styles of grieving having been ascribed as dominant gendered ways of grieving, some men may grieve in an intuitive way and some women may grieve in an instrumental way (Martin & Doka, 2011).

Process models of bereavement incorporate intuitive and instrumental ways of grieving. The Dual Process Model (DPM) of Coping in Bereavement, proposed by Stroebe and

Schut (1999), depicts grief as a process, allowing for differences in culture, gender, age, the nature of the relationship to the deceased and other factors that impact on bereavement. These all mediate grief and make grief a unique and individual experience (Stroebe & Schut, 1999; Rubin, 1999; Rubin, Malkinson & Witztum, 2011). The DPM provides a framework for understanding the processes of coping in bereavement:

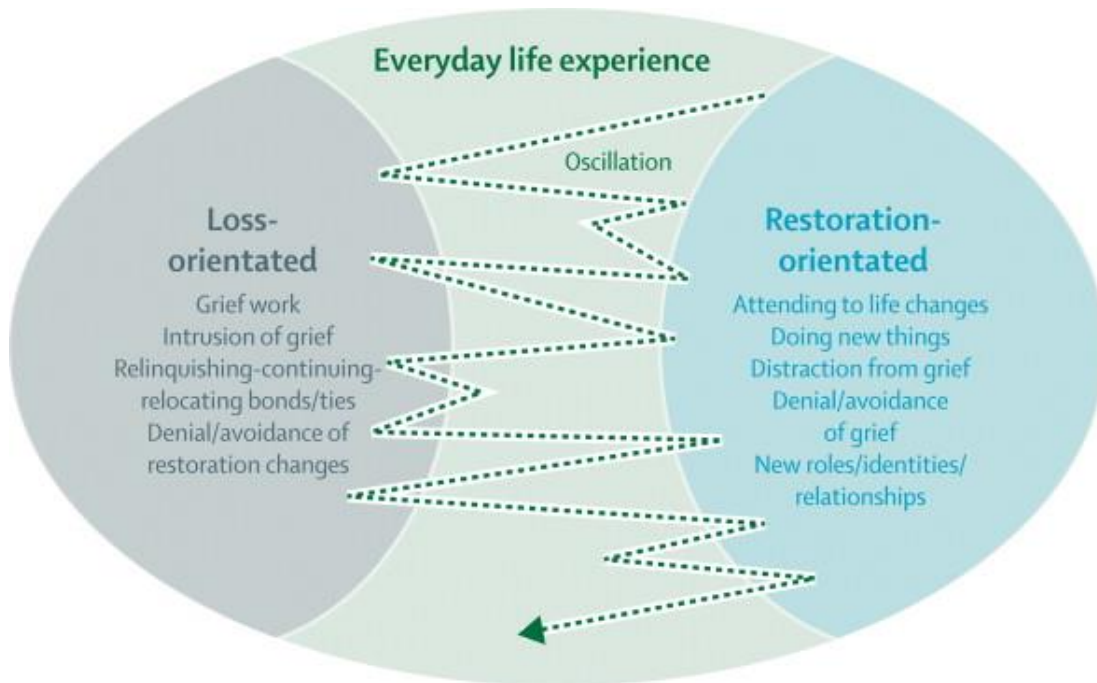
“...the grieving individual at times confronts, at other times avoids, the different tasks of grieving. It also argues the need for dosage of grieving, that is, the need to take respite from dealing with either of these stressors, as an integral part of adaptive coping” (Stroebe & Schut, 1999, p.197).

The DPM recognises the *loss oriented* features of bereavement which include making meaning of the loss and the death, and reconciling emotional and cognitive bonds with the deceased (including rumination and yearning, dwelling on life together and reflecting on memories). With loss oriented activity, positive and negative emotions occur and often re-occur throughout the lifespan (Stroebe & Schut, 1999; Zech & Arnold, 2011). This has been referred to as ‘re-grief phenomenon’ (Oltjenbruns, 2013). Re-grief has also been acknowledged in the diaspora discourse. Ogbuagu (2012) confirms that although grief can be held at abeyance or reduced tempo, it can re-emerge to its earlier crescendo.

The DPM posits that the bereaved engage in *restoration oriented* activities such as needs that have to be dealt with, for example, dealing with practical matters. Restoration oriented activities include secondary stressors such as mastering chores or tasks previously undertaken by the deceased such as cooking, child care or managing household finances.

The bereaved move between loss and restoration oriented activities. This dynamic process is referred to as oscillation in the DPM, where emotional, cognitive and behavioural resources constantly change to manage both internal and external demands. The process of oscillating as a way of coping, allows the bereaved to either pay attention to, or avoid, different stressors or activities associated with the loss (Stroebe & Schut, 1999; Zech & Arnold, 2011).

Figure 20: Dual Process Model of Coping in Bereavement



The DPM demonstrates that coping in bereavement is a complex interplay between many mediators, cognitions, emotions, behaviours, social milieus and spirituality as well as physiological changes in the brain and body (Gundel, O’Conner, Littrell, Forth & Lane, 2003; Najib, Lorberbaum, Kose, Bohning & George, 2004; Freed & Mann, 2007; Coan, 2010). According to Hansson and Stroebe (2007), the DPM is a comprehensive model informed by theoretical constructs from Lazarus and Folkman’s (1984) Cognitive Stress Theory, Horowitz’s (1986) Stress Response Theory, Rubin’s (1981) Two Track Model of Bereavement, Cook and Oltjenbrun’s (1989/1998) Model of Incremental Grief, Parkes’ (1993) Psychosocial Transitions, Worden’s (1991) Tasks of Mourning and Bowlby’s (1969/1980) Attachment Theory.

The DPM is the only bereavement model that recognises the bereaved deal with concurrent stressors and has explained the process of how people cope in bereavement. The bereaved are constantly needing to address restorative activities such as *dealing with practical matters* and balance this with their grieving. This was consistently demonstrated throughout participant narratives in this study.

Diaspora Findings to Concept: Coping in the *Bereavement Diaspora*

Coping in the *bereavement diaspora* reflects the DPM. Coping is dynamic, developmental and changes through time. Voicu (2013, p.x) describes a process where diasporics move through ‘*middle passages*’ where the person ‘...moves itself, displaces itself, loses itself in, resists to and mixes with the receptive culture...’ This is similar to the process of individuals getting used to being in the world again, where they incrementally expose themselves to people and events, and is dependent on their personal, emotional and psychological resources at any given time. There is a dynamic interplay between internal and external inter-dependent mediators.

Recent developments in the bereavement discourse have described an epigenetic approach to adaptation in bereavement that is rooted in the ecological, person-in-environment approach (White, Hayes & Livesey, 2013; Assareh, Sharpley, McFarlane & Sachdev, 2015; Neimeyer & Cacciato, 2016). Epigenetics is the study of how the environment affects the genes and can alter the course of brain development in ways that can have a profound effect on psychological functioning over the lifespan. Epigenetic systems theorists claim that humans adapt to changing environmental conditions and if changes occur in one part of a system (individual, family, ecosystem, species, society) it can result in changes in every other part of the system, including the individual. This interdependence is recognised in Bronfenbrenner’s Ecological Theory (White, et al., 2013; Assareh, Sharpley, McFarlane & Sachdev, 2015). The diaspora discourse reflects this epigenetic perspective. As a result of environmental conditions, changes can occur to biological processes of growth and decline, cognitive functioning, psychological transformations and the adoption of new social roles (Titzmann & Stoessel, 2014).

The diaspora discourse reflects the bereavement literature of dynamic systems perspectives. Diaspora concepts of displacement and dispersion of a cultural group into another culture highlight the dynamic process of adaptation to the new environment. This is often referred to as acculturation and is influenced by factors such as the availability of resources, stability of legal situation, psychosocial adaptation, discrepancies between

family members or expectations on, and from others, can overburden coping abilities (Titzmann & Stroessel, 2014). The way people cope with adjusting to a new environment way of being, is similar to the oscillation that occurs with the DPM. Zeleza (2010, p.211-212) describes a fluidity of engagement in the diaspora and this notion of fluidity can be applied to bereavement between the diaspora (bereaved) and the homeland (metaphor for the deceased and life that was before):

'...the fluidity of these engagements is best captured by the notion of flow...flows are heavy or light, they can be continuous, interrupted or change course and may even be beneficial or baneful...all along they are subject to the unpredictable twists and turns of history...'

The flows include images, representations, ideas, ideologies, people, cultural practices, resources and organisations (Zeleza, 2010). This reflects the process of oscillation in the DPM where the bereaved engage in loss and restoration oriented activities, which can occur concurrently.

Participants in this study discussed how dealing with practical matters was extremely challenging, time consuming and had an overall negative impact on the mental and emotional wellbeing of participants. The subthemes of *'dealing with practical matters'* include issues in the *'immediate aftermath of death'*, for example, *'funeral arrangements'*, *'donating body to science'*, *'interment'*, *'notifications' and costs*, *'resources'* (*'written'*, *'human' and 'technologies'*), *'legal matters'* which included issues of *'probate'*, *'transferring assets'* and *'dispersing assets'* and *'costs'*. Other practical matters include *'financial issues'*, *'housing'* and *'work'* related issues. *'Dealing with practical household tasks'* was also another practical issue that participants discussed. Participants described *'good'* and *'bad experiences with institutions'* and *'the impact'* that this had on their emotional and psychological state. Dealing with practical matters is a normal part of being-in-the-world and is shaped by socio-political-geographical factors. There is very little in the extant literature in relation to dealing with practical issues in bereavement and the impact of this. There is also scarce empirical evidence in relation to the use of humour when talking about bereavement experiences and this was a common feature to all participants who were interviewed.

'Keeping busy', *'independence-self-reliance'*, *'awareness of difference'* including concepts of *'othering'* and *'not othering'* (which are features of the existential literature) emerged from the data in this study as ways participants coped in bereavement. The process of *'othering'* and *'not othering'* help people to cope through feeling an affiliation, or difference, with others. *'Valuing memories'* was another prominent finding in this study and the diaspora discourse attributes the role of memory as significant in how successfully people can mediate the diaspora (Clifford, 1994; Clarke, 2010; Chen, 2015; Marat, 2016).

The perspective of *bereavement diaspora* is a broader view of the bereavement experience. Subthemes from the findings are reflected below and are categorised under diaspora concepts subheadings. The findings demonstrate the linkage to diaspora concepts to create the theme *bereavement diaspora*. In keeping with a similar framework with the previous chapter, as the data relates to coping in the Diaspora, the experiences of coping will be discussed within the same framework using concepts from the diaspora literature:

- a) Diaspora: the experience of being-in-the-world
- b) Hybridity and Lived Tensions: (re)shaping identity
- c) Displacement: memory and shared narratives
- d) Disruption: learning to manage thoughts and emotions
- d) Embodied diaspora and Transcendence: coping with absence-presence
- e) Deathscapes: places of comfort

The diaspora literature provides concepts that demonstrate the 'situatedness' of a person's experience. Like diasporics, the bereaved are impacted by socio-political forces that influence their bereavement experience. Cacciatore and Bushfield (2008) assert that there are overarching socio-political systems within a society that shape legislation, policy, attitudes, beliefs and values about a particular social issue. There is extraordinary energy by the bereaved to manage the emotional and psychological impact that occurs from the disruption that death of a loved one brings. A significant part of coping in bereavement is the active process of self-reflection on one's identity, and to facilitate identity re-constitution and overcome the feeling of displacement and find a new place in the world. The bereaved engage in sharing memories and narratives of the deceased to maintain their

connection to the deceased. There are many factors that impact on an individual's receptivity to support and an exploration of the *bereavement diaspora*, particularly the experience of being-in-the-world, may provide further insights into the experiences of the bereaved, as discussed below.

a) Diaspora: being-in-the-world

When an event creates a crisis that causes a significant disturbance, this may lead to a sense of loss of efficacy to sustain life, loss of vitality, feeling of a sense of continuity of self. It may also lead to preoccupation with individual violation and social destruction as well as physical deterioration (Sideris, 2003). When a crisis occurs, one's identity is (re)constructed, relative to their situation, environment and is situated in time. The perspective of *bereavement diaspora* would recognise the 'diasporic identity' as one of complex and dynamic multiplicity of the individual and the family and community systems in which it is situated (Anthias, 1998; Voicu, 2013; Kaur, 2015). Diaspora discourse highlights how people are a product of their culture and meaning-making is consciously and unconsciously constructed, influenced by ethnicity, gender, education, class, economic status, religion, geographical location, for example city or country, and language (Waechter & Samoilova, 2014; Saketopoulou, 2015).

Although the bereavement discourse has examined how bereavement experiences are influenced by an individual's upbringing, socialisation, geographical location and experiences of being-in-the-world, there is a notable absence in the empirical literature on the role of institutions on bereavement experiences. The participants in this study discussed their experiences with institutions at length and the impact this has had on their bereavement. Receptivity to support in this area in particular, is worthy of exploring.

Socio-political Influences

Saketopoulou (2015) discusses the role of the state and how it impacts on the diaspora agent leaving them exhausted, physically and psychologically, as one participant described below on *'dealing with practical matters'*:

"...I got so tired of having to prove that my husband was dead and I wasn't. I had to express that several times to people – 'I am tired of having to prove that my husband was dead and I'm not...' ID: B: 3371: F; 77; Sp; 7-9; R2

The above quote reflects the constant experience participants had of having to prove loved ones had died to the state / system. Cacciatore and Bushfield (2008) discuss the socio-political system and its impact on bereavement. She describes the overarching socio-political system as the macro-system which shapes the values, beliefs and attitudes about a society's social problem through legislation and policy which, in turn, influences public policy administration, and social service programming. For example, in the USA, the inclusion of stillborn deaths in epidemiology studies are not included in the calculation of infant mortality. This leaves a large population of disenfranchised griever when the 'state' does not recognise their child or their loss (Cacciatore & Bushfield, 2008). Until 2001 in the USA, stillborn babies were not recognised, thus birth certificates were not issued. However, the state demanded the issuance of a death certificate for a stillborn baby and the family were responsible for the final disposition of the body. This left the parents confused – "how can you die if you never were?" (Cacciatore & Bushfield, 2008, p.381).

Addressing financial issues, dealing with creditors and debt was viewed as a main priority in the early weeks in bereavement. Corden, Hirst and Nice (2010) found there is a large volume of administrative work where errors and delays compounded an individual's grief. Findings from this study demonstrate that dealing with unhelpful institutions was found to be emotionally draining and demanded a lot of time, at a time when the bereaved had little personal resources and felt least able to cope. There were communication problems

with organisations and participants encountered insensitive staff. The bereaved participants spoke of their despair when they had to make multiple visits to organisations, or had to make repeated phone calls. Likewise, they expressed anger when receiving letters in the post addressed to the deceased from organisations already informed of the death. Sometimes this occurred on numerous occasions. The practicality of legal issues to be attended to, such as being an executor of the deceased's will, sometimes led to a heavy sense of responsibility or anxiety if the person did not feel they had the capacity to deal with these issues. Corden, Hirst and Nice (2010) highlight that the bereaved struggle with sometimes complex administrative and regulatory tasks related to the death such as handling the deceased's estate, notification to relevant government and other agencies. This study adds some new detail and understanding to bereavement, particularly in relation to dealing with practical matters.

Dealing with Practical Matters

The data in this study demonstrated a broad spectrum of activities that the bereaved needed to undertake in order to address practical matters in day to day living. These activities included funeral arrangements (organising a funeral director, venues for the service and the wake, funeral celebrant, notifications, catering); putting notices in the paper; issues related to donating body to science; applying for probate; gathering and verifying legal documents and having them certified; costs associated with notifications; notifying and liaising with many agencies and service providers; disconnecting services; finalising rental property; cleaning, transferring and dispersing assets; re-directing mail; paying ongoing costs or closing accounts; renegotiating with creditors and readjusting finances for mortgage payments; changing bank accounts; paying out of pocket expenses from own income until estate finalised; doing a final tax return; organising statutory declarations from witnesses for life insurance policy purposes; organising supplementary letters if issues with probate application; collecting deceased's ashes; organising and liaising with place for interment of ashes; organising headstones; finding out how to operate household electrical items; chopping wood; undertaking household repairs; using technologies to locate agents or pay accounts and look for work. Participants talked about the burden of

time administrative tasks took, and the volume of associated paperwork. Participants also spoke of the challenges and distress of having to attend in person to agencies when grieving. The length of time from lodging probate until letters of administration were dispersed made finalising estate matters difficult. Some participants also discussed the distress of being asked what they perceived as intrusive questions from organisations.

Significant multiple stressors commence at the moment of death. Procedures for death in the hospital are usually outlined in hospital policies and procedures, however the average layperson does not have an awareness of what happens in *'the immediate post death aftermath'* and this is portrayed by a participant whose spouse died in hospital:

"...some people would be totally lost - take away my friends with knowledge, it would be - 'oh my God, how do I bury my husband?' I had no knowledge that he stayed in the mortuary and the funeral director picked him up, and the funeral director arranged the death certificate. I didn't know what happened...and then [the nurse] said 'We'll take him down to the mortuary, I'm going to give him a bath and make him comfortable' she said. "You need to organise a funeral director" and I went 'Oh, how much time do I have?' you know, like do I have to do it tonight? Do I do it tomorrow? When do you do this? It was sort of like, 'oh my God, I've got to get him out of the morgue and into the funeral director, you know?" ID: B: 3109; F; 64; Sp; 10-12; R3

Participants described the busy-ness of dealing with practical matters soon after the death, demonstrated by statements such as *"...there so many things you have to do; you have to go around to so many places with your death certificate....it seems as if that's never ending..."* ID: B: 3073; F; 87; Sp; 6-9; R3. Many other participants echoed these same sentiments and the financial impact was identified as a significant stressor by many participants.

Financial Matters

Carers who reduced or resigned from work during the caregiving period suffer financial consequences during bereavement (Ferrario, Cardilo, Vicario, Balzarine & Zoti, 2004; Corden, Hirst & Nice, 2010). Economic transition and financial hardship that occurs as a result of bereavement can culminate in ‘financial pain’, where changes in employment, income and housing may have associated changes in social role or status. The associated practical and emotional elements contributing to ‘financial pain’ create significant stressors which impact on the grieving and bereavement experience. Financial burden and economic wellbeing has been directly linked with identity reconstruction and emotional distress, including fear, guilt and anger (Parkes, 1996; Gallagher, 2004, cited in Corden, Hirst & Nice, 2010, p.23).

Ogbuagu (2012) describes the concept of double diasporic grief where one grieves the actual loss of the deceased, but also grieves the financial impact. Research conducted by Corden, Hirst and Nice (2010) on the financial implications and experience of loss following the death of a partner demonstrates that household income drops below the official poverty line in one in five people. Women were at higher risk and remained in poverty for up to three years after the death. The commensurate financial uncertainty of being able to maintain rental or mortgage payments, changes to government benefits and security of rental tenure, contributed to emotional strain and distress (Corden, Hirst & Nice, 2010). Many participants in this study reinforced the financial stressors identified in the extant bereavement literature.

Low income and financial burden have been identified as potential risk factors for bereavement. Spousal bereavement reduces the household income to one income. Some family members may be able to manage the financial uncertainty if it is expected to be for an interim period until the deceased’s insurance or other payments are finalised. For those bereaved living with financial uncertainty, it leads to heightened negative emotional impact and psychological distress in bereavement (Corden, Hirst & Nice, 2010). One participant described feeling traumatised as a result of the financial situation she was in,

which led her to consider relocating to another town to secure a cheaper home and she stated: “...*I was left in heavy debt and I had to sell the house. That's a trauma, that's a big trauma for me...*” ID: B: 2875; F; 81; Sp; 13-18; Rem1.

The tasks associated with practical matters is reported as daunting, disruptive and stressful by the bereaved. Dealing with practical matters unfortunately, occurs at a time when people feel they have little control over their feelings, are experiencing intense grief and pain and there is a fear of penalties. Many bereaved report heightened stress and distress from dealing with financial and legal regulatory bodies and requirements (Corden, Hirst & Nice, 2010). Many participants in this study echoed the same stress and distress but also described feeling fortunate to have people in their informal networks to help with practical matters. This helped to reduce a lot of additional stressors. Some participants spoke of using their initiative and turned to the internet to seek resources that provided information on how to deal with practical matters after death. Information regarding probate or what to do and how to transfer or disperse assets was a common reason cited for using the internet to assist with practical matters. Attending to legal and financial matters has been attributed to being a positive mediator to help in coping with grief, as it provided a sense of self mastery and a feeling a sense of accomplishment.

Legal Matters

Some participants had significant stressors when dealing with legal matters. One participant, ID: B: 3109; F; 64; Sp; 10-12; R3, recounted the trouble she had with trying to locate her husband's will. It was not until she had a fortuitous encounter with a customer in her workplace and a discussion about locating wills, that she became aware of changes in the WA Public Trustee and another possible location where her husband's will might be found. Once located however, she had an additional legal issue with the will where she had to provide a supplementary letter to say that the spelling on her husband's birth certificate was different to the spelling on his will, their marriage certificate and other legal documents. As a result of the discrepancy in the spelling of his name, she stated her

'hands were tied' as she could not disperse, or transfer any assets, and had to enlist the assistance of a lawyer. It took over 12 months for probate to be finalised.

Another participant, ID: B: 3371: F; 77; Sp; 7-9; R2, described complications as a result of having a name discrepancy between her own birth certificate and other legal documents as she was required to provide proof of identification as an executor of the will. Ironically, this participant had used her birth certificate to obtain other legal documents prior to her husband's death, including her marriage certificate, drivers' licence and passport. She had to engage the services of a solicitor which was prolonging the process of probate.

One participant, ID: B: 3391: F; 69; Sp; 13-18; R3, described the many visits required to agencies to transfer the house into her name. One agency advised her they could not accept her birth certificate because it was not an Australian one and she had stated, "*...well, I can't get an Australian one. You are born where you are born...*" The participant discovered she was given the wrong advice but highlighted it did not detract from the frustration of dealing with so many agencies to get one matter resolved.

Challenges of having to change bank accounts associated with transferring the family business was highlighted by one participant, ID: B: 3110: F; 61; Sp; 19-24; R3. The bank account was in a legal trading name and they now had to change accounts as well as the trading name. The participant described feeling 'flabbergasted' that she did not know about these things and that if it was not changed, it impacted on their ability to conduct business. One participant, however, ID: B: 3388: F; 69; Sp; 13-18; R3, stated, "*...I had to have everything transferred into my name...did all that myself...that was a piece of cake...no problems there...*" Furthermore, dealing with practical matters had associated costs and participants talked about the costs of attending to legal matters such as applying for probate, getting documents certified and application fees for other relevant legal documents. These burdensome processes included dealing with other practical matters such as lodging a final tax return for the deceased and having to lodge a statement that this was their final tax return. As this needed to be accompanied by certified copies of the

will and death certificate, this created a lot of additional ‘backwards and forwards’. One participant described her experience in the following quote to illustrate:

“...I'd do something where I'd need a certified copy of the will, so I'd get a photocopy, get a bank person to sign it and certify it, go and do the ATO stuff, then come back, and then realise I've got to get a copy for someone else. So it was a little bit backwards and forwards...” ID: B: 3407: F; 44; Child; 7-9; M2

One participant, ID: B: 3407: F; 44; Child; 7-9; M2, had the additional challenge of sorting her deceased father’s estate while commuting from the city to the country town where her father lived and died. The participant described having to sort through his belongings and clean his house, which was government housing. She had a timeframe of two weeks given by the housing agency, in which she had to complete everything. She balanced this with being a full-time worker and single parent. She commuted on the weekends and spent several weekends attending to her father’s estate.

Work matters

The nascent bereavement literature on economic and social costs highlights both direct, and indirect costs. Direct costs include medical costs, acute and long-term, lost earnings due to death and disability, and higher reliance on government financial assistance. Indirect costs include loss of work, loss of school time, loss of savings, cost to the employer and society, lost productivity, legal costs and impact on family and family disruption (Clarke & Goldney, 2000; Corden, Sloper & Sainsbury, 2002; Fletcher, 2002; Stebbins & Batrouney, 2007; Buckle & Fleming, 2011).

Meeting occupational responsibilities can be difficult for the bereaved, particularly in the acute period of grief post death. Many legislative acts in relation to workplace entitlements for bereavement leave are quite nominal. For example, in Australia, the *Fair Work Act*

2009 governs workplace leave entitlements for compassionate leave. Bereavement leave sits under this entitlement and legally, all employees (except casual employees) are entitled to two days of compassionate leave after the death of a member of the employee's immediate family or household. The *Act [2009]* defines who constitutes an employee's immediate family which includes a "...spouse, de facto partner, child, parent, grandparent, grandchild or sibling of an employee, or a child, parent, grandparent, grandchild or sibling of the employee's spouse or de facto partner..." (Fair Work Ombudsman, 2015, p.1). It is uncertain if the *Act [2009]* also applies to, or recognises, civil partnerships under the de facto criteria.

The following participant ID: B: 3407: F; 44; Child; 7-9; M2 discusses some of the challenges with finalising estate matters of her deceased father with the commitments of her paid employment:

"...so I had a week off work. Well, I initially was just going to have just a Monday and a Tuesday off because I went up Monday morning, he passed away the Tuesday morning... I was only allowed to have 2 days' bereavement leave - so the rest, the other 3 days, had to come out of my annual leave, and I didn't have a lot of annual leave, so unfortunately, that's why I had to go back then on weekends and get some stuff sorted out. I was able to do some stuff on my lunch break, I had to go in and see the bank. I had to still take some documentation into a bank in Perth, so I just did that on my lunch breaks, so I did other things on my lunch breaks. ...I think 2 days' bereavement leave is not really enough. If I had a funeral to organise on top of everything else, I certainly would have needed more than just the one week off work. I mean, ideally, I think bereavement leave certainly shouldn't be just two days for a family member that passes away, particularly if you've got to organise everything. But ideally, I would have had two weeks and I would have been able to get everything sorted..." ID: B: 3407: F; 44; Child; 7-9; M2

The legislation in different countries reflect similar leave restrictions when it comes to bereavement. For example, although the US provides for 12 weeks of unpaid leave under their *Family and Medical Leave Act* to care for a dying family member, it does not include provisions for bereavement leave. However, there is allowance for federal civil service workers to take up to 13 days leave to make arrangements in relation to the deceased's estate or to attend the funeral of a family member. Canada allows for three days paid leave if they have been employed for at least three consecutive months. China and Luxembourg have three days paid leave, Taiwan has three, six or eight days depending on their relationship with the deceased and Chile has seven days' allowance for paid leave for bereavement. Spain has similar legislation to Australia of two days paid leave (Meagher, 2013).

Despite legislation that outlines employees' rights in terms of leave for bereavement, conditional on the legally recognised relationship with the deceased, organisations exercise discretion with terms and conditions. Some participants described their workplaces as extremely supportive however this is an area that requires further exploration.

The Impact of Dealing with Practical Matters

The bereaved have to balance what Stroebe and Schut (1999) would describe as loss-oriented and restoration-oriented activities to cope in bereavement. However, dealing with institutions further impacts the psychological and emotional state of the individual. Even though some participants had *good experiences with institutions*, the dominant thread of participant narratives were '*negative experiences with institutions*'. One participant ID: B: 3072; F; 52; Sp; 6-9; R3, described the numerous phone calls she had to make to cancel her deceased husband's account. She recounted that it took over five months of persistence to cancel his account and described how she was sent a bereavement form, filled it out and sent it back. She would then receive a notice for his account and would have to repeat the process over and over again. Despite the organisation reassuring her that the account

was cancelled, she would continue to receive correspondence addressed to her husband. When she finally cancelled the account, she received a letter in the mail addressed to her husband that stated “...we notice you’ve shut your account. If you ever want to get back to us, ring us on this number...or give us any feedback on your experience...” This participant rang the organisation again to complain how distressed this drawn out process had made her.

One participant, ID: B: 3076: M; 52; Child; 4-6; R1, described getting ‘red letters’ to pay his mother’s account and when he requested they stop sending them until probate was finalised, they stated they could not deal with him as he was not the account holder. Despite being the executor of the will and having to wait for the time period for probate to go through the supreme court, he continued to be harassed to pay accounts. This participant also received a letter from a debt collector representing a pathology laboratory for an overdue account for his deceased mother. This participant described feeling significant distress when receiving a notification from a debt collector:

“... it just pisses me off to the max, I wrote to them on a number of occasions. I posted a letter off yesterday ...I said to them, ‘getting a letter from a debt collector - where do you get off!’ I was that pissed with them... I was just dreaming, having this fantasy, take the bastards to court. But at the end of the day, you just want to get things sorted and move on with your life. You don’t need to take on another fight. As much as it irks me...”
ID: B: 3076: M; 52; Child; 4-6; R1

One participant, ID: B: 3109: F; 64; Sp; 10-12; R3, described how the superannuation company paid her husband’s money into the wrong bank account, despite the correct bank account number being written on all the paperwork. This led to a six-week delay in getting superannuation funds.

One participant, ID: B: 3725: M; 63; Sp; 7-9; R1, described dealing with Centrelink as a 'nightmare'. Based on experiences with other organisations, bereaved participants were concerned about dealing with other agencies:

"...I've now got to put his tax return in and I don't know what sort of obstacles I'm going to come across there. I haven't gone there yet..." ID: B: 3072: F; 52; Sp; 6-9; R3

"...you ring a company and they give you some information, and then you ring them back to do something and they go, 'oh no, that's not right. Who told you that?'" ID: B: 3433: F; 60; Child; 13-18; R1

One participant, ID: B: 3109: F; 64; Sp; 10-12; R3 described the intrusiveness of an organisation her husband had life insurance with. Following the death of her spouse, the organisation asked questions such as 'If your husband survived, would you still be living with him?' This participant was required to have two witnesses prove she was still in a relationship with her husband at the time of his death. The organisation also requested her children fill out a form each to say they were not going to contest the will. This participant was not only perplexed with the questions being asked as she was the only beneficiary, but she also felt imposed upon and distressed that her children were required to complete a statutory declaration.

Some complex legal or financial matters which could take several years prevented people from feeling that they could rebuild their lives after the death. Dealing with the volume and urgency of financial matters that required attention, may compound an individuals' capacity to cope with their grief. People may not feel they are in a position to make important financial decisions (Corden, Hirst & Nice, 2010) and this was echoed by participant narratives in this study. However, some people found the associated paperwork a welcome distraction in their grief.

Although there is extensively literature on complicated grief and other adverse psychological outcomes in bereavement, the role of institutions within the situatedness of the bereaved's environment, has not been addressed in the empirical bereavement literature. The impact of dealing with organisations is described by participants:

"...there's so many things you have to do. You have to go around to so many places with your death certificate, it seems as if that's never ending...there's so much to do that really you can only grieve when you're on your own because you're really taken up with problems.... It's the unreality of it all and the fact that you've got things to do and you can't be crying..." ID: B: 3073; F; 87; Sp; 6-9; R3

"...I had [daughter] with me - these were early days - and the lady was helping and I was trying to tell her and I was trying to not cry and I'm thinking, 'how can I tell this woman what I need?' ..." ID: B: 3369; F; 53; Sp; 13-18; R1

"...it was very upsetting; it was very emotional...we had to go and see the funeral directors on the Friday just before the Christmas...so four days before Christmas...it was a struggle. I don't know how I got through it..." ID: B: 3373; F; 64; Sp; 13-18; R1

"...when it came time to give us access to the accounts as executors - probate had been issued...they had the letter of probate, they also wanted to see the will, which I found offensive...The bank wanted not only the letter of probate, but they wanted a certified copy of the will, which initially I refused to give them, I said 'It's none of your fucking business'..." ID: B: 3076; M; 52; Child; 4-6; R1

“...It’s really hard. I still now get a statement from the bank in her name even though I’ve rang up and told them that she’s deceased. I still get a three monthly statement that comes in with her name on it and I don’t know why they print it -probably because the computer doesn’t recognise that somebody has passed away - and it’s a bank statement for the months of such and such, with 0, 0, 0, 0. That’s crazy, it just brings it all back - when I’m feeling good, it just brings it back ...” ID: B: 3398: M; 67; Sp; 10-12; R3

“...it made me angry. It made me angry. I mean you get a widow on the phone saying my husband's died and they say, ‘well you've got to send the death certificate’ and all this sort of stuff...” ID: B: 3371: F; 77; Sp; 7-9; R2

“...I said, ‘finally you cancelled the account because you actually accepted the fact that he's passed away! Then you have the gall to write him a letter! That's just terrible!’ That was just really upsetting. I was furious.... [they have] a lot to answer for. People just can't seem to get through to them, that they're [the bereaved] going through this process and they have to do a million and one things...a person has compassion - but a big corporation - there's people working for them...and you speak to people, it's not like you're just filling out electronic forms. You're actually talking to people and they're promising you things that they're just not following through.... That's heartless! I've got no explanation as to why it took that long. They just didn't do it...I rang them and I gave them some bloody feedback. That was just really upsetting. I was furious...” ID: B: 3072: F; 52; Sp; 6-9; R3

“...I always walked out with the feeling that I was suspected of being a rorter or a con job or something...” ID: B: 3725: M; 63; Sp; 7-9; R1

“...I wasn't overly happy in the end...there was only \$12.00 that came back to me from his bond which was \$800...I was just exhausted and I thought, 'well, I'm not going to argue'...I was just gobsmacked...I was just at that point where I didn't care ... I probably would have kicked up more of a fuss, but you know I was back at work, it was hard to have these long conversations with the government agency and I just thought, 'well, I'm just too tired, I'm not going to bother on this one' ...” ID: B: 3407: F: 44: Child: 7-9: M2.

“...it's coming on nearly 9 or 10 months now since he passed away and I've still got this \$65-dollar cheque, so that was a bit painful in so far as it kind of just drags it out a little bit, because there's that constant reminder, and maybe because I've got this cheque in my purse, every time I open my purse and see it there ...and it just does bring everything back up a little bit, it doesn't really allow for a lot of closure...” ID: B: 3407: F: 44; Child: 7-9; M2

“...to actually get that death certificate in the mail...open it up...and there it was. I said, 'this is my husband's death certificate, I won't see him again'...” ID: B: 3110: F; 61; Sp; 19-24; R3

“...he rang me about 5 or 6 times to come and sign the paper and I found it hard. I just couldn't go in there to sign the papers. When I went in there I just broke down, I just said to him, 'I don't want to do this. I just want my life back; I want [G] back. I know I need the money but I don't want it'...” ID: B: 3386: F; 53; Sp; 19-24; R1

Participants described that they ‘just had to cope’ (ID: B: 3725: M; 63; Sp; 7-9; R1), and they felt they did not have a choice but to continue. One participant, ID: B: 3109: F; 64; Sp; 10-12; R3, described a sense of ‘erasing’ her spouse as a result of having his name

removed from documents. When reflecting on experiences of dealing with practical matters, participant ID: B: 3407: F; 44; Child; 7-9; M2, stated “...it is a little bit frustrating when there's that - 'this is what we do, and we don't make exceptions for anybody'...”. This participant said on numerous occasions that dealing with the practical matters was ‘exhausting’. All participants struggled with bureaucratic processes, conveying a sense that there was little compassion and consideration for unique circumstances and that organisational policies and protocols were rigid. Some participants experienced significant challenges with policies and protocols of organisations they dealt with. One participant, ID: B: 3076: M; 52; Child; 4-6; R1, experienced significant stress when dealing with banks and stated “...I thought we planned as much as we possibly could, but they're just a.....s, they really are, banks...”

As a way to cope with being overwhelmed, many participants described ‘*pacing self with tasks*’ as portrayed in participant quotes below:

“...you just step back in the end... and you think, 'you know what, if I don't do this, the world's not going to end. If I don't talk to that person right now, or if I don't send that form, life will go on and when I'm ready, I'll do it.' ...it's not going to matter if that account isn't changed straight away, and the title from the house isn't done immediately ...”. ID: B: 3433: F; 60; Child; 13-18; R1

“...I actually had a book. Every time I had to do something, or Landgate would ring me, or [accountant] would ring me, or I had to go and do something for [A]'s estate, I'd write it all down ...the death certificate, go down to Clerk of Courts and get it copied out because everyone wants it. It's sort of a learning curve, it really was a learning curve...no-one else was basically there to do it. I had to do it myself...”ID: B: 3110: F; 61; Sp; 19-24; R3

The challenges of dealing with practical matters are significant and time factors are another element that compound the stress and distress of participants. Some participants talked about the time it took for finalising some matters. For example, participant ID: B: 3113: F; 61; Sp; 19-24; R3 stated it took 18 months to finally get the house transferred into her name due to legal technicalities. The lawyer who initially drew up the title deed of the house had written “...tenants in common instead of joint names...” The participant stated: “...so just that one - two little words that that lawyer had written on our title caused me to take 12 months to get one job done...” One participant, ID: B: 3076: M; 52; Child; 4-6; R, described the impact of the state government reducing funding to the supreme court which caused time delays in processing wills for probate: “...6 weeks is the normal time to extend it [probate] out...now double that to 3 months or more, it just prolongs the agony. I find that very unnecessary...”

There is an additional complexity that culture brings. Aboriginal Health Professional participants described their personal experiences with dealing with practical matters and the increasing legal requirements around death:

“...the Will side of it, is a white thing... In our ways, everything gets sorted out, but we are getting caught up in the Will thing...people are asking themselves, ‘who’s done the right thing by me in my life?’ ...but in the old days - and I remember when my sister passed - the youngest one, and that was 30 years ago - she didn’t have a Will but the Aboriginal Affairs department had a ruling - her kids get it, and if the kids aren’t there, it’s amongst her siblings. It’s always the closest people to that person. And that’s the sort of like the old days - it happened naturally - not these days...”

ID: HP: ALO: 3448: M; 64; R1

“...Aboriginal people don’t have Wills, don’t worry about Wills because they don’t have nothing to leave really, but what they don’t realise really is you can’t access their bank account...just trying to access those things and

just finding a way to go about things. It's just so different...” ID: HP: ALO: 3412: F; 39; R1

The Aboriginal Health professional participants described the impact on their people in dealing with practical matters and cited feelings of *'frustration'*, *'anger'*, *'feeling lost'* and that it was *'too much for one person'*. One participant, ID: HP: ALO: 3448: M; 64; R1, stated a family member was not getting support and the whole family were relying on them to deal with all the practical matters so it resulted in the family member *'going to pieces'*. The participants also talked about the impact it had and can result in *'conflict in the family'*. Participant ID: HP: ALO: 3448: M; 64; R1, also highlighted that people do not know where to start and where to go. They described the stress it caused a family member and how “...it did take a lot of back and forth movement trying to work out what's the go...”

Cacciatore and Bushfield (2008) place death within a socio-political context and highlight the impact that systemic macro-system issues have on the bereavement experience. Harris (2009-2010) asserts that western society legislates who is validly bereaved and this is done through structural and institutional legislation and workplace policies, such as the constraints identified in this study on bereavement leave. Harris (2009-2010) describes the *'social pain'* experienced by bereaved individual's as they attempt to conform to social grieving rules. When the bereaved are having to deal with practical matters at a time when they are experiencing *existential diaspora*, and they are overwhelmed psychologically, emotionally and spiritually, there is an implied *'mandate'* to maintain a veneer of control and functionality when interacting with institutions and organisations. Harris (2009-2010) views this as a unique form of oppression as others attempt to help them regain control over their emotions and vulnerability, distract them from their grief or minimise their loss.

Bereaved individuals, in an attempt to conform to social expectations, take their grief into their own private domain. However, identity is a dynamic process of construction and deconstruction, and the re-formation of the *'self'* is influenced by the situatedness of the

individual in their environment. This is known in the diaspora literature as *hybridity* (Anthias, 1998; Voicu, 2013; Kaur, 2015).

b) *Hybridity and Lived Tensions: Reshaping identity*

Hybridity highlights the bereaved diasporics shift between transforming their own histories and character to reshape identity and Johnson (2012) refers to ‘diasporisation’, which connotes active engagement in re-constituting one’s identity. Neimeyer and Sands (2011) state that identity occurs through narrative, stories we tell about ourselves and stories others tell about us. The bereaved can experience a sense of dis-synchrony as demonstrated by one participants as she reflected on who she thought she was as a mother, and protector, with who she became throughout her husband’s illness and subsequent death. The following quote portrays her sense of impotency as a mother:

“...I’ve said to friends too when you’re a mum you take control of everything, you fix everything you make everything better and all this was just taken out of my hands and I just had to go for the ride and I couldn’t do anything about it...” ID: B: 3386: F; 53; Sp; 19-24; R1

This crisis in identity is common in bereavement. As discussed in chapter five, one participant, ID: B: 3371: F; 77; Sp; 7-9; R2, described how she asked herself “...*who are you? Are you daughter? Wife?*” and then stated “...*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...*”. People described their sense of self using the following types of descriptors:

Negative descriptors	<i>‘being stubborn, not silly’, , ‘naïve’, ‘not very wise’, ‘cautious’, ‘tough’, ‘guarded’, ‘a sufferer of well-hidden anxiety’ and ‘I’m a cynic’</i>
Positive descriptors	<i>‘givers’, ‘amazing’, ‘lucky’ ‘I have a positive impact on</i>

	<i>people's lives', 'I love people – I'm interested', 'focussed', 'not shy' and 'I talk a lot',</i>
Descriptors about independence	<i>'taken care of our own business', 'I'm my own best company', 'very strong sense of pride', 'don't want to lean on others', 'independent', 'being strong', 'don't want to prevail on others', 'I've kept to myself' and 'I'm a big boy'</i>

Although many participants felt a high sense of self efficacy, they discovered new things about themselves such as *'I'm quite self-sufficient', 'I've become more opinionated, very much so', 'proud of myself...I can do things'*. The following participant described how loss and restoration activities are developmental processes that shape a person's identity:

"...I think maybe that takes a bit of time to get around to - is realising that you have capabilities 'because I think you do feel a little bit, vulnerable and weak at the beginning and you need to get your strength back.... knowing your limitations, I knew I needed help with that.... But I surprised myself...how strong I was..." ID: B: 3072: F; 52; Sp; 6-9; R3

Identity is not just an internalised, intrapsychic construct but is influenced by external forces. For example, in relation to the diaspora discourse, Kaur (2015) describes how women from ethnic minorities learn to cope with the norms and values of the dominant culture and simultaneously be excluded by the dominant group. Coping strategies include internalising, using the medium of personal narrative and developing multiple identities. Fongang (2013) describes the intersubjective fluidity of diasporas' as individuals constantly reconcile the conflicting social and ideological factors impacting on their 'self' as they try to create a space, and place, for themselves in the world again.

In this study, participants reflected on their internal, representational world and reorganised this based on previous knowledge about themselves, new knowledge they

learned about their capabilities, and subsequent changes to their global outlook. Participants demonstrated experiences similar to the *double consciousness* and *lived tensions* concepts in the diaspora literature of reconciling life as a couple to life as a single person, from holding the pain of their own grief to compassionately holding the grief of others, from wanting to stay connected with others with wanting to withdraw into themselves, from being stubborn, to having to relinquish control and allow others to help.

Self-reliance and independence

Independence was a strong feature that emerged from the data and is a common characteristic reflected by participants in research on receptivity (McGrath, 2013; Pascal, Johnson, Dickson-Swift, McGrath & Dangerfield, 2016). Statements made by participants in this research supported the notion of the ‘independence factor’ as demonstrated in the following phrases: ‘*I do as much as I can, I very rarely ask for help*’ (ID: B: 3372: F; 75; Sp; 4-6; R3), ‘*I’m fairly independent*’ (ID: B: 2875: F; 81; Sp; 13-18; Rem1), ‘*I look after myself*’ and ‘*I don’t like to think that I need help...I always try myself*’ (ID: B: 3407: F; 44; Child; 7-9; M2), ‘*I’m not used to people taking care of me*’ (ID: B: 3109: F; 64; Sp; 10-12; R3) and ‘*it never occurred to me to reach out for help*’ (success ID: B: 3725: M; 63; Sp; 7-9; R1). Some participants felt they had to do things themselves:

“...I do feel at times that I need to stand a bit more on my own 2 feet, because other women have to so I should...” ID: B: 3180: F; 70; Sp; 0-3; R3

“...I felt as though I should have been able to do it myself...” ID: B: 3373: F; 64; Sp; 13-18; R1

“...I just kept thinking you’re going to have to do it by yourself now, and I think, ‘okay you [deceased spouse] told me I will have to do it by myself.’”

I guess I have kind of looked at it like that and just did things... ID: B: 3113: F; 61; Sp; 19-24; R3

“...I had to do it myself...I just worked on one bit, and went to the next, and then the next, and eventually got it all done... I think there’s just this sense that you are now responsible for things by yourself...” ID: B: 3391: F; 69; Sp; 13-18; R3

“...now that I’m alone I have to do things for myself...” ID: B: 3725: M; 63; Sp; 7-9; R1

For some participants, they felt that there was nobody able to provide assistance or that things had to be done within a certain timeframe so they had to attend to matters themselves or things would not have got done:

“...it really was a learning curve, and no-one else was basically there to do it. I had to do it myself...” ID: B: 3110: F; 61; Sp; 19-24; R3

“...I knew I had to get through it within a certain length of time, otherwise I probably wouldn't have done it at all...” ID: B: 3373: F; 64; Sp; 13-18; R1

“...I know I am very strong and I think I am stronger than most of my friends, so there’s nothing that I feel they can say or do to make me any stronger than what I am...” ID: B: 3369: F; 53; Sp; 13-18; R1

One participant did not feel they needed any support at all as they were coping well and stated: *“...I really haven't had the need for anyone to give me any help ...”* ID: B: 3400: M; 70; Sp; 13-18; R3. For many participants, self-mastery was an important aspect of

gaining a sense of control at a time when they felt they had lost control over so many other parts of their lives. Many participants wanted to do things for themselves to feel a sense of accomplishment as demonstrated in the following participant statements:

“...I didn’t think I’d need anything [help] ...I felt driven to do what I did and I feel that once I’d done it, there was a huge feeling of achievement...”
ID: B: 3371; F; 77; Sp; 7-9; R2

“...I got it all fixed and sorted and that...I was a bit proud of myself. I thought, ‘oh yeah I can do things!’ I said to myself after that, ‘don’t get upset now...just see if I can work through it and then if I can’t then, then I can get upset...” ID: B: 3386; F; 53; Sp; 19-24; R1

Activities that aid self-mastery and promote a sense of control are types of support desired by the bereaved (Dyregrov, 2008). Boss (2006, p.114) reiterates the importance of facilitating self-mastery and states that “...when people no longer believe they have influence over their own lives, resilience is depleted...” Different personality types have been identified as a moderator of loss (Pai & Carr, 2010). Participants who described narratives characteristic of introverted traits described intrinsic ways they coped through self-reliance and a preference for their own company, as reflected in the following participant statements:

“...I just wanted to be on my own. I do like my own company. I’m really comfortable with it. Keep myself amused...” ID: B: 3072; F; 52; Sp; 6-9; R3

“...I know that sounds awful, but I don’t need anybody to be honest, I enjoy my own peace, my own quiet time...” ID: B: 3373; F; 64; Sp; 13-18; R1

“...I've had offers from other people to come with them and I've just said, 'no, I don't want to'" At the moment it's just me so it's just me... I've found times that I'm my own best company...” ID: B: 3400: M; 70; Sp; 13-18; R3

“...most times I like my own company. I don't know how to explain that to you. I don't mind socialising like come up today [to participate in the research] - this is socialising day!” ID: B: 3370: M; 73; Sp; 10-12; R2

Extraverts have been identified in the literature as personality types who effectively manage negative events and experiences (Pai & Carr, 2010). However, participants in this study who demonstrated introverted traits may also be able to cope just as well and be as resilient as extraverts in coping with loss. Irrespective of personality type, there is an almost universal experience of re-negotiating one’s identity in bereavement (Neimeyer, Harris, Winokuer & Thornton, 2011).

The bereaved re-negotiate their identity where their strengths can become more pronounced, or they can experience a sense of displacement within their own placement. This can influence their thoughts and feelings about where they now sit within the family and community. The notion of a *'layered simultaneity'* can enable the bereaved to adopt diverse identities selected for specific places, or when interacting with specific people (Canagarajah & Silberstein, 2012). Bakare-Yusuf (2008) asserts that our identity, cognition and emotions are a product of dynamic relations between the self, others and the world

c) Disruption: Learning to manage thoughts and emotions

Voicu (2013, p.x) describes a process where diasporics move through *'middle passages'* where the person *'...moves itself, displaces itself, loses itself in, resists to and mixes with*

the receptive culture...’ This is similar to the process where bereaved individuals get used to being in the world again, where they incrementally expose themselves to people and events, depending on their personal emotional and psychological resources at any given time. *‘Dosing exposure’* is a way of coping and learning to manage thoughts and emotions.

Participants in this research engaged in many coping strategies to manage their emotional and psychological wellbeing, such as *‘mentally processing things’*, engaging in activities in which they felt they were *‘achieving or accomplishing’* something, *‘avoiding’* areas or people that evoked emotional distress; *‘being selective’* with friends and who to invite into their grief; *‘building a psychological protective space from others’*; *‘connecting with others’*; *‘dealing with deceased estate’*, *‘belongings and ashes’*; *‘learning to control emotions’* and using them to help with processing grief; *‘giving themselves permission not to commit’* to things; *‘hiding vulnerability and weakness’*; *‘using music’* in their grief; being *‘open to new opportunities’*; learning to *‘park’* grief; using *‘pet therapy’*; activities to *‘replenish the body, mind, soul’* and overall health and wellbeing; *‘setting goals’*; *‘staging’* life; *‘self-talk’*; *‘using faith, religion and spirituality’*; *‘travel as therapy’*; *‘using routine’* and engaging in activities. The subthemes from the findings on the experiences of coping in bereavement were *‘nurturing relationships’*, *‘awareness of difference’*, *‘using humour’* and *‘channelling grief energy’*.

Nurturing relationships

Participants described how their loss led them to re-evaluate relationships and that they invested more emotional and psychological resources into relationships where they felt some reciprocity. Although relationships are discussed in depth in chapter seven, participants in this study nurtured relationships to help them cope in their *bereavement diaspora*. One of the challenges that was an issue for one participant was the financial cost of maintaining their relationships at a time they were already experiencing significant financial burden, stating:

“...phone bills and stuff like that goes up because you have to keep in

Making decisions about who to socialise with was an element of how people coped in undertaking either avoidance or approach as a restoration activity. One participant, ID: 3072: F; 52; Sp; 6-9; R3 stated ‘...you certainly keep away from certain types...’ when referring to who they socialise with. Even when in the company of others, loneliness was experienced by the bereaved which only served to heighten their feelings of loss and feeling alone (Wittenberg-Lyles et al., 2015). However, many participants discussed the role of their informal networks and how the support from them helped them cope in the bereavement. It is through relationships, that the bereaved described a heightened awareness of difference in experiences. Participants identified the difference in experiences with the loss of a parent, child, sibling or other and differences in the ways individual family members and friends coped with their own bereavement experiences.

Awareness of Difference

The bereavement discourse highlights the uniqueness of each individual’s experience. The bereaved in this study demonstrated an awareness of different experiences within their own family members and also with friends who experienced personal bereavement. Participants in this study engaged in *othering* and *not othering* as a way of coping. Othering was reflected by bereaved participants when they referred to individuals who have not experienced a loss through the death of an intimate other. The bereaved thus belonged to an actual or perceived social group which is a version of the ‘self’ (Brons, 2015; “Other”, 2016). This concept is reflected in the diaspora literature and is referred to as ‘affinity diaspora’.

‘Affinity diaspora’ is a concept where diasporics feel an affinity to other diasporics from the same homeland (Yamashiro, 2013). Although this is in reference to a geographical place, the bereaved feel an affinity to others who are bereaved, and this was demonstrated under the subtheme *not othering*, recognising they are not alone in their grief. The participants also engaged in *othering*, which helped to either inform them of who had

legitimacy to share their grief with, and thus receive support from, or to justify who to avoid. The following quotes are examples of *not othering* and *othering* from participant narratives in this study:

Subtheme	Participant Quote
Not Othering	<p><i>“...everybody has troubles, has problems. Mine are no greater than anybody else’s ... the worst part is that there is nothing abnormal about it, nothing unusual... that’s something I keep reminding myself of. I’m not alone, I’m one of millions. It’s part of the circle of life. We are born, we live, we love, we die ... for the most part I think people are pretty understanding, especially those who have also lost a loved one...”</i> ID: B: 3725: M; 63; Sp; 7-9; R1</p>
Othering	<p><i>“...other people, unless you’ve been through it, you don’t understand. I mean, I’ve had friends - husband or wives died - and I’d been sorry and that sort of stuff, but unless you’ve been through it, you don’t know...”</i> ID: B: 3372: F; 75; Sp; 4-6; R3</p>

There was a concern expressed by one participant who was fearful of being ‘othered’ themselves:

“...it does help I find, to have somebody to talk to without boring one person to tears and driving them away. That’s something I think I’m subconsciously afraid of, that I don’t want to push people to a point where they say, ‘Oh God, that’s [name]! Quick! Cross to the other side of the road!’ I don’t want that. So I try to stay up beat - not always easy - in fact, it’s quite often very damned difficult...” ID: B: 3725: M; 63; Sp; 7-9; R1

Many participants in this study engaged in ‘not othering’ and ‘othering’ simultaneously – a *double consciousness* of feeling that unless someone has been through a similar

experience, they could not understand the reality of the lived experience, balancing this with having compassion for others who were grieving the loss of their intimate ‘other’ as demonstrated by the following participant:

“...even though you are one of the close bereaved, I think it’s also important to know that other people are also grieving in their own little way... I recognise that my friends and all the people that were there when he died. They all have their own grief to you know so it’s not just about you...” ID: B: 3433: F; 60; Child; 13-18; R1

Ben-Rafael (2013) states that individuals feel an affiliation to people with whom they see as fellow members of their group and will actively engage in processes to build and maintain a collective identity. Diaspora references a connection between people and groups across different localities. A new identity through connection is often constructed (Anthias, 1998). They often perceive the group as having a singular commonality, and they may distance themselves from others whom they consider non-members. In the context of this study, connection comes from feeling an affiliation with others who are in the *bereavement diaspora*.

Using Humour

Many participants used humour throughout the interview when recounting events or in self-deprecating ways. This was a particularly striking feature throughout the interviews and was an identified way of coping. When asked specifically about the role of humour, participants answered how it helps them cope in the following statements:

“...all our lives, if something goes wrong, we’ve learnt to laugh about it and that’s how we sort of cope...” ID: B: 3109: F; 64; Sp; 10-12; R3

“...sense of humour is really, really important. You surround yourself by funny people. All my friends are stupidly, ridiculously funny. That's the sort of person I like to be around...” ID: B: 3072: F; 52; Sp; 6-9; R3

“...inappropriate laughter we call it. The girls and I do this all the time...when anything is tense, or hurtful, or sad, we've got a choice - we can either drop our bundles, or we can laugh inappropriately...” ID: B: 3369: F; 53; Sp; 13-18; R1

Humour has been identified as a cognitive strategy of coping through relieving tension, providing opportunity to express emotion, aid diversion from emotional pain and it also stimulates memories (Martin & Doka, 2000; Lund, Utz, Caserta & de Vries, 2008-2009). There is very little in the extant literature on the use of humour in bereavement. however, participants in this study described scenarios which they found humorous such as collecting a loved one's ashes – in two separate containers as the person was large, or when there has been a debacle around funeral services. Some participants used humour when reminiscing about their loved one and this usually occurred within the context of families sharing memories. Some participants used humour as a form of self-deprecation as depicted in the following participant statements:

“...the worst thing you can do is give advice. I have to say having said that, saying 'I always tell people what to do'...” (laughs). ID: B: 3371: F; 77; Sp; 7-9; R2

“... [I'd give] the same advice I was given - take your time making decisions...(laughs). But I didn't...(laughs)”. ID: B: 3072: F; 52; Sp; 6-9; R3

“...I talk to him heaps. I don't talk, when people are around because I

don't want people to think I'm stupid [laughs]... ID: B: 3386: F; 53; Sp; 19-24; R1

Having a sense of humour has been found to be associated with cultivating positive emotional states that facilitate resilience, enhance psychological well-being and overall quality of life (Lund et al., 2008-2009). All of the participants used humour throughout the interview, indicating humour may be an inherent personality trait of nearly all of the participants. Examples of the use of humour are demonstrated in the participant statements below:

...oh, I'll find anything to laugh at (laughs)... ID: B: 3371: F; 77; Sp; 7-9; R2

...so I have a very bad track record as a carer - they all died...to tell you the truth, by the third, the funeral director and I knew each other quite well. (laughs)... ID: B: 3111: F; 68; Friend; 13-18; R3

...it's [sense of humour] a life saver. It's natural because I'm not a depressive person. I find it hard to be. ID: B: 3369: F; 53; Sp; 13-18; R1

...honestly, we've been given a designated parking spot at the cemetery (laughing). We're such locals at the Fremantle Cemetery - they're probably going, 'oh here they come again! (laughing). It was just horrible. (laughing)... ID: B: 3433: F; 60; Child; 13-18; R1

...[got] a letter from the crematorium 10 days after we'd scattered mums' ashes, saying, 'we're holding your mums' ashes, do you want to come and collect them? Holy shit! The funeral directors rang me and said "[name], 'just wondering if there's been a bit of confusion here?' I

said 'Well I'm not confused, but someone is...' (laughs) ID: B: 3076; M; 52; Child; 4-6; R1

"...the funeral itself...turned out like a script out of Monty Python. Oh it was ridiculous... all it would've needed would've been John Cleese jumping up and down screaming at somebody to make it a Python script...(laughs)... even at that point I still have a sense of humour..." ID: B: 3725; M; 63; Sp; 7-9; R1

When participants were reminiscing about their loved ones, they would talk about the sense of humour of the deceased. One participant who took on the responsibility of caring for her adult sibling with an intellectual disability used humour, and highlighted her Dad's sense of humour when fostering the connection between her brother and deceased father:

"...I say to my brother, 'look out mate your father is watching you'... or... 'if you don't come and dance, I'm telling dad!' And he even laughs, you know, he gets it as well. But I think that comes from dad...he had a great sense of humour and a great outlook on death on life..." ID: B: 3433; F; 60; Child; 13-18; R1

One participant used his sense of humour as a measure of self-diagnosing depression:

"...I convinced myself I wasn't depressed by visiting Beyond Blue.org...and within 10 minutes I thought, 'well I can still laugh at things so I'm not depressed.' Sometimes the laughter is a bit harsh and a bit forced. If I'm with my riding mates from the Ulysses Club, I join in and I will laugh along at something without really even, at times knowing what the hell we're laughing at... ID: B: 3725; M; 63; Sp; 7-9; R1

The presence of positive emotions such as love and humour have been shown to have a positive influence on stress and depression levels (Ong, Bergeman & Bisconti, 2004). Predispositional humour has been associated with reduced incidence of negative emotional and physical symptoms, greater coping efficacy and aids functioning during grief. Humour has been recognised as a strategy to diffuse, manage and cope with negative emotions in bereavement (Martin & Doka, 2000; Lund et al., 2008-2009; Booth-Butterfield, Wanzer, Weil & Krezmien, 2014).

Channelling grief energy

Another way of diffusing and coping with negative emotion was through keeping busy. Phrases were used by participants in this study such as *'I'm flat out'*, *'I was so busy'*, *'tried to kept myself busy'* and *'I threw myself more into work'*. Participants described how keeping busy could enable them to take respite from their grief:

"...I found that I always tried to keep myself busy, I just didn't want to stop - because if I stopped and thought where I was, I just couldn't cope, I just couldn't think about where I was, or what I was doing, or what was happening to me. So I found that I kept really, really busy so I didn't have to think about it. You can just keep going - it's once you stop and sit down and think about things, I just couldn't cope then..." ID: B: 3386: F; 53; Sp; 19-24; R1

Doka and Martin (2000) discuss how emotion regulation in bereavement occurs through attunement of emotional experience, or 'grief energy'. Grief energy can compel the bereaved to keep busy, mentally and physically. On the other end of the continuum, participants described feelings of exhaustion and fatigue which they attributed to caring for their loved one before they died:

...it's just exhausting, I mean physically and emotionally... it sort of

hits you with both barrels, you know, it's not just a long day at work where you're tired. You're just exhausted on the inside, as well as your body...” ID: B: 3407: F; 44; Child; 7-9; M2

“...each time [someone died] I was so exhausted, I just slept and slept and slept. You don't really have any energy for anything else. You have to get the energy to arrange the funeral, but you're so tired; it's really a godsend to be so tired...” ID: B: 3111: F; 68; Friend; 13-18; R3

One of the ways participants learned to cope was through ‘*the role of routine*’ and ‘*need for purpose*’. Participants set themselves goals and adopted strategies to aid coping such as keeping things consistent through routine or leaving their loved one’s things in place; preparation, such as making plans with social networks to reduce a sense of feeling socially isolated and finding purpose and meaning in their day. One participant made a commitment to herself to set a goal and stick to it as a means of helping her cope:

“...I had 2 determinations when he died, one was that I would not stay in bed for a whole day, because it's too easy to get into that habit, and you just get down and down and down and down. I made myself get up every day. It may not have been till 12 o'clock, but I made myself get up every day. I made myself get dressed and put a bit of makeup on - they were my 2 things...” ID: B: 3180: F; 70; Sp; 0-3; R3

There is a diverse range of strategies the bereaved employ to learn to manage their thoughts and emotions. Participants in this study demonstrated a re-evaluation and re-investment of emotional and psychological energy into activities that reduced their sense of existential aloneness, such as through the process of *not othering* or they engaged in activities that enhanced their sense of wellbeing. Remembering and sharing stories with others was also another significant feature of positive coping in bereavement.

d) Displacement: memory and shared narratives

The past is ‘creatively re-defined’ over time to mediate a person’s psychological and social condition (Clarke, 2010). The auto-biographical process of re-writing one’s story thus becomes a dynamic narrative which enables the person to reinterpret past experience, to provide a sense of self in the present, and in the future. This self-construction also occurs within the shared co-construction of narratives from interactions with others (Voicu, 2013). Identity is about narratives of belonging (Anthias, 1998). Cognitive adaptation in bereavement occurs through a process of sharing narratives with the bereaved with family, friends and others in comparable situations. Some participants talked about the role of memory and sharing stories as depicted in the following participant statements:

“...the boys often reminisce about things that have happened...” ID: B: 3371:
F; 77; Sp; 7-9; R2

“...it's just a case of you've got to accept it and try and just sort of remember the good times, which has always been the focus, you know. When you lose them you, you try and remember...” ID: B: 3112: F; 75; Sp; 13-18; R3

One health professional participant recognised her role as a conduit in fostering a continued connection and bond between a daughter and her deceased mother, through sharing memories. The mother was a stolen generation Aboriginal woman who never knew her biological family and had two daughters. The health professional stated:

“...so in the dying, it's a real passing of a generation in that family system...and for the daughter to know that I knew her mother so well. So when I rang up, it was an opportunity to talk about her mother in a way that was full and rich and open as well as sad and happy and grieving...” ID: HP: 2874: F; 53; Rem1

One of the forums for fostering memory and shared narratives in contemporary society is through the use of technology. Technology has been a means for mediating the *bereavement diaspora* through providing a ‘virtual’ space for people to share memories and connect with others, fostering a sense of belonging and identity with a ‘diasporic affiliation’ (Raghuram, 2010; Marat, 2016). This ‘*collective identification*’ creates a ‘we’ versus ‘them’ (Voicu, 2013) and was evident in participant narratives in this study of ‘othering’ and ‘not othering’. Participants expressed an affiliation with those who have had a similar experience and some turned to the internet to read about the stories of others, or to maintain connection with others. Cyberspace provides a safe forum for self-expression and self-determination (Bakare-Yusuf, 2008; Marat, 2016). However, it does have its disadvantages as portrayed by Aboriginal health professionals’ participants who talked about the use of technologies and social media and the impact it is having on the social mores of the Aboriginal community. One participant shared a personal story of the role of social media and community narrative in death:

“...it’s the first thing that comes on Facebook about a death and if it’s a horrific death it’s plastered all over there. I mean that is no respect. I’ve just had an incident where my brother was walking home and a little boy came up to him and said did you hear about your son - this is coming from a 10-year-old - did you hear, uncle, did you hear about your son - he just died in a car accident. This is coming from a child! So he actually came home - and he just...I said, ‘what the hell is wrong with you?’ [he said], ‘did you just hear?’ ‘What?’ He said ‘a little fella just came up and said did you hear about your son? - he’s just died in a car accident? This is coming from a 10-year-old boy...” ID: HP: AHW: 3438: F; 43; Rem1

The bereaved and other individuals use technology to: communicate with others about the deceased; seek information about online burial options; create multimedia presentations for memorials services (Massimi & Baecker, 2010); funeral celebrants use social networking and other sites to gain insight into the deceased’s character and

networks; 'virtual' attendance at funerals with the service being streamlined to people around the world; creation of cyber-cemeteries and cyber-memorials; online bereavement support (Walter, Hourizi, Moncur & Pitisillides, 2011-2012; Kasket, 2012; Maddrell, 2012 & 2013; Pennington, 2013) and to research legal and financial issues. One of the participants in this study 'streamlined' her husband's funeral to family living in the US. Evidence from the research demonstrates that use of social networking sites such as Facebook facilitate Klass, Silverman and Nickman's (1996) notions of continuing bonds as participants have reported they continuously visit the deceased's profile page, sometimes post comments on the profile page 'wall' or read comments from others which reduces feelings of isolation in their grief (Walter et al., 2011-2012; Kasket, 2012; Maddrell, 2012 & 2013; Pennington, 2013).

Today's technology has enabled 'digital legacies' to be available for generations to come and this fosters the shared narratives of the bereaved community. Historically, the 'diasporic agent' has passed memories on to family members which was passed on from generation to generation (Chen, 2015). Valuing memories in the future will be much easier with the technologies providing a virtual repository of videos, 'vlogging', blogging, pictures and stories of the deceased (Kasket, 2012).

e) Embodied Diaspora and Transcendence: coping with the absence-presence

From the 'virtual' to the corporeal, memory of the deceased is embedded in virtual memory, mental and emotional memory and embodied memory. Hockey, Penhale and Sibley (2001, p.743) discuss the experiences of widows and state: "...*even when people could manage their domestic spaces in a practical sense, phenomenologically nothing was the same...*" Krasner (2004) describes the concept of 'body schemas' and how we experience the bodies of loved ones as contiguous with our own, so that when one experiences loss, their grief can be likened to body dismemberment and that the associated pain can be a phantom pain. The empirical literature on health outcomes in bereavement highlight the increased risk to mortality in older individuals as there is often associated

chronic disease or other co-morbidities, and those over the age of 65 years of age have been found to have reduced immunity (Schulz et al., 2001; Christakis & Iwashyna, 2003; Vitlic, Khanfer, Lord, Carroll & Phillips, 2014).

Embodied grief includes the notion that love for a deceased person exists within an embodied environment and that when there is a physical loss of a person, there is also the loss of one's bodily engagements with it. This includes bodily memories of physical habits in which daily interactions occur. Each time the bodily presence is misperceived, so the sense of loss is continually renewed, and there is a sense re-bereaving. "...We witness the loss again and again as our minds construct the absent-presence of bodies we can no longer hold, through images we are unable to touch..." (Tanner, 2006, p.131 cited in Baptist, 2010, p. 299). Gudmundsdottir (2009) highlights that the disenfranchised voice of the body in grief has been ignored due to the emphasis on grief as a predominantly psychological phenomenon. Responses of grief on the body include, feeling unfamiliar, strange, heavy, or physically hurting. Baptist (2010, p.294) described her bereavement as corporeally paradoxical and that:

"the gravitational pull of grief was a heavy burden I carried each day, weighing me down, dragging me every earthward. And yet, I felt at the same time, unfettered and groundless for the landscape of home and of family seemed now lost to me forever"

To Baptist (2010), grief was viewed as a spatial, temporal and corporeal dynamic in which the bereaved question their relationships with the deceased and the living, in a landscape that reflects, amplifies and redeems lives that have been shattered by loss.

Another explanatory perspective of spatialized habits that occurred from sharing physical spaces with the deceased, is from the 'neurobiology of bereavement narration'. Rynearson and Salloum (2011) describe the brain's neural patterning, or 'plasticity' as it relates to phantom limb sensation following an amputation. The neural circuitry of attachment figures is not dissimilar, in that there is a phantom presence conveyed through narrative memory. The cortex and subcortex in our brain continues to signal the deceased's

presence, but it diminishes and becomes recontextualised over time, but never completely disappears (Rynearson & Salloum, 2011).

Embodied habits include the physical habits of daily routine where the relationship continues to be experienced spatially, but is interrupted by death. The absence of the physical body of the deceased changes the habitual motions of the bereaved through space (Hockey, Penhale & Sibley, 2001; Krasner, 2004). The following participant ID: B: 3386: F; 53; Sp; 19-24; R1 describes the ‘*changes in habits*’ as a way of coping with the physical absence of her spouse:

“...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. So I was always outside at those times because I couldn't handle those times of nights because I'd think that's when we would sit down...”

and

“...I found it very hard to go into our bed as well, which that's what I found hard too, to go into our bedroom...I sleep on his side of the bed, I can't sleep on my side anymore and I actually told my friend down the road that and she said that she did that for a long time too. And I said, 'but if I sleep on my side, I know his side's empty so I sleep on his side and I don't know why, it's not so hard, it just feels like I can get to sleep. But if I lie on my side of the bed, it's, it's horrible, it's a horrible feeling ...”

Transforming the relationship to the internal world is an active process that creates a lasting and ongoing relationship (Ogbuagu, 2012). Bereaved participants kept the deceased ‘alive’ through engaging in dialogue with them, ‘*talking to the deceased.*’ One participant described how he had conversations with his mum when he returned to her home:

“...it still gets me - you walk into the house and you walk into the bedroom

where I spent so much time looking after her and I'll talk to the walls and say, 'g'day mum'..." ID: B: 3076: M; 52; Child; 4-6; R1

Another participant discussed how she spoke to her deceased spouse every night:

"...He doesn't answer me back though (laughs) but I talk to him (laughs)..." ID: B: 3110: F; 61; Sp; 19-24; R3

Many of the participants used humour when talking about talking to the deceased and would be *'cursing the deceased if not coping'* and *'cussing with humour'*, as demonstrated in the following participant statements:

"...if I'm upset because [G]'s not here, I'll swear at him. Like "What are you doing you asshole" you know - yeah that's how we sort of learn to deal with it..." ID: B: 3109: F; 64; Sp; 10-12; R3

"...I swear all the time "[A], you bastard" you know, "stop laughing at me, I'm doing my best!" You know, there's a lot of things that I struggle with..."
ID: B: 3072: F; 52; Sp; 6-9; R3

"...I'm growling at him - I do - and I speak to him most nights and I just say 'where are you. Where are you?'..." ID: B: 3369: F; 53; Sp; 13-18; R1

"...A couple of times I've said, 'why have you put this bloody thing here?'..." ID: B: 3370: M; 73; Sp; 10-12; R2

Weiss (1993, p.277 cited in Baptist, 2010, p.304) highlights the bereaved desire to maintain a continuing bond with the deceased and this can reduce a sense of isolation. As

a way to deal with the ‘*absence-presence*’ of the deceased, several participants described their experiences of ‘*visiting psychic mediums*’:

“...*I just went there with an open mind, I don't believe in feeding information, but I just sort of went there, and he was very, very good, very good. So that sort of cemented - yes I do believe there's afterlife...*” ID: B: 3109: F; 64; Sp; 10-12; R3

“...*I found after he passed away too, I went to quite a few clairvoyants and mediums to get readings and that and I found that was so good, the things they told me was absolutely amazing...*” ID: B: 3386: F; 53; Sp; 19-24; R1

The bereavement discourse recognises connection or continuing bonds. Participants described different ways they continue a relationship with the deceased to help them continue to make meaning of their life as articulated in the quote below. The participant engaged in activities to foster a *continued relationship* with the deceased by engaging in activities they used to do together that the deceased enjoyed, namely gardening:

“...*when I go to get a few plants and that now, I go to Bunnings and Home Hardware place in Perth there where she used to get all the plants from. We used to go up there every 3 months. They used to have an open day there and show and the nursery people what's coming on. I used to drive up there. So you know, it's all that stuff. It's still related, you know what I mean?*” ID: B: 3370: M; 73; Sp; 10-12; R2

The bereaved engage in telling stories as well as using ritual, in an endeavour to continue bonds and make meaning out of their loved one's death. This enables the person who is grieving to integrate the deceased into their life and emotionally or psychologically relocate them (Neimeyer, 2000). Worden (1991 cited in Vickio, 1999, p.163) states that “...*the challenge facing mourners is to relocate – not relinquish – their relationship with*

the deceased...” and that this process allows mourners to maintain some kind of ongoing relationship with the deceased.

f) *Deathscapes: Places of comfort*

Deathscapes provide a space for memorialisation, however, some families’ loved one who donated their body to science after death, experienced challenges in terms of being able to use some form or ritual, or memorial, to aid the grieving process. One participant, ID: B: 3407: F; 44; Child; 7-9; M2, described feeling in “...*a kind of limbo...*” as a result of being told their loved one’s remains “...*could take anywhere between 2 months and up to 2 or 5 years...*” to be returned. Being unable to have some kind of ritual may impact on the process of being able to emotional and psychologically relocate the deceased. This may impact on the grieving experience.

When there is no longer the physical presence of the deceased, material entities such as their belongings become permeated with a hyper-real significance. Tangible materials and spaces provide temporary places of dwelling for the deceased, and provide comfort to the bereaved (Baptist, 2010). Some participants engaged in *creating sacred spaces*, or as the diaspora discourse refers to, ‘*deathscapes*’. Although these material substitutions that represent the deceased trigger pain, they also allow the bereaved to externalise their pain of grief to something outside the body. Re-visiting these tangible spaces or objects aids in the process of reconciling and facing the reality of the death, but also to honour the deceased (Baptist, 2010). Participants in this research described the ‘*deathscapes*’ they created in honour of their loved one:

“...*those cushions that you're leaning against are his shirts. I had all his clothes to deal with which was a really confronting thing...I did everything really quickly, all of his personal stuff. I packaged it all up and had to just take it out of the house. I just didn't want it here. It was too hard to have that.... too personal...I've kept a few things. But there was some beautiful*”

clothing left and someone put this idea in my head of 'you should make a quilt out of it'. So we've got a local community Facebook page and I just put it out there – 'who's interested in talking to me about making a quilt with [A]'s shirts?' ...these ladies that call themselves the 'balance bunch' - a bunch of women that just get together once a month and do things - they just do stuff, whatever takes their fancy that nurtures them - they invited me on board and I took all these shirts, one night to their meeting and it was amazing. They asked me to talk about each shirt that I wanted in this quilt and, how important it was, and should we use all of it or a pocket of it...it was amazing. It was a very healing experience for me. It was fantastic..."

ID: B: 3072; F; 52; Sp; 6-9; R3

Johnson (2012) discusses the notion of using sacred objects to represent or embody the absent-but-remembered, as a way to reduce the spatial and temporal distance since the person died. This helps to reduce the diasporic crisis, or '*existential diaspora*'. *Deathscapes* include the home environment which is imbued with memories (and belongings) of the deceased. Women participants viewed their '*home as haven*' as portrayed in the following quote:

"...my home is my refuge...even though home meant I was by myself, I just feel more comfortable in my home..." ID: B: 3180; F; 70; Sp; 0-3;

R3

Some participants, however, struggled with being in the house without the deceased as illustrated in the following statement, '*home not haven*':

"...I hated coming home - I hated the house, I hated everything..." ID: B: 3369; F; 53; Sp; 13-18; R1

One participant's 'haven' was to make a *geographical change* so she could allow herself the psychological and emotional space to grieve:

"...one of the good things when I came to Greece last year was that I'd never had time to grieve and I could do that. And that was good...So I never had any time for myself to grieve and that was hard. And that's why I love being here..." ID: B: 3111: F; 68; Friend; 13-18; R3

'*Travel as therapy*' was an activity undertaken by a large number of participants in this study, where the bereaved travelled intrastate, interstate or overseas for various reasons, including scattering a loved one's ashes on Malibu beach in California; embracing the opportunity to try something different through house-sitting up north; going to a meaningful place on the deceased loved one's anniversary; going to places on their deceased loved one's 'wish list' that they never got to; to escape from the attention of the local community, particularly in rural areas; to get respite from going to a new and different environment; to continue tradition in honour of their loved one; and, to have time out and 're-group' as a family.

Bereavement brings a 'diasporic space' in which shared or similar experiences bind together those who are bereaved. As a way of belonging, the bereaved develop a narrative about the features of this new group to which they belong (Hess, 2008).

Experiences of Coping: Transformative Change

Castle and Phillips (2003) describe grief as a transformative experience in which grief can be the catalyst for personal change and growth. Transformation occurs when individuals reach a point where their priorities change, or what was previously valued is no longer valued the same way. This often creates a new coping pathway or purpose. Personal transformation is a global change in perception which changes a person's worldview (Keenan, 2010). Lund, Utz, Caserta and deVries (2009) demonstrate that bereaved

widows learn new skills and discover previously unrecognised strengths. The sense of *growing through loss* was conveyed in participant narratives in this study, as portrayed in the following statements:

“... a gay couple who are really good friends of mine...they're very resourceful, and one of them is quite 'blokey' and fixes things and stuff and I've had them over here and they've said to me, 'you're gonna be surprised how much you're gonna learn' and it's true! I am! From just being alone!”

ID: B: 3072: F; 52; Sp; 6-9; R3

“...I didn't know how I would cope. But because this is such a nice environment and I've had the responsibilities, I've looked after the dog and the chooks and the garden, I look back and think, 'well, this has been a, quite a good experience' ID: B: 3112: F; 75; Sp; 13-18; R3

“... I've probably surprised myself in the fact of I've been stronger than I thought I would be, and I don't know where I sort of got that strength from...” ID: B: 3373: F; 64; Sp; 13-18; R1

“...I found some inner strength which I didn't know I had, which has helped...” ID: B: 3725: M; 63; Sp; 7-9; R1

Recognition of personal growth as a result of trauma and grief has been recognised in the literature and resilience is gaining increasing acknowledgement as a key mediator in coping in bereavement (Koop & Strang, 2003; Coifman, Bonanno, & Rafaeli, 2007; Bennett, Stenhoff, Pattinson, & Woods, 2010).

Receptivity and coping in the *Bereavement Diaspora*

Anthias (1998) describes the influence of push-pull factors that influence a person at different times. In bereavement, MacCallum, Sawday, Rinck and Bryant (2015) discuss the push-pull factors of approach and avoidance as a coping strategy as described in the DPM in bereavement. The connections that the bereaved had to others in receiving support, either practically or emotionally, have also been identified as a protective factor in mediating the *bereavement diaspora*. However, the bereaved often do not want to burden their family and friends (Yancy, 2011; Breen & O'Connor, 2011). External support resources, informational and social support may be helpful (Wittenberg-Lyles et al., 2015).

The narratives of the participants in this study highlighted the extensive time, and labour, required to deal with practical matters after death. By the very nature of dealing with a socio-political system in which legislation, policy and protocols direct organisational activities, the bereaved can experience a sense of frustration and demoralisation as evidence by participants' narratives in this research. Understanding what the bereaved cope with in relation to practical matters can inform service and program design that may enhance receptivity to support with practical matters, thus reduce psychosocial morbidity. Receptivity to psychosocial support in relation to practical matters is an area for further exploration.

Much of the diaspora literature highlights internalisation as a way of coping (Muller, 2011; Waechter & Samoilova, 2014; Saketopoulou, 2015). The findings in this study reflect the bereaved participants' desire to maintain their independence, a receptivity factor found in studies by McGrath (2013) and Pascal, et al., (2016). Another receptivity factor noted by McGrath (2013) was an inherent trait of introversion, and this was supported by findings in this research. An interesting trait that emerged from the findings in this study, however, was humour, which was intrinsic to all participants. There is a paucity of research on humour and bereavement so this may be worthy of further exploration. It would also be

of interest to see if humour plays a role in receptivity. Booth-Butterfield, Wanzer, Weil and Krezmien (2014, p.439) states “...*humour-oriented communication [in bereavement] rests not only on what the individual does, but how he or she views others responding to humour attempts...*” They also identified gendered differences in the use of humour. How professionals and others respond to use of humour by the bereaved may have implications for receptivity.

Bereavement diaspora is not a static and stable identity (Canagarajah & Silberstein, 2012). Neimeyer (2016) applies an epigenetic systems perspective and describes grieving as a developmental process that is influenced by biogenetic, personal-agentic, dyadic-relational and cultural-linguistic factors. Developmental processes of grieving thus reflect ‘*situated interpretive and communicative activity*’ (Neimeyer, 2016, p.4). Neimeyer’s (2016) perspective recognises the dynamism of grieving and a salient point raised by McGrath (2013) is that one’s receptivity to support can change at any given point in time. In the context of current palliative care bereavement programs which have fairly prescriptive structures, receptivity should also be viewed as a dynamic and developmental process.

Exploring *bereavement diaspora* through the receptivity lens can provide some insights into the provision and planning of bereavement support services.

a) Bereavement Diaspora: being-in-the-world

Gender role socialisation has historically played a significant role in help seeking behaviours. Contemporary research in recent decades has identified that gender role conflicts and attitudes toward seeking professional psychological help influence help seeking behaviours (Chan & Hayashi, 2010; Stapleton & Pattison, 2014). Help seeking is often viewed by men as an admission of failure and a threat to success and power. Additionally, engaging in counselling has connotations of yielding power. Men are more likely to disclose personal information to an intimate other, as there is a reduced sense of stigma and loss of power and control (Chan & Hayashi, 2010). However, if it is the

'intimate other' who is deceased, this leaves men with little options of who they would feel comfortable with to share their *existential diaspora*. Men who demonstrate high levels of gender role conflict experience higher levels of alexithymia, which reflects difficulties in imagining, contemplating, experiencing or expressing emotions (Chan & Hayashi, 2010; Ridge, Emslie & White, 2011). Gender is thus a receptivity issue: although men may be reluctant to engage in help-seeking behaviours such as counselling for psychological distress, they may be more amenable to activities where they are provided with a safe environment in which to explore their grief, such as the Men's Shed program or where they feel they are educating others, such as contributing through research (McGrath, 2003; Buckle, Dwyer, & Jackson, 2009).

The socio-political contexts and dealing with practical matters is a significant receptivity issue. Instead of focusing on risk assessment or coping style approaches to planning bereavement care, there may be more benefit to focus on proactive and anticipatory planning to pre-empt potential short and long term impacts in bereavement (Corden, Hirst & Nice, 2008). In light of the impact described by participants in this study, and the level of stress and distress they experience as a result of dealing with the practical issues related to the death, assistance with practical support may be indicated. Ogbuagu (2012) advocates that assisting with taking care of matters related to the deceased such as closing accounts, paying outstanding debts and helping them to reinvest energies in other relationships and activities, may help to alleviate some of the stressors associated with the practical matters related to death. Receptivity to support with practical matters warrants further exploration.

Many participants identified bereavement has been a time where they were emotionally and psychologically vulnerable, they were dealing with a macro-system of bureaucracies which have their social constructs based on mechanistic, formal, impersonal and power oriented concepts (Morand, 1995). The experiences of the bereaved in this study would support this claim as the psychological and emotional impacts of dealing with institutions to attend to practical matters was significantly detrimental. Corden, Hirst and Nice, (2010, p.27) state

...perceptions of adverse change in financial circumstances following a partner's death were related to increased psychological distress among women, for up to two years after death..."

Psychosocial morbidity of the bereaved, which includes emotional and psychological problems, can possibly exponentially increase the demand for healthcare and social resources as a result of financial burden and stressors (Ferrario et al., 2004; Corden, Hirst & Nice, 2010). As discussed in chapter five, using complicated grief criteria for assessment in the first 12 months of bereavement may be a receptivity issue. If people are being pathologised as having complicated grief and may be experiencing either implicit or explicit messages from professionals that there may be something wrong with their grieving process, that is, they are not grieving within conventional norms, this may make them feel isolated or become withdrawn and may impact on their receptivity to support. For some participants, dealing with practical matters of the deceased's estate continued for up to 18 months' post death. Kristensen, Elklit, Karstoft and Palic (2014) state the bereaved may be pathologised as having a disorder at a time when they are still trying to deal with practical matters. If the focus continues to be on the psychological experiences of bereavement as the dominant discourse, this discounts the broader systemic issues and stressors the bereaved are experiencing. If the bereaved feel they are being pathologised as a result of the psychological impact of dealing with socio-political factors, this may influence their receptivity to support. Kristensen, Elklit, Karstoft and Palic (2014) identified that a lack of progress in PTSD related symptoms in the bereaved following an expected death, may be due to responses related to economic and practical worries that are connected with the death. Planning for psychosocial support in bereavement should thus consider the benefits of providing assistance and preparation with dealing with practical matters and an understanding amongst health professionals that this is a transitory stage in the bereavement experience.

b) Hybridity and Lived Tensions: (re)shaping identity

McGrath's (2013) seminal work identified introverted traits, along with 'not being good at reaching out for help' as individual factors that influence receptivity, and these are supported by the findings of this study. Likewise, Pascal et al.'s (2016) found that the desire to retain independence and look after oneself, influenced receptivity to support. There is a *lived tension* in which an individual wants to maintain their independence but also recognise their inherent vulnerability (Pascal, et al., 2016). One participant in this study reflected on engaging support and identified it is personality dependent as demonstrated in the following statement:

“...I would have to say it all boils down to basic human psychology. 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 an answer to that one...” ID: B: 3371: F; 77; Sp; 7-9; R2

The characteristics and traits described by participants in relation to self-narratives, have implications for receptivity to support. If individuals have a positive self-efficacy, they may not feel a desire to seek support. One participant described having a 'well-hidden anxiety' and this may be a contributing factor that influences receptivity to support, as she may not actually have the ability to seek support. As with McGrath's (2013) and Pascal, et al.'s (2016) study, an individual's determination, will, judgement, perception, stoicism and desire for independence influences help seeking behaviours.

c) Disruption: Learning to manage thoughts and emotions

The notion of 'othering' and 'not othering' may have implications for receptivity. For some bereaved individuals, there is a legitimacy in others who have experienced bereavement. This may enhance receptivity to support if it is provided from people who have a shared experience. The link between the concept of othering/not-othering in

relation to receptivity, particularly in the context of peer support groups is worthy of exploration.

The presence of humour in bereavement has implications for receptivity. As there is little in the empirical literature about humour in bereavement, professionals and others in the bereaved individual's support networks, may perceive the use of humour as going against the social norms of grieving. There is implicit in social mores of death and bereavement a kind of 'death etiquette', where responses that occur that are against the norm are frowned upon, such as the use of humour in bereavement or applauding after speeches at funerals. Openness to the use of humour to cope in bereavement needs to be acknowledged and normalised.

The polarity of exhaustion-hyperactivity raises challenges for planning support programs. Recognising and normalising the range of responses is important. Keeping busy has been identified as a receptivity factor (McGrath, 2013). For those who are experiencing fatigue and exhaustion, they described it as an emotional and physical exhaustion. One health professional, ID: HP: 3390: F; 43; R3, described how the bereaved *'feel like crap'* so would resist attempts at contact or support. Fatigue and exhaustion may also be factors that influence receptivity to support and require further exploration.

d) Displacement: memory and shared narratives

The internet and its role in bereavement has been studied in the USA and UK but there is limited research conducted in Australia. The accessibility of the internet any time of the day or night, wherever an internet connection is available, and from any desktop or mobile device, indicates that technology may play an increasing role in bereavement. Receptivity to the uses of technology will be worth exploring further, particularly in relation to its use by those living in rural, regional and remote areas, where support services are limited.

e) Embodied Diaspora and Transcendence: coping with the absence-presence

Just as spatialised habits can re-trigger the loss, a way to cope with this is through changing habits in the once ‘shared domestic space’. Raising awareness of embodied diaspora, along with the notion that physical embodiment of grief can have health implications is indicated. Embodied experiences of bereavement have been identified as impacting on physical health with increased morbidity and mortality due to immune-suppression and changes to cardiac function (Buckle, et al., 2012; Vitlic, Khanfer, Lord, Carroll & Phillips, 2014). Receptivity to embedding health checks into bereavement programs is worthy of further exploration.

f) Deathscapes: Places of comfort

Contemporary society has seen a change in memorialisation and grieving practices where there is an increased incursion into public space of sites of commemoration, such as roadside memorials (Maddrell, 2013). The presence of deathscapes is a receptivity issue. Some bereaved individuals like ‘markers’ that provide a physical space to commemorate a loved one, whereas others may share different values. One person’s sacred memorial is another person’s vandalism or litter (Maddrell, 2013). If the bereaved are not pathologised for holding on to the belongings of the deceased or create sacred spaces to commemorate the deceased, they may be more receptive to engaging in activities that foster the continuing bond with the deceased, or foster connection with others.

Conclusion

Grieving is not seen as a one directional journey but rather, allows for the individual to “regress” back into intensive grief (loss-orientation) and/or retreat from the “work” of grieving to get away from the intensity of emotional work that is required and concentrate on learning new tasks, and getting on with the practical part of living (loss-restoration). The DPM attempts to more accurately fit what is often observed in the real world, that is, that some individuals have good days and bad days, and the process of grieving is

developmental. The findings from this study reflect the way the bereaved cope, which is consistent with the DPM thus the DPM provides a suitable framework to understand how people cope in bereavement.

Key concepts from the diaspora discourse, particularly in relation to the influence of socio-political agents on the bereavement experience was discussed extensively in this chapter. The disruption and displacement that occurs in bereavement leads to individuals dealing with a macro-system which is inherently dehumanising (Jones & May, 1999). The findings that emerged in this study identified the plethora of issues that participants had to deal with when addressing practical matters and the impact of dealing with institutions on the bereaved. The bereaved discussed how they coped with the dual processes of attending to their grief and dealing with day-to-day matters.

Focus of bereavement support in palliative care is centred on identifying risk, or providing psychological support for grief, or complicated grief, yet there is further exploration required to identify if there is any correlation between the impact of dealing with practical matters and adverse outcomes. This is an area of bereavement worthy of further exploration, particularly in relation to receptivity. The added burden of having to cope with bureaucratic entities may weigh people in the restoration oriented activities at a time when the bereaved need to attend to loss oriented activity. Alleviation of these stressors may have a significant impact in the bereavement experience.

The focus on this chapter was on discussing findings as they apply to the *bereavement diaspora* with an emphasis on coping with socio-political influences on the bereavement experience. Other diaspora concepts were used to frame the discussion on the way people cope in bereavement. The next chapter will discuss the role of relationships and how these influence the experiences of the *bereavement diaspora*