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

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## **Chapter 10: Overview of the thesis: Implications for Practice, Further Research and Conclusion**

### **Introduction**

This study explored the concept of receptivity to bereavement support. As discussed in chapter four, diaspora was a theme that evolved from the findings to the formulation of a concept, *bereavement diaspora*. *Bereavement diaspora* provides a different lens in which to view bereavement and encompasses the many aspects of the bereavement experience that were discussed throughout chapters four to eight and are outlined in *Appendix E: Overview of Bereavement Diaspora Receptivity Issues (Chapters 5-8)*. *Bereavement Diaspora* also provides an integrative lens in which to examine receptivity issues which were identified and discussed throughout chapters five to nine and are outlined in *Appendix F: Desired Characteristics and Technical Skills of Professionals: Bereaved & Health Professionals and Appendix G: Receptivity Enablers and Barriers to Bereavement Support*). *Bereavement diaspora*, is a broader socio-cultural-political milieu and thus views the bereaved from an ecological perspective, situating them within the context of their environment. This chapter provides a brief overview of key findings of this study, their relationship to previous work in these areas and new contributions to the fields of bereavement, diaspora, receptivity and palliative care.

### **Bereavement Diaspora and Receptivity: Review of the Thesis**

#### *The bigger picture*

Findings that emerged from participant narratives in this study identified four overarching themes, *existential diaspora*, coping, relationships and language. These overarching themes provide a ‘bigger picture’ of *bereavement diaspora*. The ‘bigger picture’ of *bereavement diaspora* and receptivity were discussed in-depth in chapters four to nine and are summarised in this section.

Inherent in the participants' narratives in this study was the cataclysmic disruption that occurred as a result of death of a significant other, and the impact this had existentially, socially and practically. When a person experiences a significant disruption through loss of a loved one in their life that creates a crisis in their assumptive world, they feel existentially displaced. This may lead to a re-evaluation of their life view and priorities (Wong, 2008a; Neimeyer, Gillies & Milman, 2016). Many of the participants described a sense of feeling displaced, lost, existentially alone and often not feeling understood in their bereavement. The bereaved participants in this study described the experience of an existential crisis following the death of a loved one and the key message from the bereaved was drawn from the overarching theme of '*existential diaspora*':

*“try to understand the reality of my world and the language of my world first and foremost. This is important if I am going to invite you in. My world has been disrupted, I have been displaced and I am trying to find my way in this new world which is foreign to me. If you are open to learning about my world, without any judgement, I may be open to letting you in to this private world.”*

Receptivity plays a key role in generating meaning from our personal reflections and being open to others (Schoolman, 2011). Receptivity is an inter-dependent concept in which a person is open to an 'other' if the 'other' shows an openness to them (Hinchman, 2009; Lewandowski, Ciarocco, Pattenato & Stephan, 2012). If the bereaved feel safe, understood and feel 'compassionately held in a space', or have a close or positive relationship with an individual or group, they are more receptive to support from others and findings from this study echoed these same sentiments by other researchers (Dyregrov, 2004; Cherlin, et al., 2007; Roberts & McGilloway, 2008; Bergman & Haley, 2009; Schoenfelder, Sandler, Millsap, Wolchik, Berkel & Ayers, 2013).

The findings in this research highlighted the importance of relationships, including family and non-family support such as friends, work clientele and pets. Central to receptivity is trust (Huntington, 2009) which forms the basis for positive relationships. The key message from the bereaved in this study drawn from the overarching theme '*relationships*':

*“if you want to come into my world, or for me to feel safe to come out of my world, I need to connect with people who I can trust, who have empathy, compassion and who care. Connection helps me to cope in the bereavement diaspora.”*

Just as relationships with non-family support is important, consistent with other research, the relationship the bereaved had with the deceased is central to the experience of bereavement (Worden, 2009; Neimeyer & Sands, 2011), whether it was positive and nurturing or characteristic of estrangement and negativity. The deceased represented a ‘world creating’ person who provided a frame of reference in which the bereaved developed their identity. The death of this person led to a re-constructing of a whole new world and the ways people coped with this was varied.

Factors such as self-efficacy, religious affiliation, age, geographical location, health, education level, social networks and socio-political factors all influence the way people cope. These also influence their receptivity to support (Ganzevoort, 2004; Cacciatore & Bushfield, 2008; Howell et al., 2013). These multifactorial elements are all permeated throughout the diaspora and bereavement literature. The key message from the bereaved in this study, drawn from the overarching theme of ‘*coping*’ was:

*“the way I cope is influenced by many factors and my world is filled with lived tensions, longing and memory. Part of the way I cope with this new world is through hybridity where I am re-constituting my identity as I try to manage the dialectical stances that occur, creating a sense of double consciousness. I will struggle with ‘what was’ to ‘what is now’ and will feel a sense of belonging in two worlds. Recognise there are so many new things I have to deal with and that I will cope in many different ways, some will be new ways of coping I have never done before. Sometimes I may find my usual ways of coping are not working, so be patient and open to supporting me where ever I am at.”*

There is an emphasis in the bereavement literature on the desire for self-mastery in coping. Self-mastery “,,refers to the extent that one has a sense of control over outcomes in one’s life...” (Majer, Jason, Ferrari, Olson & North, 2003, p.386) Dyregrov (2008) posits that

strategies and support in relation to existential, practical, economic and therapeutic help, such as psychological assistance and advice to reduce stress reactions, can help promote self-mastery in the bereaved. Participants in this study portrayed a sense of wanting to maintain their own independence as much as possible as a way of coping. Findings from this study highlighted secondary stressors that the bereaved were dealing with. This is recognised in the Dual Process Model (DPM) developed and refined by Stroebe and Schut (1999; 2015). The DPM posits that the bereaved oscillate between loss orientation and restoration focussed activities and this was reflected in the findings of this study. Participants discussed their grieving and the impact this had on them while concurrently engaging in activities out of necessity, or to feel a sense of normalcy. The diversity of experiences of the bereaved, the different ways of coping and the variety of support desired by the bereaved that emerged from the findings in this study is consistent with findings in research conducted by Dyregrov (2008) and Breen and O'Connor (2011). Of interest, however, is that these studies examined sudden death whereas participants in this study were bereaved through what the discourse describes as an 'expected death'. Although mode of death has been identified in the literature as a confounding factor in adjustment in bereavement, Barry, Kasl and Prigerson (2002) highlight that the impact of certain modes of death is based on the researcher's evaluation and not the experience of the survivors. This is important as professionals may perceive a 'hierarchy' of mode of deaths in which some are worse than others without taking into account the subjective experience of the bereaved. There is a misconception that those bereaved through 'expected death' fare better in bereavement, however evidence suggests this is not the case (Barry, Kasl & Prigerson, 2002; Kristensen, Elklit & Karstoft, 2012; Sanderson, Lobb, Mowll, Butow, McGowan & Price, 2013). The findings in this study echo the research conducted previously and highlight the subjective experience of the bereaved is key to understanding, responding to and supporting the bereaved. An initial step in understanding and responding to the bereaved is through the role of language.

Language shapes and delimits a person's understanding and expression of their subjective experience and can foster either a sense of affiliation or division (Spearey, 2016). Language is subjective expression and provides the foundation for bounded and discrete

subjectivities of individuals, collective groups or communities (Molbak, 2010). The key message from the bereaved in this study drawn from the overarching theme of *language* was:

*“look to the language of diaspora to get insight to my world; listen to my language, not the version professional discourses have given bereavement – these don’t fit with my world, or experiences. This isn’t about needs, closure or moving on; this is about being understood. Some things you say will make me turn into myself, or will encourage me to open up.”*

The bereavement and grief counselling discourse advocates for the ‘tuning in’ to metaphors. However, the dominant bereavement discourse features metaphors of ‘letting go’, ‘resolution’ and ‘acceptance’ (Bowman & MacDuff, 2015). However, many participants in this study voiced their dissonance with this dominant discourse with their personal subjective experiences. Anderson (2001, p.137) states “...words, language and conversation act as metaphoric catalysts of experience...and therefore as evocative components not only for managing grief but for constructing it also...” The findings in this study on the role of language was discussed in chapter eight and reflects the position of Bowman and MacDuff (2015) who highlight that the language of the griever is often subjugated to that of the language of the discipline.

### **The thesis’ original contribution to knowledge**

Findings in this study build on the work of some of the researchers discussed throughout the previous chapters and this chapter. This study offers several different contributions to the field of diaspora, bereavement, receptivity and palliative care. The most significant finding of this study is that it advocates for a paradigm shift in thinking about bereavement and diaspora.

## ***Diaspora and Bereavement***

The diaspora discourse relates to Judaism, African, Asian and Black diaspora (Clifford, 1994; Anthias, 1998; Brubaker, 2005; Bakare-Yusuf, 2008). Through invoking diaspora as a contemporary perspective in which to explore bereavement, the author does not mean to disrespect these groups or in any way diminish the experiences of diaspora agents and authors. The researcher acknowledges the oppression, marginalisation, suffering, transformation and transcendence reflected in the diaspora discourse. However, diaspora provides a new and exciting perspective in which to explore bereavement. The most significant contributions of this study to the diaspora and bereavement literature are:

1. ***Theoretical Constructs:*** bereavement adds a new theoretical construct to the diaspora discourse and *bereavement diaspora* adds a new theoretical construct to the bereavement discourse. Diaspora is characterised by multiplicity – “multiple practices, multiple world views” (Wofford, 2016, p.74) and the many elements contained within the diaspora discourse such as disruption, displacement, hybridity, double consciousness, existential perspectives, *deathscapes*, socio-political and temporal factors provide the foundations of *bereavement diaspora* as a theoretical construct. *Bereavement Diaspora* thus contributes to a paradigm shift in thinking about bereavement.
2. ***Bereavement and Diaspora: Holistic Conceptual Links Providing an Integrative Ecological Perspective:*** *Bereavement diaspora* provides an integrative lens that places the bereaved within their social environment and integrates individual, cultural, social, gendered, class, geographical, temporal and political contexts. These elements all act interdependently to influence the bereavement experience. Although some findings in this study are compatible with the empirical literature and with other perspectives on bereavement, no perspective integrates such a broad and holistic approach to bereavement. Stroebe and Schut (2015, p.873) highlight that researchers continue to study bereavement as “...intra- and interpersonal

phenomenon largely independently...” This is the first perspective to assimilate all known multifaceted concepts that influence the bereavement experience under the one overarching theoretical construct.

3. ***Existential Applications to Diaspora: Bereavement diaspora*** highlights the cataclysmic nature of the loss of a loved one through death. Even with expected deaths, the loss causes a significant disruption to one’s world and propels the bereaved into an existential state where they have to create a new world. The existential experiences articulated by participants in this study reflect an *existential diaspora*. Diaspora has existential applications and has been discussed in the context of existential aspects to experiences by Bakare-Yusuf (2008) and Chen (2015). As Bakare-Yusuf (2008, p.147) states, “...diasporicity concerns the lived experience of embodied beings and bodily practices which have been (actual or by association) ‘rooted in a place, and which by being uprooted and re-routed to another place produce a sort of dis-positioning and re-positioning...” Existential perspectives can be thus used “...to articulate an account of the lived experience of diasporicity...” (Bakare-Yusuf, 2008, p.147). Thus, the introduction of bereavement to the diaspora discourse contributes another perspective and supports the existential application of understanding diaspora.
  
4. ***Diaspora Emphasises the Importance of Language and Discourse: Application to Bereavement:*** The discourse of *diaspora* emphasises multiplicity of experiences, thoughts, emotions and language in understanding and communicating one’s experiences. Language enables the bereaved to construct, convey and manage their grief and bereavement experiences (Anderson, 2001; Bowman & MacDuff, 2015). The language of diaspora provides a paradigm shift in awareness, and use of, language that is different to the perceived wisdom of the dominant bereavement discourse. *Bereavement diaspora* moves away from the dominant discourse and position of ‘clinician as expert’, and instead, asks the clinician to enter into the subjective world of the bereaved. *Bereavement Diaspora* is a different contribution to the bereavement discourse as it does not give the



clinician pre-determined tasks or phases of grieving that people must work their way through to ‘successfully resolve or recover’ from grief. The language of *bereavement diaspora* also provides a paradigm shift away from the metaphors commonly used in the dominant discourse such as ‘closure’, ‘moving on’ and ‘acceptance’ as discussed in chapter eight and supports the openness to metaphors created by the bereaved.

5. ***Bereavement Diaspora: Making Power Visible:*** The diaspora discourse is imbued with issues of power. Power may be a different perspective and a central concept to adjustment in bereavement. Thus *Bereavement Diaspora* brings to the forefront awareness of power and oppression experienced by the bereaved. *Bereavement diaspora* creates an awareness of power in key areas such as the socio-political-cultural environment and within relationships, both with professional and informal support networks.
  - i) *The bereaved within the therapeutic relationship:* Through the lens of *bereavement diaspora*, the bereaved’s subjective experience is no longer subjugated to the clinician’s expert wisdom. Awareness of the diversity of the bigger picture of grief, loss and bereavement may reveal experiences of the bereaved at a more in-depth level. Small and Hockey (2001, p.119) assert that professionals who work in bereavement care have ideological and organisational agendas’ and that the “...emergence of experts can occur only in tandem with the disempowering of lay populations...losses associated with bereavement can be compounded by the subordination of the individual to the discursive practices of experts...”
  - ii) *Within relationships with informal support networks:* There may also be issues of power dynamics within the social support system. Power differentials may occur in the family dynamics as the family re-organises itself in bereavement. Although there were indications of power dynamics within this study such as those discussed in chapter seven regarding role shuffles and a shift in power dynamics within the family unit, this requires further exploration.

iii) *The bereaved person in their socio-cultural context:* Power as a concept in the bereavement experience was evidenced in this study when examining the socio-political environment. Participants described being at the mercy of bureaucratic processes in dealing with the deceased's estate. There was also reference to experiences as a result of legislation which dictated the validity of relationship to the deceased which determined bereavement leave and prohibitive timeframes for leave from work as a result of bereavement. One other author who examines power dynamics within a social analysis framework of bereavement is Harris (2009-2010) who posits that the bereaved are oppressed as they are 'regulated', particularly in Western society which favours male dominated patterns of denial of emotionality and stoicism. Harris (2009-2010, p. 241) asserts that "...bereaved individuals often experience profound social pressure to conform to societal norms that constrict the experience of grief rather than support it...". Small and Hockey (2001, p.103) support this notion and highlight the bereaved engage in self-surveillance to reflect "...what is deemed proper into their everyday actions..." This was evident in participant narratives in this study. Harris (2009-2010, 2447-248) asserts that society legislates that the bereaved suppress grief responses and that "...this mandate to minimise one's experience and to deny a potentially adaptive grief response in favour of the maintenance of a veneer of control and functionality represents a unique form of oppression...". The pressure experienced by bereaved to return to 'normal functioning' as quickly as possible, the inclusion of "Complicated Grief Disorder" into the Diagnostic and Statistical Manual V, along with advocacy for medications such as antidepressants, anxiolytics and sleeping aids that can all enable the bereaved to 'control' their grief and return to their previous functioning, reinforces the medicalisation of bereavement. Hence, the juxtaposition of the reality of the bereaved experience with what is deemed socially acceptable can lead the bereaved to feel compelled to grieve in private. In effect, Harris (2009-2010) advocates that this is oppression of the bereaved. Harris (2009-2010) examined social norms and mores that govern the expression of grief in Western

societies. The notion of *bereavement diaspora* making power visible expands on Harris' (2009-2010) discussion and reflects the findings that emerged in this research of issues of power in terms of legislative and policy issues and of power within bureaucracies and the impact this has on clients or consumers and service delivery *per se*.

6. ***The Impact of Socio-political Factors:*** This study provides insights into the experiences of the bereaved in dealing with institutions and governmental and organisational legislation and policies that impact on bereavement. Bereavement has not been placed within a socio-political framework in terms of processes of dealing with institutions, the significant time and labour involved in attending to practical matters and settling the deceased's estate, and the impact of dealing with bureaucratic and dehumanising institutions. Although Stroebe and Schut's DPM (1999) and R-DPM (2015) recognise concurrent stressors the bereaved have to deal with, there is an absence in the empirical literature of the processes the bereaved have to engage in when dealing with the deceased's estate and the impact this has on them psychologically, emotionally, physically and financially. Although Kristensen, Elklit, Karstoft and Palic (2014) recognised economic and practical worries connected with the death may contribute to a lack of progress in PTSD related symptoms, there is an absence in the literature that links the experiences of dealing with the deceased's estate with psychological outcomes. There is also a dearth in the empirical literature in relation to bereavement, legislation and policy informing timeframes for compassionate leave from work. As one participant stated: "...I think I was only allowed to have 2 days bereavement leave, so the other 3 days had to come out of my annual leave, and I didn't have a lot of annual leave... I certainly would have needed more than just the one week off work..." (ID: B: 3407: F; 44; Child; 7-9; M2). The diaspora discourse is imbued with the influences of socio-political factors and as *bereavement diaspora* is the experience of being-in-the-world, it provides a lens in which to examine these broader impacts on the bereavement experience.

7. ***Enduring Features of Bereavement, not a Pathology:*** A distinction between contemporary bereavement discourse and the diaspora discourse is that connection and yearning is a normal, enduring and common state of being. Yearning was evidenced by participants in this study and may thus be an intrinsic feature of bereavement. Clifford (1994, p.310) asserts that a strong sense of connection resists "...erasure through the normalising processes of forgetting, assimilating and distancing..." and that there is a constantly lived defining tension in the diaspora consciousness of loss and hope. Despite researchers demonstrating the long-term 're-grieving' that individuals and families can experience after the death of a loved one (Chow, 2010; Buckle & Fleming, 2011) the dominant discourse is that yearning may indicate difficulties in successfully 'resolving' grief. The findings of yearning as intrinsic and enduring feature in this study is at odds with contemporary constructions of grief. Yearning is an item on the psychometric instrument used to measure complicated grief (Robinaugh et al., 2016). Findings from this study indicate yearning may not be indicative of an underlying pathology but rather, a normative experience and response to the grief from the loss of another through death. The use of *deathscapes* and *memorialsapes* by participants may not only be symbolic of the transformation of the transcendent relationship, but also as a catharsis for the outlet of yearning and to retain a social presence of the deceased.

### ***Receptivity***

Receptivity to bereavement support was the focus of this study and findings that emerged from the data support a plethora of receptivity issues that were discussed throughout chapters five to nine (*See Appendix E: Overview of Bereavement Diaspora Receptivity Issues (Chapters 5-8)*). The most significant contributions of this study to the diaspora and bereavement empirical knowledge base are:

1. ***Seminal Work in Palliative Care:*** This is the first time receptivity has been applied to the palliative care arena which promotes a different perspective to looking at bereavement and bereavement support. Bereavement support in palliative care is permeated with the language of ‘needs’ whereas receptivity to support provided by palliative care services has not been explored previously. Receptivity is a concept that can inform the design and delivery of psychosocial support in bereavement.
2. ***Promotes Paradigm Shift in Bereavement Service Design and Delivery by Palliative Care Services:*** receptivity provides a paradigm shift in service design and delivery, with a move away from programs of bereavement support being ‘organisational process driven’ to bereaved ‘client experience driven’, thus emphasising the subjective perspective of the bereaved. Many of the findings from this study indicated the bereaved were universally receptive to informational support through ‘next steps’ processes of what to do after the death in dealing with practical matters. The significant impact of dealing with practical matters and the processes individuals encounter to deal with the deceased’s estate was perhaps one of the few universal receptivity factors where all participants were open to support either informational, instrumental, emotional or appraisal (Vachon & Stylianos, 1988) and this is consistent with research by Dyregrov (2008) and Breen and O’Connor (2011). Instrumental support in the way of practical assistance was universally indicated as a factor where people would be receptive to support. *Bereavement diaspora* and receptivity thus promotes a move away from focusing on psychological and emotional support to expanding support to broader instrumental and informational support.
3. ***Emphasises Humanising Approaches to Foster Connection and Understanding, not Needs Based Approaches:*** receptivity is a developmental and dynamic process throughout bereavement and the goodness of fit between what the bereaved want and what is offered changes over time. This means that *bereavement diaspora* has temporal elements however, support provided within the palliative care bereavement support model is time-limited where support provided is variable from three to 12 months’ post death.

#### 4. Receptivity Pillars

This study builds on McGrath's (2013) receptivity factors and identifies four key pillars of receptivity which include individual factors, social factors and geographical factors. However, for the purpose of this study, social factors are delineated between social factors such as agents with whom the bereaved interact or have relationships with, and social factors which relate to the situatedness of the individual, which incorporates geographical factors. Thus the second pillar is 'social factors' and the third pillar is 'situatedness'. The final pillar is the nexus, which is the interconnection between all of these factors.

##### *Pillar One: Individual Factors*

There was a plethora of individual factors that emerged from the findings which influence receptivity. Findings that emerged in this study support much of the findings from research into receptivity by McGrath (2013) and Pascal et al., (2016) who identified the following individual factors. These individual factors have been categorised under intrapersonal and interpersonal in the following table.

<b>INDIVIDUAL FACTORS &amp; RECEPTIVITY</b>	
<b>Intrapersonal</b>	<b>Interpersonal</b>
A sense of privacy	Lack of confidence in social situations
Being an introverted person	Minimal engagement in social activities
Will and determination	Dislike of talking in groups
The tendency to minimise	Lack of comfort starting up conversations
Managing vulnerability	Lack of need to talk to others
Transformation outlook	A belief that talking will not help
Independent personality	An inability to reach out even though connection with others was wanted
Caring for self	The emotional energy required of talking to others

	Prefer informal contact such as through social gatherings Preferring to talk in person Prefer to talk to others who were going through the same journey Avoiding listening to the trauma of others
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Where this study builds on their work, individual factors that were identified as influencing receptivity are outlined in *Appendix E: Overview of Bereavement Diaspora Receptivity Issues (Chapters 5-8)*, *Appendix F: Desired Characteristics and Technical Skills of Professionals: Bereaved & Health Professionals* and *Appendix G: Receptivity Enablers and Barriers to Bereavement Support*). However, new contributions that distinguish this study from other research into receptivity of individual factors is the introduction of new concepts which were discussed in chapter nine including *shame resilience*, *ego depletion* and *perceived merit-ability*. Although *introversion* was referred to in the literature by McGrath (2013), this study expanded on this concept and explored its relationship to receptivity.

Individual factors encompass both intrapersonal and interpersonal factors and the elements that make up individual factors based on the findings in this study and receptivity research by McGrath (2013) and Pascal et al., (2016) are outlined in the table below:

<b>INDIVIDUAL FACTORS</b>	
<b>Intrapersonal</b>	<b>Interpersonal</b>
Physical status and health literacy Personality traits: such as a desire for privacy, introversion, humour, will, determination Values: independence	Social skills Level of comfort in social settings Emotional and psychological energy required Preferences for informal versus formal contact

Insight: sense of self, skills, abilities and capabilities Attitude Drives and Motivation Cognition Behaviours Knowledge Experiences	Desire for sociability Social role within a family and non-family system
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Individual factors in the receptivity literature often refer to intra-psychic phenomenon in which cognition is the dominant feature influencing judgement and will (Hinchman, 2009; Lewandowski, Ciarocco, Pattenato & Stephan, 2012). However, as demonstrated in the research and this study, individual factors have both intrapersonal and interpersonal elements.

***Pillar Two: Social factors***

Social factors that that emerged from the findings in this study support much of the findings from research into receptivity by McGrath (2013) and Pascal et al., (2016). The following social factors were identified in these studies and are outlined in the following table:

<b>SOCIAL FACTORS &amp; RECEPTIVITY</b>
care for others, reciprocity (concern and worry for loved ones), loss preference for talking to family or friends wanting personal space – not interaction strong family and friend support lessens the need for formal services work leaves little time/cannot attend during the day knowing few or no other people with same experience health professionals within family unit



very busy with family  
strong community connection  
living alone or without support

Where this study builds on their work, social factors that were identified as influencing receptivity are outlined in *Appendix E: Overview of Bereavement Diaspora Receptivity Issues (Chapters 5-8)*, and *Appendix G: Receptivity Enablers and Barriers to Bereavement Support*). Additional new contributions that distinguish this study from other research into receptivity of social factors is the introduction of new concepts which were discussed in chapter nine, expanding on Pascal et al.'s (2016) concept of *Reciprocity*:

- × *desired traits and characteristics of professionals* - identified by both the bereaved and health professionals are outlined in *Appendix F: Desired Characteristics and Technical Skills of Professionals: Bereaved & Health Professionals* and identify characteristics of professionals that would engender receptivity to support,
- × *the therapeutic relationship*
- × *Professionals and shared trauma*; and
- × *The role of non-family support*.

Although social factors in the receptivity literature include strong informal support networks, having a busy family or work life and caring for others (McGrath, 2013, Pascal et al., 2016), this study has separated social factors into social agents with whom the bereaved interact or have relationships with, and social factors that relate to the socio-cultural-political context within the bereaved person is situated.

### ***Pillar Three: Situatedness***

Situatedness represents the social milieu in which the bereaved individual lives. It represents an ecological perspective which incorporates temporal as well as socio-cultural and political elements. This person-in-situation perspective considers the individual's experience of being-in-the-world at any given point in time, recognising the

developmental and dynamic changes and experiences that occur across the lifespan. Factors such as age, gender, culture, religion, geographical location, environmental factors such as accommodation, finances, legal issues, infrastructure and resources and technologies along with different organisational, policies and legislative factors constitute the socio-political environment.

Social factors that incorporate the situatedness of the person that emerged from the findings in this study support findings from research into receptivity by McGrath (2013) and Pascal et al., (2016) in relation to geographical location, availability of resources and services available, distances required to travel to these, whether transport was available or if an individual has the material resources such as a car to enable them to access services and the individuals' financial security. Where this study builds on their work, social factors in relation to 'situatedness' that were identified as influencing receptivity are outlined in *Appendix E: Overview of Bereavement Diaspora Receptivity Issues (Chapters 5-8)*, and *Appendix G: Receptivity Enablers and Barriers to Bereavement Support*). However, new contributions that distinguish this study from other research into receptivity of social factors is the introduction of new concepts which were discussed in chapter nine including *cultural safety of organisations*, having an agency, place or person that acts as a *centralised coordination* point, and rural practice where *personal and professional worlds meld*. Although this last concept was discussed in relation to the role of Aboriginal Liaison or Health Workers, the nature of rural practice is such that this is a common experience of practitioners in the country area. As this study had a focus on bereavement experiences in rural settings, this is a salient point.

The most significant new contribution as discussed in previous chapters and in relation to a new contribution to the bereavement literature is the processes and impact of dealing with institutions and agents when dealing with the estate of the deceased and receptivity to support in relation to these.

### ***Pillar Four: Nexus***

The final pillar to receptivity represents the nexus point in which the individual interacts, and is influenced by, the world around them. The nexus occurs between the individual's inner and outer world. Findings that emerged from this data demonstrate the interactions between internal and external processes of the individual and the influence this had on their bereavement experiences. Bereavement thus occurs within the context of complex dynamic systems. Bereavement cannot be examined using a siloed approach of looking at individual level (intra- and/or interpersonal perspectives) or family level impacts, but needs to view the dynamic and interdependent relationships of the all the multifactorial influences.

In the diaspora discourse, Anthias (1988, p.559) states the "...tendency to homogenise ethnic groups coexists uneasily with the empirical work which shows diversity within groups...". Likewise, the growing body of research on bereavement has led to heterogeneous views and explications. However, paradoxically, the practices of health staff, bereavement services and programs, all seem to approach bereavement support in the same way. Palliative care bereavement programs focus on emotional and psychological support (Mather, Good, Cavenagh & Ravenscroft, 2008; O'Connor, Abbot, Payne & Demmer, 2009). Despite the diversity of experience and support needs in bereavement, programs essentially perpetuate a practice homogeneity of adopting a universal approach to interventions.

This thesis has introduced a new concept to the bereavement and diaspora discourse and concurrently explored receptivity issues through the lens of *bereavement diaspora*. *Bereavement diaspora* and receptivity have holistic conceptual links and implications for practice and research require exploration as follows.

## **Implications for Practice**

This study has identified three key areas that have implications for practice, namely, a paradigm shift in thinking, assessment and interventions. Implications for practice and policy development will contribute to enhancing insights and catalysing change for those experiencing bereavement through refining discursive practices and modalities.

### ***1. Paradigm shift***

A first implication from the findings is a paradigm shift in thinking about bereavement. The introduction of *bereavement diaspora* as a new concept which encompasses the multiplicity of bereavement experiences, encourages practitioners to reconsider the discourse. This places *bereavement diaspora* on the education agendas for any professional working with the bereaved and on community education and awareness campaigns.

Concepts from the diaspora discourse encourage a move away from pathological and prescriptive frameworks such as psychological tasks that must be achieved. *Bereavement diaspora* takes the tasks approach to bereavement counselling off the agenda and instead encourages clinicians to use strategies that enhance the therapeutic alliance and engenders a humanising approach in bringing humility into clinical responses. Reflective of much of the bereavement counselling discourse, implications for practitioners include being non-judgemental and open, and being cued into and curious about the language and metaphors used by the bereaved. This reorients focus to the centrality and importance of the therapeutic alliance. This also promotes a move away from a perspective of an expected bereavement trajectory where expectations include that a person should be at a certain stage within a certain timeframe within their bereavement. As stated in chapter five, intrinsic to the findings from this research is the need for professionals to be open to the non-dominant discourse. *Bereavement diaspora* is more about a change in outlook and flexibility to enter into the bereaved person's world. Increased understanding engenders feelings of being understood and supported by the bereaved and of feeling connected.

## **2. Assessment**

A second implication from the findings demonstrate that the current assessment practices of bereaved carers and families by palliative care services need to be reconsidered. Services need to explore receptivity issues as a prelude to assessment of needs of the bereaved. Findings that emerged from this study demonstrate that a broader biopsychosocial approach to assessment is indicated. Although findings from this study compel clinicians to look more broadly than psychological and emotional factors, there is caution not to ‘throw the baby out with the bathwater’. Participants in this study discussed their experiences of PTSD and suicidal ideation which they directly related to the caring and death experiences. PTSD and suicide have been identified as risk factors in bereavement, even with ‘expected deaths’ (Ajdacic-Gross et al., 2008; Elklit, Reinholt, Nielsen, Blum, & Lasgaard, 2010; Kristensen, Elklit, & Karstoft, 2012). Despite evidence in the empirical literature linking PTSD and suicide in bereavement, the current palliative care doctrine, or dominant discourse, is a focus on screening those at risk for complicated grief, including during the pre-death period, and clinical guidelines and frameworks in palliative care direct clinical practice in relation to this (Hall, Hudson & Boughey, 2012). In light of the *existential diaspora* experiences articulated by participants in this study, overall assessment practices may require a review.

## **3. Interventions**

The third implication from the findings relate to interventions. The future vision of bereavement support in palliative care is for moving the focus away from screening for complicated grief or endeavouring to identify those potentially at risk of adverse psychological outcomes to starting where the bereaved is at, at a given point in time. Central to this perspective is that the bereavement trajectory does not move in a forward direction, it is reflective of Stroebe and Schut’s (1999; 2015) DPM where people oscillate between grieving and restoration oriented activities. This is a continuously dynamic process of change.

The most significant implication for practice is through normalising experiences. Although there is an abundance of empirical literature in the bereavement discourse regarding the psychological, emotional and spiritual impacts in bereavement, there were some experiences in this research in which there is little or emergent evidence in the empirical literature. Some features, particularly a sense of freedom, feelings of embarrassment in bereavement, embodied diaspora and spatialised habits are relatively new or uncommon concepts to the palliative care bereavement discourse. Likewise, yearning and nostalgia are intrinsic in the diaspora discourse and this has implications for assessment by palliative care services, particularly for complicated grief. Interventions that require openness to the non-dominant discourse are vital to ensure the bereaved do not feel there are concerns regarding their bereavement experiences.

Another important implication for practice is that, as stated earlier, interventions that are broader than traditional approaches of providing emotional and psychological support. Findings in this research demonstrate the need to expand the repertoire of interventions to include instrumental support along with informational support where participants described a wish for an allocated 'go to' person, or a centralised place with up to date knowledge, experience and practices in relation to bereavement, particularly in relation to dealing with the deceased's estate and other practical matters. Thus, interventions would require exploration of concurrent stressors the bereaved are dealing with as per Stroebe and Schut's (1999) DPM, the impact of these and strategies to alleviate these stressors. As evidenced in this study, the duration of dealing with these practical matters can take up to 18 months or more to resolve.

Support needs to match the individual and ascertaining what individuals are receptive to is integral to ensuring client driven care. Findings from this research identified individual factors such as personality traits that included introversion and use of humour, which may inform practice interventions. For example, introverted individuals may prefer resources such as DVD's or other technologies to aid them in their grief and bereavement. Interventions which allow for the expression and acceptance of humour may also be indicated.

Yamashiro (2015) discusses diaspora strategies under the categories of ‘diaspora-connecting’, ‘diaspora-cultivating’ and ‘diaspora-creating’ strategies. Although these are applied to governmental or national perspectives, if applied to bereavement, relevant approaches could include ‘diaspora-connecting’ strategies such as connecting bereaved with other bereaved either through support groups or the use of technologies. ‘Diaspora-cultivating’ and ‘diaspora-creating’ strategies would aim to enhance insight, understanding and better practices in supporting and caring for the bereaved. This would be targeted at professionals and organisations to develop or create ‘bereavement sensitive’ approaches and support. This would be achieved through increased public ‘death and bereavement literacy’, education within corporate, government and private agencies on how to respond to bereaved clients. The bereaved who prefer support from informal networks may appreciate the opportunity for community education to the general community of how to support the bereaved. Whilst being cognisant of the limited capacity and resources of palliative care services, building social capital through joint initiatives by palliative care services and community groups may better equip the community to support bereaved individuals and families in their local community.

A salient point raised by McGrath (2013) is that receptivity will change over time depending on circumstances, need and desire. Participants in this study identified interventions they would be receptive to as part of a bereavement program and these are outlined in *Appendix G: Receptivity Enablers and Barriers to Bereavement Support*. As grief in *bereavement diaspora* can be seen as enduring, receptivity to support may change in the bereavement journey. This places practice interventions within a dynamic and developmental perspective.

### **Implications for Research**

This study, being exploratory and descriptive in nature, raises a number of opportunities for future research agendas. More research will in fact be necessary to refine and further elaborate on the findings in relation to *bereavement diaspora* and receptivity.

### ***1. Bereavement Diaspora***

*Bereavement diaspora* is a new conceptual category requiring further exploration, and with larger and different population groups. Research driven by the concept of diaspora can provide further insights from the perspective of the bereaved and how this might inform the development of therapeutic modalities and supportive care service delivery.

The findings in this study highlighted a linkage with personality traits, namely introversion, and receptivity. As discussed in chapter nine, personality has been identified as a predictor of grief severity however focus has been on the Big Five classification of personality traits of extraversion and neuroticism. Personality buffers against other concurrent stressors associated with spousal death, such as dealing with estate matters. (Pai & Carr, 2010, p.194). Further research could explore the link between personality and loss on a broad range of psychological tasks and how these influence receptivity.

Significant findings from this study was in relation to the processes and impact of attending to practical matters related to the deceased's estate. Research in this area could be used to explore experiences and gain in-depth insights on the impact of dealing with deceased's estate. This could inform legislation for requirements around bereavement leave and workplace policies. In light of the challenges many participants had in this study with organisations, further research could also inform organisational practices, protocols and policies in responding to the bereaved. Research could also be undertaken to explore if there is any correlation between the impact of dealing with practical matters and adverse psychological outcomes. Research in this area would also enhance insights into receptivity.

Findings in this study revealed the challenges of legislation and organisational policies in relation to bereavement leave. Bereavement needs to be placed on the research agenda in relation to bereavement leave, particularly time needed to deal with practical matters associated with the death of a loved one. This would inform legislation and government and organisational policies.



## ***2. Receptivity***

Receptivity is a new concept in the palliative care arena and requires further exploration. Putting receptivity on the research agenda can contribute to changes in the discourse of needs based language to receptivity focussed language.

The issue of individual power and receptivity is an area requiring further empirical exploration to identify if, and how, power differences impact on family functioning in bereavement. As discussed in chapter seven, receptivity in terms of maintaining or relinquishing one's power within the family unit is an area of interest to explore as it has implications for receptivity in terms of how family members view their role and what values they hold about being that social role. This is an area of research that could provide greater insights to receptivity of individual members and of family units.

Receptivity issues identified in this study require further in-depth exploration. There were many receptivity issues identified in the findings including humour, support with practical matters, exhaustion and fatigue, the 'culture' of rural communities, education of informal support networks to better equip them to support a bereaved loved one and use of technologies. Placing receptivity on the research agenda can provide significant insights to inform the design of psychosocial support programs and services.

Although outside the remit of palliative care services, experiences of the workplace and their role in bereavement emerged from the findings and need to be placed on research agendas. This will help to inform the growing movement of 'compassionate workplaces' and initiatives to help support staff, more from the perspective of leave entitlements or informational or instrumental support in dealing with practical matters related to the deceased's estate.

Of interest in the findings was the experiences of health professionals in working in palliative care. The nature of the work required clinicians to enter emotionally charged

situations which leave them open to vulnerability and experiences of shared trauma. Insights on the notion of shared trauma and the therapeutic alliance would help to inform education and practice strategies to enhance the resilience of health care practitioners in palliative care.

Findings in this study also identified the impact between lack of truth telling and negative experiences in the palliative care or caring period and subsequent death. The notion of truthfulness, missed opportunities and receptivity to psychosocial support are areas requiring further exploration.

### **Limitations**

In terms of the methodology, a limitation of the study was the recruitment processes amongst different regions which was beyond the control of the researcher. Some regions adopted a targeted approach and invited participants whom they thought would be appropriate to participate in the study whereas other regions adopted a universal approach and sent an invitation to all bereaved clients. Participants self-selected for this study. Most bereaved participants were over 45 years of age, with a quarter of the cohort comprising males and 79% of bereaved participants experienced spousal loss. The cohort was homogenous in their ethnicity except for one bereaved participant who identified as Aboriginal. Generalising findings to wider populations is a limitation of qualitative research however this method of inquiry is not so much about generalisability but about gaining in-depth insights from a particular group about a particular phenomenon.

Although Aboriginal Health Workers and Aboriginal Liaison Officers were included in this study, this was in no way an in-depth exploration of their experiences. Research methodologies with Indigenous groups are extremely in-depth in relation to consultation processes, establishing reference groups and having Indigenous involvement in the shaping of the design and implementation of the research as well as the interpretation of the findings. This study recognises the importance of including Aboriginal participants as

they are such an important group in rural Western Australia so inclusion of their perspectives, albeit small, was imperative and provides a building block on which to gain further insights into their experiences and receptivity to support.

### **Postmodernism and Diaspora**

Reflective of postmodern perspectives, a bereaved diaspora community should be treated and recognised as one that embodies difference. This ‘community’ may experience a sense of affinity which is achieved situationally through language (Canagarajah & Silberstein, 2012). However, Yamashiro (2015) states that diaspora is about a way of identifying a subpopulation and highlights the need to view the Diasporan as heterogenic and not necessarily having an affinity with other Diasporans of a subpopulation ie. bereaved. The empirical literature on bereavement and diaspora highlights diversity within the bereaved population demonstrating that a ‘one size fits all’ approach to bereavement theories and service design and delivery is not efficacious. Findings from this study identified the multiplicity of experiences and the multifactorial issues which impact on the bereavement experience.

### **Conclusion**

The main aim in this study was to explore the concept of receptivity to bereavement support. This seminal research has identified a constellation of bereavement issues and applied the concept of diaspora which links all the facets of bereavement experiences together. *Bereavement diaspora* thus provides a conceptual framework that can be built upon by further research.

This study has initiated and provided a firm foundation for further research into *bereavement diaspora* and receptivity. Receptivity is an important contribution to the literature to inform the design and delivery of psychosocial support programs. One of the major practical contributions of this study is that it provides empirical data on the lived

experience of bereavement and factors that influence receptivity to support. This is important given that palliative care services continually endeavour to enhance bereavement support.