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

Submitted for the degree
Doctor of Philosophy

2017
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B.S.W.
Master of Palliative Care
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Declaration of Authorship

This thesis is the candidate's own work and contains no material which has been accepted for the award of any degree or diploma in any other institution.

To the best of the candidate's knowledge, the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

P. Blackburn
Candidate's Name

17th May 2017

Date

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Dedication

To my precious daughter, Mia, who always wanted to be a fairy when she grew up - but became an angel instead.

My arms still yearn for our snuggles,

My ears still yearn to hear your beautiful singing voice and your gutsy belly laugh,

My lips still yearn to smother you with kisses

My eyes still yearn to behold your beautiful eyes and smile, and to watch you in all your wonder

My nose still yearns to inhale your beautiful smell of strawberries and sunshine

My mind yearns to know the girl you would have grown in to, and the woman that you would have become.

For it is in the yearning, that memories and love endure.

This is for you.

This is because of you.

I love you.

I miss you.



To my beautiful sister, Terri. You shaped so much of the woman I am. Your never-ending faith in me that I could achieve anything I set my mind to, is your legacy. The world is a lesser and smaller place without you in it. This is also for you. I miss you every day. I love you.



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Abstract

Background: Palliative care services are primary organisations that provide bereavement support in Australia and aim to mitigate potential adverse outcomes of grief and bereavement. The success of bereavement services depends, in part, on how ‘receptive’ the bereaved are to receiving support. Although palliative care services provide support services for bereaved carers and families, there still remains a discord between what is delivered, what is needed and factors that deter or encourage a person’s receptiveness to support.

Purpose: The aim of this research was to examine utilisation of bereavement support through the ‘lens’ of receptivity. Bereavement and receptivity are complex multifactorial phenomena. This study aims to contribute further insights on receptivity to better inform bereavement service design and delivery.

Method: A qualitative descriptive research design was utilised in order to remain close to the complexity and richness of participant stories. Experiences of bereaved individuals and health professionals who provide bereavement support were explored. Participants were recruited via rural palliative care services. Thirty-four interviews were completed using open ended questions within semi-structured interviews, were transcribed verbatim and thematically analysed.

Results: Diaspora was a key theme that emerged from the findings of this study and transformed into a conceptual framework, *bereavement diaspora*. *Bereavement diaspora* integrates the key themes from the findings which include: 1) *existential diaspora*, 2) coping, 3) relationships, and 4) language. *Bereavement diaspora* situates the bereaved individual within the intrapsychic, socio-cultural, socio-political and temporal contexts which all interact to influence the experience of bereavement. It is through the *bereavement diaspora* perspective that receptivity was examined and facilitators and barriers of receptivity to support were identified.

Conclusion: *Bereavement diaspora* integrates the many factors that impact on the bereavement experience and demonstrates how the individual and broader social and systemic issues influence receptivity to support. Findings from this study provide further insights into receptivity to bereavement support which can inform palliative care bereavement support program design and delivery.

Chapter 1: Bereavement support in palliative care and receptivity of the bereaved

Introduction

This chapter will present an overview of the aim or purpose of the thesis and its genesis, including reflections of personal and professional influences of the researcher. The issue of receptivity in bereavement support explored in this study was identified through the researcher's clinical practice and also informed by personal experiences of bereavement. Perspectives of bereaved individuals and health professionals living and working in rural, regional and remote Western Australia inform the findings of this research. In order to remain close to the complexity and richness of participant's narratives and reflections, a qualitative descriptive research design was adopted for this study. Researcher reflexivity articulating values and assumptions and how these shape the study is a core component of qualitative research. The process of researcher reflexivity provided insights into how the research process was monitored and consistently re-oriented by the researcher (Dwyer & Buckle, 2009).

This chapter sets the scene of this research, with a dominant focus on researcher reflections. The 'voice of the researcher' and reflexive insights will be explored in this chapter by articulating the researchers' position within this study. As this chapter has a dominant focus on researcher reflections, the author will speak in the first-person voice. How findings from this research contribute to the broader field of bereavement will also be discussed, along with a chapter overview of the thesis.

Genesis of the Research

“...the effect we have on other people is in turn passed on to others, much as the ripples in a pond go on and on until they're no longer visible but continuing on a nano level. The idea that we can leave something of ourselves, even beyond our knowing, offers a potent answer to those who claim that

meaninglessness inevitably flows from one's finiteness and transiency..."
(Yalom, 2009, p.83).

It is this concept of 'ripples' that was the catalyst for this research. Unfortunately, people do not often feel the effects, or have gratitude for, the ripples of positive legacies left behind following the death of a significant person. This research only has the richness it does because of the ripples left behind from others who have died and from the bereaved, sharing their experiences of love, loss, grief and transformation.

My interest in bereavement support within palliative care¹ services arose from my frustration at trying to integrate clinical social work practice within current clinical system and practice constraints. In my role, I was provided with the 'bereavement program' which involved contact at specified timeframes post death, a phone call at two to four weeks, then again at three months, six months and a card and phone call at 12 months. The aim of the contact was to provide emotional support. At times, I felt I was being intrusive as some of the bereaved families I contacted were not known to me or sometimes those that were, I felt I was intruding into their grief. I also did not feel adequately equipped with the skills to provide bereavement support. I asked questions of my colleagues and managers about why the program was structured in the way that it was. The response was "because that's just the way that it is done". In my role, I did a lot of social work oriented activities for bereaved individuals and families related to providing information, or assisting with the practical matters after death, however this was never considered part of the 'bereavement program'.

Bereavement support programs currently adopt generic universal approaches to providing support within prescriptive timeframes. From my perspective, existing bereavement support programs seemed more about meeting organisational administrative processes.

¹ Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2002).

These processes include completing bereavement risk assessment tools and demonstrating contact had been made with the bereaved within specific timeframes. However, these processes did not demonstrate meaningful and individualised approaches to supporting the bereaved. When I explored the genesis of current bereavement support practices in palliative care, there was no evidence that palliative care bereavement programs were informed by any empirical evidence base, yet the same program structure was, and continues to be, replicated both nationally and internationally.

Additional insights through my own personal experiences of bereavement, enabled me to understand the lived experience of bereavement. With my own personal experiences, I was contacted by palliative care services and at that time I felt that people were being 'intrusive' into my grief. I did not give people permission to contact me and felt that I would seek support if I required. Working in palliative care provided me with insights into how bereavement support was structured. If I was to change practice, I realised I would have to undertake further study and contribute to the bereavement research and ultimately, change practice.

As bereavement is a complex, individual and multifactorial phenomenon, Qualitative Descriptive Research (QDR) was the method intended to use from the outset. In acknowledging the complexity of bereavement, I wanted to explore the multiple experiences of the bereaved and also the health professionals in order to gain in-depth insights. Qualitative research gives voice to the multiple perspectives of a phenomenon. I wanted to explore if there were different ways of providing support and what support was meaningful. As the famous quote from movie, *Field of Dreams* says: "...if you build it, he will come...". It is not enough to design a service and expect people to engage in it. If palliative care services are to change the way bereavement support is provided, at the core of effecting change, is whether the bereaved are receptive to support.

The purpose of this study

This study explores the concept of receptivity in the implementation of bereavement programs by health and palliative care services in rural, regional and remote settings of Western Australia. As a clinician, I have predominantly worked in rural, regional and remote areas in Australia, Scotland and England and have an interest in the unique context of rural practice. I have an interest in the ‘culture’ of country people. I have a specific interest in bereavement.

Bereavement support by palliative care services is an important service to the community. However, features of bereavement programs that I was particularly concerned about include a) no consent process in place from the bereaved² to participate in bereavement support programs; and b) although bereavement support was available, many bereaved families I worked with did not utilise this support. Although there was access to bereavement support, there was little uptake. I became curious about what would make people more receptive to support. Exploring receptivity to support will provide a different perspective to inform service development and provision. For the purpose of this study, the following definition of receptivity was adopted;

“...the range of factors (individual, social and geographical) that affect an individual’s desire or ability to receive or engage with supportive care services designed to meet his or her needs...”

(McGrath, 2013, p.36)

The success of bereavement services depends in part on how ‘receptive’ bereaved family members and friends are to receiving support. Although palliative care services provide support services for bereaved carers and families, there still remains a discord between

² Bereavement programs currently adopt universal approaches of contacting the bereaved without prior consent. Filmer (2002) and Walsh, Foreman, Curry, O’Driscoll & McCormack (2008) highlight that unsolicited contact or advice can be intrusive. However, Breen and O’Connor (2011) argue there is an operating assumption by service providers that the bereaved are aware of their own need for help and that they are willing and are able to seek help.

what is delivered, what is needed and factors that deter or encourage a person's receptiveness to support. The aim of this research was to examine utilisation of bereavement support through the 'lens' of receptivity. The research question which is the focus of this research is: **What are the factors that influence bereaved individuals in rural, regional and remote Western Australia to be *receptive*, or otherwise, to bereavement support from palliative care services?**

What will this study contribute?

Questions of service utilisation and receptivity provide a fresh approach to analysing bereavement support, moving the focus from service-provider centric practices to consumer-centric reasons for engagement (McGrath, 2013, p.46). Although data from this research highlighted factors that influence receptivity, serendipitously, this study also surprised me and provided a new insight to understanding the lived experience of bereavement. Analysis of the findings revealed a new concept – attributed to the theme Diaspora.³ At the time of embarking on my PhD, diaspora was not a concept with which I had anticipated being a key theme in regard to the topic of my thesis. However, the more I listened to the stories of participants, the diaspora metaphor was consistently visualised in my mind.

I first became familiar with the concept of diaspora through an interest in history, particularly after watching the movie *Sophie's Choice* in the early 1980's. The protagonist of the story, Sophie, was a Polish woman interned in Auschwitz concentration camp and was given an unbearable choice, she was forced between choosing which one of her children could go with her and live, and which child would be left behind and be killed.

³ Academic constructions of Diaspora have changed over the decades. The use of Diaspora for the purpose of this research does not, in any way, have the intention of diminishing or disrespecting the historical etymology or origins of the term and the experiences of Diasporic individuals. The concepts and themes within the Diaspora discourse mirror many features of bereavement. Further details of the application of Diaspora in bereavement are discussed in chapters four to nine.

The story of Sophie was one of torment about her choice, of finding herself in a world in which she had no control, where she felt powerless, and in a world, that was foreign to her. This sparked my interest in the plight of the Jewish people, and introduced me to the concept of diaspora. I had gained further insights into this concept over the years from literature and film about Jewish diaspora. I also visited the Museum of Tolerance in Los Angeles and Verzetsmuseum, the Dutch Resistance Museum in Amsterdam in 2011.

The concept of diaspora provided a different perspective into the bereavement experience. It is hoped this perspective may enhance clinician knowledge and skills, and vicariously inform bereavement support services and clinical practice. A change in practice may also lead to enhancing receptivity by the bereaved to support. Receptivity to bereavement support, framed within a Diaspora concept, will contribute new insights to the empirical literature on bereavement.

Reflexivity: The voice of the researcher

Knowledge is inherently constructed and sustained by social processes. Reflexivity is integral to research in human sciences, recognising discursive possibilities that deepen our understanding of the lived experience of others. Researchers' reflexivity should acknowledge the interactions between the researcher and research participants, and recognise how this inter-subjectivity produces different versions of knowledge (Colombo, 2003). Within stories, there are a multiplicity of complex conceptual structures (Sarbin, 1986 cited in Colombo, 2003, n.p.). The researcher must position themselves so that they reflect on self-understanding and also in understanding others. Positioning themselves within and outside the research enables the researcher to note differences and similarities between researcher and participants. This can enhance the validity of the research as Whittlemore, Chase and Mandle (2001, p.532) state, "...reflexivity, open inquiry and critical analysis of all aspects of inquiry contribute to validity in qualitative research..." (p.532). Dwyer and Buckle (2009, p.55) highlight the paradox of the researcher citing Maykut and Morhouse (1994, p.123);

[T]he qualitative researcher's perspective is perhaps a paradoxical one. It is to be acutely tuned in to the experiences and meaning system of others – to indwell – and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand.

Qualitative researchers are not separate from the study as they are embedded in all aspects of the research process. Qualitative research is described as having a level of intimacy which does not accommodate true outsider perspective of the experience under study (Dwyer & Buckle, 2009). Sullivan (2002, n.p.) reinforces the influence of the researcher, citing Monk (2001, p.9) who discussed the work of Wittgenstein (1953) "...we have an inner life, that we have thoughts that we do not share with other people and desires that we deny even to ourselves..." Dwyer and Buckle (2009) assert that an outsider perspective might conceptualise an experience more adequately as this will reduce the risk of professionals or researchers who are enmeshed in their own experience, and are unable to distance their experiences from the experience of the client, or participant.

Roth and Breuer (2003) highlight that the research *per se* is inextricably tied with the researcher and recognises the biographical experiences of the researcher and how this shapes a research study. Researchers may identify contradictions in their study and this contributes not only to growth in knowledge but growth in the researchers' identity as well (Roth & Breuer, 2003). Sullivan (2002, n.p.) reiterates the role of the researcher and how "...our own perspective and experience enter into, transform or change the issue or area being investigated...". If researchers have experienced a similar phenomenon, such as bereavement, this may place them in a position of 'insider' but this does not mean they are a better or worse researcher, just a different type of researcher (Dwyer & Buckle, 2009, p.56).

I specifically chose Descriptive Qualitative Research as my methodology as I wanted to remain close to the voices of participants and their stories, in order to minimise the influence of my own beliefs and assumptions in interpreting results. Detailed reflexivity of my own assumptions and values and subjectivity within the research process required

disciplined bracketing in order to help reduce potential concerns regarding ‘insider’ membership (Dwyer & Buckle, 2009).

Bolam, Gleeson and Murphy (2003) posit that the debate on reflexivity in qualitative research is often targeted at the level of methodology however, they articulate how qualitative investigators can move from theory to research praxis. The role of the researcher is acknowledged in the development, process, interpretation and documentation, or write-up. It is imperative the researcher’s reflexivity throughout these processes is made transparent. Researchers are considered as being positioned as ‘insiders’ and ‘outsiders’ in the research process. For example, the author was positioned as an ‘insider’ in some respects in relation to shared characteristics such as experiencing bereavement and being a recipient of palliative care services. My own philosophical commitment to the study that led to qualitative methods and a desire to be as close to the voices of the participants *per se*, provided the framework in which I was positioned more closely as a ‘lay person’ rather than a position of ‘expert’ (Bolam, Gleeson & Murphy, 2003).

Dwyer and Buckle (2009) argue that researchers occupy the position of both insider and outsider and that data collection and analysis is influenced by the intimate role the researcher plays in qualitative methodology. Insider researcher refers to researchers who conduct research with population groups of which they are members, hence share an experiential base, identity and language with study participants. The personhood of the researcher, a constant present aspect to the investigation, warrants that the researcher be aware they may be a part of the culture under study, but may not understand the subculture and this is where ‘bracketing’ of assumptions needs to occur. Dwyer and Buckle (2009, p.55) cite Rose (1985, p.77) who states “...there is no neutrality. There is only greater or less awareness of one’s biases...” In fully engaging in researcher reflexivity throughout the study, my values and assumptions were a ‘compass’ to which I consistently re-oriented myself throughout the research process, asking myself, what is ‘their stuff’ and what is

‘my stuff’?⁴ If I even thought there was an inkling I was looking through the lens of ‘my stuff’, I would repeatedly go back to the data to ensure ‘my stuff’ was bracketed.

I was cognisant of bracketing my own experience, knowledge and assumptions to ensure the participant’s voice was promoted. As Sullivan (2002, n.p.) reflects, there is a potential risk for “...qualitative researchers to become connoisseurs of the inner lives and narratives of others...” Reflexivity can help qualitative researchers achieve clarity about the interrelations between their work and personal life. If a researcher is heavily influenced by a particular theory which distorts the research processes, or the researcher lacks a sensitivity to the narratives of the research participants, this may lead to inconsistency in researcher reflexivity (Sullivan, 2002).

Reflective processes involve thinking about something more closely than usual to try and gain a fresh perspective or understanding of a subject. Although meaning is situated in the data, finding the meaning is an active and analytical process engaged in by the researcher who allows some meanings to emerge and others to diminish through the method used that serves as the lens. I was committed to ensure reflexivity was consistent in this research in order to ensure participants’ voices were represented honestly and accurately (Sullivan, 2002). In order to be reflexive as possible, it was essential to reflect on professional and personal factors that inform the research.

The professional

The importance of the therapeutic relationship has always been emphasised as an integral part of clinical social work education and practice, this has never been more evident than

⁴ According to Corey (2005), when counsellors engage in a therapeutic relationship, they must be aware of their own “...conflicts, needs, assets and liabilities...” (p.21). This is called counter-transference which describes the process of counsellors seeing themselves in their clients or over-identifying or meeting their own needs through their clients. I have used the vernacular of ‘stuff’ to encompass this notion of counter-transference. Awareness of counter-transference is just as important in researchers as it is with therapists and counsellors. The researcher needs to be constantly self-reflexive on what they are projecting on to participants. If they are using the research more for their own purposes than for being available to the participants and their stories, this becomes an ethical issue.

in my role working in palliative care. My clinical role in a regional Western Australian health palliative care service centres on the provision of interventions that aim to empower and equip families with the skills and resources to reduce stressors from all aspects of their lives. Working in palliative care, I use myself inter-subjectively. I bear witness and hold intimate spaces for those in their suffering, and I “companion” them on their journey. I companion those who are dying and their loved ones, both prior to the death and then in bereavement. The tenets of companioning are very much reflective of the positive therapeutic relationship and although these tenets have been applied to supporting those who are bereaved (Wolfelt, 2005), they apply to working with people who are living until they die. Companioning:

is about honouring the spirit, it is not about focusing on the intellect.

is about curiosity, it is not about expertise.

is about learning from others, it is not about teaching them.

is about walking alongside, it is not about leading or being led.

is about being still, it is not about frantic movement forward.

is about discovering gifts of sacred silence, it is not about filling every painful moment with talk.

is about bearing witness to the struggles of others, it is not about judging or directing those struggles.

is about being present to another person’s pain, it is not about taking away or relieving with pain.

is about respecting disorder and confusion, it is not about imposing order and logic.

is about going to the wilderness of the soul with another human being, it is not about thinking you are responsible for finding the way out.

(Alan D. Wolfelt, 2005)

This notion of companioning and the importance of therapeutic relationship underpin my core practice values. In my current role, I recognise significant challenges of working within current frameworks and guidelines for bereavement services, or programs that are situated more within a medical or psychological model. In my experience, these perspectives adopt pathologising and deficit based approaches to working with those who

are bereaved. As a social work clinician, I prefer to adopt a strengths-based approach and a person-in-environment perspective that views the individual and their multiple environments as an interactive and dynamic interdependent system, each component simultaneously affects, and is affected by, the other. This approach recognises the individual in the context of all the systems in which they have reciprocal relationships, the environment in which the individual is placed, and all the mutual inter-relationships that occur between the various subsystems with the individual (Harris, 2009-2010). This approach integrates medical, psychological, spiritual, social and anthropological aspects.

Contemporary bereavement theories often do not incorporate all factors impacting an individual's life. The challenge I face as a clinician is trying to practice within contemporary policy and practice modalities whilst reconciling these with clinical practice. This tension led me to co-develop a framework to help guide clinicians to deliver bereavement support that is holistic and contemporary (Blackburn & Dwyer, 2016). I draw on best practice research, however my clinical practice wisdom and personal experience has provided insights that have helped shape my practice and inform my work in this field.

The personal

My first introduction to palliative care and bereavement was following the diagnosis of a rare brain tumour in my daughter, Mia. Mia was diagnosed when we were living and working in the UK and given a short prognosis of weeks to live, she died 40 days after diagnosis. In a whirlwind, we returned to Australia, had nowhere to live, no source of income, no jobs and chaos reigned around us. I was paralysed with terror. I was powerless to protect my baby and support my family in their grief. The story of Mia is a long one and I doubt I would have the verbal language that could adequately portray the devastation of the loss of my child, my experience, and that time in my life, and yet my six-year-old daughter poignantly told me one day what dying was like for her: "*Mummy. I feel like I'm crying hard inside my heart.*" She knew she was dying, she knew we were devastated and

that we would be sad for the rest of our lives (portrayed in the stories she wrote). The devastation of her loss continues to have an impact, ten years later.

On the anniversary of her death, her final hour plays through my head vividly over and over again. From the moment she started making noise, to gently bathing her and turning her over when she opened her eyes. It was the first time she had opened her eyes in two days, she looked straight into my eyes and was making a sound. Her eyes were so clear, a clarity I had not seen for over a week, a clarity that indicated she was trying to tell me something. Perhaps that it was her time to go? She once told me during her illness that she would tell me when the angels would come to take her to heaven. Despite never talking to her about God or Jesus, she also asserted one day “*Mummy, Jesus will be there waiting for me you know.*” In the last minutes of her death, we turned her on to her back, her eyes flicked opened, I could hear the sound of the first school siren in the distance (we lived near a number of primary schools). Her pupils grew gradually larger and larger; her brain was dying. Her heart was so strong, it continued to beat, with the final beat of her heart stopping to the distant sound of the second school siren. These images, return over and over in my head with vivid clarity, every anniversary, of every year.

I held her gently as the light left her exquisite blue eyes, whispering words of love the whole time “thank you sweetheart for the years you’ve given us”, “thank you baby, for being such a beautiful daughter and sister”, “we’re going to miss you”, “it’s ok to go,” ”you’ll be ok” and “we’ll see you again” – all the while my inner essence, my core, the depths of my soul was exploding, shattering, obliterating, splintering, into infinite painful particles simultaneously to the background of the metronomic scream in my head crying “don’t go, DON’T go, DON’T GO!”.

(Personal journal entry, 9/6/16 on the 10th anniversary of Mia’s death, forever 6 years old).

The death of my precious six-year-old daughter launched me into a world that was so very foreign to me, I lost who I was, who we were as a family, our security and safety in the world. I lost who I was going to be and I lost so much of my future. So much of me died

that day, a light extinguished forever, a piece of my heart and soul irrevocably lost. My time since has been of rebuilding a life, supporting my family and trying to change the way clinicians understand and work with bereavement. I have studied dying, death, grief, loss and bereavement for nearly ten years and have learned there is a name for almost all types of grief or loss but the death of a child is so profound, there is no label, except that of 'bereaved parents.' Mia's death has led me, albeit serendipitously, into the field of palliative care and bereavement.

During my PhD candidature, I experienced another devastating loss, the loss of my sister, best friend and confidante. I had been working in palliative care for some time then, so knew what to expect and used my skills to be a companion and clinician. The death of my sister re-affirmed my motivation and desire to understand bereavement, what makes people receptive to support and how this can contribute to informing the development and delivery of bereavement support.

I was privileged to do dignity therapy with Terri and an excerpt describes below her thoughts about life after death and what she has left behind;

I don't know where I will be going to, I really don't. That's what makes it a big adventure... Stepping off into the unknown....and you hope...you hope...that what you have always believed will be there, WILL be there. In fact, you know it will...you just don't know in what form it will be. I know something will be there because it's too profound not to have a continuation...far too profound. Just as everyone leaves a legacy on your life, you hope you have left some kind of legacy on theirs.

(Terri Davidson, Dignity Therapy session, 11th March 2013)

Terri died a little over one month later after completing her dignity therapy. Both Mia and Terri have left profound legacies on my life. Although my work and my PhD is Mia's legacy, both Mia and Terri have shaped me and helped me become the woman and clinician that I am. The world has been a far more beautiful, love-and-laughter-filled world because they were in it - and blessed my life. My life has been richer, happier, compassion-

filled and humbling because they made sure I felt, and knew, I was worthy of their unconditional love. I could not think of greater gifts to bestow on another human being than the gift of wholesome, absolute and pure love. This is their ‘ripples’.

There are two key lessons I have learned from Mia and Terri, humility and wisdom. It is through my work, I feel they continue to leave their footprints on the world, I honour them in my work and in my personal life. As Steve Maraboli (2009) said;

I don't want my life to be defined by what is etched on a tombstone. I want it to be defined in what is etched in the lives and hearts of those I've touched.

I only hope to continue to touch the lives and hearts of my friends and family, my colleagues and my clients in a positive way. In the time I have on this earth I would like to leave a legacy of compassion, love, laughter and wisdom on others, honouring the love Mia and Terri brought into this world and my life. These will be my ‘ripples’.

Although my personal experiences have been the primary motivator for this research. My desire to provide meaningful and individualised bereavement support based on my clinical experiences are concurrent motivators for undertaking this research.

Making the unconscious conscious: Assumptions and attitudes

Examination of my own assumptions enabled me to reduce my own ‘researcher angst’ of interpreting results based on my own assumptions and values and not being truly attentive to what participants were saying. The process of ‘bracketing’ my own assumptions began with asking myself some pertinent questions. How did I make the unconscious conscious? By identifying my own assumptions and values I have about bereavement, support in bereavement and factors that may influence receptivity, I was able to orient myself to analyse the data as objectively as possible. I asked myself “What is the participant saying?” “Is it really what they are saying, or am I putting my own interpretation on it based on what I think they are saying, or based on my own assumptions?” “What are the assumptions I hold about the research topic?” Another question I asked myself as part of

engaging in researcher reflexivity was “What are my values and life experiences? How do my values and experiences shape how I read and interpret the data?”

Potter and Wetherill (1987, p.33-34), cited in Colombo (2003, n.p.) use an analogy of construction that depicts processes of reflexivity. A researcher and participant bring to the research pre-existing experiences, assumptions, knowledge and values which are representative of the bricks and beams which form the foundations of a building. As the building is constructed, some resources are omitted and some included. This represents the ‘filters’ of the researcher and participant in terms of what is paid attention to, what is shared or not shared in the narrative or interview process. The final notion of construction is viewed as the consequential nature of accounts ie. the finished building. Similarly, the research study findings and implications are revealed or ‘constructed’ following analysis of the data (Colombo, 2003). Meek (2003, n.p.) states “unconscious mental processing is a necessary part of qualitative research, lying under what we call ‘reflective processing.’” As part of reflecting on my role and how it might influence the research, I stayed committed to my own personal values of taking the individuals’ lead, being invited into their story and acknowledge that they are the experts of their experiences and that I have a lot to learn from the stories of others. I want to authentically represent the ‘ripples’ of participants and their deceased loved ones. The findings based on the stories of participants are discussed over six chapters.

Overview of the thesis

This thesis is discussed over ten chapters. The introduction chapter (1) frames the genesis and background to the research question. I have outlined my personal and professional interest in the topic and reflected on assumptions. The introduction provides a brief overview of the chapters, discussed below.

Chapter two (2) provides in-depth discussion into the evolution of bereavement theories over the decades and how this has informed bereavement programs in the palliative care

setting. Palliative care and bereavement support will be discussed within state-wide, national and international contexts. To conclude this chapter, an overview of the concept of receptivity will be discussed.

Chapter three (3) discusses the methodological procedures undertaken for the data collection, analysis, ethical considerations, limitations of the study and includes a profile of the sample demographics and an introduction of the core findings. This chapter also references *Appendices A to D* which provides the documentation for ethics approval, patient information sheets, consent process and interview schedules for each of the participant cohorts.

The following chapter four (4), discusses the findings from the data in-depth and provides an overview of the core theme, *Bereavement Diaspora* and how this has subsequently been conceptualised. Insights from the bereaved, health professionals and Aboriginal health professionals will be discussed.

Chapter five (5) discusses the concept of *Existential Diaspora* and how concepts of the diaspora and existential literature provide insights from the voice of participants of the psychological, emotional and spiritual impact of bereavement.

Chapter six (6) discusses coping as it relates to the Diaspora and the multiple ways the bereaved cope with their experience and how staff cope in working in this field.

The next chapter, seven (7), explores the role of relationships and how they influence the Diaspora experience. Data from the bereaved and respective health professional cohorts will provide insights into the role of relationship in bereavement.

As language and discourse is such an inherent process of how people interact with their world, the discourse as it relates to bereavement and what evolved from the research will

be discussed in Chapter eight (8). The influence of discourse on receptivity will be explored.

Receptivity issues that emerged from the data, will be discussed in Chapter nine (9) and these will include enablers and barriers of receptivity that emerged from the data. This chapter also references *Appendix E* which provides an overview of receptivity issues from chapters five to eight that have been examined through the lens of diaspora, *Appendix F* which outlines desired characteristics and technical skills of health professionals and *Appendix G*, which provides a table of receptivity enablers and barriers to bereavement support.

The final chapter, ten (10), concludes with implications for research and practice and recommendations.

Conclusion

In this chapter, the personal and professional background which informs this research project was discussed. As this research adopts a descriptive qualitative research design, researcher reflexivity is a critical part of engaging in the research process. The voice of the author in this process was discussed in reflections on the personal and professional ‘self’ of the researcher.

The issue of receptivity in bereavement explored in this study was identified within the researcher’s clinical practice, and also informed by personal experiences of bereavement. The concept of receptivity is the foundation of this research and is a new area of scholarship to bereavement. The findings from this research identified receptivity factors however revealed another perspective of exploring bereavement, through the lens of Diaspora. This is a new contribution to the bereavement discourse.

In the following chapter, further contextualisation of the research through the exploration of bereavement theories and models which have informed palliative care bereavement programs, and a discussion of receptivity as it relates to help-seeking behaviours will be discussed.

Chapter 2: Setting the Context

Introduction

The previous chapter outlined the genesis of the research, personal and professional influences and discussed the voice of the researcher through reflexive exploration. This chapter sets the scene for bereavement and palliative care as the context through which the concept of receptivity is explored. An outline of grief, loss and bereavement will be discussed, highlighting the effect of theoretical influences on bereavement programs in palliative care. A discussion of bereavement support in palliative care in relation to policy issues, assessment practices and service delivery from national and international perspectives will also be explored. Due to the fact that this research has a specific focus on country areas in Western Australia, broader rural issues and Aboriginal perspectives around bereavement support will also be briefly be discussed. This chapter will conclude with a discussion on support needs of the bereaved, receptivity as a concept and the application of receptivity to bereavement support.

Grief, Loss and Bereavement

Clarifying the concepts: Grief and Bereavement

The literature on grief and bereavement often use the terms interchangeably and palliative care services typically provide grief support under the umbrella of a bereavement program. Grief is defined as a “...primarily emotional (affective) reaction to the loss of a loved one through death. It is a normal, natural reaction to loss...” (Stroebe, Hansson, Schut & Stroebe, 2008, p.5). Bereavement is defined as a ‘...broad term that encompasses the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one...’ (Christ, Bonanno, Malkinson, & Rubin, 2003, p.554). Thus the experience of bereavement not only encompasses internal psychological processes, but also includes individual’s and family members’ adaptation and experiences of grief as a response to changes in external

circumstances. This can include alterations in relationships and living arrangements amongst other changes (Stroebe et al., 2008).

In this research, bereavement is understood as encompassing the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one. It encompasses psychological processes, adaptation of individuals and family members, impact on physical, psychological, emotional, spiritual, behavioural, social, financial and vocational domains. This includes alterations in relationships and living arrangements, tasks of daily living and difference in duration and intensity of secondary impacts following the death of a loved one (Schulz et al., 2001; Stebbins, & Batrouney, 2007; Breen & O'Connor, 2011).

Bereavement Research

The most extensively studied phenomenon of adult loss has been that of bereavement (Lendrum & Syme, 2004). Bereavement has been linked to a variety of psychological and somatic complaints and thus, has been associated with increased mortality and a higher incidence of chronic disease (Schulz & Beach, 1999; Schulz, Beach et. al. 2001). Research into bereavement has primarily focussed on medical and psychological perspectives where coping is viewed as 'adaptive' or 'maladaptive'⁵ and interventions or treatment may be required. These perspectives have contributed to the pathologising of grief in bereavement which will be explored later in this chapter. However, contemporary research is now

⁵ The terms 'adaptive' and 'maladaptive' coping are commonly found in the bereavement literature. 'Adaptive' coping refers to the use of positive or constructive coping behaviours that enable people to adapt with the changes that occur as a result of the bereavement. Examples of adaptive coping behaviours include utilising social support, attending to health needs and counselling. Negative or 'maladaptive' coping strategies indicate people are not adjusting to changes which is impacting on their ability to function and care for themselves in a health way. Maladaptive coping can be manifest through behaviours such as avoidance, artificial stimulation (drugs, alcohol), dissociation and depression. Dynamic coping processes in bereavement include cognitive focussed strategies such as appraisal or problem focussed coping; emotion focussed and occupation or behaviourally focussed strategies (Meagher & Balk, 2013; Stroebe, Hansson, Schut & Stroebe, 2011; Neimeyer, Harris, Winokuer & Thornton, 2011).

beginning to consider the impact of bereavement on the many facets of an individual's life. There is increasing exploration of the social and economic burden of bereavement as well as differences in individual processing of death (Schulz et al., 2001; Stebbins, & Batrouney, 2007; Breen & O'Connor, 2011; MacDuff, 2013).

Contemporary bereavement research continues to contribute different perspectives to the evidence base. Rumbold and Aoun (2015) have conducted studies into a public health model approach, advocating for strengthening community social networks, known as an 'assets based approach.' Neurobiological and psychological sciences continue to examine the impact on bereavement. For example, neuropsychology studies have explored the impact of grief on executive functioning (Fernandez-Alcantara et al., 2016), trauma and depression in bereavement continue to be explored in the research (Barle, Wortman & Latack, 2015; MacCallum, Galatzer-Levy & Bonanno, 2015; Moriarty, Maguire, O'Reilly & McCann, 2015) and funding was granted in 2015 for a three-year study on the role of oxytocin in reversing the biological and psychological factors associated with complicated grief (Dana Foundation, 2015). There are cultural studies exploring bereavement in countries where palliative care and thus bereavement support is relatively new, such as China and Japan (Morgan, 2016; Breen, Aoun, O'Connor & Rumbold, 2014). In the past decade, there has been a surge in research examining the role of technology in bereavement (Gibson, 2015; Frost, 2014; Rossetto, Lannutti & Strauman, 2015). Despite the extant literature however, there still remains a lack of definitional clarity of bereavement in the literature.

Impact of bereavement on family and community

Death affects the family system in a variety of ways. With the death of a family member, the 'wholeness' of the family is often temporarily broken, and the family has to reconstitute itself to become whole again. Roles that family members typically played may be disrupted. Furthermore, roles other than those that describe a person's place in the family structure such as father, husband, mother, daughter, brother etc., may also be

affected (Clarke & Goldney, 2000; Fletcher, 2002; Buckle & Fleming, 2011). Firth (2005) cited in Firth, Luff and Oliviere (2005, p.187) argued that the experience of grief is not universal, but socially constructed. A variety of factors that influence how individuals 'process' their grief, derive from the culture, their gender, age and the family or community context. (Doka & Martin, 1998; Benkel, Murray, 2001; Wijk & Molander, 2009; Aho, Asted-Kurki, Tarkka & Kauonen, 2010).

Death can affect the broader community of family, friends and community with whom we are connected such as a sporting teams, work colleagues or online friendships. There is limited literature on the impact of death and the bereavement experiences of people who resided or interacted in the community of the deceased such as nursing homes (Moss, Moss, Rubinstein & Black, 2003), prisons (Ferszt, 2002; Olson & McEwan, 2004) and 'virtual' communities (Walter, Hourizi, Moncur & Pitsillides, 2011-2012; Kasket, 2010; Maddrell, 2012; Pennington, 2013) and the way people respond to and experience bereavement varies. Contextual issues play a significant role in how an individual adapts to a significant event (Bussolari & Goddell, 2009; Murray, 2001; Murray, 2002). The impact of grief, loss and bereavement is broad in scope (MacDuff, 2013; Breen & O'Connor, 2011) however current approaches to assessing and measuring bereavement focus on intrapsychic dynamics to the exclusion of the interdependent systems that interact with an individual.

An increasing need for bereavement support is likely in light of societal changes particularly urbanisation whereby there is a breakdown of the extended family unit and informal support networks due to people having moved away from their family, friends and local communities, alongside a rise in secularisation and loss of rituals (Silverman, 2005; Field, Hockey & Small, 2002). As a result, people may increasingly find a need to access professional bereavement support services. As palliative care services are a primary organisation that provides bereavement support in Australia, the demand for bereavement support may increase, burdening the often under-resourced services further. Palliative Care Services aim to improve bereavement support and to mitigate potential adverse outcomes of grief and bereavement such as increased psychosocial morbidity including

depression, anxiety, suicide risk, poverty and social isolation. The role of bereavement programs in palliative care services is discussed later in this chapter. However, to understand what informs bereavement support in palliative care, we need to look at the evolution of grief and bereavement theories and how these have informed and shaped palliative care bereavement programs.

Theoretical perspectives of grief and bereavement

The medical model has characteristically provided the dominant framework within palliative care services for understanding and working with grief, often including a diagnosis and interventions which are pharmacologically or psychologically based. Bereavement assessments are typically conducted through the use of a cumulative checklist⁶ of factors to identify potential bereaved people who may be deemed to be at risk of prolonged grief disorder (or complicated grief) (Kubler-Ross, 1970; Sanders, 1989; Worden, 1991; Agnew, Mangkletow, Taylor & Jones, 2010). Freud's seminal work exploring depression arose out of his comparison of observable symptoms of grief with those of depression and in his paper, *Mourning and Melancholia* (1917 cited in Shapiro, 1996, p.5) and discussed in Rothaupt & Becker, (2007), Freud endeavoured to articulate the grieving process and indicated the need for the grieving person to 'disengage' from the deceased and invest the grieving energy into something or someone else. This process of emotionally and psychologically disengaging from the deceased has been termed 'decathecting' (Rothaupt & Becker, 2007). The process of 'decathecting' is where the bereaved remember and reflect on memories associated with the deceased in order to sever the emotional connection, thus the emotional energy can be channelled into forming new bonds and relationships. The continued bonds or relationship with the deceased was

⁶ These instruments aim to identify those at high, medium or low risk of a difficult grief reaction. A separate BRI should be completed for each bereaved person as appropriate. The BRI is not intended to be completed by the bereaved person. The BRI is completed at the death of the patient by the primary nurse in consultation with the interdisciplinary team (information can be obtained any time from admission). Looks at risk factors **a**) children under 14 at home; **b**) occupation of principal wage earner; **c**) anticipated employment of bereaved person; **d**) clinging or pining (resistance to reality of patient's death); **e**) anger; **f**) self-reproach (self-blame / guilt / feeling bad and/or responsible); **g**) current relationships; **h**) how will key person cope? Risk category for total score is: high risk = 19 or higher; moderate risk = 13-18; low risk = 12 or lower (Agnew, Mangkletow, Taylor & Jones, 2010).

deemed as serving no healthy psychological purpose (Silverman, 2005; Klass & Chow, 2011). Zimmerman and Rodin (2004) argue that Freud's influence has been instrumental in bereavement interventions in the 20th century whereby the bereaved were encouraged to decathect. This approach resulted in the stifling of normal and natural feelings expressed in grief and failure to 'decathect' resulted in pathologised maladaptive responses for which 'treatment' or 'intervention' was required for 'maladjustment' (Hooyman & Kramer, 2006).

The next major influence on the conceptualisation of grief and bereavement in Western society was that of Elisabeth Kubler-Ross. Kubler-Ross developed a *five stages of dying* model, based on her research of the dying experience in the terminally ill. This model delineates five stages – denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1970). Other contributors to a wider, less pathologising view of grief and bereavement included Worden (1991), who was the first theorist to give the griever an active role in the process of grieving by delineating the grief process as 'tasks' rather than stages. These tasks include: accepting the loss, experiencing the pain, adjusting to the new environment without the deceased, and taking up new relationships and activities. This model places an emphasis on the behavioural and social aspects of grief (Worden, 1991). Bowlby (1980) hypothesised that the grief process reflects early attachment behaviours⁷ and that the experience of bereavement occurs within a cognitive behavioural framework (Pomeroy & Garcia, 2009).

Klass, Silverman and Nickman (1996), among others (Boss, 1999; Gamino, Sewell & Easterling, 2000), began a trend away from the historical medical model of grief that

⁷ Bowlby (1980) describes the psychological reorganisation that occurs following loss. This process entails four phases 1) numbness and denial (periodically disrupted by extreme and physically exhausting emotions); 2) yearning and searching (involves interpreting events as signs from loved ones and seeks out their [incorporeal] presence); 3) disorganisation and desolation (the person feels overwhelmed, depleted of energy; there is realisation attachment bond has been severed; there is subsequent re-evaluation of mourner's identity and self-concept which can lead to massive psychological upheaval); 4) gradual movement towards reorganisation (recognises need to construct a life without the deceased temporal presence) (Pomeroy & Garcia, 2009).

pathologised reactions and behaviours and introduced the notion that continuing bonds with the deceased could be adaptive or healthy coping. This is a significant change to historical practices in working with the bereaved where people are no longer expected to ‘de-cathect’ or forget about the deceased, but instead are encouraged and supported to maintain a relationship with the deceased that emotionally relocates them but continues (Klass, Silverman & Nickman, 1996). Process models such as the Dual Process Model (DPM) of coping in bereavement recognise the many concurrent stressors bereaved individuals contend with while attending to their grief. The DPM has key features of loss-orientated activities (that encourage grieving through affective, cognitive and behavioural means) and of restoration-oriented activities (which facilitate re-engagement in tasks, relationships and living). The bereaved adapt in bereavement through adopting dynamic coping strategies and processes that oscillate between loss and restoration oriented activities (Rubin, 1999; Stroebe & Schut, 1999). Hence bereavement should be viewed as 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).

Theories and models of grief, loss and bereavement have shaped clinical practice when working with the bereaved since Freud’s seminal work in 1917. It is the medical and psychological perspectives that have long influenced the way clinicians assist clients with ‘grief work’ and adaptation in bereavement. Contemporary models of grief and bereavement are starting to consider other factors that influence the bereavement experience and move away from coping and adaptation as a solely intrapsychic event. Bereavement programs have historically provided emotional support and screened for those needing more specialist psychological support, but are now endeavouring to expand services that foster connection with others through support groups, memorial services and education.

Bereavement Support in Palliative Care

Bereavement services were initially established to respond to an unanticipated demand for help to prevent the health problems and reduce the psychological and emotional distress associated with bereavement (Firth, Luff & Oliviere, 2005). Despite this need for bereavement support, research shows there is often a lack of managerial and organisation support in allocating sufficient financial and staff resources to bereavement programs. Breen, Aoun, O'Connor and Rumbold, (2014) highlight, there is a clear incongruity between practice and palliative care policy, particularly as palliative care budgets in Australia usually allocate less than 5% to the bereavement program component of the service.

In the case of bereavement support in Australia, palliative care services are the primary organisations for delivering bereavement care to families who had a significant person die from an expected and life limiting illness. Bereavement support is also provided by hospital, palliative care and hospice services, nationally and internationally. Bereavement support is an important area of service to the community that is increasingly being highlighted on service and policy agendas, particularly in palliative care services area.

Bereavement is a key area identified in palliative care quality initiatives, state and national policies and strategies. As bereavement is increasingly becoming a key agenda item for health and palliative care services in particular, there is an impetus to provide bereavement care informed by a sound evidence base and best practice (Commonwealth of Australia, 2010; Australian Institute of Health & Welfare, 2010). There is increasing emphasis on palliative care services to identify gaps in bereavement support and use quality initiatives to audit and benchmark their services. In Australia, the introduction of quality initiatives such as the National Standards Assessment Program⁸ and the Palliative Care Outcomes

⁸ The National Standards Assessment Program (NSAP) is a quality improvement program under the auspices of Palliative Care Australia. NSAP provides a continuous quality improvement framework for specialist palliative care services across Australia to benchmark against the *National Standards for Providing Quality Palliative Care for all Australians*. There are 13

Collaborative (PCOC) along with Caresearch, compel palliative care services to embrace quality as an inherent part of service delivery. Variability in bereavement programs may have been attributed to a lack of frameworks in the past however these quality initiatives and policies provide the framework for organisations in Australia to plan, develop, implement and evaluate bereavement services and standardise practices nationally and internationally (Palliative Care Australia, 2005; WA Cancer & Palliative Care Network, 2010; Commonwealth of Australia, 2010)

The “*National Palliative Care Strategy 2010*” outlines one of its goals to ‘...support a national bereavement care framework collaboration...’ (Commonwealth of Australia, 2010. p.9) and Palliative Care Australia’s (2005) “*Standards for Providing Quality Palliative Care for all Australians*” Standard 8 advocates that ‘...[f]ormal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services...’ (p.33). ‘*Clinical Practice guidelines for the psychosocial bereavement support of family caregivers of palliative care patients*’ (2010) are evidence based guidelines linked to national quality standards and were developed to inform bereavement support for palliative care services in Australia. The national strategy, quality standards and clinical guidelines provide the direction for expectations of palliative care services in Australia.

Despite national quality programs and strategies, the evidence suggests that palliative care bereavement services need to be strengthened so that the models or programs that shape service delivery meet the needs of the bereaved (Breen & O’Connor, 2011; Department of Health, 2012). Remedios, Thomas and Hudson (2011, p.49) assert that in relation to bereavement programs, there is ‘great variation in the nature and extent of these services’ and this has been attributed to limited resources, skill and knowledge base in relation to staff providing bereavement support as well as lack of managerial and organisational support in relation to allocating financial and staff resources to bereavement programs

Standards with quality elements that address quality of care and service governance (Palliative Care Australia, 2016).

(Relf, Machin & Arthur, 2008; Roberts & McGilloway, 2008; Remedios, Thomas & Hudson, 2011). Agnew, Mangkletow, Haynes and Jones (2011) highlight that the bereaved are often passive recipients in the current delivery of bereavement support as they are often not aware that they are being assessed for being 'at risk', unaware that information or data is being collected about them and thus bereavement programs are 'done to them'. Ideally, there needs to be working agreements between the palliative care service and the bereaved that promotes clarity regarding consent, service delivery, duty of care, assessment methods, care planning, confidentiality and complaints procedures (Agnew, Mangkletow, Haynes & Jones, 2011).

Bereavement support is often provided by palliative care services in Australia but is generally delivered in an ad hoc manner due to resource constraints and by staff with limited skills and the evidence base underpinning the efficacy of bereavement programs has been largely inconclusive (Relf, Machin & Arthur, 2008; Roberts & McGilloway, 2008; Remedios, Thomas & Hudson, 2011). Bereavement programs currently delivered by palliative care services tend to follow the same format – a condolence card and follow up phone calls or home visits at specified times ie. two to four (2-4) weeks, three (3) months, six (6) months and twelve months' post death. Universal approaches to current bereavement programs consist of phone calls, cards and memorial services within prescriptive time frames (Milberg, Olsson, Jakobsson, Olsson & Friedrichsen, 2008; Walsh, Foreman Curry, O'Driscoll & McCormack, 2008; Mather, Good, Cavenagh & Ravenscroft, 2008). In exploring the literature on international perspectives, the structure of bereavement programs is replicated internationally.

International perspectives on bereavement support in palliative care

Much of the research on grief, loss and bereavement has focussed on western perspectives. Grief evolved in the Western discourse in the middle of the 20th century within the context of researchers exploring the impact on mental health and illness in bereavement. Grief has primarily been researched in Western culture and thus led to the development of

‘Westernised’ concepts of deactivation, ‘maladaptive’ and ‘adaptive’ coping, ‘bereavement risk’ and ‘bereavement outcomes’. Psychological constructs of grief have limited what research questions are asked and has focussed research mainly on psychological and health outcomes (Keenan, 2010).

Bereavement programs delivered by health and palliative care services universally focus on the psychological or emotional impact of bereavement with the physical impact often being a secondary focus, particularly in Australia, the United Kingdom (UK), United States of America (USA) and Sweden (Snyder, Ellison & Neidig, 2002; Demmer, 2003; Forte, Hill, Pazder & Feudtner, 2004; Roberts & McGilloway, 2008; O’Connor, Abbot, Payne & Demmer, 2009; Milberg Appelquist, Hagelin, Jakobsson, Olsson, Olsson & Friedrichsen, 2011). Breen et al., (2014) provide an international analysis and state that palliative care and hospice services in other countries struggle with limited resources to effectively deliver bereavement support programs. However, there are some universal approaches to bereavement support in the USA, Canada, UK, Australia and Japan including telephone calls to bereaved, home visits by volunteers, pastoral care and health/allied health care staff, postal information such as brochures about grief, support groups, professional counselling, workshops and memorial services. However, there was variability across and within countries of services that used formal tools for assessment and screening for those at risk of having difficulties in their grieving (Breen et al., 2014).

Bereavement support provided by intensive care or acute care settings in Australia, the UK, Canada and the USA also focus on psychological or emotional support. These programs adopt a universal approach of phone contact or contact via a card, often at prescribed timeframes. With some programs, there is some type of formal assessment (Jackson, 1996; Garber, Soronodo, Manning & LaBrie, 2010). Few services incorporate practical support (Reid, Field, Payne, & Relf, 2006; Cherlin et al., 2007). Some programs in the USA and UK adopt a strengths based approach focussing on normalising grief, enhancing resilience and promoting autonomy in a deliberate move away from pathological approaches to grief (Walsh, Foreman, Curry, O’Driscoll & McCormack, 2008; Roberts, & McGilloway, 2008; Agnew, Manktelow, Haynes & Jones, 2011).

The literature of bereavement support by palliative care services in non-western countries is limited. Palliative care and thus bereavement support is relatively new to Japan and China. The Chinese had no word for 'grief' until recently but did, however, have other terms to describe their experiences in bereavement such as words that describe the emotion of sorrow or sadness, *bei shang* (Chow & Chan, 2006, p.254 cited in Klass & Chow, 2011, p.343). The Chinese term for missing the deceased, *sei bu de*, or not wanting to abandon or let go of the deceased is the same as the western concept of 'continuing bonds' (Klass & Chow, 2011). There are similarities between Chinese and Vietnamese communities and to some extent Japanese, in being reluctant to express emotion since feelings are considered private and their expression may upset others (Firth, Luff & Oliviere, 2005). There is extremely limited uptake of bereavement support in Taiwan as grief is associated with a negative emotion. Expression of grief such as crying would be viewed as shameful, especially when displayed to others outside the family unit. Taiwanese people are conditioned from an early age not to express grief to others. To effectively meet the needs of bereaved in this culture, the resources required are prohibitive⁹ however a study by Liu and Lai (2006) reported that 90% of bereaved Taiwanese believe they have adjusted well due to the support of people around them. Irrespective of culture, mourning practices and ritual are culturally bound and to this end, bereavement support will vary depending on the culture and location.

Grief and mourning practices differ between different cultures and ethnicities. Western notions of socialising grievers to grieve in private and that stages or tasks of grief are necessary in order to successfully adjust in bereavement have been criticised as ethnocentric. As bereavement assessment tools and services have been developed within the context of western thinking and influences, provision of multicultural bereavement support in Australia poses additional challenges. Screening for risk of adverse health and mental health outcomes or bereavement needs and in ethnically diverse groups is challenging with current assessment tools. Western concepts of counselling or support

⁹ Economic and accessible ways of assessing bereavement needs are restricted as, like in Australia, costs, workforce, time and other factors impact on the ability to predict needs and provide bereavement support in a meaningful way (Liu and Lai, 2006).

may not be translatable into other language. Palliative care services may not have adequate training or access to resources to enable clinicians to provide culturally congruent bereavement support. (Golden, 1996; Firth, Luff & Oliviere, 2005). Rubin and Malkinson (2011) posit that religious, cultural and gender aspects need to be integrated in developing and providing culturally safe bereavement support by health care and mental health professionals. Research indicates bereavement services are often delivered by staff with limited skill and knowledge in contemporary understandings of grief, loss and bereavement, and that bereavement assessment tools that are utilised are open to subjective interpretation and consequently are not accurate predictors of bereavement outcomes¹⁰ (Relf, Machin & Archer, 2008).

Bereavement assessment in palliative care

As outlined in the section on grief and bereavement theories, bereavement research is situated within the medical and psychological sciences which are themselves embedded in concepts of determinism, reductionism and rationalism. As a result, that which can be empirically grounded through scientific enquiry that helps identify patterns of stability and order is highly valued and prioritised. Cause and effect (or linear dynamic) approaches to examining a phenomenon can provide explanation for interim experiences or outcomes but may not provide adequate guidance for understanding the longer-term impact across the lifespan. Until recently, it has been Freud's perspective that has dominated approaches to bereavement interventions, that is, that the 'goal' of grief work for the individual is to relinquish ties to the deceased, or decathexis (Hooyman & Kramer, 2006). Failure to decathect is presumed to lead to maladaptive responses and maladjustment. This focus on pathologising grief has led to the flourishing of screening tools within clinical settings.

¹⁰ Bereavement outcomes are factors that indicate positive or detrimental effects as a result of bereavement. Outcomes such as general health, psychosocial and psychological functioning can be improved or diminished. For example, people who have been caring for their loved one during illness may have the capacity to concentrate on restoring own health and wellbeing or psychological functioning could decline and they become debilitated through depression (Stroebe, Hansson, Schut & Stroebe, 2011; Neimeyer, Harris, Winokuer & Thornton, 2011).

Grief becomes pathological when the ‘grief work’ is not attended to and signs and symptoms (four or more) persist for a year or two after loss and it impacts significantly on a person’s ability to function. Thus, diagnostic criteria for mental health disorders stemming from ‘unresolved’ grief (also known as complicated grief or prolonged grief disorder) have been established in the Diagnostic and Statistical Manual V (DSM-V) (Raphael, Minkov & Dobson, 2001; Howell, 2008). Buckle and Fleming (2011) argue that this is highly contentious and highlight that it has evolved within the socio-cultural contexts of America in which help seeking is influenced by whether individuals have medical and health insurance that covers the costs for therapies with focussed psychological strategies. Certainly, in Prigerson’s seminal work of developing the complicated grief inventory with elderly bereaved individuals, half of the items are based on clinician experience and clinician interpretation. The remaining items of the tool were developed based on the scientific literature around the topic. The statistical analysis TETRAD II that was used in this seminal work recommended removal of two of the items pertaining to loneliness and hallucinations however the researchers kept them as part of the tool as these were viewed as pathological events (Prigerson, et al., 1995). The introduction of ‘complicated grief’ to the bereavement discourse has led to the use of a psychometric instrument being used in palliative care settings as a tool for screening clients at risk of complicated grief.

The Prolonged Grief Disorder (PG-13) is a ‘diagnostic’ tool used to identify ‘symptoms’ of those who are considered at risk of complicated grief (Hall, Hudson & Boughey, 2012). The PG-13 is a short screening tool developed to screen those at risk of complicated grief or prolonged grief disorder. The domains assessed using the Complicated Grief Inventory tool look at ‘symptoms’ such as ‘yearning or longing’, ‘feeling stunned, shocked or dazed’, ‘avoidance’, ‘confused about your role in life (feeling that a part of yourself has died)’, ‘having trouble accepting the loss’, ‘difficulty trusting others’, ‘bitter over loss’, ‘difficulty moving on’, ‘emotionally numb’, ‘feeling that life is unfulfilled, meaningless or empty’.

A glut of grief and bereavement assessment tools have been developed to enable practitioners to identify clients who are at risk of difficult grief reactions. Psychometric tools which are psychologically or cognitive focussed include the *Grief Cognition Questionnaire (GCQ)* (Boelen & Lensvelt-Mulders, 2005), *Bereavement Coping Self-Efficacy (BCSE)* (Benight, Flores & Tashiro, 2001), *Bereavement Phenomenology Questionnaire (BPQ)* (Kissane, Bloch & McKenzie, 1997), *Continuing Bonds in Coping (CB Coping)* (Field & Friedrichs, 2004), *Continuing Bonds Scale (CBS)* (Wakosic & Chartier, 2003; Minton & Barron, 2008), *Grief Experience Inventory (GEI)* (Minton & Barron, 2008), *Grief Evaluation Measure (GEM)* (Jordan, Baker, Matteis, Rosenthal & Ware, 2005), *Inventory of Traumatic Grief (ITG)* (Prigerson, et. al., 1995), *Hogan Grief Reaction Checklist (HGRC)* (Hogan, Greenfield & Schmidt, 2001), *10 Mile Mourning Bridge (10MMB)* (Huber & Bryant, 1996), *Complicated Grief Inventory (CGI)* (Prigerson, et. al., 1995), *Self Regards Questionnaire (SRQ)* (Horowitz, Sonneborn, Sugahara & Maercker, 1996), *Texas Revised Inventory of Grief (TRIG)* (Nam & Eack, 2012), *Adult Attitude to Grief Scale (AAGS)* (Machin & Spall, 2004), *Core Bereavement Items (CBI)* (Holland, Nam & Neimeyer, 2012) and the *Grief Reaction Assessment Form (GRAF)* (Ho, Chow, Chan & Tsuru, 2002; Blackman, 2008). Use of the tools that capture thoughts and feelings in the ‘past two weeks’ or are used too early in bereavement may inadvertently pathologise what is a normative grief reaction.

Other tools measure broader domains such as the *Bereavement Dependency Scale (BDS)* which includes household management, getting around, social adjustment and health (Johnson, Vanderwerker, Bornstein, Zhang & Prigerson, 2006), *Bereavement Needs Assessment Tool (BSNAT)* developed specifically for bereaved persons with a learning disability and includes assessment of practical, social and emotional needs (Blackman, 2008), *Bereavement Risk Assessment Tool (BRAT)* includes concurrent stressors such as income, other caregiving, non-death losses eg. employment, relocation and financial, practical and physical resources (Rose, Wainwright, Downing & Lesperance, 2011), and the *Bereavement Risk Index (BRI)* which is commonly used by palliative care services for risk assessment screening (Kristjanson, Cousins, Smith & Lewin, 2005). However, many of the bereavement assessment tools adopt a deficit approach and do not factor positive

grief mediators in their assessment such as high self-efficacy measures, resilience factors, strong and positive support networks, hobbies and interests, connection with others and financial, legal and accommodation stability.

Bereavement Support Standards for Specialist Palliative Care Services developed for the Department of Health, Victoria (Hall, Hudson & Boughey, 2010) advocate the use of the PG-13 around six months' post death. If the Victorian Department of Health Standards are nationally adopted, this will perpetuate the pathologising of grief which is often a normal response to a painful life experience. It is argued that use of the PG-13 seems paradoxical to what the bereaved are describing as the normal lived experience and that use of this tool at six months may be premature. The International Work Group on Death, Dying and Bereavement (IWG-DDB), (2013) would argue these are normative responses in grief and the use of the tool pathologises what is considered within normal ranges of grief reactions. The IWG-DDB published a paper "*When does a broken heart become a mental disorder?*" to highlight their concerns about the increasing trend to classify grief as a depressive mental disorder. Horowitz and Wakefield (2007, cited in Buckle and Fleming 2011), argue that "... contemporary psychiatry fails to distinguish sadness (the normal response to misfortune) from major depressive disorder by relying exclusively on the symptom profile while ignoring the context within which symptoms occur" (Buckle & Fleming, 2011, p.7). Klass, Silverman and Nickman (1996), among others (Boss, 1999; Gamino, Sewell & Easterling, 2000), began a trend away from the historical medical model of grief that pathologised reactions and behaviours by introducing the notion that continuing bonds with the deceased could be seen as being adaptive or healthy coping. Contemporary approaches advocate for strengths based and resiliency approaches (Pomeroy & Garcia, 2009; Bonanno, 2010) and a public health approach to bereavement support that builds resilience of communities in which the bereaved live, as the way for the future (Currow, 2004; Breen et al., 2014). This is particularly relevant to rural communities in which there are limited resources.

Bereavement in Rural Western Australia

A review of the literature has highlighted the dearth of empirical research specifically related to rural bereavement experiences and service delivery programs (Gray, Zide & Wilker, 2000). Issues unique to rural practice include practitioners having few guidelines for professional practice in small communities, challenges around confidentiality as information about others is commonly known, merging of personal and professional relationships, distrust or suspicion of outsiders, lack of resources, fear of stigma (requesting help and using services where a culture of self-reliance is valued) and the transparency or high visibility of the practitioner (Gray, Zide & Wilker, 2000; Filmer, 2002; Giljohann, et al., 2008; Gray & Wilker, 2008; Kosteniuk, Morgan, Bracken & Kessler, 2014).

Cheers, Darracott and Lonne (2007) highlight the diverse social and health needs of rural communities and argue that service providers need to be aware of these unique needs. The experience of bereavement in rural communities include challenges for the both the bereaved and the service providers. These include issues of anonymity, confidentiality, personal and professional boundaries, geographical isolation, the 'ripple effect' of a death on the whole community and limited services or barriers to accessing services ie. due to financial issues or distances to travel (Cheers, Darracott & Lonne, 2007).

Filmer (2002, n.p) highlights the positive aspect of 'social collateral' of rural communities and how "...members will go to extraordinary lengths to ensure their community remains vital and intact..." leading to highly developed community bonds. Furthermore, Filmer maintains that the informal support of others within a rural community is identified as an essential element that diminishes isolation. Characteristics often attributed to rural communities include attitudes of self-reliance and a strong work ethic so programs need to be tailored to the customs and needs of individuals in the local communities and practitioners need to be mindful they are not being intrusive or offering unsolicited advice. Practice modalities that enhance community norms of independence and self-reliance may

strengthen practitioner credibility and thus improve practitioner acceptance as an intrinsic member of the rural community and less of an outsider. Community members place more value on how their problems are solved rather than extent of experience and training of the practitioner (Filmer, 2002; Gray & Wilker, 2008). Receptivity to bereavement support by those living in rural, regional and remote areas is an important area in light of the unique issues of 'rural culture'.

Bereavement and Aboriginal people

According to the Australian Institute of Health and Welfare (2015), rural areas in Western Australia comprise the greatest proportion of Aboriginal people in outer regional, remote or very remote areas (55%) and the Aboriginal population is a minority cultural group, comprising 3.6% of the total West Australian population. O'Brien et al., (2013, p2) state that Aboriginal people "...have a sense of cultural isolation when accessing mainstream services..." as there is a lack of understanding of Aboriginal cultural, spiritual and kinship linkages by mainstream services. These linkages all influence belief systems and behaviours (O'Brien et al., 2013), so it is important to explore the experiences of bereavement of Aboriginal people to gain insights into receptivity to support.

It is imperative that individuals grief experiences are contextualised within the socio-cultural rules of grief. There is a noticeable absence in the literature of bereavement support provided to Aboriginal families by palliative care services. McGrath and Phillips (2008, p.130) cite Sullivan, Johnston and Colyer (2003) who highlight that there is significant diversity of Aboriginal post-death practices and posit that this may provide challenges to palliative care services in providing bereavement support. McGrath and Phillips (2008) and McGrath (2008a; 2008b) in their research on Aboriginal cultural practices in end-of-life care and post death emphasise the need for cultural safety¹¹ when

¹¹ Cultural Safety is defined as '...an environment, which is safe for people; where there is no assault, challenge or denial of their identity, of who they are and what, they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening...' (Williams, 1999, p.2).

providing programs to Aboriginal individuals, families and communities. The care and support of Aboriginal people requires health professionals to have an awareness of religious pluralism. Research conducted by McGrath and Phillips (2008, p.158) identify the ‘duplicity of world views’ and that statements associated with dying “...refer both to the Christian god and the notion of heaven alongside ideas of animal spirits and Dreamtime...” (McGrath & Phillips, 2008, p.165).

As this research focuses on pilot work looking at receptivity to bereavement support and Aboriginal and Torres Strait Islander peoples in rural WA, it is hoped findings will contribute to the evolving evidence base that will inform culturally appropriate and sensitive responses by health services in the provision of bereavement support.

Support needs of the bereaved

In exploring the support needs of the bereaved, it is important to distinguish between needs, access and receptivity. *Needs* is a relative term and refers to the discrepancy between what is the present state and a desired or ideal state. The need is the gap between these states and is usually focussed on deficiencies. Individuals are assessed on a continuum of having more or less needs (Reviere, 2013). *Access* often refers to availability of services which includes the physical location of services, the adequacy of the supply of services (Royse, Staton-Tindall & Badger, 2016) and according to McGrath (2013, p.31), is “...limited to broad sociological factors associated with clinical care...” *Receptivity* however, is influenced by complex factors in relation to an individuals’ *ability* or *desire* to meet their own needs (McGrath, 2013). McGrath’s (2013) concept of ‘ability or desire’ are reflected in the work by Anderson and Newman (2005) who identified that societal and individual determinants influence behaviours in relation to utilisation of medical services. This demonstrates that examining issues of accessibility alone does not suffice. Utilisation of support or professional services is influenced by receptivity, which is a multifactorial and complex phenomenon. The success of bereavement services depends, in part, on how ‘receptive’ bereaved family members and friends are to receiving support.

Research into the perceived needs of the bereaved have identified the need for a range of psychological, social and practical support from formal and informal networks. Support that is client centred and promotes self-mastery are core needs identified by the bereaved. Episodic contact by people with skills in working with the bereaved, who knew the deceased and who had the capacity to visit in the home were also identified as key themes. Support needs include

- having a preference for someone to visit them in the home, particularly those who had been involved in their loved ones' care and knew them;
- someone who had good listening skills and knowledge and experience of grief, loss and bereavement;
- being acknowledged and having their grief experience normalised;
- being supported in thinking about the future;
- having others who can help them or motivate them to return to as normal a life as possible;
- encouragement to take part in social activities;
- having flexibility in the workplace and school (particularly early in their bereavement);
- support for the networks around them and education of what to expect with grief;
- not to leave initiation of contact to the bereaved person – to initiate the contact and not to expect reciprocal contact for some period of time;
- practical help such as assistance with children, cooking or household duties;
- early, quick and episodic contact from professionals to prevent reliance on services and predominantly help towards self-help to aid self-mastery and some level of control over their lives again;
- acknowledgement that the bereaved struggle with difficulties for a much longer period of time than what their networks and formal services are aware of;
- to be linked in with others who have had similar experiences and
- to get feedback from professionals who counsel/support their children as they wish to play a more active role in helping their children

(Wilkinson, Croy, King & Barnes, 2007; Milberg, et al., 2008; Dyregrov, 2008; Bergman & Haley, 2009; Patterson, 2009).

Receptivity and Bereavement

The concept of ‘receptivity’ is the focus for this study, particularly its applications to rural environments where there are limited resources and an implicit ‘rural culture’ (Cheers, Darracott & Lonne, 2007). Receptivity is a complex multi-factorial phenomenon influenced by internal and external factors (Blackburn, McGrath & Bulsara, 2015).

Exploring the concept

In exploring bereavement support, the concept of receptivity is a relatively new area of scholarship. The application of receptivity to support is a critical factor in relation to participation by the bereaved in palliative care bereavement programs. There is limited exploration of the concept of receptivity in the extant bereavement literature, particularly as it applies to rural, regional and remote contexts and in relation to bereavement support to Aboriginal families. Receptivity is a factor that contributes to the success of bereavement support programs by palliative care services. Exploring receptivity to bereavement support is an important contribution to the literature that can help to inform service development and provision (Blackburn, McGrath & Bulsara, 2015).

Palliative care services provide bereavement support however uptake of that support by the bereaved is variable. Receptivity to bereavement support can provide new insights. McGrath (2013) highlights the complexity of factors that influence an individuals’ *ability* or *desire* to meet their needs. Using a ‘receptivity lens’, this moves the approach of bereavement support from one of ascertaining ‘need’, to considering the complex interplay of factors of how receptive individuals are to having their needs met. When rurality or cultural factors add to the complexity, receptiveness to different support modalities may need to be revisited. Ultimately, any bereavement support that is offered has to be meaningful to the individual (Blackburn, McGrath & Bulsara, 2015).

Although the concept of receptivity has been explored in the philosophy, sociology, theology, psychology, political and health discourses as a complex multifactorial concept, it remains predominantly as an intrapsychic or intrapersonal phenomenon (Blackburn, McGrath & Bulsara, 2015). An individual's openness, judgement and will are all factors that influence receptivity with 'openness' being relational, based on an interdependence between people (Hinchman, 2009; Hooghe, Neimeyer & Rober, 2011; Lewandowski, Ciarocco, Pattenato & Stephan, 2012). There has, however, been recognition that receptivity is also shaped by internal and external factors (Schoolman, 2011; Breitkopf et al., 2014). The notion of 'openness to' or 'openness with' an 'other' has been explicated in the literature in which external factors impact on individuals' spiritual or psychological state (Hooghe, Neimeyer & Rober, 2011; Robinson, 2014) which in turn, impacts on receptivity. This demonstrates the complexity of receptivity as a concept.

In applying an internal psychodynamic perspective to understanding receptivity, a person's judgement of whether an issue is actually of concern and if it is, what the level of concern is, will influence a person's receptivity to support. Levels of distress have been identified as contributing factors for receptivity to support (Basen-Engquist et al., 2012). In conjunction with choice, intention (the will) and judgment, internal states of hope, avoidance and presence are also factors that influence receptivity (Zimmer & Chappell, 1999; Erby, Rushton & Geller, 2006; Hinchman, 2009; Lewandowski, Ciarocco, Pattenato & Stephan, 2012). A sense of subjective self-efficacy has been recognised as a significant factor for receptivity to support (Howell, et al., 2013). As a coping strategy, receptivity has been attributed to playing a key role in the process of meaning-making and openness to new and unfamiliar possibilities as well as mindfulness practices (Ganzevoort, 2004; Schoolman, 2011; Nedelsky, 2011). Although receptivity is mainly applied to internal intrapsychic processes, it is recognised however that external forces influence this internal state and thus receptivity is situated within socio-cultural-political environmental contexts.

The environment in which individuals live has been demonstrated to influence receptivity and includes the availability of resources, financial situation, gender, culturally

appropriate services, financial and education status and involvement with similar services in the past. Other factors influencing receptivity is scheduling conflicts, family dynamics and other responsibilities, modalities of service provision and geographical location (Stark, Hollingsworth, Morgan & Gray, 2007; Schoolman, 2011; Goodridge, Quinlan, Venne, Hunter & Surtees, 2013; Breitkopf et al., 2014).

Rurality has been identified as a factor influencing receptivity to support. Social mores and norms of rural communities that emphasise rural values of self-reliance and independence are common factors that influence an individuals' receptivity to support. External factors such as lack of anonymity and confidentiality, geographical isolation, tyranny of distance, terrain of the roads, financial issues and community bonds all impact on utilisation of services or support in rural areas (Cheers, Darracott & Lonne, 2007; Castleden, Crooks, Schuurman & Hanlon, 2009).

Receptivity Definition

Cherlin et al., (2007) identified receptivity to bereavement services as a critical factor for participation in bereavement support programs. In light of the complexity and multiple perspectives on receptivity, the guiding definition of receptivity used for this study is by McGrath (2013, p.36);

“the range of factors (individual, social and geographical) that affect an individual’s desire or ability to receive or engage with supportive care services designed to meet his or her needs.”

As the bereavement literature highlights individual, social and geographical factors as impacting on an individual's bereavement experience, McGrath's (2013) definition sets the context for this study through exploration of bereavement experiences of individuals in country Western Australia. Areas explored within this framework include questions such as those posed by Blackburn, McGrath and Bulsara (2015, p.5)

1. Are individuals living in rural, regional and remote areas receptive to universal approaches to bereavement support?

2. Are individuals living in rural, regional and remote areas receptive to bereavement support at all and if so, what support would they like?
3. Are there pivotal times in bereavement when people are more likely to be amenable to support?
4. Are Aboriginal Australians receptive to accepting bereavement support from health professionals?
5. Are bereaved individuals receptive to a wider range of support services beyond those that focus on psychological or emotional support?"

These questions culminated in the research question that is the focus of this research:

What are the factors that influence bereaved individuals in rural, regional and remote Western Australia to be ‘receptive’, or otherwise, to bereavement support from palliative care services?

Receptivity to bereavement support

Exploring the concept of receptivity to bereavement support can provide a different perspective that recognises the many mediators that influence the bereavement experience. There is a dearth of literature that focuses on the intrapersonal experiences of bereavement and in the past decade, there has been an increasing evidence around the financial, legal and vocational impacts thereof (Corden, Sloper & Sainsbury, 2002; Stroebe, Folkman, Hansson & Schut, 2006; Bent & Magilvy, 2006; Ha, Carr, Utz & Nesse, 2006; Stebbins & Bountrey, 2007; Stroebe, Hansson, Schut & Stroebe, 2008). Strong and positive informal support networks have been identified in the bereavement literature as a critical factor in how people cope in bereavement (Cherlin, et al, 2007). Other factors such as having a busy work or family life, financial security, strong sense of privacy, inherent introversion, a desire to stay at home, independent personality, subjective sense of self-efficacy and preferring informal contact have been identified as factors that influence an individual’s receptivity to support in the bereavement literature (Carrow, Allen, Plummer, Aoun, Hegarty & Abernathy, 2008; Milberg, et al., 2008).

Although the needs of the bereaved have been identified in the literature, how these translate into meaningful, appropriate and client centred programs needs further exploration. Receptivity provides a frame of reference to enhance understanding and inform the design of support services. This will facilitate a shift away from “...service provider centric views of supportive care to consumer-centric reasons for engagement...” (McGrath, 2013, p.46)

There is currently a discord between practice, policy and research in bereavement despite the evidence of the broad range of factors that influence the bereavement experience and utilisation of support. Just as receptivity in the literature has a focus on the intrapersonal factors, bereavement support is targeted at psychological and emotional support. The interdependence of internal and external factors shows the reciprocal relationships between the individual and the environment or systems in which the individual lives. In order for receptivity to support be enhanced, this ecological ‘person-in-situation’ perspective needs to be considered in the development and design of bereavement support programs by palliative care services (McGrath, 2013; Harris, 2009-2010; Blackburn, McGrath & Bulsara, 2015).

Conclusion

Utilisation of palliative care bereavement programs is contingent on an individual being receptive to bereavement support which is influenced by a range of factors. There has been little attention to receptivity to bereavement support in the extant literature. The basis for this thesis is examining support services utilisation through the lens of the concept of ‘receptivity’. The purpose is to inform and enhance bereavement support by contributing to the evidence base through this ‘receptivity’ lens. Exploring receptivity through individual, social and geographical perspectives provides insights into utilisation of bereavement support in rural, regional and remote areas (Blackburn, McGrath & Bulsara, 2015).

This chapter provided insights into bereavement, its applications in palliative care and the notion of receptivity to support. As discussed in this chapter, receptivity is a concept that can provide a different perspective for exploring the reasons for uptake of support in bereavement, particularly in rural and remote areas. The next chapter will discuss the methodological approach taken to operationalise the aims of the research and to identify factors that influence engagement in support in bereavement. This will be explored through different perspectives from bereaved individuals and health professionals.

Chapter 3: Methodology

Introduction

The previous chapters set the context for this study. Namely, examining contemporary bereavement practices in palliative care, the theoretical discourse that has informed bereavement support and posited the importance of exploring receptivity factors that influence whether people access or utilise available support. This chapter will discuss the methodology used to conduct the research. Qualitative Descriptive (QD) research design within a Postmodernist paradigm set the framework for the study. Details of the methodology, which consisted of open-ended, semi-structured, exploratory, in-depth interviews with a purposive sample of research participants, will be discussed. The treatment of the interview data, including the transcription, coding, analysis and presentation will also be outlined. This study utilised Qualitative Description (QD) to prioritise the voice of bereaved participants as these were the largest cohort and the primary group in which receptivity was explored. Viewpoints from health professionals and Aboriginal health professionals were also sought and will be included throughout the findings chapters. The study is situated within a postmodernist theoretical framework.

Epistemological Framework: Postmodernism

A Postmodernist research framework aims to ‘give voice to the multiple perspectives’ of a phenomenon. By using a methodology of descriptive phenomenology, the researcher has endeavoured to remain close to the complexity and richness of participants’ narratives and reflections (Agger, 1991; Gergen, 2001; Tomso, 2009). Postmodernism recognises that discourses are often developed within a ‘discourse community’. Downs and Wardle (2011) describe a discourse community as a community that shares a common interest or public goals, has mechanisms to communicate between members, providing information and feedback, has defined purpose and features of one or more genres, shares specialised language and jargon and has enough members with content and communication expertise to ensure operation of the group as a community. As outlined in chapter two, the

bereavement discourse has predominantly been developed within the science-based professions – medicine, psychiatry and psychology (Olsson, 2008). Assumptions underpinning postmodernism include that meaning is socially constructed and that language is an inherent by-product of social interaction (Gergen, 2001; Olsson, 2008).

Casstevens (2010) posits that language is culturally bound and can act as a form of oppression. Current prevailing bereavement discourses may be considered as hegemonic discourses, perpetuating knowledge and power. As the science-based disciplines have provided much of the language of bereavement, this maintains their knowledge and power as being the ‘experts’ of bereavement experiences, effectively silencing or at the very least ‘muting’ the voices of the bereaved. Bereavement discourse in the psychological and medical sciences has led to a dominant approach of viewing coping in bereavement from a pathological perspective, rather than as normative experiences (Valentine, 2006; Ord, 2009). Bereavement discourse is discussed in further detail in Chapter Eight.

The narrow focus of medical and psychological discourse in bereavement may be attributed to the ‘blanket approach’ informing many bereavement programs with palliative care services.¹² However, it will be shown in this research that the experience of bereavement occurs within the context of discourse constructs, both with bereaved individuals, health professionals and the general community and postmodernism is an approach that fosters a polyvocal perspective.

A Postmodernist theoretical perspective compels the researcher to engage in collaborative pedagogies¹³ with research participants and to maintain reflexive practice when

12 The narrow focus refers to viewing bereavement through a physical-psychological lens whereas the broader bereavement experience of the person-in-situation is often not given as much consideration eg. the socio-political environmental factors that impact on the person’s experience.

13 Collaborative pedagogies occur through the inter-personal engagement between researcher and participant. The emphasis is that critical thinking occurs through this interaction and that there is an intention to learn by the researcher. Pedagogic research “...is systematic and sustained enquiry, planned and self-critical, which is subjected to public criticism and to

undertaking qualitative research. Postmodernism acknowledges the role of intersubjectivity in research process and hence discursive practices (Parsons, 1995; Gergen, 2001). Utilising a qualitative methodology allows for the study of personal experiences, narratives and language in order to seek understanding and meaning about a phenomenon (Berglund, 2001). However, as Sandelowski (2000, p.336) asserts, "...qualitative researchers cannot insulate themselves from the data..."

Descriptive Qualitative Research

Qualitative description (QD) is a suitable method in healthcare research as it helps to focus research questions on the experiences of patients, families and professionals (Neergaard, Olesen Anderson & Sondergaard, 2009). QD studies are the least encumbered method of all qualitative approaches that has pre-existing philosophical or theoretical commitments (Sandelowski, 2000). Neergaard et al., (2009, p.2) assert that QD differs from other qualitative methods as it is "...thoughtful linkages to the work of others in the field and clinical experience of the research group..." They further differentiate QD from other qualitative methods as it is not thick description (ethnography), theory development (grounded theory) nor interpretive meaning of an experience (phenomenology) but is 'rich, description of an experience or an event' (Neergaard, et al, 2009, p.2). QD analysis enables researchers to stay closer to the data, describing participants' experiences in language similar to their own. QD research is the preferred method when descriptions of phenomena are desired (Sandelowski, 2000).

It is acknowledged, however, that descriptions are influenced by the describers' perceptions, sensitivities, inclinations and sensibilities.' In QD, the presentation of the facts of the case are done in everyday language by the researcher. Sandelowski (2000, p.336) asserts that "...language is a vehicle of communication, not itself an interpretive structure that must be read...". Through language, the researcher portrays the stories of

empirical tests where these are appropriate..." (Stenhouse, 1985, pp.18-19; cited in Moron-Garcia & Willis, 2009, p.3).

their participants using their own language as much as possible. The process of presenting the data in a useful and coherent manner is a significant part of QD research (Sandelowski, 2000).

Gathering data within QD research often utilises a purposive sampling approach to source cases that are deemed information-rich for the purposes of the study (Sandelowski, 2000). In conjunction with purposive sampling, QD often uses semi-structured interviews with open-ended questions. Strategies such as authenticity, credibility, criticality and integrity inform rigour. Integrity is the most important criteria when using QD and strategies include reflection on researcher bias, dual role clinician/researcher during the interview, dual role in the process of analysing, peer review and researcher triangulation (Neergaard et al., 2009). QD uses a slightly more structured interview guide which is iterative in that it is modified and transformed as themes emerge. The QD interview guide is often based on expert knowledge to focus on areas that may need to be further understood or are potentially amenable to intervention. QD is a useful method for exploring experiences in health care at the intersect of patient-professional experiences and helps to inform service delivery or models of care (Sandelowski, 2000; Neergaard et al., 2009). QD frames the methodology for this study in which the experiences of the bereaved in the context of palliative care services occur and includes the perspectives and experiences of the palliative care clinicians.

Methodology

Purposive Sampling

This research utilised non-probability purposive sampling. This sampling technique enables the researcher to target subjects who typify the issue to be studied in order to achieve particular objectives (Henry, 1990; Coyne, 1997; Alston & Bowles, 1998). Non-probability sampling enables the researcher to seek participants that may provide a range of variations in, and depth of experience of, the phenomenon (Coyne, 1997). The purpose

of this study was to explore the lived experience of bereavement and identify the role of receptivity with regards to professional support. Letourneau and Allen cited in Whittlemore, et al., (2001, p.525) state "...critical multiplism encourages the critical and exhaustive study of a phenomenon from multiple perspectives." As this research collected the views of both bereaved and health professionals regarding bereavement support, the focus was mainly on the views of the bereaved. The bereaved participant cohort had the greater number interviewed and the focus of discussion on the findings in relation to receptivity is predominantly on their perspectives and experiences.

Ethical Considerations

Ethical guidelines and principles specifically for conducting research aim to protect participants and researchers. Principles of non-maleficence, beneficence, autonomy, respect, justice, research merit and integrity all provide standards of how to conduct ethical research (National Health and Medical Research Council, (NHMRC), 2007). To conduct socially responsible research, researchers need to ensure that vulnerable groups are protected and that the research is conducted with integrity. The bereaved are considered a vulnerable group and this presented some challenges with obtaining ethics approval.

Ethics proposals were submitted to respective organisations in Western Australia, namely the WA Aboriginal Health Council, WA Country Health Service (WACHS), St John of God Health and Silver Chain. A National Ethics Application Form (NEAF) was completed online via the National Health and Medical Research Council (NHMRC) website and outlined all aspects of the study. The NEAF was used as a master document to submit to respective organisations in conjunction with their specific protocols. It was originally proposed to recruit participants across 13 different sites. Silver Chain did not approve progression of the ethics application at pre-submission review stage due to organisational priorities. St John of God Health required four clarification responses to the committee before ethics was approved, however there was no successful recruitment

of participants via this organisation. Ethics approval was granted by Griffiths University, the Western Australia Aboriginal Health Council WACHS (*Appendix A: Human Research Ethics Committee Approval Documentation*). All ethical and cultural issues were addressed in accordance with NHMRC guidelines for ethical conduct in Aboriginal and Torres Strait Islander Health Research. The researcher submitted an ethics proposal outlining the research to the WA Aboriginal Health Council Ethics Committee and was granted approval. As WACHS is comprised of seven (7) regional areas, all regions within WACHS approved access to recruit participants in their area.

The palliative care field in Western Australia is relatively small and many clinicians are known to each other or have ongoing working relationships. The researcher completed a conflict of interest form as part of the ethics submission for WACHS to acknowledge the researcher had existing collegial relationships or that some participants were employees of the same organisation in which the researcher is employed, the WA Country Health Service (WACHS). WACHS comprises seven (7) regional areas: Kimberley, Pilbara, Midwest, Wheatbelt, Goldfields, South West and Great Southern (*Figure 1: WACHS Regions, page 69*). This research was reliant on recruiting participants via established palliative care services in these regions. This was a mechanism put in place to minimise risk of harm in recruitment processes and was required as part of ethics approval by organisations.

The researcher discussed the research with Nurse Managers and Senior Social Workers of palliative care services in each respective region and provided information on the study. Each region adopted their own approach to recruitment and the researcher acknowledges this variability can lead to bias, however, in order to have access to participants, this was a strategy organisations required to ensure risk mitigation. Some regions did screen their bereaved clients and provided selected participants with the information whereas other regions provided all participants with the opportunity to participate. Health professionals working in health and palliative care services are often familiar with the potential participants, their mental health and physical health status and their capacity to participate in research or quality improvement activities. As Palliative care clinicians screened

individuals who are bereaved and were eligible or interested, participants were recruited at any time post death as long as they were assessed by the clinicians as having capacity to engage in the interview process. Health professionals were self-selected in response to invitations promoted by the palliative care services sent to health care services. The total number of invitations is unknown so ascertaining a response rate is not possible.

Previous studies that have recruited bereaved participants have recommended that recruitment should be done indirectly, such as through advertising or via third parties (Buckle, Dwyer & Jackson, 2009). Evidence also suggests that recommendations for recruitment is to allow individuals to decide for themselves if they feel they are ready to participate in research as there is not a clear consensus on the most appropriate time to initiate recruitment. Research has indicated that participants in bereavement research do not ascribe any importance to the length of time passed since the death of a loved one, but emphasise that the emotional impact does not change (Feigelman, Jordan & Gorman, 2008-2009; University of Haifa, n.d). It has been noted that there needs to sensitivity to avoiding special dates such as major holidays or anniversaries for recruitment of research. One participant in this study (ID: B: 3112: F; 75; Sp; 13-18; R3) participated in an interview on what would have been her 55th wedding anniversary. The researcher was very mindful of the impact this may have on her psychological and emotional wellbeing and checked with her via email prior to the interview date, offering the opportunity to reschedule, however she declined. Transcript from the email communication:

Participant:

Tuesday, 15 July 2014 2:12 PM

“Hi Pippa

I don't believe this!! 25th July was our wedding anniversary -It would have been 55 years this year!! Perhaps it would be better on another day - I don't really wish to dissolve into a blubbing heap!!

Regards

[name]”

Interviewer:

Tuesday, 15 July 2014 6:38 PM

“Goodness me, [name]. I know anniversary dates are usually very difficult...please know I will be holding you in my thoughts and my heart next Friday. How do you feel about doing the following Friday on the 1st August?

Warm regards,

Pippa

Participant:

Wednesday, 16 July 2014 10:20 AM

“Hi Pippa

Let's go for the 25th July - I'm sure I will be OK - it will be good to talk to some-one!!

Regards

[name]”

Prior to commencing the interview, the researcher clarified with the participant again if she was okay to do the interview on her anniversary and she advised she was fine to progress with the interview:

Interviewer:

“[name] I'm very mindful of what today is...your anniversary...so I just wanted to see how you are at the moment.”

Participant:

“I'm fine, Pippa...when you first sent the email I got sort of a shock and fell into pieces but I'm over it now, I'm fine.”

At this point the researcher reminded the participant of what was written in the information sheet that had been sent out to her prior to the interview and reiterated that:

“If at any point you want to stop, just let me know. If you want me to stop the tape recorder in particular, just let me know....even if you're half way through a sentence and think ‘nah, I don't want to do it anymore’. That's fine as well. You can just let me know and, if you just want to pull out, then what's been recorded will just be deleted.”

When nearing the termination of the interview, the researcher again re-visited that it was an anniversary day and checked in with the participant again:

Interviewer:

“[name], it is your, it would have been your 55th anniversary today?”

Participant:

“yep”

Interviewer:

are you doing anything in particular around it?

Participant:

“No. No, I've got friends up here. We're going out to lunch with the friends but not, not to celebrate that. No. It's, that's finished, over”

The researcher was cognisant throughout the interview of the significance of the date for this participant. Evidence demonstrates that many bereaved individuals welcome the opportunity to express or talk about their grief and although they are aware that discussion of their loss(es) may be painful, they are often not deterred by this (McGrath, 2003; Buckle, Dwyer & Jackson, 2009).

Risks of the Research

When participants first registered interest in participating in the study, they were provided with Participant Information and Consent Forms (PICF's) outlining the nature of the study, the process of the interviews, the consent process, how the researcher would

maintain confidentiality and were provided contact numbers for telephone counselling lines for those who may have required emotional or psychological support after the interviews. PICF's were administered via email or post. Prior to each interview, the researcher reiterated the process outlined in the PICF's and continuously monitored participants' wellbeing throughout the interview. (*Appendix B: Participant Information Sheets: Bereaved & Health Professionals; Appendix C: Consent: Information Sheet Outlining Process: Bereaved & Health Professionals*).

There are nuances in conducting qualitative research in which the researcher needs to maintain awareness. These nuances include working with 'gatekeepers' who can facilitate or hinder access to potential participants, participant recruitment (such as whether they were coerced by staff or family members), lack of insight on behalf of the researcher who may have a paternalistic viewpoint that the participant will benefit from the interview process *per se* and thus negating the potential harms that may occur as a result of exploitation or exposure to inappropriate questions or in divulging more information than they would have preferred. Participants from smaller communities may not realise that although anonymity will be maintained in reporting the research, participants may still be identifiable by others in their community by the very nature of their narratives (Rosenblatt, 1995; Mitchell & Irvine, 2008; Aluwihare-Samaranayake, 2012; Silverman, 2013).

It is important researchers ensure confidentiality is maintained and that individuals are not identifiable in any subsequent publications. Another responsibility of the researcher, outlined by Aluwihare-Samaranayake (2012), Rosenblatt (1995) and Mitchell and Irvine (2008), is managing the emotional and psychological risks wherever possible prior to the interview, when discussing a potentially emotional or distressing subject like bereavement. Researchers need to be aware of, and responsive to, participants' distress and have strategies in place to manage this, such as allowing participants to set the pace and depth of the interview, 'sitting with' extended periods of silence, changing or diverting the subject, enabling participants to opt for time-out or to cease the interview and turning off the recording device (Mitchell & Irvine, 2008; Aluwihare-Samaranayake, 2012; Silverman, 2013).

Qualitative interviewing allows for consent to be an ongoing, mutually negotiated process that is integrated into the researcher and participant relationship. This allows for ongoing monitoring of participant wellbeing throughout the interview thereby minimising risk and is more effective than a single initial signing of a consent form at the commencement of the study (Buckle, Dwyer & Jackson, 2009). One recommendation made by the bereaved to qualitative researchers is that researchers have sufficient training to conduct the interview in a professional and supportive manner, with knowledge of the process and expression of grief (McGrath, 2003; Buckle, Dwyer & Jackson, 2009). Researchers need to be cognisant of the emotional risks experienced to their own personal agency and Finlay (2003) and Wojnar and Swanson (2007) highlight processes around researcher self-reflexivity through the utilisation of memoing, diarising, field notes, outsider verification and the use of supervision to continue to ensure the integrity of the research. Reflexivity of the researcher was discussed in chapter one. The researcher regularly engaged in supervision and diarised as part of their self-care throughout the research process.

Benefits of the Research

Evidence demonstrates that when bereaved participants are provided with a safe environment, or emotional space, that allows expression of their grief, they often do not see participation in research as a risk. Thus, even if some experience tears during interviews, this is not considered as a negative consequence. The bereaved expressed gratitude for having the opportunity to sit with a person who was willing to sit with them in their pain and that participating in research is neither distressing or invasive (McGrath, 2003; Buckle, Dwyer & Jackson, 2009). Qualitative bereavement researchers do not intend to induce pain but invite listening to the stories of others that are often shrouded in sadness (McGrath, 2003). Some participants did cry throughout the interview, but cited different motivations for participating in the research, whether it was;

To help others¹⁴;

“I hope it helps you out. I didn't think I'd be as tearful as I was but I haven't really talked about it, like this until now.”

“It would be nice to see something come out of it.”

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

“I thought it's the kind of thing that people say oh no, I don't want to do that, or else they say oh yes, I suppose I, well...and they don't get around to it, and then you've got people that don't like doing surveys. So I thought oh you poor thing you need somebody.”

ID: B: 3391: F; 69; Sp; 13-18; R3

To help themselves:

“I got you, the letter that you were doing this research, I thought well, it might help others but it might also help me”

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

“I don't think I should dwell on it anymore. That's why I've agreed to talk to you and I thought, this must be the final bit.”

ID: B: 2875: F; 81; Sp; 13-18; Rem1

“I will never ever pretend I am ok when I am not, and, I will be eternally grateful that a lady by the name of Pippa Blackburn came into my life who enabled me to put all of this journey into perspective.”

ID: B: 3388: F; 69; Sp; 13-18; R3

¹⁴ Throughout this thesis, participants are represented by the following descriptor: ID: Cohort (bereaved/health professional/Aboriginal health professional) / ID Number / Gender / Age / Relationship to deceased / duration since death / RRMA status.

Or as a precursor to see if they need counselling:

*“She [my neighbour] seeks counselling but she says I should do it.
But I really don't think at the moment - that's why I've agreed to come
down and do a face to face and sit down and talk to someone and see
how I feel at the end of it.”*

ID: B: 3400: M; 70; Sp; 13-18; R3

There is a plethora of evidence regarding the benefits of the qualitative approach to research, particularly as it allows participants to set the pace of the interview and shape the focus, discussing what they are most comfortable with and what is relevant to them and their experience (McGrath, 2003; Buckle, Dwyer & Jackson, 2009). Participation in research by the bereaved has been explored in the literature and has demonstrated that the experience has been positive and therapeutic for participants as the bereaved appreciated the opportunity to tell their story and they felt that the research may also be helping others in some way. Although participants acknowledged that it can evoke distress, many of the participants reported it to be a positive experience (Cook & Bosley, 1995 cited in Buckle, Dwyer & Jackson, 2009, p.117; Dyregrov, 2004; Koffman, Higginson, Hall Riley, McCrone & Gomes, 2011). The research indicates that risks are minimalised and that participating in research may be more of a benefit as discussing issues can have a cathartic benefit - people feel listened to and the process of contributing gives them a sense of being able to make a difference to others. Benefits identified by participants in qualitative research included being able to release pent up emotional energy, having an important emotional space to reflect on and gain insight into their experience, normalisation of their experience (hearing about similarities and differences) which reduced the sense of aloneness; valuing the opportunity to educate others, a sense of empowerment in a life situation in which individuals felt very disempowered, providing help to others and contributing to a better understanding of grief issues (McGrath, 2003; Buckle, Dwyer & Jackson, 2009).

Recruitment

Participants were recruited via palliative care services currently operating in the WA Country Health Service (WACHS). Eligibility criteria for participants were:

1. People over the age of 18 years
2. *Bereaved*: People who have had a deceased loved one who was under the care of a palliative care service
3. *Health Professionals*: Professionals who provide support to those who are bereaved
4. People from rural, regional and remote areas of country WA
5. People who speak English
6. Between 0-3 months and five years post death

Health professionals were recruited via regional palliative care team members within WACHS. A promotional flier was sent to regional teams which provided information on the research allowing staff members to self-select or opt-in. Nurse managers and senior social workers from respective teams circulated the flier to their networks (both palliative care staff and bereaved families) to highlight the research project. All bereaved participants involved in interviews were identified by their involvement with palliative care services and who had a loved one cared for by the service. The research was communicated to patients via post, email or telephone and

Figure 1: WACHS Regions



recruitment processes differed for individuals and regions. Health professionals were tasked with ascertaining suitability of clients for participation. This was embedded as a protective buffer to ensure participants were not approached directly by the researcher. Regions did not feedback formally on processes of recruitment however anecdotally advised some sent letters to all bereaved and others were specifically identified by staff who believed it would not have a detrimental impact on the person's psychological or emotional wellbeing to participate. Despite the fact that this may be recognised as having contributed to a level of bias within the study given the sensitive nature of the topic, a certain degree of pastoral care amongst service providers is expected. Experienced clinician/researchers advocate to let the bereaved decide when they want to participate in research as some feel ready shortly after a death, some may not be ready for a number of years and some may never wish to participate (Buckle, Dwyer & Jackson, 2009).

Palliative care clinicians screened individuals who are bereaved, were eligible for the study and interested in participating. Participants were recruited at any time post death as long as they were assessed as having capacity to engage in the process. Health professionals working in health and palliative care services are often familiar with the potential participants, their mental health and physical health status and their capacity to participate in the research study.

There was no set length of bereavement period before participants were enrolled. As recruitment was through palliative care services, existing clients were usually within their first year of bereavement. However, some services identified participants linked in with their service, who had been bereaved for longer. As the literature identifies that three to five years' post death is a time where there is a change in the grief, or there are secondary effects from bereavement that impact on them, the time frame was left open to bereaved participants up to five years post death (Stebbins & Bountrey, 2007; Corden, Hirst & Nice, 2008; Feigelman, Jordan, & Gorman, 2008-2009; Rubin & Nadav, 2009; Chow, 2010). Evidence from research with participants soon after death indicate that less than 10% of bereaved individuals reported a great deal of stress from an interview (Emanuel, Fairclough, Wolfe & Emanuel, 2004).

As rurality was a focus of this study, participants were categorised according to the Rural, Remote and Metropolitan Areas (RRMA) Classification systems in which classifications are based primarily on population numbers as an index of remoteness. The aim was to have representation of participants from the following areas as classified by the RRMA:

1. Rural Zone

- R1 - large rural centre (urban centre population 25,000 - 99,999)
- R2 – small rural centres (urban centre population 10,000 – 24,999)
- R3 – other rural areas (urban centre population < 10,000)

2. Remote Zone

- Rem1 – remote centres (urban centre population > 4,999)
- Rem2 – other remote areas (urban centre population < 5,000)

(Australian Institute of Health and Welfare, 2004, p.5).

Aboriginal and Torres Strait Islander Participants

Aboriginal and/or Torres Strait Islander (ATSI) peoples were targeted as a specific sub-group. The initial aim was to recruit approximately five to eight ATSI participants to comprise this sub-group. This research is a pilot work looking at receptivity to bereavement support within Aboriginal and Torres Strait Islander peoples. As they are such an important group in WA, especially in relation to rural and remote areas, there needs to be inclusion, albeit small, in this research which can contribute to the evolving evidence base that will inform culturally appropriate and sensitive responses by health services in the provision of bereavement support.

The researcher has worked as a clinician with numerous Aboriginal groups and is familiar with the culture and practices of Aboriginal and Torres Strait Islander peoples. The researcher recognises the cultural distinctiveness of Aboriginal and Torres Strait Islander communities and groups and the methodology selected respects and acknowledges such

diversity. This research aims to highlight the voices of the bereaved to inform health services of their needs leading to enhanced bereavement support that can improve the health and wellbeing of participants and communities. Therefore, including the perspectives of ATSI peoples was an important part of this study as the focus is on country areas in Western Australia in which a higher proportion of Aboriginal populations live. Additionally, bereavement programs are developed by health professionals and there has been little to no contribution invited by ATSI peoples to providing guidance, knowledge and experiences to better inform culturally appropriate and responsive bereavement support.¹⁵ It is hoped that the research will contribute to the social and cultural bonds by recognising that bereavement support needs to include emotional, social, practical, financial, legal, family and other support.

As this research was a state-wide project, there was no specific Aboriginal community to be addressed, however written support was obtained by Aboriginal Liaison Officers within the WA Health Department. Aboriginal Liaison Officers (ALO's) and an Aboriginal Health Worker within WA Country Health self-selected to participate in the research in their roles as health professionals who provide bereavement support and as they have had personal experiences of bereavement. Although the number of this sub-group within the health professional cohort was small, when compared to the percentage of Aboriginal people within the total population in Western Australia, information provided throughout the interviews was very informative and gave some diverse insights into receptivity to bereavement support from an Aboriginal perspective which will be discussed further in the following chapters of this thesis.

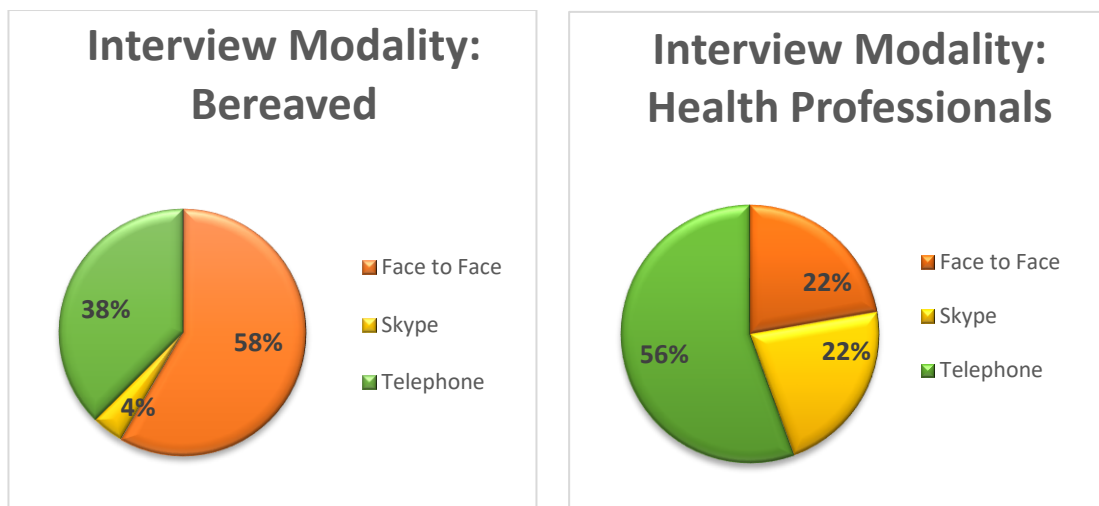
15 There is no empirical literature that evidences involvement by ATSI peoples in the design of bereavement programs that the researcher could find as part of a review of the literature.

Data Collection

Additional data was collected on income amount and income source with bereaved individuals to ascertain if there was any link between the experience of bereavement and financial status (Australian Bureau of Statistics, 2012.) The financial impact of death has only been examined in some depth in the past decade in relation to bereavement (Corden, Sloper & Sainsbury, 2002; Stebbins and Batrouney, 2007; MacDuff, 2013). There is a correlation between rurality and lower socio-economic determinants of health and wellbeing (Cheers, Darracott & Lonne, 2007). There is also a link between receptivity and perceived financial cost or burden (McGrath, 2013). As a result, socio-economic status of the bereaved was included in the data collection for this study.

Data was obtained through in-depth semi-structured interviews and lasted between 37 to 143 minute's duration. Depending on the location of the participant and the modalities available to parties, methods of collection varied and included face-to-face interviews, telephone interviews and interviews via Skype. Although Skype was only used for three interviews overall, there were issues with internet signals 'dropping out' leading to disruption to interviews. This did not have a significant impact on the content of the interviews however there was some transmission lag. Sedgwick and Spiers (2009) advocate for using a high-bandwidth connection when conducting interviews using video-conferencing as a medium.

Figure 2: Interview Modalities

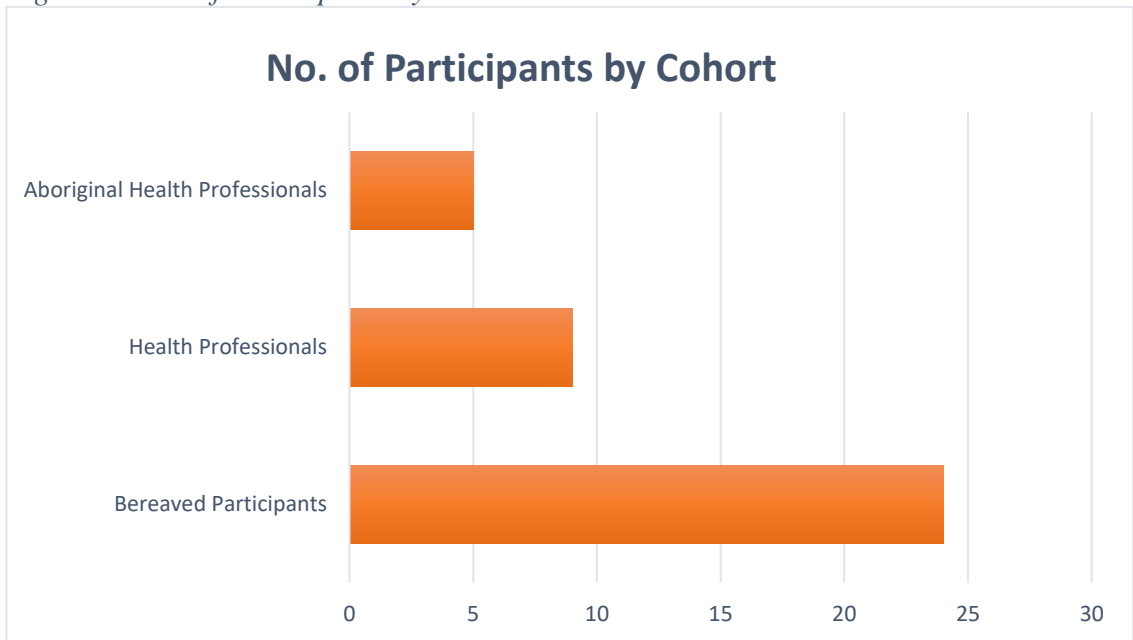


As recruitment was driven by regional services, there is no information of how many individuals were invited to participate. Recruitment occurred within four of the regions within WACHS. Forty seven (47) people initially expressed interest to participate in the project and PICF's were sent to all. A total of 37 interviews were completed. The cohort of Aboriginal participants interviewed as a group ($n=4$). Two of the health professionals preferred to be interviewed together and the remainder were interviewed individually. There was a total of nine health professionals interviewed. A total number of 24 bereaved participants were interviewed. Ten (10) participants who were not interviewed included three health professionals, four bereaved individuals and three Aboriginal health professionals. Of these participants, one was male and the other nine were female. One bereaved individual declined to be interviewed, instead forwarding a letter sharing her experiences of bereavement, providing a message for health professionals and others who have a loved one die. This was included in the data analysis.

Description of the Sample

The final sample for this study was a total of 37 participants, of which 24 were bereaved, nine (9) were health professionals and four (4) were Aboriginal health professionals. Bereaved participants comprised the majority of the total number of participants at 65%, health professionals 24% and Aboriginal health professionals (11%) respectively. Some health professional and Aboriginal health professionals shared some of their personal experiences of bereavement as well as their professional roles in providing bereavement support.

Figure 3: No. of Participants by Cohort



The Bereaved

The following section will discuss the demographic information of the bereaved. The total number of bereaved participants categorised by age is depicted in the following figure:

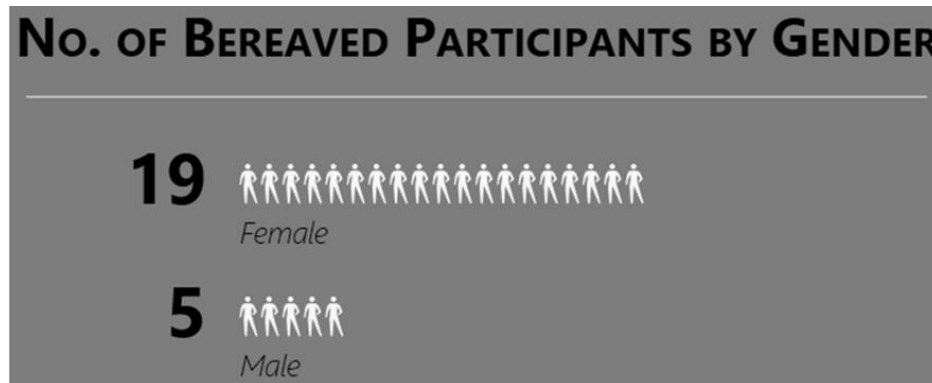
Figure 4: No. of Bereaved Participants by Age Range

NO. BEREAVED PARTICIPANTS & AGE RANGE



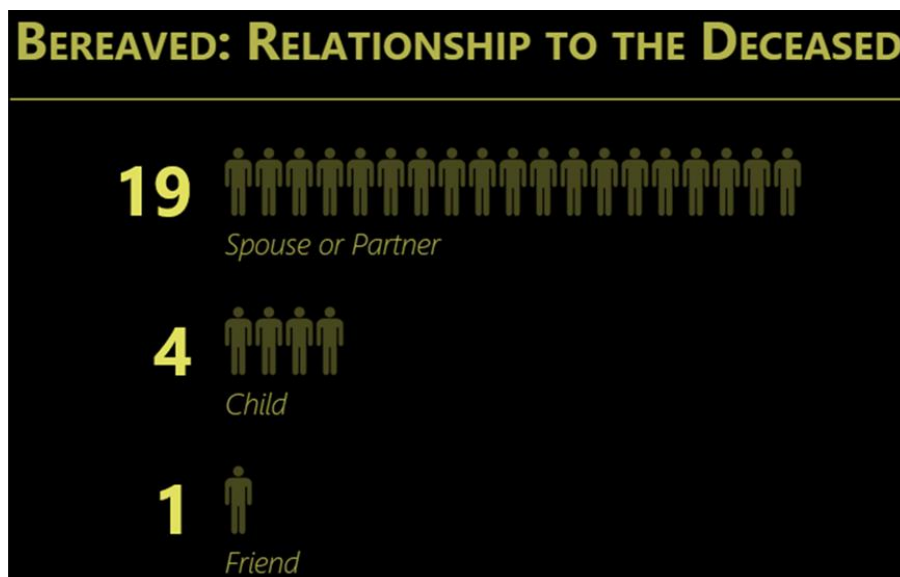
The youngest participant was 44 years of age and the eldest was 87 years of age. One (1) participant identified as being of Aboriginal descent.

Figure 5: No. of Participants by Gender



Female participants comprised 79% of the total cohort ($n=19$) and ages ranged from 44 years to 87 years of age. Fifteen (15) of the female participants experienced spousal bereavement (79%), three (3) adult child bereavement (16%) and one (1) bereavement of a friend (5%). Males comprised 21% of the total cohort ($n=5$). Male participant ages ranged from 52 years to 73 years of age. Four (4) male participants experienced spousal bereavement (80%) and one male experienced adult child bereavement (20%).

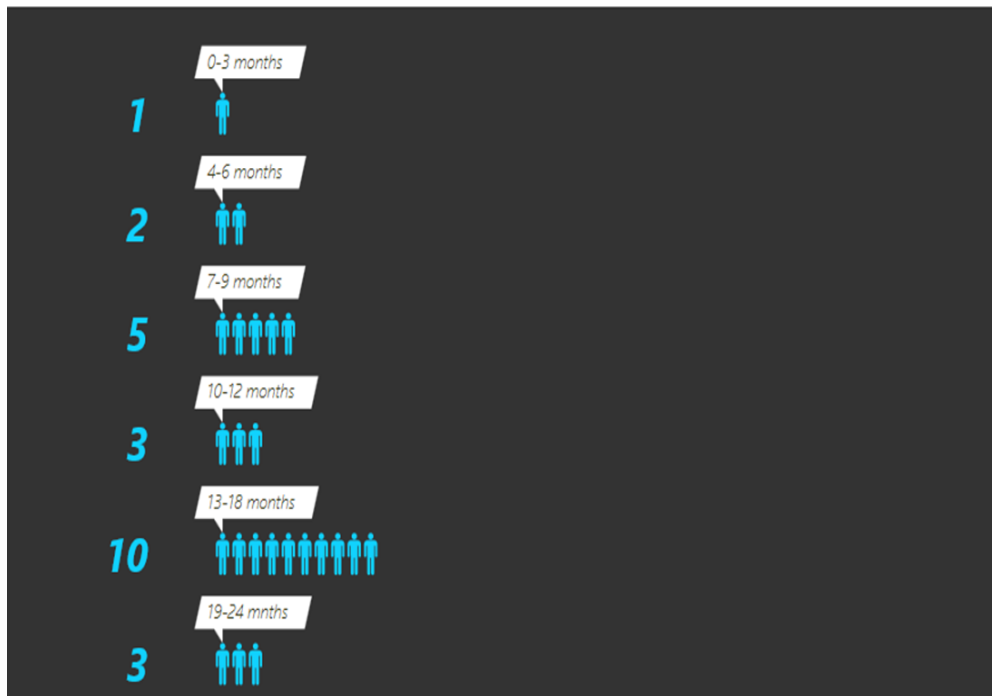
Figure 6: Relationship of Bereaved to the Deceased



Time since death ranged from as early as 0-3 months up to 24 months' post death. The majority of participants (42%) were 13-18 months' post death followed by 21% at 7-9 months' post death, 12.5% at 19-24 months and 10-12 months respectively, 8% at 4-6 months and 4% at 0-3 months' post death.

Figure 7: No. Bereaved Participants & Time Since Death

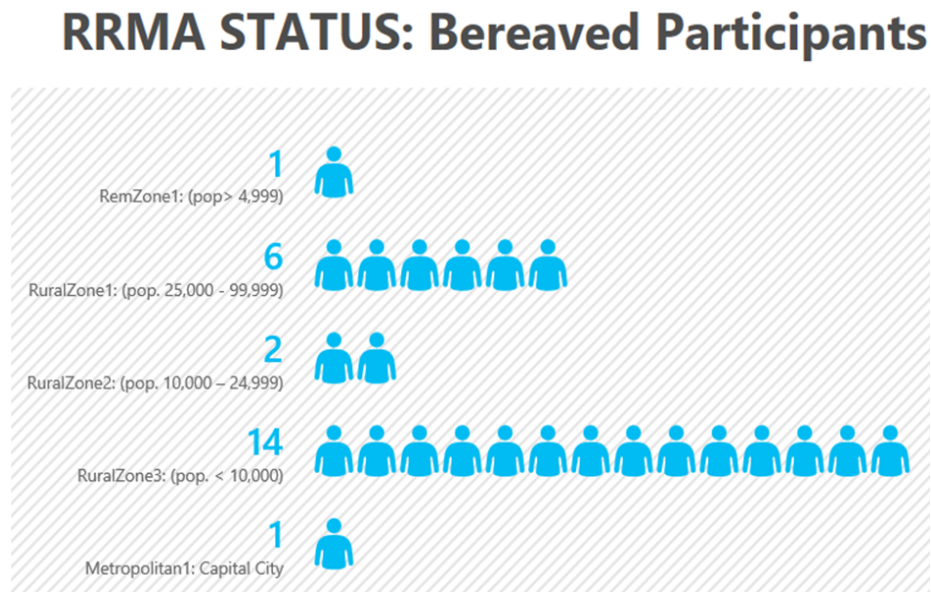
NO. BEREAVED PARTICIPANTS: TIME SINCE DEATH



There was representation from different rural zone classifications with the majority of participants (58.3%) being from Rural Zone 3 where towns have a population of less than 10,000 people. The next largest cohort (25%) were from Rural Zone 1 where towns have a larger population of between 25,000 to 99,999 people. There was 8.33% of participants from a Rural Zone 2 where the population ranges from 10,000 to 24,999 people. There was small representation 4.2% from participants living in Remote Zone 1 where populations are less than 4,999 people. One participant representing 4.2% from a Metropolitan 1 Zone which represents a capital city. Although this participant lived in the city, their deceased loved one was from a Rural Zone 3 (Australian Institute of Health and

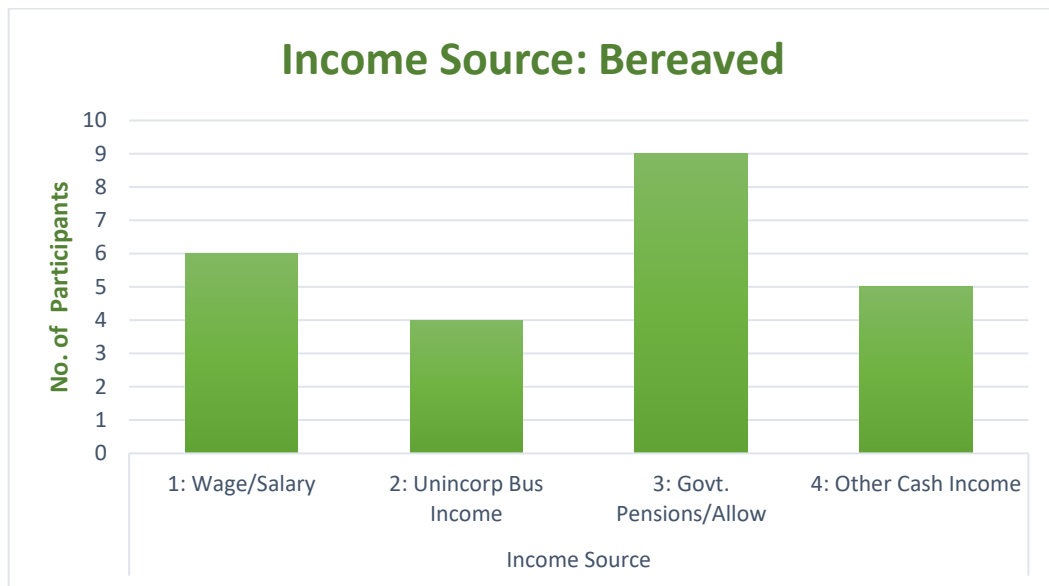
Welfare, 2004, p.5). This participant spent a lot of time attending to practical matters in bereavement dealing with local agencies and services. She also accessed the local palliative care service and attended their local memorial service. Much of her experiences with coping in bereavement occurred in the rural context so she was included in this study.

Figure 8: RRMA Status: Bereaved Participants



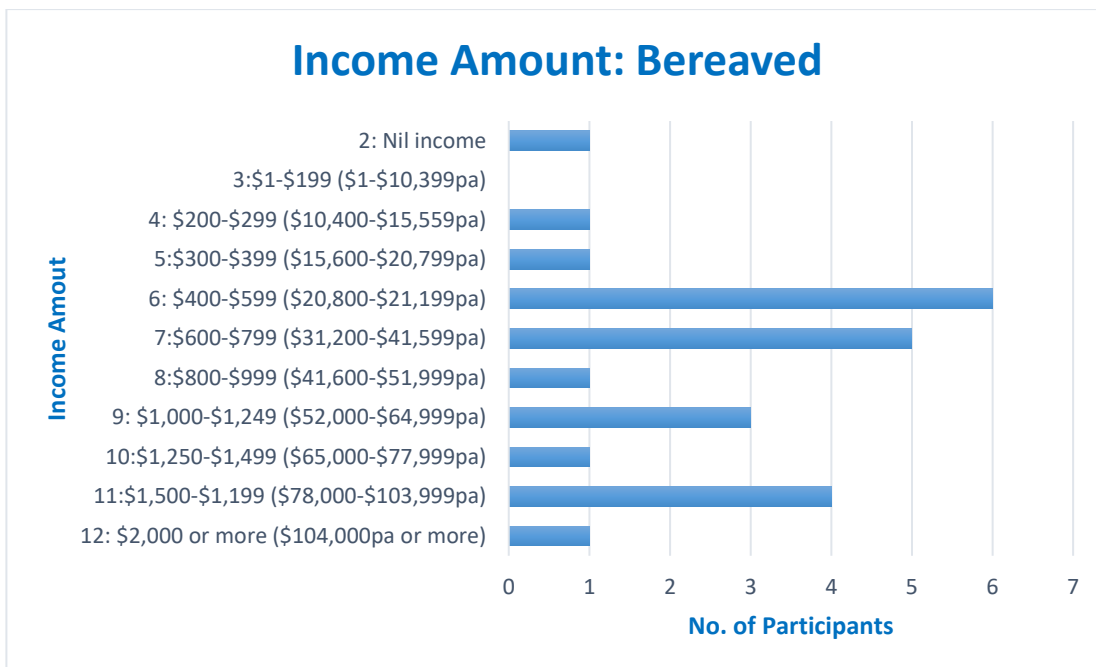
Other demographic data was collected based on income amount and source (Australian Bureau of Statistics, 2012) and demonstrates 37.5% of bereaved participants received income via government pensions, 25% were earning incomes via wages or salary and 37.5% received earnings from businesses or other sources.

Figure 9: Income Source: Bereaved



The majority of bereaved participants earned between \$20,000 to \$41,599 per annum however there was also representation from the extreme ends of one participant earning no income and another participant earning in excess of \$104,000 per annum.

Figure 10: Income Amount: Bereaved



Based on the Melbourne Institute of Applied Economic and Social Research Poverty Lines: Australia Report (December, 2015), nine of the participants sit below the poverty line and potentially an additional five (5) participants sit below the poverty line depending on their earnings within category seven (7) of \$21,200 to \$41,599 per annum. Participants in this study represent 58.33% of total bereaved participants as being from a low socio-economic status.

Health Professionals

The following section outlines the demographic information of the cohort of health professionals. The total number of health professional participants categorised by their professional role is depicted in the following figure:

Figure 11: Health Professionals by Profession

HEALTH PROFESSIONALS BY PROFESSION



The age range of health professionals was relatively narrow with the youngest health professional participant at 42 years of age and the eldest at 55 years of age. Forty-four percent (44%) of health professionals were between the ages of 40-50 years and 56% were between the ages of 50-60 years.

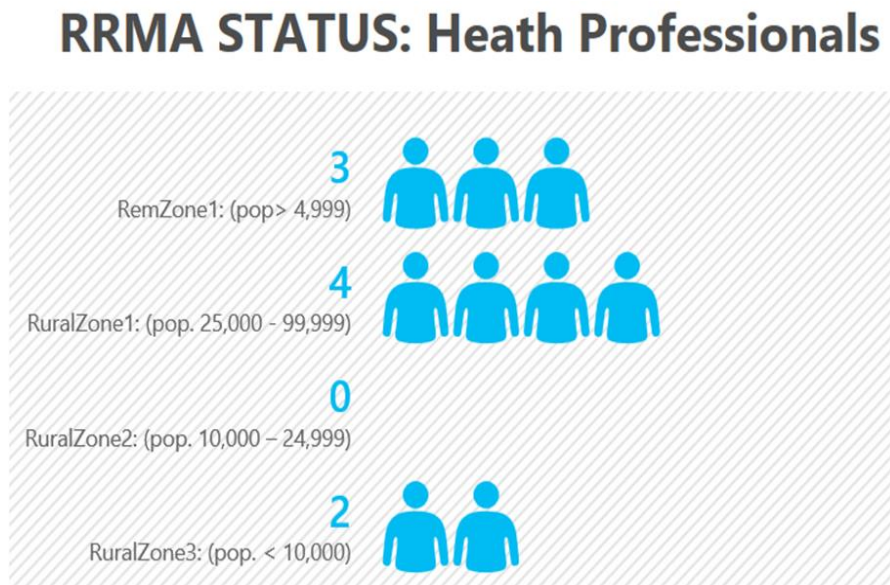
Figure 12: Health Professionals by Profession



Female participants comprised 89% of the total cohort and males comprised 11% of the total cohort.

There was representation from different rural zone classifications with the majority of participants (44.53%) being from Rural Zone 1 where towns have a population ranging between 25,000-99,999 people. The next largest cohort of health professionals (44.5%) was from Remote Zone 1 where towns have a smaller population of less than 4,999 people. There was 22% of participants from a Rural Zone 3 where the population is less than 10,000 people. There was no representation from health professionals living in Rural Zone 2 where populations range from 10,000-24,999 people (Australian Institute of Health and Welfare, 2004, p.5).

Figure 13: RRMA Status: Health Professionals



Aboriginal Health Professionals

Figure 14: Aboriginal Health Professionals by Gender and Age

ABORIGINAL HEALTH PROFESSIONALS

- 1  Male: 49 years
- 1  Male: 64 years
- 1  Female: 39 years
- 1  Female: 43 years

Three (3) of the Aboriginal health professionals were Aboriginal Liaison Officers¹⁶ and one (1) was an Aboriginal Health Worker. As per RRMA categories, three (3) of the participants were from Rural Zone 1 and one (1) was from Remote Zone 1. The Aboriginal health professionals expressed a wish to be interviewed as a collective group and face-to-face.

The Interviews

Participants are acknowledged as being expert informants and were invited to share their stories, in their own words, and at their own pace. Throughout the interviews, I engaged in active listening techniques, asking probing questions, clarifying and summarising points in participant narratives. Interviews for individuals who are bereaved were initiated by the following open-ended invitation: *“Could you talk about your bereavement and the impact it has had on your life?”* Additional prompt questions were included to provide a semi-structure for the interview. Questions exploring factors that encouraged or deterred receptivity to professional support included: who did they turn to for support? Did they feel the need for professional bereavement support? What experiences did they have with formal and informal support? These exploratory questions provided additional insights into bereavement experiences. (*Appendix D: Cohorts Schedule of Interview Questions*).

Interviews for health professionals who provided bereavement support were initiated with the following open-ended invitation: *“Can you talk about your work in providing bereavement support?”* and examples of prompter questions included, *“What do you think the bereaved require for support?”* *“What are some lessons you have learned from the bereaved?”* *“Are there things that bereavement programs do not include that you think*

16 An Aboriginal Health Worker (AHW) differs from and Aboriginal Liaison Officer (ALO) as AHW’s complete a Certificate III or IV in Aboriginal Primary Health Care via a tertiary institution or recognised training organisation whereas ALO’s do not have any formal qualifications required for the role.

might be helpful for the bereaved?” (Appendix D: Cohorts Schedule of Interview Questions).

Although these questions were the starting point for the researcher, interviewing participants was an iterative process. Qualitative interviewing techniques may lead to learning more about a subject and questions may be altered if they are not eliciting the necessary information. Therefore, the researcher needs to be flexible in the interview as digressions may be very productive in revealing rich information as the interviewee’s interest and knowledge shape the interview. Iterative processes in qualitative research allow for ‘reaching out’ to other participants who may be able to contribute further to developing descriptions or themes. Iterative processes enhance reliability and validity of the research and occur concurrently with data analysis as this informs data collection. This iterative process continues until the description is comprehensive and leads to a point where saturation occurs and no new themes emerge (Morse, Barrett, Mayan, Olson & Spiers, 2002; Polkinghorne, 2005; Diccico-Bloom & Crabtree, 2006; Kuper, Lingard & Levinson, 2008).

Data Saturation

Mason (2010, no page) cites Bertaux’s (1981, p.35) guidelines for sample sizes in qualitative research and posits that within PhD studies, 15 participants is the smallest acceptable sample size in qualitative research and relates sample size to saturation. Data saturation occurs when there is ‘informational redundancy’ where no new concepts or dimensions for categories can be identified. It does not necessarily mean that nothing new can be found (Holloway & Wheeler, 2010). Mason (2010) advises that saturation is influenced by many factors and can occur at any point in a qualitative study. This study comprised 24 bereaved participants and 13 health professionals of which four of these comprised a sub-cohort of Aboriginal health professionals. This study had a total of 37 participants which were predominantly female and over the age of 44 years. The potential for further insights could be found with younger, male and more ATSI participants. The

researcher conducted all of the participant interviews and was thus ideally situated to identify when all issues of primary importance were identified and data saturation was reached.

Data Storage

Recordings and transcripts were stored on the QUADRANT website. All information collected was stored as an encrypted computer file on a secure, password protected Australian central server, the QUADRANT computer management package which was used for data storage and management. This is a password protected computer package where access to data can be limited to those nominated. User access was controlled only and solely by the researcher. Access to the server also required password protected and encrypted authentication processes. De-encryption is only possible for the users (investigators) defined by the researcher. The central server and access is professionally maintained and is physically secure and located in Australia. Encryption and access procedures use 256-bit shared public-private keys and are current best technology. Information collected will be stored for a period of five (5) years after the completion of the project to meet the mandatory time period for the Griffith University and Notre Dame Code of Conduct respective policies for data storage.

Data Analysis

Rigour in qualitative research

Morse et al. (2002) emphasise the importance of the researcher focusing on verification at all stages throughout the study to reduce the risk of missing threats to reliability and validity. In effect, qualitative research is an iterative process where the researcher moves back and forth between design and implementation to ensure congruence between formulation, literature, recruitment, data collection strategies and analysis (Morse et. al., 2002, p.17). Verification strategies enable the researcher to identify when to modify, stop

or continue the research. These strategies contribute to, and build, validity and reliability thus ensuring rigour, enhancing researcher responsiveness and constantly reminding researchers to take responsibility and be proactive. Verification strategies included:

- *methodological coherence* where there is congruence between the research question and components of the method
- *appropriate sample* of participants who represent the research topic
- *collecting and analysing data concurrently*, an iterative process between data and analysis
- *thinking theoretically* where ideas emerging from data are reconfirmed in new data, checking and re-checking
- *theory development* moving between micro perspectives and macro conceptual or theoretical understanding.

(Morse et al., 2002, p.18)

Consultation between the researcher and supervisors can encourage probing questions which may help highlight researcher preferences and biases, promoting refinement of methods, greater explication of research design and strengthening of arguments (Shenton, 2004). Researcher reflexivity around these, alongside impressions of data, will reveal patterns emerging from the data which can play a key role in the monitoring of the researcher's developing constructions. Guba and Lincoln (1989, cited in Shenton, 2004, p.68) refer to this process as 'progressive subjectivity'. Ongoing discussion with the primary supervisor enabled the researcher to refine analysis processes and the overall study design. According to Shenton (2004, p.70) boundaries of the study should be documented and include:

- a) the number of organisations taking part in the study and where they are based
- b) any restrictions in the type of people who contributed data
- c) the number of participants involved in the fieldwork
- d) the data collection methods that were employed
- e) the number and length of the data collection sessions
- f) the time period over which the data was collected

- g) geographical area (as the results of qualitative research must be understood within the context of the characteristics of the organisations or geographical area in which the study was conducted)

and for any reason during the interview (Shenton, 2004).

Mays and Pope (1995, p.110) advocate that researchers need to “...ensure rigour is systematic and self-conscious in research design, data collection, interpretation and communication...” Strategies that can promote rigour include researcher transparency about the method so that another researcher could analyse the data in the same way and draw the same conclusions. This is achieved through clearly articulating assumptions and methods, particularly with regard to data analysis. When a researcher can present the study in such a way that the reader can distinguish the data, analytic framework and interpretation, this can minimise researcher bias in the presentation of results (Mays & Pope, 1995, p.111). Rigour is also achieved through sampling techniques that identify specific population groups that possess characteristics that reflect the phenomenon being studied. In qualitative research, as data is often collected in relatively unstructured forms, such as recording or transcripts of interviews, meticulous records of interviews and documenting the process of analysis in detail also promote rigour. Collection of data from different sources provides validity to the data collected as referencing multiple sources can potentially help to identify patterns of convergence between data sources (Mays & Pope, 1995). This is the underlying reason for including representation from three different cohorts within this study.

Trustworthiness is a term introduced by Guba and Lincoln (1985, cited in Morse, Barrett, Mayan, Olson & Spiers, 2002) in the and refers to credibility, transferability, dependability and confirmability. Specific methodological strategies within these aspects for demonstrating rigour include “...audit trails, member checks when coding, categorising, confirming results with participants, peer debriefing, negative case analysis, structural corroboration and referential material adequacy...” (Morse, et al., 2002, p.14). It is essential that the investigator remain open, to be willing to relinquish ideas that are poorly supported within the data (Morse et al., 2002). Researchers might begin with pre-

existing coding systems and these are often modified in the course of analysis or may be discarded in favour of a new system to ensure best fit to the data (Sandelowski, 2000). Some initial codes in this study were modified to ensure accurate representation of the data following re-review of codes to ensure they were developed within the language of the participant and not the researcher. For example, 'closing out the world' was a code created by the researcher but on further review and discussion with the supervisor, this code was changed to 'building a protective space from others' when it was determined the individual was not closing out the world as an avoidance or pseudo-pathological behaviour but rather, as an intentional 'psychological bracing', so that when people did or said perceived harmful things, they felt some resilience in being able to manage these difficult situations.

Whittlemore et al., (2001) highlight the tension between rigour and creativity and discuss criteria (standards) and techniques (methods) to diminish threats to the trustworthiness of the research. As this research utilised a descriptive methodology, the researcher engaged in the process of 'bracketing' which draws from the phenomenology literature. Husserl, (2001, cited in Wojnar and Swanson, 2007, p.173) describes the process of bracketing as transcendental subjectivity in which the researcher consciously and successfully "...abandon(s) his or her own lived reality and describe the phenomenon in its pure, universal sense..." In essence, the researcher consciously puts aside *a priori* knowledge and personal bias so they do not influence the description of phenomena from participants. Strategies the researcher utilised to enhance rigour in this study involved re-reading transcripts and confirming in-vivo codes were representative of participant narratives and reflected the open code to which they were assigned. The researcher also engaged in peer debriefing with the supervisor to confirm process and thematic analysis.

Qualitative research is characterised by fluidity, uncertainty and emergent ideas. Authenticity involves the portrayal of research that reflects the lived experiences and the meanings ascribed to these experiences by participants. Authenticity is essential criteria for validity in qualitative research. Accurate representation of the multivocality of interpretive perspectives of participants is important to ensure the researcher stays true to

the phenomenon under study. Acknowledgement of the influence of the researcher can influence authentic representation of participant voices and requires conscious attention to this influence by the researcher (Whittlemore, et al., 2001). *Congruence* is a secondary criteria of validity and is evident between the "...research question, the method and findings, between data collection and analysis, between the current study and previous studies, and between the findings and practice..." and methodological congruence and theoretical correctness (Whittlemore et al., 2001, p.532). *Sensitivity* where research is implemented in such a way that is sensitive to the nature of human, social and cultural contexts, representative of the multivocality of perspectives and voices. *Techniques* employed by the qualitative researcher needs to evidence the linkage between thought, technique, philosophy and research question.

Exploring negative instances,¹⁷ alternative hypothesis and examination of biases are all components of criticality that seek to enhance integrity at each phase of inquiry, a recursive and repetitive process of interpretations. Themes emerging from the data in this study demonstrated alternate and negative instances and contradictory experiences of bereaved participants. Threats to validity in qualitative research include investigator bias, not giving consideration to alternative understandings or not paying attention to discrepant data (Whittlemore, et. al., 2001). Researchers need to be open about their own beliefs underpinning decisions made, methods adopted and reasons for favouring one approach over another and this should be documented within the research report (Shenton, 2004). Researchers using descriptive qualitative research are compelled to maintain a critical self-awareness and consciously 'bracket' their own subjectivity, assumptions and vested interests on how these impact on the research process and to be open to the 'other' to see the phenomenon in a fresh and different way (Finlay, 2009).

¹⁷ Negative instances are where findings contradict findings. When the researcher includes negative instances, this enhances rigour of the study as it demonstrates the researcher has considered supporting and negating evidence. Evidence of negative instances helps to guard against error as research is developed within the construct of researcher perspective (Whittlemore, et al., 2001).

Transcription

A total of 33 interviews that were digitally audio recorded. The size of transcripts ranged from 11 pages to 45 pages, depending on length of interview. There was a total of 758 pages of transcribed interviews. The shortest interview was of 37 minutes and 17 seconds duration and the longest interview was of two hours and 23 minutes' duration. The total number of hours of transcribing was 334 hours and 35 minutes. All interviews were transcribed verbatim and included incidences of non-verbal language such as pauses when crying or when laughter occurred. Transcription was done using NVivo 10 data analysis software developed for qualitative research.

From the transcribed conversations, patterns or experiences were identified by quotes or the paraphrasing of common ideas. The process of thematic analysis is a descriptive strategy that enables the researcher to identify, analyse and report patterns, or themes, within data. These themes capture salient points in the data that relates to the research question and represents patterns of meaning or responses within the data set (Buetow, 2010). All participants were de-identified when coding and will be referred to by ID references which include:

- The cohort they belonged to – bereaved (B), health professional (HP) or Aboriginal Liaison Officer/Aboriginal Health Worker which will be under the one auspice of Aboriginal Health Professional (AHP)
- ID No. generated to de-identify participant
- Gender of participant
- Age of participant
- Relationship to deceased eg. spouse, child, friend
- Time since death eg. 0-3 months; 4-6 months, 7-9 months, 10-12 months; 13-18 months, 19-24 months and 24+ months
- RRMA status

Throughout this thesis, the bereaved participants will be represented by the following descriptor: ID: B / ID Number / Gender / Age / Relationship to deceased / duration since death / RRMA status. Health Professionals will have a descriptor as follows: ID: HP / ID Number / Gender / Age / RRMA Status. Although one of the Aboriginal Health Professionals is an Aboriginal Health Worker which distinguishes them from and Aboriginal Liaison Officer by the formal training they have undergone to receive the qualification, Aboriginal participants are identified by the following descriptor: ID: AHP / ID Number / Gender / Age / RRMA Status.

There was a significant amount of data and this was initially overwhelming for the researcher. However, by immersing themselves in the data, the researcher initially reads the transcripts and familiarises themselves with the material and with repeated revisiting of the data, new material and ways of understanding begin to emerge. This repetition enables the mind to process the material in different times and in different ways (Meek, 2003). Meek (2003) discusses Bollas' (1995, p.28) perspective of reflective processes where the researcher oscillates between condensing disparate information, synthesising thoughts and ideas with dissecting and deconstructing things into component parts. In effect, the processes of condensation and deconstruction are highly demanding intellectual and cognitive processes. Qualitative research entails active and high intellectual application. The processes of learning about the phenomenon and meta-learning, learning about context, requires a level of cognitive sophistication.

Namey, Guest, Thairu and Johnson (2007) recommend that when dealing with copious amounts of information, a system to identify large pieces of text on broad topics can provide a mechanism for indexing or grouping initially. Delineation of data in this study occurred by grouping the data separately where bereaved, health professionals and Aboriginal Health Professional participants were grouped respectively. Data was further grouped into pre-death and post death groupings however themes relevant to receptivity that occurred pre-death were included in the data analysis.

Thematic Analysis

As the focus of the research was on receptivity of the bereaved to support, there is a strong focus on discussing the findings from the data of this cohort throughout the following chapters (chapters four to nine). Data was examined within a framework of how discourses operate in society and influence experiences, meanings, realities and events, in effect, enabling analysis that reflects participants' reality while simultaneously unravelling the surface of 'reality'. According to Braun and Clarke (2006), key phases of thematic analysis include:

1. The researcher familiarising themselves with the data
2. Generation of initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report.

Thematic analysis is not linear and the process may even commence during data collection when the analyst "...begins to notice and look for, patterns of meaning and issues of potential interest in the data..." (Braun & Clarke, 2006, p.86). Analysis is a recursive process which entails moving back and forth between the data and it is in the early stages that the researcher commences writing notes about ideas or potential coding schemes and this continues through the coding and analysis process (Braun & Clarke, 2006; Buetow, 2010). The interview question schedule for both bereaved participants and health professionals were amended throughout data collection based on iterative process of themes emerging from the data.

Thematic analysis is to identify and describe implicit and explicit ideas. Codes are developed to represent ideas or themes and are linked to raw data. This helps to provide summary markers for later analysis. The researcher adopted a data-driven approach for thematic analysis as it compels the researcher to read and re-read the data, identifying

keywords, ideas, trends or themes and helped to provide an outline to inform analysis (Namey et al., 2007).

Participant comments were coded into 'free nodes' whereby reading through the data several times led to the creation of tentative labels for chunks of data that emerged from participant narratives. Categorising themes became easier as participant descriptions of their experiences provided the themes or categories to organise the prolific amount of qualitative data. The Rashoman effect describes the process of analysing and coding data where themes begin to emerge and the researcher arranges data where the same event is described from the perspective of more than one participant (Sandelowski, 2000) which led to the development of parent nodes and child nodes. 'Parent nodes' were created that reflected key 'bigger picture' themes that emerged from the analysis, with the creation of 13 (bereaved), eight (8) (health professionals) and eight (8) (Aboriginal health professionals) parent nodes created respectively. Further coding occurred *in vivo*, using the participants' own language as much as possible to stay within the philosophy of qualitative descriptive methodology. Simultaneous coding also occurred where the researcher applied multiple codes to the same text (Holloway & Wheeler, 2010). A total of 416 'child nodes' were created within the 13 'parent nodes' for the bereaved (B). A total of 218 'child nodes' were created within the eight (8) 'parent nodes' and a further two (2) sub-nodes created under the relevant 'child node' heading for the health professionals (HP). A total of 95 'child nodes' were created within the eight (8) 'parent nodes' and a further two (2) sub-nodes created under the relevant 'child node' heading for the Aboriginal health professionals (AHP). A helpful analytic technique is to look at frequencies of individual participants who mention a particular theme as this is an indicator of thematic importance than the number of times a theme is expressed and coded (Namey et al., 2007). The number of sources (participants) and references (statements) varied between the cohorts and there were different nodes ranging from one to 24 sources (AHP), one to 54 sources (HP) and one to 206 (B) respectively.

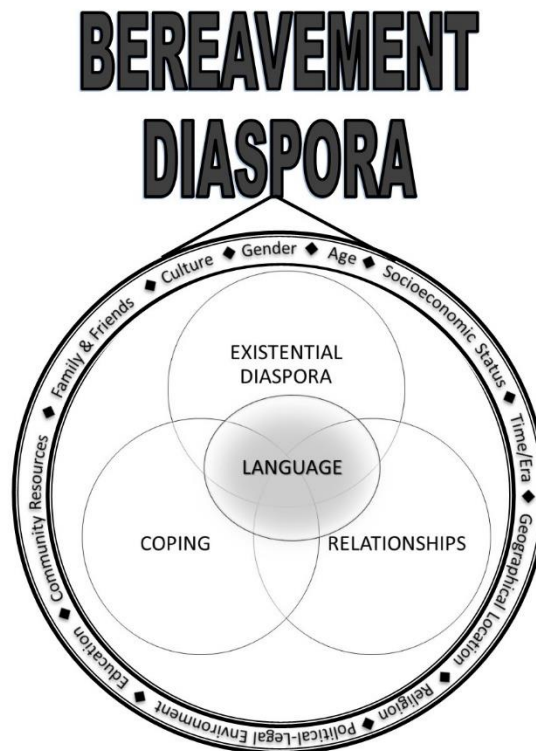
Themes

In listening to the voices of the bereaved and the health professionals who provide bereavement support and being aware of one's own values and how this can influence the research process, the researcher continuously had dialogue with the data. Findings that emerged from the data with bereaved individuals resonated with tenets from the postmodern and the Diaspora discourse which encompasses experiences of an individual's inner and social world from the multiple perspectives of gender, culture, class and other group affiliations (Agger, 1991). Existential, coping and relationship experiences were core themes in the data and characteristic of the lived experience of Diaspora. Conceptually, findings from the research demonstrate:

1. The bereaved experience existential distress that reflects the profoundness of the diaspora lived experience.
2. There is a myriad of ways in which individuals cope.
3. Relationship is an integral component to how people make meaning of their experience and mediate their bereavement.
4. Language is a central feature that constructs experiences and connects the individual with their outside world; it is also a discourse created by professional lens.

These four domains are all reflected in the Diaspora literature. Diaspora can be viewed as an existential state (Chen, 2015) and can also be viewed as an all-encompassing experience which comprises individual, relational and social factors and will be discussed in detail in subsequent chapters. The findings have thus been conceptualised in the following way:

Figure 15: Bereavement Diaspora Conceptual Model



This conceptual diagram provides the framework through which data emerged and these domains were identified as key areas influencing receptivity to bereavement support. Throughout the interviews in this study, use of language to describe experiences was diverse and contradictory and not only highlighted the multiplicity of experience but also highlighted that language and the ways in which a person conveys their experiences may be an important factor underpinning a person's receptivity to seeking and engaging in support.

Limitations

Limitations of this study include that bereavement experiences were explored only within the context of individuals who had been under the care of a palliative care service. The methodology entailed utilising third parties ie. regional palliative care services for recruitment of participants however there was no insight in to how respective regions did

this ie. advise all previous clients or selection bias based on staff assessment in communicating the research study to all parties. The cohort of bereaved participants were over the age of 44 years and were predominantly from the perspective of spousal bereavement. Younger participants and participants of varying relationships to the deceased could provide broader insights. Depending on where participants are in the life cycle, bereavement experiences could vary as a result of specific generational health and psychosocial developmental influences. There was only a small sample size of Aboriginal participants who engaged in the process as a professional who provides bereavement support. There was only one bereaved participant who identified as Aboriginal.

Conclusion

In this chapter, the methodology which operationalised the exploration of bereavement experiences and receptivity to bereavement support has been discussed. This chapter provides an overview of the iterative procedure used throughout this study including purposive sampling, data collection, the demographic profile of the sample participants, data analysis, ethical considerations, limitations of the study and an overview of the core theme that emerged from the data, Diaspora. The core concept of Diaspora will be discussed in the following chapters.

Chapter 4: Diaspora: From findings to Concept

Introduction

The previous chapter outlined the methodological approach of this study and introduced the main concept that emerged from the data, *bereavement diaspora*. This chapter will discuss how diaspora emerged as a theme from the findings to conceptualise *bereavement diaspora*. The transformation of diaspora from a theme to a conceptual framework will be discussed, with a focus on the theoretical linkages between bereavement, existentialism and diaspora. The origins of diaspora, and the application of diaspora and existential discourse to bereavement, will be explored.

As discussed in the overview in chapter one, subsequent chapters will discuss in-depth, the core themes that make up the conceptual framework of *bereavement diaspora*. These themes will be discussed in relation to their influence on the *bereavement diaspora* experience. Chapter five will discuss the concept of *existential diaspora*, chapter six will discuss coping, chapter seven will discuss the role of relationships and chapter eight will explore the role of language. The subsequent chapters will comprise data from this study to provide in-depth articulations, connecting diaspora with bereavement. The four main themes within the *bereavement diaspora* will then be interlinked in chapter nine, which will discuss receptivity as it applies to diaspora and bereavement.

The Origin of Diaspora

The term diaspora originates from the Greek verb *speiro* meaning ‘to sow’ and the preposition *dia* meaning ‘over’ (Cohen, 1997, p.ix, cited in Hua, 2013, p.31). Diaspora originally referred to the displacement of Jews from their homeland throughout history but more tragically after the Holocaust of WWII (“Diaspora”, 2016). Empirical literature links diaspora with the language and history of Judaism however, the concept of diaspora

emerged in the African studies discourse in the 1960's (Clarke, 2010) and with Asian studies in recent times (Chen, 2015; Aguilar, 2015).

Historically diaspora discourse is concerned with geographical displacement and the processes the diasporic individual or community employ to assimilate, integrate and accommodate to their new world (Anthias, 1998). In this way, diaspora recognises and acknowledges postmodern pluralities of identities (Marat, 2016). Themes relating to social, cultural, geographical and political factors framed within a historical context are engendered in the diaspora discourse, along with themes of power and oppression. All of these features are recognised as impacting on a person's identity and subjective experience of being-in-the-world. Diaspora discourse highlights anti-essentialism and anti-reductionism perspectives, echoing the underlying epistemology of this research, postmodernism. (Anthias, 1998).

There have been concerns expressed that diaspora has been used by academic researchers in inconsistent ways, leading to diaspora becoming a somewhat nebulous concept (Yamashiro, 2015). Diaspora has been used in multiple ways such as to describe a collectivity (diaspora), a condition (Diasporicity or diasporism), a process (diasporisation, de-diasporisation and re-diasporisation) and as a field of inquiry (diasporitics or diasporology) (Brubaker, 2005). Diaspora is representative of 'identity' and moving from a technical term of psychoanalysis and philosophy, to a key term to describe disruption to 'life flow' or 'liminality of experience' in social sciences and humanities (Brubaker, 2005).

The concept 'diaspora' is seeing an increasing presence within the social science and humanities disciplines and their subfields, including religion, philosophy, folklore, black and women's studies, history, cinema, theatre, music and dance (Brubaker, 2005; Johnson, 2010; Clarke, 2010). The 'lens' of diaspora now transcends geographical dispersion and dislocation and conveys a theory of movement and of dynamism (Clarke, 2010). Kaur (2015, p68) posits that "...diaspora is both a physical condition of dislocation and a

postmodern intellectual notion expressing existential loss...” From this research, the scholarly use of the notion of diaspora, describes the lived experience of bereavement. The intent of the use of the term diaspora for the purpose of this research, is to explore bereavement through the lens of difference. This views grief and bereavement as heterogenic, incorporeal, spatial, temporal and dynamic inter-relationships and states of being (Baptist, 2010).

Diaspora: what the literature says

Much of the diaspora discourse has similar concepts to existential related phenomena and this was reflected by bereaved participant narratives in this study. Existential related themes of despair, suffering, sorrow, feeling alone and feeling displaced from a world that was once familiar, emerged from the findings in this study and echoes the diaspora discourse. Participants also felt displaced from the person they once were. However, as with the existential and diaspora discourse, the experience of bereavement also identified the potential for transcendence and transformation (Yang, Staps & Hijmans, 2010; Yancy, 2011).

There is heterogeneity and contradiction in the bereavement discourse and the diaspora discourse also includes contradictions, positives and negatives of the diasporic experience. The diaspora literature identifies the following overarching themes that coincide with the narratives of participants in this study;

- × Diaspora creates existential crises;
- × There is a tension between disruption and continuity;
- × There is a tension of double consciousness or layered simultaneity in which two thoughts, two ideals and two unreconciled strivings co-exist in one body and mind;
- × There are constant tensions in reconciling identity in relation to past, present and future (ie. ongoing relationship with the deceased);
- × Diaspora is characterised by longing and nostalgia;

- × Memory plays a key role in mediating between the old and the new - it creates the emotional and psychic condition of existential diaspora;
- × Diaspora is enduring and dynamic;
- × Diasporics co-exist as a unit, for example family or community;
- × There is a collective identification amongst the Diasporic – an us and them perspective;
- × Language constructs the diasporic identity. Language is inherently linked to power;
- × The Diasporic individual constantly embodies lived tensions. For example, there are lived tensions between grief from the inherent sense of loss from displacement, and the desire to (re)connect to homeland and community;
- × Transcendence in the Diaspora occurs through a spiritual connection with homeland and community

(Clifford, 1994; Anthias, 1998; Brubaker, 2005; Bakare-Yusuf, 2008; Baptist, 2010; Clarke, 2010; Raghuram, 2010; Yancy, 2011; Canagarajah & Silberstein, 2012; Johnson, 2012; Ogbuagu, 2012; Ben-Rafael, 2013; Hua, 2013; Voicu, 2013; Chen, 2015; Kaur, 2015; Yamashiro, 2015; Hunter, 2016; Marat, 2016; Wofford, 2016).

Key themes from the diaspora literature emerged clearly in the study data. The psychological, spiritual and socio-cultural-political features in the diaspora literature were reflected in the participant narratives in this study. Although the core concept being explored in this study was receptivity, what emerged from the data were profound stories of the lived experience of bereavement. There was a distinct existential impact in bereavement and the ‘bigger picture themes’, or overarching themes of relationships, the diversity and breadth of the way people coped, the influence of language, the landscape of grief, loss and bereavement, the sense of disruption and displacement and the metaphors used by bereaved participants described the existential experiences of their grief.

Diaspora: Findings to Concept

Data analysis of the narratives of the bereaved commenced via open coding. The researcher wanted to keep as close to the participants' narratives, metaphors and language as possible, so used these in identifying the node descriptors, or subthemes. Through constant iterative processes, listening to the voices of the bereaved, the researcher began to understand what it meant to the bereaved participants to live with, and continue to survive, bereavement. Brene Brown (2010) states, "...maybe stories are just data with a soul..." and the soul of participants' stories in this study revealed a diasporic landscape in which they found themselves lost, alienated, scared and alone. One participant described the frightening experience of finding themselves '*in foreign territory*' following the death of his spouse;

"I found myself in foreign territory... there's no guidelines when you're grieving and I guess it's very frightening because you don't really know what to expect, or how to be, and for me it was scary..." ID: B: 3371: F; 77; Sp; 7-9; R2

Feeling displaced in his world which was now alien to him, the participant was left feeling frightened and confused and was not sure of how to respond to the experience, or what to expect. This was a common narrative of participants in the early period after the death of their friend or family member, where the experience left them feeling disorientated and displaced. However, some participants described how they found comfort, connection, love and hope throughout their experiences;

"...I just got a lot of strength, more from my friends and people who just won't leave me alone, in a nice way..." ID: B: 3072: F; 52; Sp; 6-9; R3

"...when you're not even looking for it [hope]. It just raises its delightful smiling face..." ID: B: 3371: F; 77; Sp; 7-9; R2

Many participants described finding comfort and connection with intimate others in their informal support networks such as family and close friends. The experiences of finding hope was often reported as occurring as time progressed.

The concept of diaspora consistently emerged from the data. Participants described the dominant features that characterised their bereavement as existential despair. The psychological, emotional and social diaspora experienced by the bereaved in this study represents a world of dislocation, disruption, disconnection, being in limbo or in foreign territory and feeling empty. Disruption and displacement are common tenets in the diaspora discourse and was demonstrated in participant stories. The following quote by a participant depicts the sense of disruption that occurs as a result of the death of a loved one;

“...now all those plans, everything's just gone; everything. Everything we'd planned to do has just gone out the window and I just, I feel empty, there's no plans, there's no future where I had a future before...” ID: B: 3386: F; 53; Sp; 19-24; R1

Participants described feeling cheated by the death of their loved one, where the plans they had for their future together, would no longer happen. The uncertain future led participants to describe a sense of hopelessness. It is from this space that the struggle of getting used to being in the world again occurs, at a pace unique to the individual, as is their grief. Much of the discourse on bereavement in the psychological literature is in reference to the re-adjustment of the surviving bereaved person. It does not adequately capture the violence and tumultuousness of the diasporic, temporal and incorporeal states described by participants in this study. One participant used the metaphor of a tsunami to depict the violent impact on the psyche;

“...the tsunami of grief just hits you and all of your guts ache and it's just awful!” ID: B: 3371: F; 77; Sp; 7-9; R2

Many participants expressed a level of violent tumultuousness to the psyche that death of a loved one caused, despite it being an expected death. However, as time went on, participants described the violence to the psyche diminished to feelings of yearning and nostalgia. The stories that emerged from this study showed there is a yearning for a world that once was for the bereaved, a poignant or sometimes raw nostalgia for the world that was before the death of a loved one, a social and psychological diaspora rather than a corporeal one. One participant describes the struggle of reconciling past and present and the sense of nostalgia and yearning that comes with this struggle;

“I had a future before... I was so loved...I was so lucky that I did have that, but I want it back too; I wasn't ready to let it go.” ID: B: 3386; F; 53; Sp; 19-24; R1

This participant's quote echoed many of the narratives by other bereaved participants in this study. The struggle with reconciling the life that was, with the life that is going to be for the future, was common to many of the participants. Over time, the struggle became internalised, and the bereaved person's world of grief became private. The findings demonstrated that this *existential diaspora* is a place where grief becomes a private world, where people navigate what to share with others and who to invite into their most intimate thoughts and feelings. The bereaved feel a constant tension of reconciling the world that was, with the world that they have to live in now. Some examples of the subthemes include *'in foreign territory'*, *'being in the fog'*, *disrupted world*, *'grief is brutal, raw and cruel'*, *'feeling lost'*, *'having no anchor'*, *'the shock factor'*, *'scary experience'*, *'tormented by what if's'*, *'feeling vulnerable'*, *'suffering'*, *'world profoundly changed forever'* and *'hope-hopeless'*. These subthemes, along with others, began to form a picture of the psychological, emotional and spiritual landscape of bereavement. It was not until half way through the coding that the concept of diaspora as an existential state came to mind. The subthemes were thus categorised under the main or overarching theme *diaspora*. As data analysis is an iterative process, the researcher returned to the literature to gain further insights into diaspora. The diaspora discourse alluded to many existential concepts that

were enmeshed within the experiences of geographical disruption and displacement. Thus, subthemes based on participant descriptions of the existential impact in bereavement evolved into the theme '*existential diaspora*'.

A dominant feature in the diaspora literature were social and political factors that influence the Diasporic person's experiences of being-in-the-world. Martin Heidegger, an existential philosopher, created the concept of *dasein*, a term often used to refer to a state of being-in-the-world, commonly used in phenomenological studies. *Dasein* incorporates temporal notions of existence in which a person lives within a certain geography, point of history, culture and language. Basically, Heidegger's ontological stance is that the world provides the context for a person, or *entity*, to understand their experiences and existence (Lewis & Staehler, 2010). Although this study does not adopt a phenomenological approach, the researcher was reluctant to use the term in the main body of this thesis so as not to cause confusion. Diaspora as a state of being, or *daisen*, provides an explanatory and exploratory framework for bereavement and has implications for future research, especially with a phenomenological perspective. For the purpose of this thesis, *daisen* is thus referred to as being-in-the-world.

Experiences of '*dealing with practical matters*', '*financial issues*' and '*funeral arrangements*', along with other practical issues, emerged from the data. Participants described feeling frustrated and distressed by their experiences with institutions when having to notify them of their loved one's death and administer the deceased's estate. The following quote depicts how overwhelming dealing with practical matters can be;

“...I remember one day I had all these sheets of paper out, all over here and I'm thinking, 'now this has got to be done here, and the funerals got to be paid for, and then I've got to transfer the licence over, that's got to be done on that date. Oh, I've got to go to that department to do that'...and just trying to sift through it all and put it in date order...I found it really overwhelming. I mean, I got through it, but there were times when I was

panicking and thinking, 'I'm never going to be able to sort this out'..." ID: B: 3180: F; 70; Sp; 0-3; R3

Participants reported dealing with practical matters was a significant part of the bereavement experience and this impacted on their grieving. The barriers of organisational policies and procedures and workplace legislation regarding compassionate leave all impacted the bereavement experience of participants. There is an absence in the literature in relation to these issues.

Rurality was also a feature as geographical location impacts on availability of resources as reflected in subthemes such as *'tyranny of distance'*, *'higher costs'*, *'limited resources'*, *'social isolation'* and *'ever changing resource landscape'*. The following quotes demonstrate some of the challenges of rural issues including the changing resources and geographical isolation that contributes to social isolation;

"...I had a new GP - because they keep turning them over a bit, you know - they do different areas when they're in the rural areas..." ID: B: 2875: F; 81; Sp; 13-18; Rem1

"...because we live so far out of town...people say to me, 'oh, come into town and have a cup of coffee', you know. No-one comes out here for a cuppa. I always have to go into town..." ID: B: 3110: F; 61; Sp; 19-24; R3

The role of the environment on the experiences of individuals and communities is reflected in the diaspora literature. Factors such as geographical location, along with organisational, policy and legislative factors, are framed within the socio-political environment in diaspora discourses. There is an absence in the bereavement literature of the socio-political issues, specifically relating to dealing with institutions and

administering the deceased's estate, and how these practical matters impact on the bereaved.

Many participants reported similar experiences in dealing with practical matters. Participants described how they coped with these, and coped in their bereavement in general. Examples of subthemes that emerged from the data of coping experiences include: *'pacing self with tasks'*, *'changing habits'*, *'learning to control or manage emotions'*, *'being selective with help offered'*, *'calling in favours'*, *'the role of technology'*, *'travel as therapy'*, *'replenishing the mind and soul'*, *'creating sacred spaces'* and *'using humour'*. The following quote demonstrates how the participant coped in their bereavement and reflected many of the narratives of other participants:

"...if I have a down day - and I do have them - I hide them really, really well. I have my - 'sit here and contemplate the world' - I have a down day, and then the next day, I get out of bed and I ring a friend and we go for a walk and have coffee. I go to lunch; I do lunches all the time. I do dinners all the time. I am very social..." ID: B: 3369: F; 53; Sp; 13-18; R1

Many of the bereaved participants described oscillating between giving themselves permission to grieve, but also re-engaging in day-to-day activities. Findings reflected the active process (and struggle) of the bereaved (re)negotiating their identity, for example: *'being strong'*, *'feeling worthy'*, *'finding new identity'*, *'finding strength'*, *'sense of self'*, *'independence'* and *'the influence of our upbringing'*. The process of re-constituting one's identity was often an active process of cognitive appraisal and it was also relational, influenced by interactions with others. Participants described learning new traits or abilities about themselves, or they attributed their sense of who they were to the influence of their upbringing, as demonstrated by the following participant quotes;

“...I've had to cope on my own all my life, really, I didn't ask for help...” ID: B: 2875: F; 81; Sp; 13-18; Rem1

‘...I can see through all of this who you are is how you deal with it. So if you are a glum easily depressed kind of person you would find it harder whereas I'm not that kind of a person...’ ID: B: 3391: F; 69; Sp; 13-18; R3

Many participants described learning new things about themselves and in the process of reconstituting their identity, many participants recognised changes in their attitudes and behaviours. Consistent throughout these changes however, was the need to maintain a connection to the deceased. Research shows that a part of coping is maintaining a connection to the deceased through transcending the relationship from the physical to incorporeal world (Field & Wogrin, 2011). This transformation of relationship was reflected in subthemes of: *‘honouring the deceased’*, *‘transcendental presence’*, *‘voice of the deceased’*, *‘reuniting with deceased in afterlife’* and *‘valuing memories’*. The following participant described herself as a spiritual person and found comfort from some *‘transcendental signs’* by her deceased husband, despite not wanting to pursue spiritual connection further at the time;

“...I did work in a mind, body, spirit store and I do have a connection with that sort of alternative thinking, but I haven't really felt like I've connected with him at all. I'm not even going to try. I'm not ready to do that and I don't know if I can. I've had little signs that I feel like he's around me...” ID: B: 3072: F; 52; Sp; 6-9; R3

Many participants described transcendental presence, or signs, as occurring further into their grieving and not so much in the early days and weeks in bereavement. Many participants discussed talking to the deceased from the moment of death and throughout their grief at different times. The dialogue with the deceased is an important process of

transforming the relationship to a transcendent one. This is referred to in the bereavement literature as ‘relocating the deceased’ (Field & Wogrin, 2011). This process of transcendence occurs over time, which had related subthemes of: *‘time markers’*, *‘grief of loss enduring’* and *‘timeline on grief’*. The following participant quote demonstrates the realisation that the grieving may endure for the rest of their life, enduring through time;

“...it’s just the fact that he isn’t here and even now I suppose it’s going to go on forever - it will always be like this...” ID: B: 3391: F; 69; Sp; 13-18; R3

Time and memory are concepts commonly referenced in the diaspora literature as they relate to a *lived tension* of living between the past, present and future, influencing the identity-(re)identity of an individual. Experiences with dealing with practical matters and of the way people coped evolved into the overarching theme *‘coping’*.

Central to how people cope in bereavement is their relationships with others. Nodes such as *‘cohesive family fabric’*, *‘role shuffle’*, *‘connection with community’*, *‘the disappearing’ of others’*, *‘feeling alienated’* and *‘expectations of others’* are some of the subthemes that emerged, and formed the theme *‘relationships’*. One participant emphasised how important relationships with others is in companioning the bereaved person;

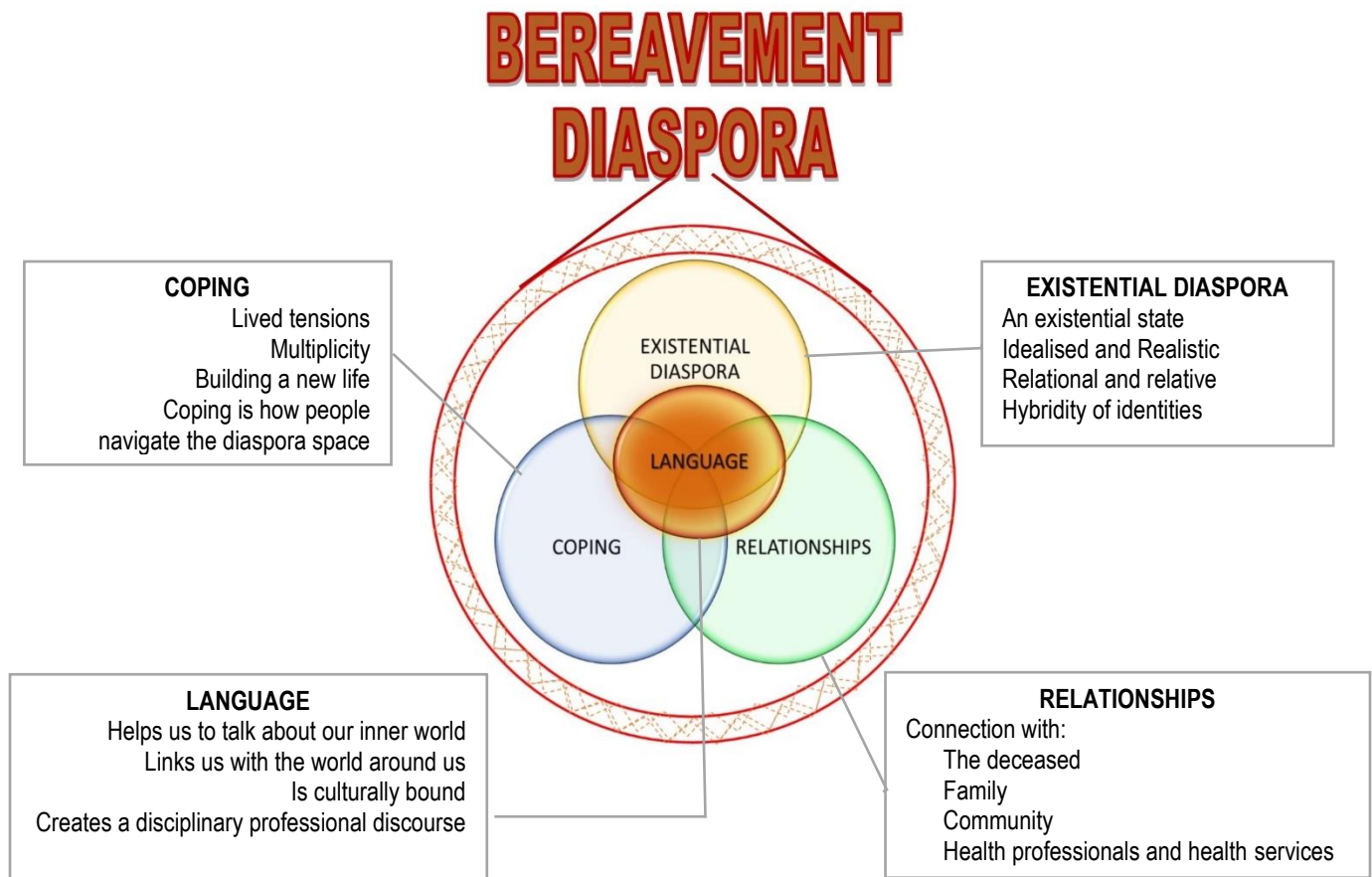
“...you need people. You need time to, to be quiet and think and grieve and cry perhaps, but you need people.... people who are just there. You don’t have to do very much...” ID: B: 3111: F; 68; Friend; 13-18; R3

Relationships are a key mediator in how people cope in bereavement. However, although many of the bereaved described the valuable emotional and practical support they received from others, they also described their negative experiences with others, and much of this was related to things people say. The diaspora discourse emphasises the role of language in how people interact with the people and institutions within society. Language is integral

to the social construction of one's world and central to how people negotiate the diaspora and find identity within it (Canagarajah & Silberstein, 2012; Hua, 2013; Ben-Rafael, 2013; Marat, 2016). The data that emerged in this research relating to language were included in subthemes such as: '*changing the language*' and '*things people say*'. Qualitative descriptive research was used as the methodology as the researcher was aware of the importance of language in analysing experiences however, when explored within the context of the diaspora discourse, it reinforced how integral language is. This led to the creation of the overarching theme '*language*'.

It will be shown that the overarching themes (findings) that emerged from the data - language, relationships, coping and existential diaspora - all embodied concepts that were embedded in the diaspora discourse. The concept of *Diaspora* that emerged from the data in this study is two-fold, diaspora as an *existential diaspora*, and *bereavement diaspora* as a broader bereavement experience which incorporates the (1) Existential Diaspora, (2) Coping, (3) Relationships and (4) Language. *Bereavement Diaspora* is the experience of being-in-the-world as a bereaved individual - as depicted in the following diagram

Figure 16: Bereavement Diaspora Conceptual Model: Major Themes from the Findings



Defining the concepts: Existential Diaspora and Bereavement Diaspora

For the purpose of this research and to explain the conceptual diagram, diaspora contains an existential crisis state, *existential diaspora* within the broader *bereavement diaspora* experience. The *bereavement diaspora* provides the ‘bigger picture’ of the whole bereavement experience. The parameters of *bereavement diaspora* for this study are defined in the following paragraphs.

The definition of *existential diaspora* is:

‘*existential diaspora* exists at a particular time, is temporary, although duration varies between individuals, is episodic and individuals can experience a recurrence, or upsurge in their grief, many times over the

lifetime. There can be (re)-grieving, which may occur on anniversaries of particular days or events, or for particular developmental or psychosocial milestones. Upsurges in grief may also occur when individuals have experiences with institutions as part of the process of dealing with practical matters. The *existential diaspora* incorporates emotional, psychological and spiritual elements that impact on an individual's existential experiences in bereavement.'

The definition of *Bereavement Diaspora* is:

'*bereavement diaspora* refers to the 'situatedness' of the bereaved individual and how they are affected. The diasporic experience is dynamic and enduring and results in *existential diaspora*, but also leads to changes in the social world of the bereaved, which can include relationships with others and changes to psycho-socio-economic circumstances. How the bereaved navigate this *bereavement diaspora* is through the many different ways of coping and central to this is individual efficacy and relationships. Language helps to give words to their experiences and to link the bereaved with the world around them.'

The Diaspora discourse refers to existential struggles, but when reviewing the literature to ascertain if diaspora had been applied to grief or bereavement, the researcher could only locate one research article. Baptist's (2010) "*Diaspora: Death without a landscape*" discusses the place of roadside memorials in a person's grief. Although Baptist (2010, p.294) described roadside memorials as dwelling places for diasporic grief, what she discussed in her article resonates with the narratives of bereaved participants in this study:

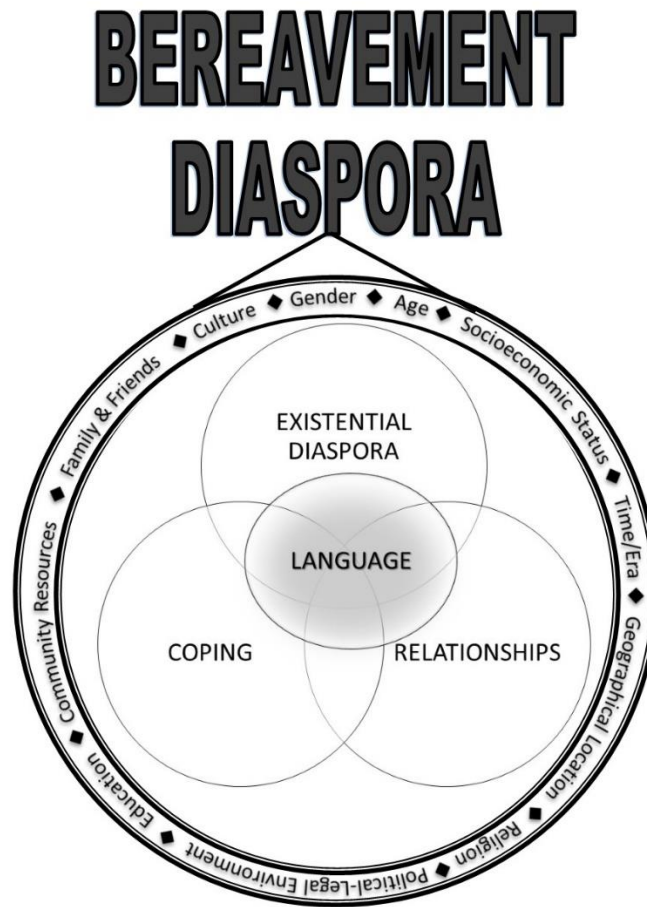
Bereavement, as I experienced it, was corporeally paradoxical. The gravitational pull of grief was a heavy burden I carried each day, weighing me down, dragging me ever earthward. And yet, I felt at the same time unfettered and groundless, for the landscape of home and of family seemed now lost to me forever.

Although existential elements have been discussed in the Diaspora literature, an existentialist adoption of the concept has occurred only in very recent times, Chen (2015, p.53) is the first author to clearly articulate the link of Diaspora as an existential phenomenon:

Instead of attempting to further complicate the term's spatial or temporal connotations, I propose to understand 'diaspora' as a state of being, an existential condition, and an emotional and psychic disruption...this proposed meaning of 'diaspora' cannot be appreciated fully without the intervention of 'memory'. Whether applied as a spatial or temporal notion, 'diaspora' always points to a state of displacement as preserved in memories.

Many theorists place grief and bereavement within an intrapsychic domain, with a focus on meaning-making or psychological and emotionally de-cathecting or relocating the deceased. What emerged from the data in this study and what the diaspora and existential literature demonstrates, is that the way people negotiate their experience is within the context of intrapsychic dynamics but also in relationships with others, new situations and new roles (Bakare-Yusuf, 2008). Experiences also occur within a socio-political environment. Language plays a central role in how individuals interact with the world they live in and thus, language plays a central role in the construction of experiences and identities in *bereavement diaspora* (Canagarajah & Silberstein, 2012; Hua, 2013; Marat, 2016). Thus the concept of '**bereavement diaspora**' was developed to encompass all of these themes as depicted in the picture below.

Figure 17: Bereavement Diaspora



Conclusion

Themes from the diaspora discourse include disruption, displacement, alienation, continued attachment, memory, embodied orientations, lived tensions, identity, suffering, connection, enduring, nostalgia, deathscapes, trauma and transformation. The literature on diaspora highlights the relationship between socio-cultural-political factors and geographical displacement that impact on the experiences of individuals and communities (Clifford, 1994; Anthias, 1998; Brubaker, 2005; Bakare-Yusuf, 2008; Baptist, 2010; Clarke, 2010; Raghuram, 2010; Yancy, 2011; Canagarajah & Silberstein, 2012; Johnson, 2012; Ogbuagu, 2012; Ben-Rafael, 2013; Hua, 2013; Voicu, 2013; Chen, 2015; Kaur, 2015; Yamashiro, 2015; Hunter, 2016; Marat, 2016; Wofford, 2016). The data that emerged from the findings in this study incorporated existential and diaspora elements

that, when combined, created a picture of diaspora as an existential state, *existential diaspora* and diaspora as an experience of being-in-the-world as a bereaved individual, '*bereavement diaspora*'. Relationships with others and the different ways of coping play a significant role in how the bereaved mediate the '*bereavement diaspora*'. Language used by the bereaved, and others with whom they interact, also impacts the bereavement experiences.

The linkage of diaspora to the data that emerged in this research was initially diaspora as a metaphor for the experiences the bereaved were describing. However, when examining the diaspora literature as part of the iterative process, it was discovered that diaspora has been linked to existential phenomenon. This led to the development of the theme *existential diaspora*. Exploration of the literature also highlighted the socio-political influences in diaspora, which revealed synergies with the data analysis. The bereaved described trying to cope with their bereavement within the constraints of institutions, their organisational policies and processes and some bereaved had to balance this with legislative requirements dictating compassionate leave, thus restricted by workplace constraints. This impacted on their ability to attend to deceased estate matters and thus, their existential state and psyche. There is an absence in the bereavement literature on these socio-political factors and their impact on the bereavement experience. The diaspora discourse embodies all of these concepts and can provide the framework for understanding bereavement in a different way to the dominant discourse. Diaspora can view bereavement as both an existential crisis and as a total experience of being-in-the-world.

This chapter discussed the findings from the data and the concept of diaspora and how it evolved from a theme, (findings), to concept. *Bereavement diaspora* in this study encompasses an *existential diaspora*, relationships, coping and language, and their role in how people navigate the bereavement experience. The focus of this chapter was to discuss the findings as they apply to a *bereavement diaspora* and an *existential diaspora*, new concept to the bereavement and diaspora discourse. Chapters five to eight will provide more discussion on the core themes from the data and how they specifically relate to

Bereavement Diaspora. The next chapter, five, will discuss the findings that underpin the concept of *existential diaspora*.

Chapter 5: Existential Diaspora

Introduction

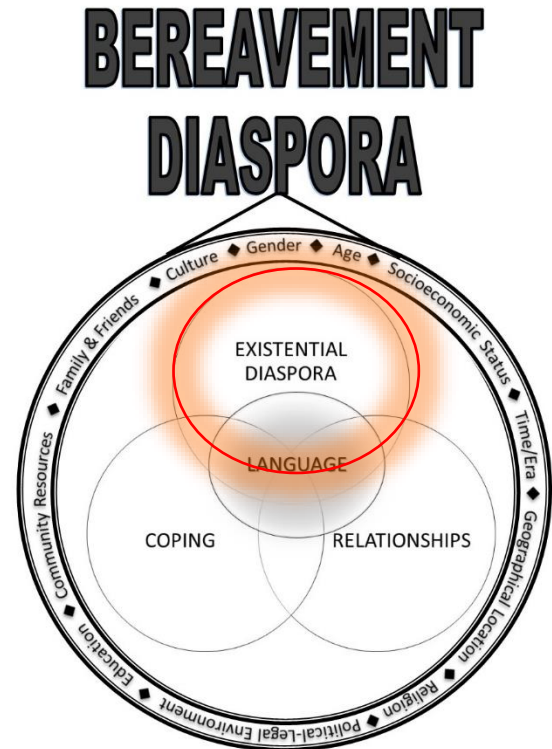
The previous chapter outlined the main concept that emerged from the data, diaspora, and discussed its transformation from findings to concept, *bereavement diaspora*. This chapter begins the presentation of the findings with a focus on *existential diaspora* in bereavement.

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

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

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

Figure 18: Bereavement Diaspora: Existential Diaspora



Existentialism, Diaspora and Bereavement

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

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

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

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

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

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

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

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

Diaspora Findings to Concept: *Existential Diaspora*

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

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

a) Existential shock: A new world

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

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

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

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

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

	<p>“...I was wrecked - I didn't understand why...” ID: B: 3369: F; 53; Sp; 13-18; R1</p>
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There is a sense of loss of hope, and loss of identifying qualities of one's self or identity. This existential world was not only unfamiliar to the bereaved, but the bereaved became unfamiliar to themselves, feeling a sense of being ‘*disconnected from themselves and others*’ as demonstrated in the following participant quotes:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

b) Disruption: Violence to the psyche

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

c) Hybridity: Identity

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

d) Displacement: Yearning and Nostalgia

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

e) *Embodied diaspora and Transcendence*

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

f) Diaspora Deathscapes

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Receptivity and Existential Diaspora

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

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

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

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

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

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

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

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

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

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

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

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

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

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

a) Existential Shock: a new world

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

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

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

b) Disruption: Violence to the psyche

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

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

c) Hybridity: Double Consciousness, Lived Tension and Identity

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

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

d) Displacement: Yearning and Nostalgia

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

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

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

e) Embodied Diaspora and Transcendence

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

f) Diaspora: Deathscapes

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

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

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

Conclusion

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

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

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

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

Chapter 6: Coping in the bereavement diaspora

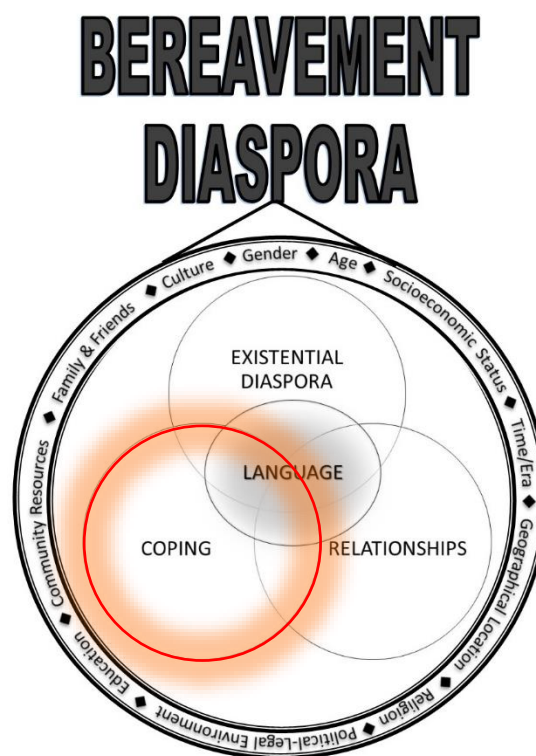
Introduction

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:

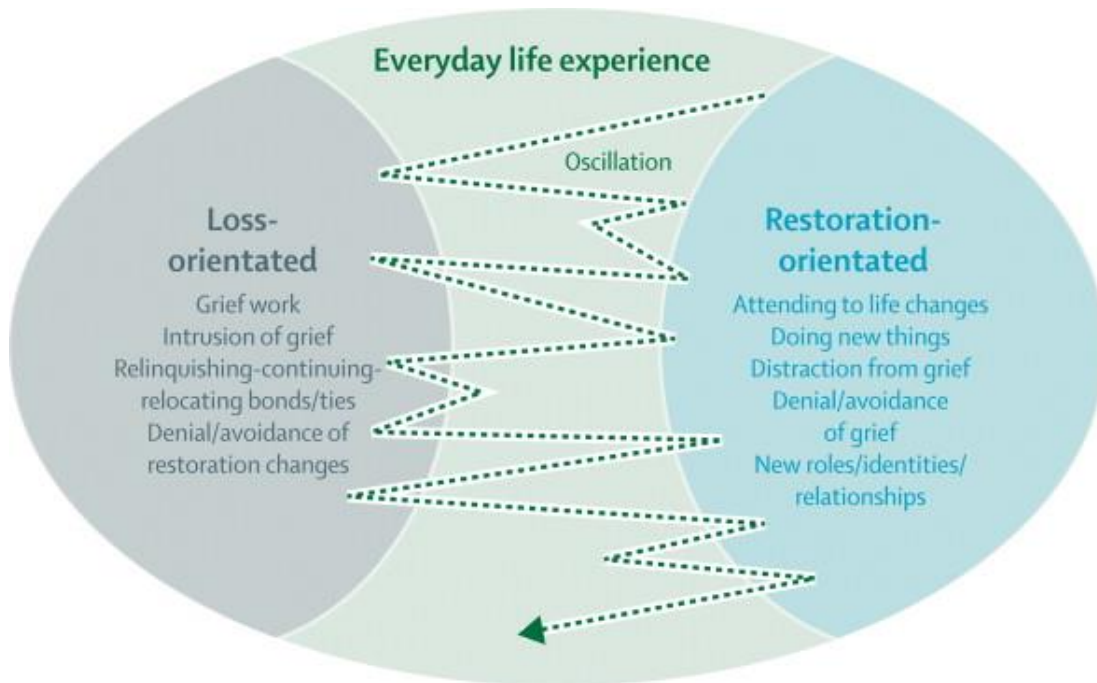
“...the grieving individual at times confronts, at other times avoids, the different tasks of grieving. It also argues the need for dosage of grieving, that is, the need to take respite from dealing with either of these stressors, as an integral part of adaptive coping” (Stroebe & Schut, 1999, p.197).

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 ‘*spacing 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*

Chapter 7: Relationships in the *Bereavement Diaspora*

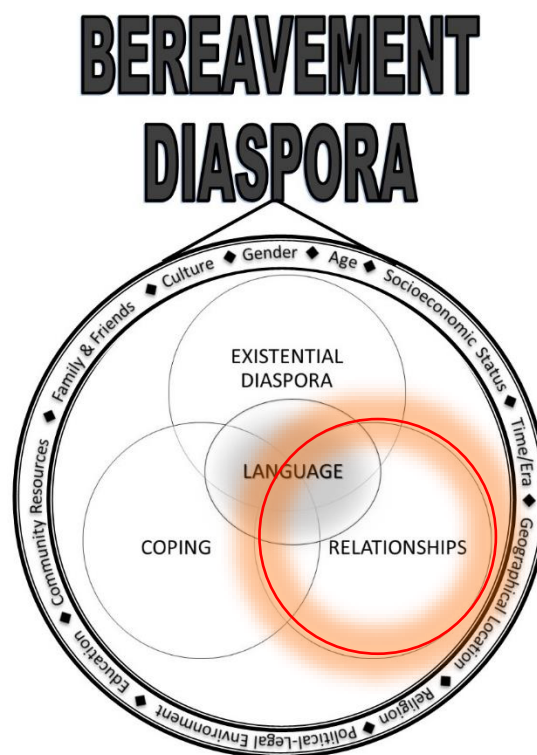
Introduction

The previous chapter used concepts from the diaspora discourse to explore coping in the *bereavement diaspora*. Discussion on emergent themes from the data identified the impact of coping with practical matters, and the impact of this as significant features of the bereavement experience in the first 18 months' post death. These experiences are neglected in the extant empirical bereavement literature. Using *bereavement diaspora* as a framework for exploration of this gap, issues of socio-political contexts and other factors described by participants were explored. Receptivity to support was also discussed in relation to coping.

This chapter will explore the role of relationships in the *bereavement diaspora*. As the diaspora discourse looks at the individual within the context of community, this provides a new perspective to explore broader perspectives of the bereavement experience. Focus on the bereaved relationships in the *bereavement diaspora* will be discussed and an exploration of the role of relationships and receptivity will conclude the chapter.

Although the broad bereavement literature discusses family experiences, it does not integrate these with individual perspectives. The role of friends, other informal support networks and broader community are not given much attention. However, findings from this study indicate the pivotal role these networks played in coping in bereavement

Figure 21: *Bereavement Diaspora: Relationships*

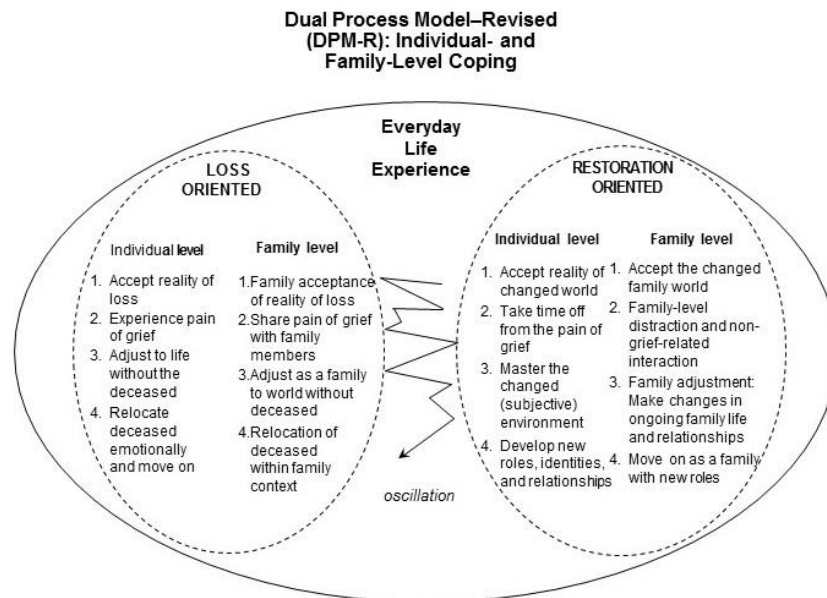


Understanding the role of interdependent relationships in the *bereavement diaspora* can provide insights into how or why people seek help during grief. The diaspora discourse contributes integration of family and community to the situatedness of being-in-the-world and coping in the *bereavement diaspora*.

Relationships: A Mediator in the Bereavement Experience

Stroebe and Schut (2015) assert that researchers need to integrate individual and family perspectives, recognising the role that family play in adjustment to bereavement. The DPM has thus been expanded in recognition of the role of family in coping in bereavement, and represents an intra-interpersonal coping model (Stroebe & Schut, 2015). This revised DPM (DPM-R) attempts to adopt a more global approach incorporating family relationships. The DPM-R recognises the family-level stressors and family-level coping in bereavement however, further research is required to explore how interpersonal relationships within the family unit influence both positively, and negatively, the bereavement experience (Stroebe & Schut, 2015).

Figure 22: Dual Process Model - Revised (DPM-R): Individual and Family Level Coping



Research by Albuquerque, Pereira and Narciso (2015) highlight that the interdependence within a family unit influences individual adjustment in bereavement. Stroebe and Schut (2015) highlight family dynamics in bereavement are influenced by changes in family relationships and legal and financial issues, however, there remains very little empirical evidence of what these issues are. In exploring the role of the family in relation to these matters, further insight into dealing with practical matters in bereavement are garnered. For example, Williams (1990) states that social roles become confused and the reorganisation of the family unit may lead to altering traditional gendered roles, creating disequilibrium for family members and the family *per se*. Within the family unit, power dynamics change when there is a death in the family that can lead to conflict, particularly when it is in relation to estate matters such as belongings and money (Litsa, 2013).

Breen and O'Connor (2011) explored the development, deterioration and collapse of relationships in bereavement among families and social support networks. Although their research was within the context of sudden death, the findings from this research echoed similar features of how relationships change in bereavement. Stroebe and Schut (2015) assert that further research is required to explore family-level perspectives and social support from friends and colleagues (Breen & O'Connor, 2011). This study contributes findings on the role of different social actors and the impact of their inter-relationships with the bereaved following the death of a significant person who had been cared for by a palliative care service.

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

Although the diaspora literature reflects the broader global culture, it also recognises the different 'culture' of individual families where levels of acculturation occur. When applied to bereavement, this perspective recognises the family is an ecosystem of varying levels of adaption and coping in bereavement (Shapiro, 1996).

This chapter will utilise the same framework as previous chapters, using concepts from the diaspora discourse, which inform the role of relationships in the *bereavement diaspora*:

- a) Diaspora: Connection with others
- b) Hybridity: Changing roles in relationships and family identity
- c) Disruption: Changed relationships, role shuffles and family fabric
- d) Displacement: Collective grief
- d) Embodied diaspora and transcendence: Ongoing presence of deceased
- e) Deathscapes: Shared sacred spaces

a) *Bereavement Diaspora: Connection with others*

Intrinsic in the diaspora literature is a sense that the diasporic no longer feels a secure sense of place within the world. They feel like an outsider to the community and world they once knew. Diaspora discourse encompasses concepts of alienation, powerlessness and marginalisation. This was evidenced in some of the participant narratives as portrayed in the statements below when they spoke about *'feeling alienated'*:

"...I s'pose, this world of ours is all for couples, not singles. I find the invitations aren't there like they used to be, because I'm by myself. I sometimes think, 'was it because of [A]? Were they inviting [A] and not me?' Or, inviting us as a couple but now that we're not a couple, I don't get the invitations?"

ID: B: 3110; F: 61; Sp; 19-24; R3

"...do you know in the last twelve months of all the people that I know, nobody's ever said, "Oh [T], do you want to come up for dinner tonight?" and these are all our friends. Then you've got other friends, well I always thought they were really good friends because they were friends of my wife's before I met them, and we seemed to get along pretty well, but I've virtually got to make an appointment to sit down and have a beer with the guy up the

road...” ID: B: 3398: M; 67; Sp; 10-12; R3

Socialising with other couples has been demonstrated to become harder to deal with over time (McGrath, Holewa, & McNaught, 2010). Changes to socialising with support networks can occur as a result of self-selection or can be imposed as a result of avoidance by others (Breen & O’Conner, 2011). Although some participants felt a level of exclusion and alienation, other participants expressed a sense of comfort from a perceived affiliation with others in the world, who had experienced bereavement. This is consistent with the diasporic experience, where individuals experience networks of “...real or imagined relationship among scattered people...” Hua (2013, p.31). Several of the participants articulated an ‘affinity diaspora’ (Yamashiro, 2013), and empathised with others who were experiencing bereavement.

Brown (2006) highlights that through connection with others, we garner purpose and meaning to our lives. The connections the bereaved had to others, particularly their children, was a protective factor in preventing some participants from following through on suicidal ideations when they were struggling with ‘*losing the will to live*’. When asked what prevented participants from following through on their suicidal ideation the responses were centred around their relationships and connection with others:

“...because of my children... and watching my kids grieving so much, if I did anything to myself, I couldn't do that to my kids either...” ID: B: 3386: F; 53; Sp; 19-24; R1

“...my daughter, because I can imagine nothing worse for her after losing the mother she loved so much, to then lose her father? No that would be most unfair on her and I think, that literally stopped me from thinking any further of ending it all, taking my own life because knowing the pain that [B]’s death had caused to [L] as well as me, I remember thinking, ‘no that’s selfish, don’t do it. And it would

be selfish. So it was my darling daughter who caused me to abandon those thoughts each time...” ID: B: 3725: M; 63; Sp; 7-9; R1

“...I have [felt suicidal] some days I think, ‘why do I carry on? Why do I? Why am I here? I would rather be with [G]. I want to be with [G]’, but I know I could never do that to my kids...and I know that [G] would be so angry if I ever did anything like that to myself...” ID: B: 3386: F; 53; Sp; 19-24; R1

Clifford (1994) highlights that for people who feel there is no future, the choice of death and risk of death is the only possibility. When there is connection with others however, this plays a mediating role in how people cope in bereavement. As one participant stated:

“...You need people. You need time to be quiet and think and grieve and cry perhaps. But you need people.... people who are just there. [They] don't have to do very much...” ID: B: 3111: F; 68; Friend; 13-18; R3

The knowledge that an individual can call on support of family and friends may buffer against emotional and social loneliness and other deleterious effects of bereavement (Stroebe, Zech, Stroebe & Abakoumkin, 2005). One participant described the impact of missing ‘mixed company’ as a result of her husband’s death, as portrayed in the following statement:

“...I miss my husband's mates coming around. I was somewhere and I thought, ‘oh’ and I could hear men talking and I realised that when you get together with girlfriends, there's all this tittering and harping and when blokes get together (imitating low voices mumbling) and I heard these blokes talking and I thought, ‘I can't hear what they're saying but there obviously loving each others' company’ ...That was one of the things that I've thought I've needed to get out so there was mixed groups, so I could have that reaction with men, but

not on a personal level You can do that at Church you know, and your morning teas and that sort of stuff where blokes are mumbling at one end of the table and girls are giggling down the other...” ID: B: 3371: F; 77; Sp; 7-9; R2

Many participants described the positive impact from the emotional support provided from family, friends and others in their social networks. One participant, ID: B: 3072: F; 52; Sp; 6-9; R3, described receiving regular phone calls from a male friend every couple of weeks, providing emotional support and offers of practical assistance. She also stated she had fantastic neighbours and cited this as one of the reasons she decided to remain in the family home. Another participant, ID: B: 3372: F; 75; Sp; 4-6; R3, described how supportive extended family and friends were and that they took her away on a holiday to provide companionship and comfort. One participant, ID: B: 3407: F; 44; Child; 7-9; M2, found that her good friend was a great sounding board and this made a positive difference in her bereavement – having someone to talk to and “...*share dinner and a glass of wine with...*”. Another participant, ID: B: 3109: F; 64; Sp; 10-12; R3, stated “...*I've got wonderful family support, and wonderful friends which is a great help...*” Connection with others engenders within, a sense of companionship and active interest by others, which protects against the emptiness and despair of loneliness or *existential diaspora* (Vachon & Stylianos, 1988).

b) Hybridity: Changing roles in relationships and family identity

As has been discussed, identity is always relational, that is, we construct who we are in relation to other social beings. Yancy (2011, p.555) states that identity formation occurs through “...the experience of the self with other selves...[it] is the meaning of ‘sociality’...” This constitutes a we-relationship in which the identity of self is dynamically formed and re-formed, relational to others. Clarke (2010, p.232) posits that self-identity, particularly for those in the diaspora, is continually redefined through ‘participative and communal relationship’.

Participants found that their roles within established relationships changed following the death of a loved one. One participant described the changed role in her relationship with her deceased husband's friend, and that he now adopted a 'caretaking' role over here as portrayed in the following statement:

"...I've been lucky because I've had [G]'s best mate and [B] sort of took me over, you know what I mean? He became my carer and that has been just amazing.... because we've known [B] all the way through...and he has been such a support to me. I dreaded the time when [G] would go and I would be by myself. But as it turned out, I haven't been so much by myself as I thought I would be. So, I felt that I had [G]'s approval because the week before, when he was in hospital, there was a time when he said to [daughter], 'if mum wants to go with [B], let her go.' I felt that that was the approval, you know, like if [B] wanted me to be with him then he was happy for that..." ID: B: 3112: F; 75; Sp; 13-18; R3

Moorman, Booth and Fingerman (2006) highlight the benefits of repartnering in bereavement, particularly to ease emotional wellbeing and instrumental concerns of dealing with financial and practical matters. A new partner may fulfil the roles that the deceased previously provided.

Many participants discussed the role of the deceased in the family such as protector, comforter, joker and carer. The deceased provided a *locus* through which individual family members referenced their own identity. When the bereaved become disrupted and displaced from the world they once knew, their sense of belonging to locally rooted identities can also be disrupted. The family unit experiences a shift in 'family identity' (Wofford, 2016). One participant who described herself as a farmer's wife who maintained a traditional role within the home now found herself undertaking a more active role in the running of the farm with her son, as depicted in the following statement:

“...it was also hay season too, so busy with that and [S] needed me here. He would ring up on his mobile and say, ‘Mum I want some diesel. Could you bring it up?’ or ‘I need some new hay rack, I want some more hay rack. Go to Elders and get some more’ and take it up to him. So, I was busy. So that helped me too - mentally, too, being busy...but now decisions are made between [S] and I. I’ll say, ‘well, do we really need this hay rake now? Instead of taking four hours to do a paddock, it will only take two’, you know?” ID: B: 3110: F; 61; Sp; 19-24; R3

Family members, particularly mothers, take “...on a key supportive role to maintain a semblance of normality...” (Breen & O’Connor, 2011, p.104). Practical, psychological and social support is often expected, and received, within the family unit (Benkel, Wijk & Molander, 2009). Participants tried to maintain the integrity of the family unit through maintaining roles and nurturing family members, as described in the following statements:

“...I did spend a fair bit of time with my daughter, she's lost two babies. She's got a little three-year-old, she's lost two babies, one was at 8 weeks, one was 14 weeks. I wish that [A] was here. He was always good in a crisis - he would know what to do and say...” D: B: 3110: F; 61; Sp; 19-24; R3

“...I've told people I felt that, I had to get my kids through it first. When I knew that my kids were through it and they were okay then it was my turn to get me through it then. Not straight away, I suppose, because I was looking after the kids, I didn't really worry about myself too much. I just needed to make sure that the kids were okay...” ID: B: 3386: F; 53; Sp; 19-24; R1

As the individual and family experiences adjustment within the family and the community in which they live, hybrid subjectivities evolve and continue to change with changing contexts and experiences (Wofford, 2016). Coester (2008) states that social life is based on collective identities which are defined by the relationships within the family unit.

Waechter and Samoiloa (2014) discuss diasporic identities where there is only one 'self', but there are several aspects that constitute the 'self'. Primary aspects of gender, age, religion and ethnicity constitute only part of the self. Secondary aspects include negotiating identity in day-to-day interactions, within a family group, within a localised community group and then a more national and global identity. Piatczanyn, Bennett and Soulsby (2015) describe how a hybrid identity develops. In bereavement, individuals become selective with who they interact with and how they interact within their social networks (Breen & O'Connor, 2011). For example, one participant described being selective with how they interact with different people, in different situations, as demonstrated in the following statement:

"I had a couple of colleagues at work that were insisting on, 'Tell me when the funeral is and we'll come to the funeral' They didn't know my father and I wasn't necessarily close to them, and so I sort of just had to say "Look there will be no funeral", and they were like "When are you having a memorial, we'll come to that", and I said, 'Well, no'. I just wanted my space because I kind of, although I had friends at work. I keep my work life separate...I was using work as my escape...I just wanted to keep how I was dealing with it, as a separate work and private life kind of issue.....So I guess I only really showed that to one or two very close friends, when things were a bit more exhausting and tougher than I had hoped...I would talk about it with people that were close to me rather than talking to strangers....I guess we do say different things with different people." ID: B: 3407: F; 44; Child; 7-9; M2

The notion of a "...free zone, free of grief..." has been identified by Benkel, et al, (2009, p.145) and this may be one of the reasons why the bereaved become selective with who they talked to (Benkel, et al. 2009; Breen & O'Connor, 2011). Participants in this study echoed similar sentiments of being selective with whom they interacted and what they shared in relation to their grief and bereavement, despite having positive relationships with others:

“...you have to learn who you feel safe with and who you don’t. And sometimes you just have to pretend that you’re okay when you’re not, just because people are uncomfortable...” ID: B: 3180: F; 70; Sp; 0-3; R3

“...I do have a very close-knit group of friends, I’m with the Kangaroo Rescue Group and I’ve got a few roos and they were really good people, but I found, I didn’t want to talk to them. I didn’t want them to know how I was feeling... I found it very hard to talk to people about what I was dealing with...you select who you can talk to and there’s a lot I don’t talk about because I don’t want to tell people things but I would’ve told [G] those things, but not anyone else...”
ID: B: 3386: F; 53; Sp; 19-24; R1

Canagarajah and Silberstein (2012) describe this process of hybrid and proliferating identities, *layered simultaneity*, where diverse identities co-exist and the diasporic agent is selective in displaying identities in specific places for strategic regions. Breen and O’Connor (2011, p.111) posit that the bereaved change their behaviour “...to fit the normative standard more closely so as to not offend those in their social networks...”.

c) Disruption: Changed relationships, role shuffles and family fabric

Collective identity is constructed around deep rooted memories and sense of loyalties and a shared ‘culture’ that connects family members at an emotional level (Voicu, 2013). Brubaker (2005) reinforces the dense social relationships that link members of the diaspora. Participants discussed how they went through a process of sieving through relationships following the death of their loved one. One participant, ID: B: 3371: F; 77; Sp; 7-9; R2, stated she made a decision of “...*keeping away from other people I realised was not doing my mental health any good...*” Another participant, ID: B: 3072: F; 52; Sp; 6-9; R3, described how she was keeping away from certain types of friends who drained on her personal resources and who she described as “...*too serious for me to want to spend much time with...*”

Bereavement is a time many where relationships change. The bereaved may withdraw into themselves and sieve their relationships to a core group of people with whom they feel safe. Alternatively, people in the social networks of the bereaved may pull away because they have their own life stressors to deal with and cannot manage anything that will absorb further emotional, psychological or practical energy; they may not feel that they are in a legitimate role to provide support or they may pull away because of self-preservation so they are not reminded of their own vulnerability and mortality (Dyregrov, 2008).

One participant, ID: B: 3113: F; 61; Sp; 19-24; R3, described the changes in her social relationships and her expanding network of friends who were also widows. She stated “...it just seems to happen; you must just attract like...” This participant also described how she felt let down and really disappointed in her social networks in the community. Her husband had been involved extensively in the local community however after he died, she felt that “...it was almost like he just didn't exist...” Granie and Patterson, (2006, cited in Titzmann & Stroebe, 2014, p.282) state “...social support systems.... that would typically stabilise individuals' development are no longer available and need to be re-established before they can deploy their buffering effect...”

Some people feel disappointed or abandoned in their bereavement and others struggle with re-adjusting their role within the family unit. Hua (2013) describes diasporics who have to deal with the melancholy from disruption and displacement whilst negotiating ‘sutured relationships’ as they struggle to re-define their own place within the world. Analysis of these narratives illustrate there is sometimes a change in friendships and a ‘role shuffle’, so to speak, within the family unit in which power dynamics change following a death. Canagarajah and Silberstein (2012) highlight how relationships are often engendered in power dynamics. Generational viewpoints see that in older generations, the males of the household have historically held the power within the family unit. When role shuffles occur, the power relations implicit in the family relationships or dynamics change (Canagarajah & Silberstein, 2012). One participants’ statement reflected the family’s attempt at re-adjustment following the death of the husband/father and how the children would not undermine their mothers’ authority and independence:

“...my family - they helped - but they got more sense than to take over, you know, to treat me as if I'm not quite aware...” ID: B: 3073: F; 87; Sp; 6-9; R3

This participant wanted to maintain the power of her matriarch role, and not to be undermined by her children. Bennett, Stenhoff, Pattinson and Woods (2010) highlight that family relationships are not always straightforward and members may, or may not, be mindful of disempowering each other. However, they posit that there is often a level of reciprocity within the family unit in terms of giving and receiving of support. This was a common theme, where participants endeavoured to maintain the family fabric and keep it cohesive through maintaining their positions of power, as demonstrated in the following statements:

“... that was probably a good thing about having my daughter here from Queensland with her three little ones; you had to get meals ready, you sort of had to get things ready for them...” ID: B: 3373: F; 64; Sp; 13-18; R1

“...I felt that I had to be there for my kids, if I broke down because I could see them breaking down and what they were going through, I felt that if I did, then I would even make them go down further, you know what I mean? I just felt if they could see that mum was okay and mum was strong and I'll help them get through it, it might be better for them if I could get them through it...” ID: B: 3386: F; 53; Sp; 19-24; R1; 4-6; R1

Participants also described the struggle with power dynamics with shuffling of roles and discussed how their adult children tried to take on a carer role for their parent and the parent did not see this as their child's responsibility, as described in the following participant statement:

“...you’re going to find a daughter who is dealing with this in her own way but is putting her grief on hold so she can look after her father and get him through it. But you don’t see it that way. You see it that your daughter’s moved on after twenty-eight years, she’s moved on of twenty-eight years of a mother who loved her, who looked after her and everything and you think, ‘how can you do this, how can you just push it aside? and then when you sit down and you think, ‘well she’s only pushing it aside because she’s up here looking after me. It takes a lot of getting your head around that...”

ID: B: 3398; M; 67; Sp; 10-12; R3

This difference in perspectives can lead to conflict within the family fabric. Different ways of grieving can be an issue of contention with family members (Breen & O’Connor, 2011). Bakare-Yusuf (2008) posits that our emotions are a product of dynamic relations between the self, others and the world. Emotional pain can lead to feelings of displacement within one’s own position which in turn can influence one’s thoughts about where they now sit within the family and community units. Relationships following death can strengthen or dissolve, having a ‘polarisation effect’ (Lehman, Lang, Wortman & Sorenson, 1989, p.344). The following participant described his daughter’s struggle with the emotional pain of her grief and the conflict it caused within their relationship:

“...our daughter was the only child...she came up here about 2 weeks after her Mum’s funeral, just for a couple of days which was very good because the few days in between [B]’s death and her funeral, it was like World War III. She was fighting with me over everything. It even reached, she was hysterical one day and I just did something I’d never done before - reached out and gave a quick sharp slapping on the cheek. She was in shock and she said, ‘get out of my house’ and I said, ‘I’m not going anywhere you’re stuck with me.’ One of the painful things my beloved daughter said to me during that week of warfare - she was hysterical and in tears - she said,

'you can always get another partner, but I've lost my Mum! I can't get another Mum!' It hurt me so much..." ID: B: 3725: M; 63; Sp; 7-9; R1

Kissane and Bloch (2009) state that distress from grief can sometimes amplify, leading to a rupture of cohesive bonds and fracturing of families. None of the participants in this study reported this level of fracturing as a result of bereavement, however references to family estrangement evidenced that a *'fractured family fabric'* pre-existed prior to the death of the loved one. One participant discussed her family history and the impact of the *fracture in the family fabric* from her family of origin, as portrayed in the following statement:

"...as far as bereavement went, I was sad that he died but I was never close and never had an emotional, very closely emotional relationship with my father. I don't think he was capable of loving anybody really..." ID: B: 3399: F; 65; Child; 13-18; R3

This participant story was the exception. Nearly all participants described a *'cohesive family fabric'*, consistent with the following participants' statements:

"...It was lovely; we were together but we were independent. It was really nice, and I think that gives you strength as well, to know that they're not going to take from you and you don't have to take from them either. It was really nice..." ID: B: 3109: F; 64; Sp; 10-12; R3

"...I'm really close to all my children, so I could talk to them about just about anything, particularly my daughter. So I could say something to her and she understood exactly what I meant..." ID: B: 3113: F; 61; Sp; 19-24; R3

Family and friends are predominantly the primary source of support for the bereaved

(Benkel, et al., 2009; Li & Chen, 2016). One participant described how he was overwhelmed by the death of his mother. Consequently, he was unable to attend to practical matters on his own and required the assistance of his daughter. This role shuffle of having to put *'pressure on family'*, is described in the following statement:

"...having to rely on my daughter to step-up at a time when she's been dealing with other things in her life. I didn't have many choices. I didn't, and couldn't, rely on my sister, not that she's not reliable it's just she's locked in her own shit. Having to rely on a young woman who's going through a divorce herself at a young age, and dealing with settlement and shit like that, I found that really difficult - obviously as a dad, not wanting to put any more pressure on her than I had to...that would have been the most difficult for me..." ID: B: 3076: M; 52; Child

Ogbuagu (2012) describes the expended physical and emotional resources of the 'chief mourner' which leads them to having little strength for pursuing other activities of daily living. Family and others in the chief mourners' support networks may be required to fulfil tasks that the bereaved are unable to attend to.

d) Displacement: Collective grief

Franzenburg (2013) describes the 'group coping' of integrating past, present and future through remembrance of collective narratives. Kaur (2015) states the diaspora subjects are carriers of memory and connection with the deceased and share the stories of the deceased. The diasporic identity is thus shaped by collective memory (Marat, 2016). All family members play a role in this collective memory and engage in the sharing of memories as demonstrated in the following participant statements:

"...I think humour does help, I know when we all get together and we sit over in the lounge or we'll sit around the table and it was just yesterday

that I had my son and my daughter sitting here and what we do is, we talk about all the funny things that happened when [G] was alive. And we were just sitting here for a couple hours yesterday just laughing about things. We don't like to talk about it when he was sick or... Anything like that but we loved to talk about and remember the things that happened and when they were little kids and what dad did and what they did and things like that. So I think humour does help a little bit too... ID: B: 3386: F; 53; Sp; 19-24; R1

“...We have our little jokes with each other about how he was bossy and how he did this and how he wouldn't listen when [M] gave him my instructions on how to use the mobile and how to put on the tv and things like that. We have our little, you know, quirky moments about that so it's something we remember together and we remember the good things...” ID: B: 2875: F; 81; Sp; 13-18; Rem1

Some participants described feeling that they would burden members of their family in sharing their grief and this is supported in the empirical research (Breen & O'Connor, 2011). Although the family grieve as a collective group, participants in this study still conversely expressed a sense of feeling alone in their grief. As one participant stated: “...I find I can't talk to my son and my daughter about it because they are both hurting in their own way...” D: B: 3110: F; 61; Sp; 19-24; R3. This sense of not wanting to burden loved ones leads to withdrawing from the social world (Yancy, 2011; Breen & O'Connor, 2011), many bereaved acknowledged, and were comforted by, the community sharing their collective grief. Inter-relationships with other diasporic agents is critically significant in shaping the bereavement experience and co-narrating life stories. The community co-author the deceased's life narrative, as demonstrated in the participant quote below:

“...dad was a strong member of the surf club. Immediately the surf club came around and said, 'you know, what can we do? where can we be? what

can we? - you know?’ And we had the service and everything at the club...the following week we took his ashes out to the beach and he had a surf boat named after him. The guys rode the boat out and we went out and put his ashes out in the - all the kids paddled out and so in that respect the surf club were fantastic.... they rode the boat and then we had these ashes in this special box that dissolves. Beautiful box and they sat their boat and put the oars vertical and we all waited until all the ashes - you know the thing had all gone and the young paddlers had all thrown rose petals around and it was beautiful...” ID: B: 3433: F; 60; Child; 13-18; R1

The bereaved often find comfort in having others remember and share stories of the deceased (Riches & Dawson, 2000; Breen & O’Connor, 2011). One participant however, expressed frustration and despair that people in the local community would start to share memories of his wife and then stop:

“...everybody is - instead of coming out and saying what they mean, a lot of people watch what they say. They’re going to say something about when [K] was alive and she used to dance and sing in the cool room while she was putting everything away, but they get to that point and they say [K] and then they stop. And you actually have to prompt them, oh well didn’t want to bring up bad memories. Well they’re always going to be there and if you’ve got some good funny ones about my wife when she worked here for a year or whatever then hey, I’m interested...” ID: B: 3398: M; 67; Sp; 10-12; R3

When the bereaved are ignored or others do not wish to talk about the deceased, their feelings are disregarded and their grief not legitimised. However, when a community empowers members to acknowledge, mourn and share the loss, creating a collective narrative, it becomes a ‘compassionate community’ (Connor & Munroe, 2011). Compassionate communities is based on the health promoting palliative care model which aims to create supportive environments, particularly social supports, strengthen

community action and develop personal skills. The compassionate communities model is about engagement of communities in relation to matters of death and dying (Kellehear, 2013; “Caresearch”, 2014). The concept of compassionate communities in rural contexts and ‘social capital’ is discussed further in chapter nine.

One of the way collective narratives occur is through obituaries. Valentine (2006, p.72) cites Davies’ (1996) notion of ‘conversations with the dead’ that occur through obituaries which is one of the “...variety of ways in which the deceased continue to occupy the lives of the living...” This may include engaging with others to construct a biographical narrative, in order to locate the dead in the life of the living and restore a sense of meaning and continuity. However, one participant described the changes to this traditional approach of putting obituaries in the newspapers as a result of technology:

“...people no longer read the hatched, matched and despatched in the paper the way they used to. Once upon a time everybody read that...” ID: B: 3725: M; 63; Sp; 7-9; R1

Contemporary society is seeing an increase in commemoration via social media, as demonstrated in the following participant statement:

“...I had hundreds of cards. I think the girls said 300 and something cards that I really glimpsed at I think because I can’t even remember looking at them. 400 Facebook messages that I really - I have to go back and look at them at some stage...” ID: B: 3369: F; 53; Sp; 13-18; R1

A number of participants described using Facebook (FB) for receiving and sending private messages or for putting notices out to the community. One participant, ID: B: 3072: F; 52; Sp; 6-9; R3, described putting posts on FB in relation to appealing to the local community for assistance with making a quilt with her deceased husband’s clothes, or to communicate the issues she was having with closing accounts etc. She stated “...I posted it on FB and

the feedback I got from other people was, 'oh my God, that happened to me...[or] ...to my mum...to my aunt....to my brother...' FB thus created a community of shared experiences.

FB has been identified as one of the key social networking sites (SNS) that allows for a bereaved community to grieve communally. Maddrell (2012, p.50) states "...social forces inhibiting the public expression of private emotions have been undermined by a culture of self-broadcasting through YouTube and SNS..." Aguilar (2015) describes how ongoing relationship of diaspora is nurtured by collective memory through interrelationships that has fostered identity. Kasket (2010) notes that historically, friends have often been a disenfranchised group of mourners and SNS's allow inclusion of previously marginalised individuals. SNS's also allow for pragmatic issues such as gleaning information about the death and requesting rides to get to the memorial service (Kasket, 2010). However, the use of SNS for creating a virtual bereavement community is not without its problems. Exposing the bereaved to grieving concepts that are socially and culturally constructed (Ogbuagu, 2012) is leading to changes in cultural mourning practices. For example, the mourning practices of some cultures include wailing in chorus which conveys solidarity in protest, and empathy to help share the burden of the loss with the bereaved. As discussed previously, the presence of SNS is changing the way Aboriginal youth are grieving, which is dys-synchronous with the cultural mores, norms and elders in the community. Elders in the community state there is no respect when a person's death is "*...plastered all over there...*" ID: HP: AHW: 3438: F; 43; Rem1.

Stroebe and Schut (1999, p.199) discuss Cook and Oltjenbrun's 'Model of Incremental Grief' whereby 'dyssynchrony of grief' occurs among bereaved persons grieving together over the loss of a loved one, in that there are discrepant coping styles used by these different persons. Public grieving via 'virtual' means has its disadvantages such as reports of postings from others who express religious viewpoints that contradict an individual's own personal belief system; offensive postings disrespectful of the dead; others running the FB profile page and posting messages, photo's or logging in to chat which have left others who are bereaved to feel that their grieving has not been taken into consideration (Kasket, 2010; Pennington, 2013). Despite its drawbacks, the internet is providing a forum

for collective grief and bereavement, enfranchising griever who were historically not acknowledged, enabling them to maintain a connection to the deceased and thus co-constituting the deceased person's identity through shared narratives.

e) Embodied diaspora and transcendence: Ongoing presence of deceased

Franzenburg (2013) describes the diaspora as being committed to maintaining connection and relationship to their homeland through memory. The group solidarity of family, friends and others who are committed to fostering this connection defines the group as a diasporic community. The diasporics are bound within a *lived tension* of being in a place of 'there' and 'here' or 'elsewhere' (Schramm, 2008). Okpewho and Nzegwu (2016) describe diaspora as a *condition* where an individual's *state of being* is a process of becoming, negotiating multiple spatial and social identities, is drawn from the interstices of 'here' and 'there'. Bakare-Yusuf (2008, p.148) refers to 'pluralising new contexts' where the relationship between remembering the old, and the process of engagement and interaction with the new situation. Social and affective practices, experiences and habits of bodily being are intrinsic in this process. Changing these habits takes time. One participant described her struggle with changing and removing her deceased husband's belongings:

"...I feel odd when I sort out things and try to make more room...and I think, 'well, I've got drawers full of [B]'s polo shirts, some vests and pyjamas and socks and handkerchiefs and they're still there, but I can no more get rid of them than fly through the air,' because there's this silly feeling that if I get rid of them, it's like getting rid of [B]. ID: B: 3073: F; 87; Sp; 6-9; R3

Belongings of the deceased play a pivotal role in enabling the transformation of the relationship with the deceased from a physical one to a transcendent one. This may occur soon after death or may take some years before the bereaved are ready to relinquish physical possessions belonging to the deceased (Riches & Dawson, 2000). The deceased continue to have an ongoing presence either through the presence of physical belongings

or in household practices that occurred when the deceased was alive. One participant described how he continues to the housework, more in honour of his wife because she kept a tidy home:

“...I just try and do things that she would've wanted me to do. So I'd get the vacuum cleaner out and mop and do things like that, you know, just making sure that things are as normal as possible...” ID: B: 3400: M; 70; Sp; 13-18; R3

In undertaking tasks that would have honoured his wife's wishes, this participant maintains an ongoing relationship with her thus ensuring she has an ongoing [ethereal] presence in the home. Valentine (2006) describes how widows revealed the way deceased husbands continued to exercise agency in their lives through providing meaning, direction and support, advice and companionship. The ongoing presence of the deceased is an enduring feature of loss from bereavement and has been shown to have anticipatory effects at the time of the anniversary of death, which can continue for years, sometimes decades (Chow, 2010). Participants talked about celebrating anniversaries with others, which fostered ongoing connection with the deceased:

“...everybody is probably not as lucky as me that have friends who remember because last year, when it was 12 months since [P] died, friends came out here and had lunch with me, so there were three of them came out and had lunch. They were here nearly all day, so I was very lucky. They just wanted to make sure I was doing something on that day. I didn't really feel like going out anywhere and that was lovely...” ID: B: 3113: F; 61; Sp; 19-24; R3

“...5th of September it'll be 12 months, so it's nearly here. [T] said, 'Mum I don't know how I'll be on the anniversary.' I said, 'Just be yourself, whatever you want to be.' She said, 'I've booked the day off work. [S] is

taking me to Denmark, to his friends down there'. She then said, 'Will you come with us?' I said, 'Oh, if you want me to'. So we're off to Denmark..."

ID: B: 3109: F; 64; Sp; 10-12; R3

Acknowledging anniversaries affirms the value of the deceased person's life providing much comfort to the bereaved (Riches & Dawson, 2000). The bereaved also reported other occasions where they drew comfort from the acknowledgement of their deceased loved one by members of their local rural community, particularly at the funeral. Many of the bereaved participants in this study commented positively on how overwhelmed they were with the attendance of people from the local rural community at the deceased's funeral. The following participant statements reflect the deceased person's relationship with the local community:

"...you don't sort of realise how much somebody's loved and respected until they do go – [G] had probably close to 250 people at his funeral, which was a bit of a shock..." ID: B: 3109: F; 64; Sp; 10-12; R3

"...I just wish he was around to see how much people thought of him and what they thought of him, and the things that people said to me, how wonderful he was and how much they liked him and how much they respected him..." ID:

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

In rural communities, when a well-known member of the community dies, the direct family, and the community as a whole, grieves. The 'diasporic identity' is one of complex and dynamic multiplicity of the individual, family and community systems in which it is situated (Anthias, 1998; Voicu, 2013; Kaur, 2015).

The role of relationships is intrinsic to the process of emotionally and psychologically relocating the deceased through sharing narratives and commemorative activities. This

allows the bereaved to transform their relationship with the deceased to a transcendent one in which the deceased maintain an ongoing presence in the lives of family, friends and community. Just as the bereaved connect with people, they also have relationship and connection with geographical places. Ellis (2014) discusses the role of spiritual and affective relationships to land. This connection is reflected in the memorial sites of *deathscapes*.

f) Deathscapes: Shared sacred spaces

Maddrell (2013) discusses the incursion of informal memorials into the public spaces which provides a ‘third emotional space’ for the bereaved. Material ‘memorialsapes’ provide a place-temporal space for remembering the deceased. One participant described a deathscape created by ‘community’ in memory of her deceased husband:

“...I spoke to the people at the Bowling club and I did ask them, ‘could I sprinkle his ashes in the Bowling club?’ They actually went one better [crying], they actually made up a little garden like a little remembrance garden with a rose bush and pebbles and we’ve actually had his ashes buried in the Bowling Club. They’ve put a plaque on the top with a light which, you know, sort of one of those solar lights so that at night time there’s a light that shines over the plaque which is lovely...” ID: B: 3373: F; 64; Sp; 13-18; R1

In creating deathscapes to commemorate the deceased, individuals, families and communities create an ‘enduring biography’ for the deceased. The presence of park benches dedicated to someone or yearly memorial trophies maintain connections with the deceased (Maddrell, 2013). However, the material memorialsapes are seeing a continuing trend of moving in the virtual realm and social norms of mourning and are moving from the domestic space of home to the public and virtual arena (Kasket, 2010;

Maddrell, 2012). The use of technology by the bereaved reinforces their sense they are not alone as they read about experiences with others and join ‘virtual communities’.

Implications of Relationships in the Bereavement Diaspora and Receptivity

Receptivity studies have placed the concept of receptivity firmly within a socio-cultural context. The findings from this research highlight the important role of relationships in the *bereavement diaspora* and provides insight into receptivity to support for the individual and those social networks within their ecosystem. The bereavement discourse includes emerging research in relation to the mediating influence of interdependent relationships of the family in bereavement.

Research into the mediating effects of relationships has shown inconsistent findings and different types of social support has different impacts with different ‘receivers (Li & Chen, 2016). Vachon and Stylianos (1988) describe four main types of social support: i) emotional, which supports actions that enhance self-esteem; ii) informational, providing advice or information to promote problem solving; iii) instrumental, which provides tangible and practical assistance; and, iv) appraisal, where feedback is provided on views or behaviours. These authors describe a concept of ‘goodness of fit,’ where “...the goodness of fit between donor activities and needs of recipients is governed by the amount, timing, source, structure and function of social support...” (Vachon & Stylianos, 1988, p.176). This concept has relevance for understanding receptivity. Li and Chen (2016) state that the needs for different types of support is related to characteristics of the bereaved person.

Li and Chen (2016) highlight that spousal bereavement leads to the loss of close emotional company and that the death can increase parental burden in parenting and family chores and a decline of the family’s economic condition. There may be assumptions that psychosocial support may be of benefit however the empirical evidence is inconsistent in whether social support and bereavement outcomes are positively correlated. Li and Chen’s

(2016) study found that family and friends were primary sources of support for bereaved people and that professional support was seldom required. They also found that participants in their study received support from their workplaces. Of importance was that support from family did not decline with time however support from friends did subside. It is posited that family members are more sensitive to the need for ongoing support due to the close family ties (Li & Chen, 2016). This shows that positive relationships can play a mediating role in bereavement. Although Li and Chen's (2016) study was based on Chinese participants where the Chinese culture places a high value on family, this has implications for receptivity targeted at the community - to enhance awareness to informal support networks, the general community and professionals and change the dominant discourse to grief as an enduring, common and normal feature of bereavement.

a) Bereavement Diaspora: Connection with others

Some participants described feelings of alienation from their local community and informal support networks. This may be a receptivity issue as people may seek professional support if they are not receiving support within their own social networks. However, alienation and not feeling a connection with others may also compound an individuals' existential loneliness and make them withdraw even more. This may enhance their risk for developing a psychopathology or suicidal ideation. As demonstrated in the findings however, bereaved participants who felt a sense of connection with their family did not wish to traumatise them further, hence family provided a protective buffer against suicide. Families who perceive a member of the family to be particularly vulnerable or requiring support, may seek support themselves in developing strategies to help them support their vulnerable loved one. Receptivity to learning strategies in order to be able to better support a loved one may warrant further examination.

One of the participants described the need for mixed socialisation as the loss of her husband led to a reduction in her informal support networks of males. This may have implications for receptivity to support and service design as well as delivery. Provision of mixed gender activities or facilitating the 'linking in' of bereaved into community or

leisure networks may enhance receptivity of some bereaved. Likewise, many bereaved expressed an ‘affinity diaspora’ so linking them in with other bereaved people may be of benefit to some individuals and families however, Vachon and Stylianos (1988, p.176) state “...social support is a transactional process, requiring for its optimal provision, a fit between the donor, the recipient, and the particular circumstances...”

There is a dearth in the extant bereavement literature on the role of relationships with friends and its mediating effect on bereavement experiences. Although there is evidence of the supportive role of family in the empirical literature, friends and acquaintances who are members of social or activity clubs are relatively ignored. Many of the participants in this study discussed the close relationships they have with friends. One participant, ID: B: 3111: F; 68; Friend; 13-18; R3, stated “...*I've come back to a friend of 50 years, that's very close. It's actually better than children...*” This has implications for service design and psychosocial support. Individuals’ within a bereaved person’s social support network may be receptive to support that empowers and equips them to feel confident in supporting a bereaved friend. The need for community education or paraphernalia for support networks is indicated. Ogbuagu (2012) advocates for the community and support systems to focus their energy in providing [practical] resources to assist the family. The role of friendships in the *bereavement diaspora* and receptivity of informal support networks to education, professional support or coordination to mobilise the resources of the community, is worthy of further exploration.

b) Hybridity: Changing relationships and family identity

Receptivity to support within the family context has been briefly discussed in the previous chapters. The influence of one’s upbringing engenders belief systems around seeking help. Studies into receptivity that consider ecosystem perspectives, draw on social cognitive theory to inform receptivity. That is, the values, belief systems and attitudes socialised within the family unit, will influence one’s receptivity. Receptivity is influenced by the scripts that emerge from the family (Tharenou, 2003; Boellaard, 2005; Holt, 2012; Brietkopf et al., 2014). Li and Chen (2016, p.226) found that “...the needs for some types

of social support had to do with the characteristics of the bereaved person...” and these characteristics are formed within family-socio-cultural contexts.

Participants in this study described ways of maintaining the integrity of the family unit and family identity through adopting roles of the deceased, and changing their own roles, to try and minimise the impact on their children in their bereavement. It was important to participants to maintain the family identity as a cohesive and supportive unit. This has implications for receptivity as families are dynamic systems that change through time. If a family is struggling with changing roles, they may be receptive to support. Service design that includes appropriately skilled staff to undertake family assessment and supports prior to, and subsequent to, the death, may enable organisations to target interventions more appropriately and ensure family members are referred to relevant resources that empower and equip the family as a whole.

As previously highlighted, one participant described how she wanted to keep her workplace as a place of ‘respite’ from dealing with the practical matters and from the emotional and psychological impact of the death of her father. She described her work colleagues as being intrusive and wanted to keep work and home separate. This has implications for how workplaces can support a bereaved staff member. The nascent literature on ‘compassionate workplaces’ is gaining increasing attention and early research indicates the benefit of compassion in the workplace. These benefits include a workplace that promotes empathy, supports prosocial behaviours which lead to improved workplace culture and positive health benefits on employees and thus improves the organisations’ bottom line (CCARE, 2016). This has broader implications than what palliative care services can reasonably provide. A compassionate workplace reflects the same principles of ‘compassionate communities’ where there are policies to recognise “...compassion as an ethical imperative...” (Barry & Patel, 2013, p.10) and provides flexibility in resources and services to support needs (Kellehear, 2013). However, in terms of receptivity, development of organisational cultures that promote empathy and thus allowing employees to guide their needs, and receptivity to support from the organisation or fellow employees, is worthy of further exploration.

c) Disruption: Changed relationships, role shuffles and family fabric

Participants in this study portrayed a need to maintain their role within the family. For example, one parent who was elderly did not want her adult children to adopt a ‘caretaking’ role. However, one male participant expressed he had to rely on his daughter as he was overwhelmed by his grief, thus was unable to function. In effect this participant relinquished his power as father to his daughter. Power differentials in the family dynamics as the family re-organises itself in bereavement, is an area requiring further empirical exploration to identify if, and how, power differences impact on family functioning in bereavement. Receptivity in terms of maintaining or relinquishing one’s power within the family unit is also an interesting area to explore.

Li and Chen (2016) suggest social support in the form of practical assistance may be indicated for older people as they may experience more economic challenges or difficulties adjusting to daily life after loss. The presence or absence of resources thus may influence receptivity. The need for practical assistance may be a receptivity issue requiring further exploration, particularly for elderly bereaved.

d) Displacement: Collective grief

The bereaved carry with them memories that they share with family members and pass down to generations in the family unit. As shown, some participants shared memories with their children and other family members. However, other participants did not want to burden their children, so relied on friends or professional support in their grief. This has implications for receptivity in terms of how surviving parents view their role and what values they hold about being a parent. Assessment of open expression and sharing within the family dynamic may be a protective factor in adjustment in bereavement. This is an area of research that could provide greater insights to receptivity by surviving bereaved parents.

Current and future generations will be able to read about their ancestors through social media sources such as FB. These ‘prosthetic’ memories will be more prolific with the increase of technology legacies (Chen, 2015). Initiatives that are inclusive of family, friends and the broader community is an area that may influence receptivity to engagement with informal networks. Unlike other SNS’s, FB is limited to those who were accepted as a friend prior to the deceased’s death. Each year, reminders pop up of their birthday, reminding other FB users they are still there, prompting them to re-visit the page and redefine their connection with the deceased. Some individuals reported visiting FB pages’ days, weeks, months and sometimes years after the death, which allows the site to be a dynamic, living source that allows others to maintain a continuing bond (Pennington, 2013).

Strategies that enable collective, shared grief and co-narrating of the deceased’s life story may be worth encouraging. Use of IT platforms such as SNS may be helpful in enfranchising previously disenfranchised grievers, particularly friends. Use of IT may increase receptivity to support. As one participant stated:

“...one day my lawnmower wouldn’t start and I put on Facebook I’m geared up to mow the lawns - the bloody thing won’t start, can’t pull the thing and I had two people come and knock on my door and a girlfriend bought her son around and said you will sit down while my son’s mow the lawn...” ID: B: 3369; F; 53; Sp; 13-18; R1

The internet has played a key role in enfranchising narratives, where individuals write about, or ‘blog’, their emotional journey, of note, an increasing trend in men expressing their grief online has been noted by Maddrell, (2012). Receptivity to the use of IT may increase as younger generations are using virtual communities to cope with many life stressors. The development of IT resources may enhance receptivity to support in the future and further exploration of this area is recommended.

e) Embodied diaspora and transcendence: Ongoing presence of deceased

Families and friends share the ‘home space’ which embodies memories and tangible objects, maintaining an ongoing presence of the deceased. Participants described maintaining the home and belongings of the deceased and this ensured an ongoing presence of the deceased in their lives. One participant described how friends visited her at home on the anniversary of the death of her husband and that she found this an extremely valuable experience. Another participant talked about getting away with her family on the anniversary of her husband’s death. Families engage in rituals to maintain an ongoing presence of the deceased and this has implications for service design. Any material or resources developed that provide bereaved families with ideas to mark the occasions of anniversaries, or other special dates, and normalises the experiences may enhance receptivity of the bereaved to seeking ideas from informal or professional support networks.

f) Deathscapes: Shared sacred spaces

The bereaved participants in this study described how communities helped to create a deathscape that honoured their deceased loved one. Resources that facilitate the creation of a deathscape by the bereaved and the community around them may be of use. This has implications for receptivity if services design resources, or paraphernalia, outlining ideas on strategies, rituals or practices that commemorate the deceased. Likewise, councils can consider the creation of public areas where memorialscapes such as park benches, playgrounds or even plants can meet the need for deathscapes in the public arena but where there is oversight to ensure there is not conflict, for example, removal of roadside memorials to accident victims.

Conclusion

Bereavement does not occur within a social vacuum. The DPM-R incorporates coping in bereavement at the individual and family level in relation to loss and restoration oriented activities. The findings from this study reflect the role of relationships in helping people cope, particularly within families. However, a salient point is that the role of friends in helping the bereaved to cope is often overlooked. Given the complex dynamics of modern social systems, friends can and very often do, replace family members. Narratives from this study highlight how imperative friendships are to mediating the *bereavement diaspora*.

Key concepts from the diaspora discourse as they apply to relationships was discussed in this chapter. The focus on this chapter was on discussing findings as they apply to the mediating effect of relationships in the *bereavement diaspora*. The role of informal networks was explored in this chapter and was identified as a significant factor in mediating the bereavement experience and has implications for receptivity. The role of relationships with formal support or professional networks and receptivity will be explored in chapter nine. The next chapter will discuss the role of language in *bereavement diaspora*.

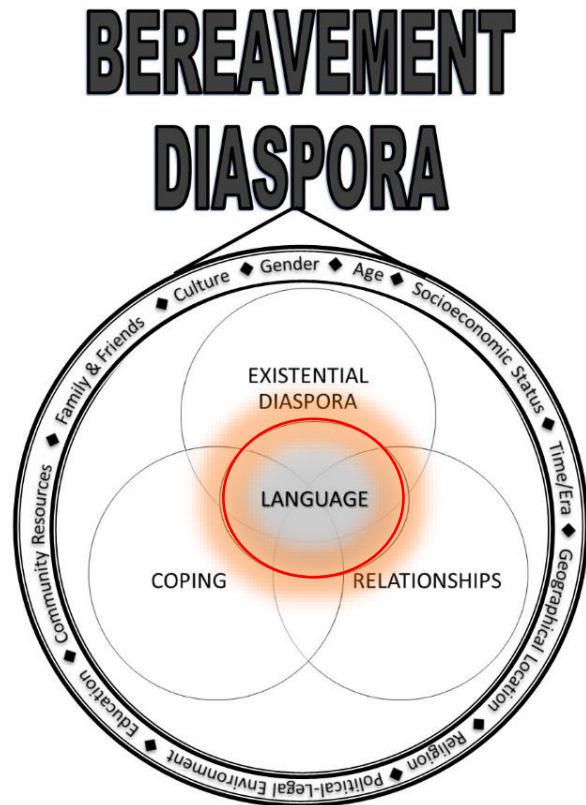
Chapter 8: Language in the Bereavement and Diaspora Discourse

Introduction

Discussion on emergent themes from the data in previous chapters explored the role of relationships, the different ways of coping and the experience of *existential diaspora*. The findings in the preceding chapters provide the platform to analyse the grief and bereavement discourse in a scholarly manner.

This chapter identifies, explains and positions the multiple, competing discourses, which is essential for understanding participant's experiences of bereavement. The term discourse has many meanings, however for the purpose of this study, the Foucaultian notion of discourse, and discourse as 'actual talk' were the guiding perspectives through which discourse was explored.

Figure 23: Bereavement Diaspora: Language



According to Foucault (1972, cited in McGrath, 1997, p.12), discourses develop over time and are socially and historically constructed through a process referred to as the 'archaeology of knowledge'. The 'clinical gaze' of medical discourse is one such discourse that has evolved over time. Medical discourse often adopts a reductionist, physiological and medical focus and is a medium for constituting knowledge and power. This perspective privileges hegemonic constructions of a point of view and silences opposing or alternative views (Foucault, 1972, cited in McGrath, 1997, p.17). Cheek

(2004, p.1142) reiterates that discourses “...enable and constrain the production of knowledge...” The analysis presented in this chapter indicates that the grief, loss and bereavement discourse is predominantly embedded in the medical sciences discourse, effectively marginalising the ‘actual talk’ of bereaved individuals.

Discourse as actual talk is “...interpreted more pragmatic, local, contextual terms as the actual words or ‘talk’ of individuals in their day to day experience...” (McGrath, 1997, p.17). Discourse of actual talk is thus the subjective experience of an individual’s reality, which is socially constructed based on the ‘situatedness’ of the person (Cheek, 2004). This situatedness is influenced by many factors, including the cultural and social contexts in which the person lives.

In exploring the thesis topic through a postmodern epistemological framework, deconstructing the language used in relation to bereavement was an intrinsic part of the data analysis. Understanding the language, or discourse, used in bereavement is just as important as the theoretical understandings of the experience, and the models and therapeutic practices developed in understanding and working with those who are grieving. Examining the theoretical perspectives of discourse provides an understanding of how language expands or limits a person’s experience. As the philosopher, Wittgenstein (1922, n.p.) stated “...the limits of my language are the limits of my world...all I know is what I have words for...”. (“Ludwig Wittgenstein”, 2016). Much of the discourse on grief and bereavement derives from medical and psychological sciences who provide the language for these experiences. Thus, the professional discourse created may not reflect grief and bereavement experiences. The findings from the study demonstrate that the role of language in the *bereavement diaspora* reflects the unique subjective experiences of participants and diaspora provides a different perspective to language used in bereavement.

The Discourse of Grief, Loss and Bereavement

Language of a phenomenon is created within disciplines through the way a social problem is defined according to the dominant assumptions and values of a specific profession, and the 'ways of working' within that professional field (Ord, 2009). Discursive rules develop as a shared set of social practices based on a specific discourse community. 'Truths' are revealed through validating a particular idea through the development of a shared understanding (Olsson, 2008). These 'shared understandings' generate a dominant discourse, sometimes known as a 'grand narrative', 'grand theory' or 'meta narrative' which is the big picture story that aims to explain everything and is used to legitimise 'norms' of what is expected within a phenomenon (Casstevens, 2010). Disciplines such as medicine, psychology, anthropology and sociology influence definitions, conceptualisations and perceptions of grief, loss and bereavement experiences and each respective disciplinary 'lens' has led to a highly contested discursive terrain (Ord, 2009). Disciplinary discourse is imbued with power and creates a hegemonic dominant world view.

Research into grief and bereavement in the medical and psychological sciences has constructed a discourse where grief is seen as an individual problem in which people and experiences are characterised by normal and pathological grief, according to an implied 'healthy' predetermined way (Turner, 1997; Lupton, 1997; Breen & O'Connor, 2007; Ord, 2009; Casstevens, 2010). Psychology has made a significant contribution to the bereavement discourse and what constitutes 'healthy' and 'unhealthy' grieving and the discourse is dominated by terms in grief and bereavement such as 'severing ties', 'letting go', 'moving on' and 'grief work'. This situates grief as being informed by a 'normalising psychology' in which grief is a goal directed activity where a return to 'normal functioning' is the desired outcome (Valentine, 2006). Discourse can have detrimental effects on those experiencing loss, if they believe their grief does not conform to what is considered as normal grieving (Ord, 2009). Although discourses can be reassuring and affirming as it can normalise an experience for individuals, discourse can also oppress and

marginalise those experiencing deviations of what is considered the expected or normal grieving process (Lupton, 1997; Turner, 1997; Ord, 2009; Casstevens, 2010).

According to Ord (2009, p.198) there has been an evolution of professionalised specialties in which "...professionals medicalise and pathologise those living with loss..." (Ord, 2009, p.198) and this is reflected in the plethora of research in the area of grief, loss and bereavement, particularly in recent decades. Along with the growth of grief and bereavement as a specialisation, there has been a concurrent emergence of assessment and measurement tools. The discourse on grief and bereavement seeks to "...discipline and control grief by creating boundaries between normality and abnormality..." such that "...grief work becomes an instrument of surveillance, a site of power and an agent of social control..." (Ord, 2009, p.199). Psychological sciences privilege emotionality and psychological adjustment in bereavement, universalising a grand theory of bereavement, predominantly as a phenomenon of the inner world, independent of social environments (Valentine, 2006; Ord, 2009). This diminutive perspective, based on an assumption of universalism, reduces the human experience to a measurable phenomenon in which "...generalisations, models and prescriptions can be developed..." (Valentine, 2006, p.59). The universal 'grand narrative' of the dominant medical and psychological grief and bereavement discourse disregards dissenting voices and experiences (Middleton, Moylan, Raphael, Burnett & Martinek, 1993; Olsson, 2008; Casstevens 2010). However, anthropological and social sciences recognise the diversity of experience and these are socially constructed.

There is contested views between medical and psychological sciences with anthropological and social sciences in what constitutes normal grieving. Dominant discourse on grief and bereavement do not give much attention to the social and relational contexts in which grief, loss and bereavement occur (Breen & O'Connor, 2007; Ord 2009). Anthropological and sociological sciences view grief and bereavement as socially constructed phenomenon which situates a person's experience within their broader social and cultural milieus (Valentine, 2006). Language is the bridge that links the individual with the socio-cultural domains.

Postmodern perspectives propose that language is not only a by-product of human interchange, but is bound by cultural processes and sits within historical contexts (Gergen, 2001). Individuals may not have the verbal language to adequately articulate their feelings or experiences (Ord, 2009) and to describe and explain the way they experience a phenomenon, their relationships with each other and their social world. Language aides in the construction, negotiation and sustaining of identities and relationships, fosters a sense of belonging and is a major feature that characterises community formation (Jain, 2010; Canagarajah & Silberstein, 2012; Ben-Rafael, 2013; Marat, 2016). Canagarajah and Silberstein (2012) posit that diaspora members create a common language within the intra and intergroup relationship. Language thus helps diasporic agents negotiate their layered identities and group relationships.

Postmodern perspectives recognise that the researcher, or investigator, of a phenomenon is also situated within a broader socio-cultural context and this influences methodological approaches to examining a phenomenon. Knowledge and discourse is thus socially constructed when examined through a specific disciplinary lens. Olsson (2008) states that researchers need to be more reflective on their research practices and conscientious in describing their influences on their work'. Although Parsons (1995, p.23) argues that the experience of participants is 'already mediated through the political ideology of a particular socio-cultural language game and is refracted yet again through the lens of the researcher in the final account', the researcher in this study was mindful not to perpetuate the subjugation of participant voices to the discourse used in the clinical health care settings in which the researcher works as a social work practitioner. When commencing this study, the researchers' intent has always been to respect the voice of the participants by trying to remain as close to their words and their narrative as possible. It was this imperative that framed the epistemological and methodological approach to this study. Throughout the analysis process, the researcher was consciously attentive to the language used by participants and of the language used to assign to nodes during the coding process to maintain the integrity of the data and the qualitative descriptive design.

The bereaved participants in this study used metaphors and language to describe their unique, subjective experiences. At the nexus of thoughts and emotions is expression. Thoughts are linguistic in their conception and expression (Steeves, 2002). Edwards (2014) highlights that language difference is a key feature when viewed through a diaspora lens. When diaspora is no longer viewed through a static, bounded and territorialised perspective, the role of language and discourse in the construction of diaspora brings a new appreciation. Language as it relates to diaspora and postmodernism is imbued with notions of power, history, and identity (Clifford, 1994; Canagarajah & Silberstein, 2010). Diaspora provides a discourse that integrates individual, social, cultural and political factors, recognising the intrinsic linkage of power with discourse.

Diaspora: Findings to Concept: Language in the *bereavement diaspora*

Clifford (1994) highlights the inadequacy of discourse and states that people are reduced to “stopgap language of ‘posts’” when they lack a description for their experiences. Hence the bereaved default to the predominant discourse, using term such as ‘moving on’ and ‘closure’. Clifford (1994) discusses past and pre-figurative loss and survival discourses and that in relation to modern day multiple pluralistic identities of individuals and communities, discourse does not adequately reflect the changing world and people’s experiences within it. In coding the data, it became evident that the dominant discourse was echoed in participant narratives. Words commonly used in contemporary bereavement discourse include ‘closure’ (Rosenblatt, 2013), ‘recovery’, *abnormal grief*, ‘*complicated grief*’, (Middleton, Moylan, Raphael, Burnett & Martinek, 1993; Ord, 2009), ‘*letting go*’, ‘*moving on*’ and ‘*acceptance*’ (Valentine, 2006; Kunkel, Dennis & Garner, 2014). One bereaved participant commented on the use of language based on his experiences:

“...I think the initial coming to terms with the death and the words used. I mean we’re all afraid of certain words. Death is number 1. We look for euphemisms. Passed on, deceased, whatever...” ID: B: 3725: M; 63; Sp; 7-9; R1

Closure is often a term used in grief and bereavement however closure has been defined as "...a feeling that an emotional or traumatic experience has been resolved..." ("Closure", 2016). Evidence in the literature suggests that grief is a lifetime experience (Buckle & Fleming, 2011) and that there is not actually a sense of closure. Thus, the lived experience of the bereaved is where closure cannot be achieved. The dominant psychological discourse was echoed in the bereaved participants' narratives, particularly when talking about 'closure', 'acceptance,' 'moving on' and 'letting go'. 'Closure' was a term numerous bereaved participants used throughout their interviews as depicted in the following statements:

"...We've managed to you know, have a lot of good opportunities for closure...I hate that word...'cause you don't...'close'..." ID: B: 3072: F; 52; Sp; 6-9; R3

"...I don't go for this business of closure. I think it's just one of those in phrases..." ID: B: 3391: F; 69; Sp; 13-18; R3

"...She'd said she wanted to be cremated fine, but that will be perhaps the final closure. Closure is a word that I don't have much time for..." ID: B: 3725: M; 63; Sp; 7-9; R1

Bereaved participants discussed the struggle with coming to terms with the loss, often referred to in the discourse as 'acceptance'. One participant used this term numerous times throughout his interviews:

"...acceptance of death is probably the hardest part of all..."
and
"...accepting that reality is still difficult. It's still hard...."
and

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

What is thought of as ‘acceptance’ in the dominant bereavement discourse can be considered more of a reconciling – the constant tension of wanting to keep hold of the old world and having to enter a new world. This dialectical stance is known in the diaspora discourse as a *lived tension* in which nostalgia and yearning endure. Acceptance has connotations of psychologically and emotionally embracing the death whereas reconciling recognises that perhaps one doesn’t have a choice, a reluctant surrendering to what has happened; forcibly having to find a different identity and navigate a new and foreign world.

Another dominant discourse in the bereavement literature is the term, ‘moving on’. *‘Moving on’* or derivatives of this phrase was noted in health professional narratives. Participants used this term in their narratives as demonstrated in the following quotes:

“...everybody else is very much, ‘let’s not talk about that, we need to move on’, and, ‘you need to move on with your life now, that’s all behind you’, sort of thing...” ID: HP: 3334: F; 43; R1

“...she was already moving on; she didn’t need me to actually make that phone call...” ID: HP: 3444: F; 50; Rem1

‘Moving on’ or derivatives of this phrase was also present in bereaved participant narratives, echoing the medical and psychological discourse as portrayed in the following statements:

“...there is probably another phrase that’s better than moving on but I don’t know what it is...” ID: B: 3113: F; 61; Sp; 19-24; R3

“...I don’t wallow, nothing can bring [G] back, but I need to move forward...” ID: B: 3109: F; 64; Sp; 10-12; R3

“...so now things are starting to move on and liven up, and we're enjoying life and we're doing this, and doing that, and I think, ‘now that I'm enjoying these things, but I'm feeling as though I shouldn't be enjoying them...’” ID: B: 3400: M; 70; Sp; 13-18; R3

“...I feel like it's a really dark place, it's horrible, and I say to her [GP], ‘I don't want to go there.’ And she said, ‘But with that pain will come a relief as well.’ So and I know what they're all trying to say that I have to, get me over it, but...” ID: B: 3386: F; 53; Sp; 19-24; R1

“...I suppose everyone says something different because some people do need to move on...” ID: B: 3113: F; 61; Sp; 19-24; R3

The phrase ‘letting go’ is another commonly used term in the medical and psychological discourse and was referred to by a bereaved participant who stated *“...I wasn't ready to let it go...”* ID: B: 3386: F; 53; Sp; 19-24; R1.

Another common colloquialism that reflects the concepts of ‘moving on’ and ‘letting go’ is to ‘get over it’ as reflected in the statement below from a bereaved participant:

“...I don’t think you ever get over it. You don’t. Those memories were there. 30 years we were married. It’s a long time. A lot of ups and downs; three kids...just a lot of stuff...life...busy; lots of laughter....” ID: B: 3369: F; 53; Sp; 13-18; R1

Tasks such as moving on and resolution are viewed as essential for the bereaved to demonstrate they are successfully resolving their grief (Valentine, 2006). Many bereaved do not wish to give up their attachment to the deceased but continue to have an ongoing relationship with them (Valentine, 2006). Bereaved participants in this study talked about sensing the deceased as a spectral presence, that they still interact with the deceased by talking directly to them and that they feel the deceased continues to be a part of their decision making and their lives. The following participant statements reflect how the bereaved talk directly to the deceased as if they are still present:

“...of course [T] goes, ‘Dad, stop it!’ like blaming - and he's not here to stick up for himself...” ID: B: 3109: F; 64; Sp; 10-12; R3

“...I've got files and receipts and bank accounts- so by the time I had to shoot off and come back, I finished about 4 o'clock in the afternoon ...I said, ‘you should be bloody doing this [C] (deceased) This is not my job!’ you know...” ID: B: 3400: M; 70; Sp; 13-18; R3

Experiences shared by bereaved participants in ‘sensing the presence of the deceased’ can sometimes be considered as pathological, illusory and part of futile ‘searching’ occurring in the early stages of grief when viewed within psychological discourses on bereavement (Valentine, 2006; Ord, 2009). Bereaved participants demonstrated numerous ways throughout their interviews of their subjective experiences, on the active role the deceased still play in their lives, as depicted in the following participant quote:

“...I just say where are you, where are you? Then he sends me the butterfly and I go, ‘okay’...” ID: B: 3369: F; 53; Sp; 13-18; R1

Sensing or ‘seeing’ the deceased would be considered a pathological item based on a commonly used tool, the Complicated Grief Inventory. Grief and bereavement assessment

tools have been developed to enable practitioners to identify clients who are at risk of difficult grief ‘reactions’. Common features of the discourse used by the health professionals in this study is framed within bereavement risk assessment discourse (Kubler-Ross, 1970; Sanders, 1989; Worden, 1991) as demonstrated in the following participant statements by health professionals:

“...when we first have our admissions, we do a risk assessment with regards to bereavement support....” ID: HP: 2888: F; 42; Rem1

“...I think there was a bit of a vague bereavement risk assessment, and not even a tool, but just more of a gut feeling, do you think this person’s at risk or not?” ID: HP: 3334: F; 43; R1

“...there has been a form and it talks about the risk - their grief - was it normal, was it abnormal...There is a score but how accurate that is I’m not sure...” ID: HP: 3333: F; 53; R1

Practitioners often learn the stories, or meta-narratives, of ‘normative’ grief and bereavement through training and education programs, which they then repeat to the clients they work with. This repetition subjugates the individuals’ narrative to that of the expert practitioner and reinforces the dominant discourse (Casstevens, 2010). Engendered in maintaining the dominant discourse is repetition, shaped by training and education. This is reflected in the following quote by one of the health professional participant:

“...I do remember many years ago doing grief counselling training, an in-service, and they talked about the stages and all this sort of stuff. It doesn’t happen like that and I think that, honestly, maybe I might have answered this differently 20 years or something when I was younger...” ID: HP: 3444: F; 50; Rem1

Ord (2009, p.207) states “...structures of discourse can be dangerous if we do not question the ways in which they are operating through our practices...” The participant from the previous statement recognised that a stage model of grief was a dominant discourse in bereavement and there was a discordance between what she was taught and what she experienced in the clinical setting. Likewise, this participant discussed how ‘bereavement risk’ was a discourse specific to palliative care as demonstrated in the following statement:

“...probably the first time I’ve come across it, definition, or that reference if you like, has been since I’ve worked in this position in specialist palliative care. Talking about people being ‘at risk’ of bereavement.... bereavement doesn’t come from the hospital. I know that for a fact. They don’t do bereavement. So it’s lacking in your general stream unless they are on a Mid ward, or specific groups. But in general, I don’t think there is that bereavement follow up...” ID: HP: 3444: F; 50; Rem1

As stated previously, evolution of specialisation discourse develops over time. The ‘archaeology’ of knowledge (McGrath, 1997) of bereavement risk in palliative care seems to be specific to palliative care as reflected in the previous participants’ statement. Interestingly, there was discordance with some health professionals in using the discourse created for their specialty (palliative care) and they expressed the inadequacy or inappropriateness of the language commonly used in this field. Olsson (2008) notes that all discourse communities can accept, modify or reject a shared understanding as demonstrated in the quote below by a health professional participant:

“...it was a very nebulous sort of term to me [bereavement ‘at risk’], I know behind it was those indicators of - was there mental illness? Is it a single parent? Are they isolated? Are there are drug and alcohol issues? All those sort of factors that might make somebody’s ability to cope a little more tricky. But I don’t know if somebody who is not a social worker would identify that that’s what at risk means...at risk of what? And can you piece them back

together at the end of the day? So it was a useless sort of term, in my book...”

ID: HP: 3334: F; 43; R1

The medicalisation of grief implies grief is a condition that needs treating, evident in the discourse which likens grief to a ‘disease’ or ‘syndrome’ with associated ‘symptomology’ (Valentine, 2006; Casstevens, 2010). Some health professional participants recognised this dominant discourse of pathologising and commented on how this influences the way professionals work with the bereaved as depicted in the following participant statement:

“...they don’t need to be pathologised, that there’s something wrong with you and we need to fix it, we need to structure your thinking around a different way, and get you out of whatever you’re thinking...” ID: HP: 3334: F; 43; R1

Health professional participants also reject the medicalised approach as reflected in the following quote:

“...I question myself about as a professional is do we need to treat bereavement as a medical condition. Now I think we’ve got to be very careful as health professionals that we don’t...” ID: HP: 3444: F; 50; Rem1

Psychometric measuring tools developed for measuring grief compels clinicians to look at the level of severity of ‘symptoms.’ This is reductionist and has the “...discursive power to prioritise certain needs over others and pathologise and discredit certain experiences...” (Valentine, 2006; p.61). A common term used in the palliative care bereavement discourse is in relation to complicated grief where ‘maladaptive’ coping occurs. Complicated grief is characterised by symptoms of yearning or longing, feeling stunned, shocked, dazed empty or emotionally numb, avoidance, confusion about role in life, difficulty accepting the loss and ‘moving on’ (Prigerson, et al., 1995; Hall, Hudson & Boughey, 2012). Research indicates individuals with complicated grief constitutes approximately less than

10% of bereaved individuals who have had a significant other cared for under a palliative care service (Aoun et al., 2015). The discourse of '*complicated grief*' or similar terms such as '*complex grief*' was reinforced through the narratives of health professionals when talking about complicated grief as demonstrated in the following statement:

"...so they bottle it up and then of course they're at risk of having a complex reaction later on..." ID: HP: 2888: F; 42; Rem1

The use of the term 'reaction' demonstrates a medicalised 'symptomology'. Another health professional discussed occasions they identify and respond to complex grief:

"...We've actually had a client in the past that we've had to refer to mental health because it was going into complex grief and bordering on suicidal ideation..." ID: HP: 3389: F; 54; R3

"...sometimes they'll continue to come back to that subject, you know, that in their mind, causative to their death. So that is where we perhaps consider it to be complex grief and that's a bit of a mark to refer on to professional counselling or their local GP..." ID: HP: 3390: F; 43; R3

Although some psychopathology has been linked as a result of the death of a significant other in bereavement, modern grief and bereavement has been medicalised and psychologised, valuing science based discourse (Valentine, 2006; Ord, 2009). Modernity has shaped perspectives of the bereavement experiences through valuing quantitative methods of inquiry within positivist paradigms. This has excluded the subjective experiences of the bereaved, creating tensions of conceptual, social policy and practice perspectives, leading to disciplinary splits. Qualitative, exploratory approaches "...allows the generation of rich contextual data that capture the process of meaning making and the complexity of human relationships..." (Valentine, 2006, p.58). Postmodern perspectives

challenge modernity's rationalising discourse and highlights the intersubjective, relational and social experiences that reveal bereavement within a 'bigger picture' (Valentine, 2006; Ord, 2009). As Valentine (2006, p.57-58) highlights "...experiences and responses of the bereaved are viewed in isolation from their social world..." Postmodern perspectives thus adopt an ecological approach and view the bereavement experience of the person within their social environment.

Throughout the twentieth century, social scientists (anthropologists, sociologists) have endeavoured to understand and address the experience of bereavement. Anthropological discourses highlight ways in which bereavement is socially constructed and provide insight into the role of the use of ritual in memorialising the deceased, mediating the bereaved existential state and helps to maintain connection to the deceased and to others in their own community or networks (Valentine, 2006). Participant narratives in this study reflect the anthropological discourses about honouring the deceased through memorialisation and ritual within social contexts which can occur within the broader extended family or larger community. The following participant quote demonstrates the small rituals family engaged in to honour their deceased in preparation for the funeral:

"...the funeral director - when they got the music - said, 'Are you sure about [the song] Poker Face? I said, 'Yep' and told them the reasons...then a couple of days before the funeral Grant said 'Mum I've just downloaded the Dockers theme song, do you reckon they'd put that in the ute from the gates of the crematorium and up to the crematorium and have it blaring out?' I said, 'We'll take it, we can ask.' So, he [deceased] arrived at the crematorium in the back of his ute. We got wild flowers put on him because he loved the bush. And then the grandchildren and I on Friday morning went up the road and picked him 3 kangaroo paws from the 3 grandsons. We took blue-bells - you wouldn't believe it - everything was in blossom that he'd planted. So we took plum tree blossom, he planted the plum trees. We took blue-bells..." ID: B: 3109; F: 64; Sp: 10-12; R3

Small rituals such as finding meaningful music and picking favourite flowers all represent “...a personal response by mourners to individualised needs embedded in their grief...” (Lewis & Hoy, 2011, p., 316). The family is the social context in which death, funeral practices and memorialisation occur. Anthropological perspectives emphasise how individuals “...make sense of their world through negotiation with each other...” (Valentine, 2006, p.66) and this takes into consideration the continued relationship with the deceased, but also relationships with others. Sociological perspectives recognise relationships but further considers the individual within the context of their social environment and the role of gender, culture, socio-economic and education status and other factors that influence a person’s experiences (Agger, 1991; Olsson, 2008; Casstevens, 2010) as referenced in the statements below. The following participant statements reflect issues of gender:

“...probably because we males do tend to bottle it up a bit. We don’t spill it out that readily or that easily...” ID: B: 3725; M; 63; Sp; 7-9;

R1

“...just to have the dishwasher put in, the plumber cost me \$1000 and to me that was excessive, and you sort of wonder if they're taking advantage because you're a woman on your own now...” ID: B: 3109;

F; 64; Sp; 10-12; R3

As culture is another broader sociological factor, the following participant narratives demonstrate recognition of the difference in grieving and funeral practices within different cultures:

“...in this town I don't know whether you know but there are a lot of Italians and they express their grief quite differently...” ID: B: 3073; F;

87; Sp; 6-9; R3

“...the Italians, the Greeks, the, even the Filipinos, they have their way. The Aboriginals with their wailing, can be quite haunting...you don't have to be empathetic, but you can just be respectful to them and the deceased. And they see that...” ID: HP: 3414: F; 49; R1

“...I was bought up in a small village in Sweden and when somebody died, well you had an open coffin. Sometimes you had to wait for months to bury somebody because the ground was frozen so you put them out in the barn, they froze, and then you waited until you could dig them up. Children would put in flowers in the coffin and so on. So it was a natural thing. But I probably have a different background for most people...”
ID: B: 3111: F; 68; Friend; 13-18; R3

Socio-economic factors also play a significant role in influencing bereavement outcomes as demonstrated in the statements below:

“...he said "I've left you plenty of money" 'cause he definitely left me plenty of money. Well, his life insurance policy has taken care of everything...” ID: B: 3072: F; 52; Sp; 6-9; R3

“...fortunately, I'd converted my superannuation to shares, sold my shares and bought a car. But people used to say to me, 'my husband's died and I can't make ends meet' I thought, that's ridiculous - your income's halved, surely you can live on half the income? However, electricity doesn't go down, phone doesn't go down, rates don't go down, insurances don't go down except for personal health insurance, that was halved car insurance. All those big costs are constant...” ID: B: 3371: F; 77; Sp; 7-9; R2

Geographical situatedness can influence the bereavement experience, particularly in relation to rural, regional and remote contexts as portrayed in the following participant reflection:

“...how much worse off would I be if I was stuck in, oh I don't know Widgiemooltha or Mingenew, any of these little towns where there is nothing in the way of help. I feel empathy for such people. They must be out there suffering in their own way...”

ID: B: 3725; M; 63; Sp; 7-9; R1

Socio-cultural-political factors all influence the bereavement experience yet are not incorporated into the dominant medical or psychological discourse. Sociological perspectives value the qualitative and subjective experience, moving away from the modernity, positivist approaches to understanding and measuring a phenomenon (Valentine, 2006). As demonstrated in the findings in this study and discussed in previous chapters, socio-cultural and socio-political factors have a significant impact on the bereavement experience. Likewise, the role of language within family, community and broader societal groups can impact the bereavement experience.

Language and a bereaved individual's narrative of their world creates a connection between people and those who share similar experiences (Hua, 2013). Valentine (2006, p.70) highlights qualitative studies which demonstrate the 'immense resourcefulness and creativity' in which the bereaved manage potentially shattering experiences in highly individualised ways'. The ways of coping revealed in this study demonstrate the myriad of ways people cope in bereavement as highlighted in the following statement by a bereaved participant:

“...if you're grieving...your relationship with your loved one was different from anybody else's so your pattern of getting over it is going to be different...I always tell people...”[laughs]. Grieve your own way. There's no rules...” ID: B: 3371; F; 77; Sp; 7-9; R2

Anthropological and sociological discourse as it relates to grief and bereavement is not as saturated with specific language in ways that medical and psychological discourse may be. Sociological approaches highlight the co-existence of competing discourses (Valentine, 2006). Individuals may reject or modify predominant discourses, as demonstrated previously in statements made by health professional participants who had difficulty reconciling the medical discourse with what she encountered in clinical practice, namely, that people did not grieve in stages.

Contemporary academic constructions of grief and bereavement have created a discourse, impacting our understanding and therapeutic practice however the privileging of the psychological aspects of the bereavement experience over social dimensions continue to place medicalising and pathologising as the dominant discourse. The psychology, anthropology and social disciplines continue to engage in narrative studies that attempt to “...capture the complex, contradictory, ambiguous, fluid and changing nature of experience...” (Valentine, 2006, p.73).

Within this study, when listening to the narratives of the bereaved, echoes of the psychology, anthropology and sociology discourse were evident however no single discourse was adequate to describe the combination of existential and social experiences of the bereaved individual. Interchange of linguistic messages occur during encounters between the bereaved and people with whom they interact. Difficulties are often encountered when words used by others are taken badly by the bereaved. In order for the bereaved to be receptive to support, meta-communication in which the bereaved and their support networks inform each other about how they are experiencing the situation, type of support desired or able to provide a mutual frame of reference which provides the scope of basic rules for support (Dyregrov, 2008).

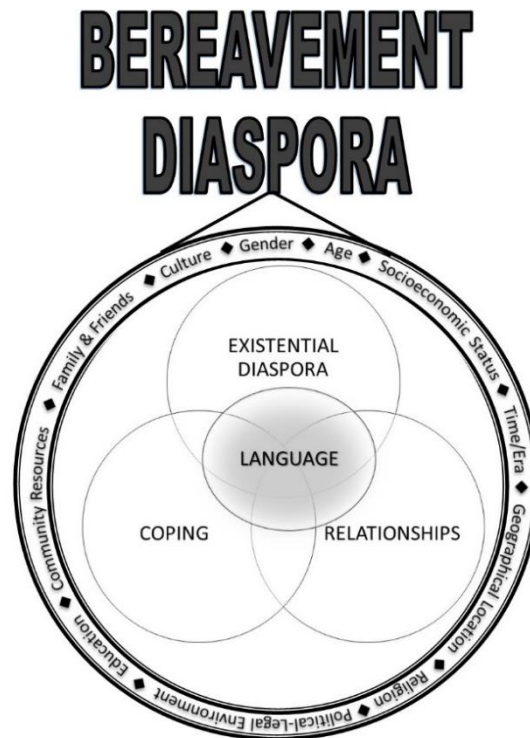
Being cued in to the bereaved person’s language and use of metaphors is imperative. The participants in this study described an extensive range of existential experiences using terms or language such as *‘lost’*, *‘alone’* and *‘foreign territory’*, and described experiences

of feeling disconnected, alienated and being in a state of limbo. However, it was evident that negotiating this existential state did not occur in a vacuum, or that it was confined to the inner world of an individual. The social environment played a key role in how a bereaved person coped in their bereavement. In fact, relationships with others was identified as a key mediating factor or influence in the bereavement experience.

Receptivity and Language in the *Bereavement Diaspora*

Intrinsic in the participant's narratives was a sense of not feeling understood and as a result, feeling somewhat marginalised. Diaspora provides a discourse for grief and bereavement that can enhance insight and understanding. Much of the language in bereavement support is related to "needs". This conceptual framework provides a model to consider that precedes needs, that is, for the bereaved to be receptive to bereavement support and have their needs met, clinicians need to understand this notion of *bereavement diaspora* and the interplay between *existential diaspora*, coping, relationships and language as depicted in the following diagram:

Figure 24: Bereavement Diaspora



Considering the criticisms of Postmodernism when applied to the grief discourse

Although the researcher has implied that the diaspora discourse would be useful when examining receptivity, the researcher is aware of one of the main criticisms of Postmodernism, 'Postmodern Irony' which highlights the problems of totalising theories, or grand narratives, which subsequently synthesise or impose a construction of reality. Although the researcher seems to be advocating for another grand narrative for grief and bereavement, diaspora, and this seems contradictory to critiquing paradigms that espouse totalising theories, the researcher would argue that diaspora is a different contribution to the discourse. It is not a meta narrative as it does not give a prescriptive language, models or frameworks or pre-determined tasks or phases of grieving that individuals must work their way through to successfully resolve, or recover, from their grief. Diaspora provides a language engendered with plurality and localism rather than universalism, and the

language is driven by those who are grieving or bereaved not subjugated to ‘expert knowledge’.

Plurality and localism are concepts that relate to the notion of relativism within the postmodern paradigm. Relativism is a critique of Postmodernism and is the belief that there is no absolute truth or one standard that is valid for everyone ie. universal theory, and that a ‘truth’ is relative to a person’s individual, subjective experience which is often socio-culturally bound (Becker, 1973). As demonstrated in the empirical literature and the findings of this study, bereavement is a subjective, multifactorial phenomenon whereby relativism should not be seen as a criticism but rather, representative of the lived experience. The researcher posits that there needs to be a shift away from discourses which provide meta narratives that focus on the intrapsychic or inner world of the individual, and that also positions the clinician as expert. Instead, based on the narratives of bereaved participants in this study, the researcher asks the clinician to enter into the subjective world of the bereaved, explore their world with them, listen to, and use, their language and give due consideration to the relational, cultural, social, gendered, class and historical contexts. Although deconstruction of the dominant discourse advocates there is no totalising theory representing a universal ‘truth’, in starting where the client is at, the clinician engages in a collaborative pedagogical co-narrative, creating a ‘truth’ for that person. As Murphy (2004, p.149 cited in Cacciatore & Bushfield, 2008, p.382) states “...how to do language about the death of another, the one event for which we cannot really have a language...”

Deeper insight to the lived experience and greater understanding of an individual’s experience makes individuals more amenable to support as they feel understood. Key to understanding bereavement is being tuned in to the language used by the bereaved, attentiveness to their metaphors and recognising diversity in the ways people cope that are not viewed necessarily as ‘maladaptive’. A move away from language engendered by deficit and pathologising approaches to language of positive possibilities, transformation, strengths and resilience may enhance an individual’s receptivity to support (Gergen, 2001).

Conclusion

The experiences shared by the bereaved could be compared to a kaleidoscope, an ever changing, constantly dynamic process of how people cope and experience their bereavement. Postmodern applications in analysing the data, place language at the forefront in the analysis and therapeutic work. Postmodernism recognises the subjectivity and influence of the researcher on the study, and self-reflexivity was an integral, dynamic and ongoing element of analysing the data in this study. The researcher was cognisant of the language used by participants, throughout the interviews and thematic analysis when ascribing of nodes, recognising the importance of language in people's subjective experiences.

Diaspora provides a new discourse to the bereavement literature. In de-constructing the language and deconstructing the power by moving away from the medical and psychological discourse, it defuses the professional as 'expert' and thus diminishes the hegemonic power bias, inherent in practice and services that aim to address bereavement. Postmodern perspectives respect the multiplicity of voices and moves away from the meta-narratives and grand theories found in the dominant grief and bereavement discourse. The narratives of the bereaved in this study demonstrated a heterogeneity of experience, and postmodern deconstruction exposes the contradictions and paradoxes of the lived experience of bereavement. Postmodernism recognises relativism and the influence on the lived experience of bereavement. This is evident in the diaspora discourse, recognising existential, temporal and corporeal states of the bereaved, and the role of coping and relationships in mediating the *bereavement diaspora*. The next chapter will focus on the concept of receptivity.

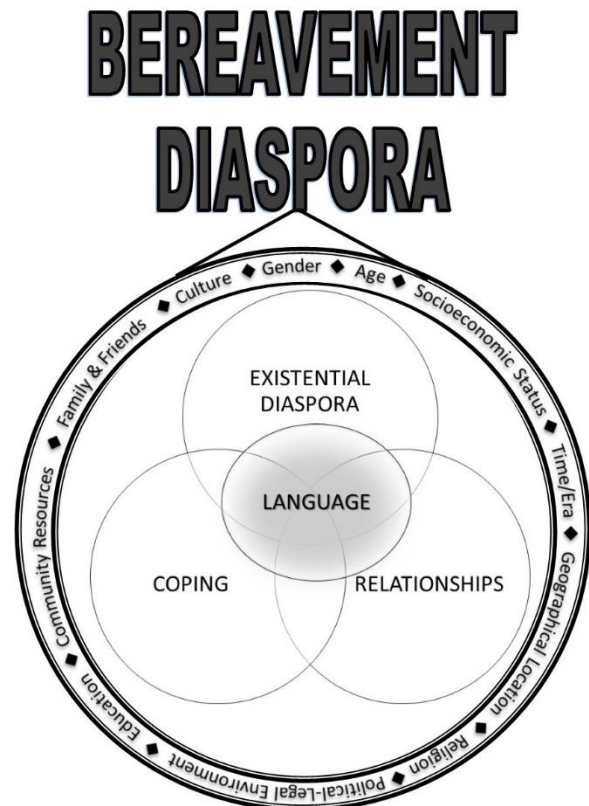
Chapter 9: Bereavement Diaspora and Receptivity

Introduction

The findings in this study reflect the interrelationship of individual, social, cultural, political and temporal factors and the role that relationships and language play in the way people cope in the *bereavement diaspora*. *Bereavement Diaspora* is thus a multifaceted concept, demonstrating the dynamic interplay between inter-dependent factors and is thus an important concept in relation to understanding bereavement receptivity factors.

Like *bereavement diaspora*, receptivity is a multifaceted and complex concept. The receptivity discourse has been applied to intrapersonal and ecological perspectives in which the environment *per se* influences human activity (Stark, Hollingsworth, Morgan & Gray, 2007; McGrath, 2013; Pascal, Johnson, Dickson-Swift, McGrath & Dangerfield, 2016). There were many receptivity issues discussed in the previous chapters with a focus predominantly on the experiences of the bereaved. An overview of these issues are outlined in tables in *Appendix E: Overview of Bereavement Diaspora Receptivity Issues (Chapters 5-8)*. This chapter will discuss additional receptivity issues not previously discussed and will include insights that emerged from health professional and Aboriginal health professionals' narratives. Convergent and divergent findings across the cohorts will be explored. There will be a discussion focusing on findings from Aboriginal health professionals' narratives due to their unique cultural issues.

Figure 25: Bereavement Diaspora



Aligning the findings to the core receptivity conceptual definition

Bereavement Diaspora and receptivity have common underpinning themes. The *individual* factors referred to by McGrath (2013) relate to ‘*existential diaspora*’ and ‘coping’ in this study. The *social* factors in McGrath’s (2013) receptivity concept align with ‘*relationships*’ and the total *bereavement diaspora* concept. McGrath’s (2013) *geographical* factors are reflected in the *bereavement diaspora* which encompasses individual and social-political-geographical-cultural factors that impact on the experience of being-in-the-world. As this study situates itself within the rural perspective, issues related to rurality permeated throughout the findings and will be discussed in this chapter. As there was a small cohort of Aboriginal Health Professionals who discussed their personal and professional experiences, issues of receptivity that emerged from their narratives will also be discussed. The focus of this chapter is on receptivity issues not previously discussed that participants from all cohorts identified that could encourage, or deter, receptivity to support. As discussed in chapter two, the following definition by McGrath (2013) was used to explore the concept of receptivity in this study:

“the range of factors (individual, social and geographical) that affect an individual’s desire or ability to receive or engage with supportive care services designed to meet his or her needs” (p.36.).

The core concepts from McGrath’s (2013) conceptual definition of receptivity will frame the following section:

- a) Individual Factors
- b) Social Factors
- c) Geographical Factors

The aim of this section is to expand on key factors already identified in the literature or to contribute new insights based on the findings that emerged in this research.

Individual Factors

Individual factors such as a strong sense of privacy, a desire to stay at home, inherent introversion, independent personality and preferring informal contact that occurs naturally are all features that have been identified in the bereavement literature that influence and individual in accessing support in bereavement (Bambauer & Prigerson, 2006; Cherlin et al., 2007; Currow, Allen, Plummer, Aoun, Hegarty & Abernathy, 2008; Milberg, et al., 2008; Johnson et al. 2009; McGrath, 2013).

Much of the receptivity literature highlights the intrapsychic dynamics of motivation and self-determination that influence receptivity. Key psychological aspects of will (intention), self-control, choice, self-efficacy, judgement, perception and self-determination are referred to in the empirical literature as factors that influence receptivity (Zimmer & Chappell, 1999; Erby, Rushton & Geller, 2006; Hinchman, 2009; Lewandowski, Ciarocco, Pattenato & Stephan, 2012; McGrath, 2013, Pascal et al, 2015). These specific psychological concepts were evident in participant narratives in this study and supported much of what was in the receptivity literature as demonstrated in the statements below.

Receptivity Concept	Participant Statement
Will (intention)	<p><i>"...you're trying to prove a point that yes you can cope...[and] I can make decisions on my own..."</i> ID: B: 3388: F; 69; Sp; 13-18; R3</p> <p><i>"I just want to get on with living – I want to get on with living and I want to do it healthy..."</i> ID: B: 2875: F; 81; Sp; 13-18; Rem1</p>
Self-control	<p><i>"...you learn to control it; you just learn to..."</i> ID: B: 3109: F; 64; Sp; 10-12; R3</p>

	<p><i>“...I’m afraid if I let down my guard and show any emotion I’ll lose control and burst into tears. So it’s more a case of maintaining control over my emotions because those emotions are still red raw and it takes very little for it to slam me like a brick between the eyes...”</i> ID: B: 3725: M; 63; Sp; 7-9; R1</p> <p><i>“...you have to have infinite patience and at a time when you're dealing with your own emotions and you think, “no, bite your tongue, just be patient”. You can't expect others to have a level of understanding as to where you are, because everyone deals with things differently...”</i> ID: B: 3076: M; 52; Child; 4-6; R1</p>
Choice	<p><i>“...I woke up one morning on the floor still drunk, looking for another drink and I walked out in the kitchen pulled the bottle out of the cupboard, stood up and said, “You’re going the same way as your mother.” So, I put the bottle back, I had a shower, went to bed, woke up in the morning, it was Sunday morning. I saw the number [Lifeline] on the table and I rang it...”</i> ID: B: 3398: M; 67; Sp; 10-12; R3</p> <p><i>“...I stopped talking to them because I was walking down the street in York one day and I met a guy, we got to talking and he said, “sorry to hear about your wife, I know how you feel, I lost my dog six months ago”. That was the key. Just don’t talk to anybody. If your wife is compared to a man’s dog, well, I just want to forget about it [talking to others]”</i> ID: B: 3398: M; 67; Sp; 10-12; R3</p>
Self-efficacy	<p><i>“...I’m quite self-sufficient...”</i> ID: B: 3373: F; 64; Sp; 13-18; R1</p> <p><i>“...I'm fairly practical and I just get in there and get things done... I don’t really like to think that I need help, I certainly like</i></p>

	<i>to try and get things done if I can, I always try myself...</i> ” ID: B: 3407: F; 44; Child; 7-9; M
Judgement	<p><i>From Chapter Five: “...you face a particular challenge in your life you think, ‘okay, what can I do about this? Can I change it? Yes? Okay go ahead and try and change it. Is it within my circle of influence? No? Have you done everything you can? Yes, right let it go, move on...”</i> ID: B: 3076: M; 52; Child; 4-6; R1</p> <p><i>“...for the first time in my life I feel so liberated... I honestly do not worry about anything. I am nowhere near that person that I used to be. I wouldn’t have thought like that before. I would have laid awake at night thinking it’s got to happen...”</i> ID: B: 3388: F; 69; Sp; 13-18; R3</p>
Perception	<i>“...sometimes you just have to pretend that you're okay when you're not - just because people are uncomfortable. I just feel that they expect more - you should be over it maybe - they’ve never said that - but it's just what they say or what they don’t say even...”</i> ID: B: 3180: F; 70; Sp; 0-3; R3
Self-determination	<p><i>“...Now that I’m alone I have to do things for myself.... you’ve got to look after yourself...”</i> ID: B: 3725: M; 63; Sp; 7-9; R1</p> <p><i>“...I don't need support of anything like... I do as much as I can. I very rarely ask for help...”</i> ID: B: 3372: F; 75; Sp; 4-6; R3</p>

These psychological concepts can be impacted by an individuals’ physical and mental state, for example, exhaustion. Exhaustion was a receptivity factor identified by McGrath (2013). Although the bereavement and receptivity literature along findings from this research identified exhaustion as a receptivity factor, Lewandowski et al., (2012) expand on the notion of exhaustion and discuss the concept of ego depletion as a receptivity factor.

Individual receptivity factors such as will, determination, minimisation, vulnerability, transformation, sense of privacy, introverted personality and independence have been identified in the receptivity literature (McGrath, 2013; Pascal et al., 2016) and were supported by findings in this study. Concepts such as ego depletion and shame resilience were reflected in participant narratives in this study and provide deeper insights to receptivity. Introversion was also a subtheme that emerged from the findings and although it has been mentioned in the receptivity literature (McGrath, 2013), further exploration of this concept, can contribute further insights on receptivity to support. Additionally, perception of value is another receptivity factor that emerged from the findings. Thus, the following discussion on individual factors will explore ego depletion, shame resilience, introversion and perceived merit-ability (worthiness, value and purposeful).

Ego Depletion

Lewandowski et al., (2012, p.1073) state the “...level of regulatory control is a situational factor that seems especially likely to influence receptiveness...” Ego depletion occurs as a result of a situation where an individual’s personal resources are depleted. This was evident in the bereavement period where participants described feelings of exhaustion as demonstrated in the following participant quote:

“...totally, totally exhausted. It was as if everything in you was tense and when they died - not so much until after the funeral - I didn't feel as though I could actually relax and have a deep sleep...I could actually sit down and think, I am so tired, I just want to lie down and go to sleep...” ID: B: 3373: F; 64; Sp; 13-18; R1

Ego depletion can contribute insights on how it can impact on a person’s capacity for self-regulation and influence executive function over feelings, impulses, thoughts and behaviours (Lewandowski et al., 2012). Ego depletion reflects a resource model where “...self-regulation works like a muscle becoming fatigued after strenuous activity...”

(Lewandowski, et al., 2012, p. 1073). Many bereaved caregivers of people with a life-limiting illness often experienced an extended period of caregiving (Hudson, 2006; Holtzlander & Duggleby, 2010) in which tasks and abilities related to information processing, decision making and emotion regulation become impaired or depleted and take time to recover (Lewandowski, et al., 2012). Participants described the impact on their own personal resources as portrayed in the following statements:

“...passionate sadness, feeling overwhelmed, numbness, particularly at first. It's not exactly numb, it's a sort of emptiness really...” ID: B: 3073: F; 87; Sp; 6-9; R3

“...I guess the first few weeks, even though you know it's happened, you're numb, and you're kind of in a bit of a daze...” ID: B: 3180: F; 70; Sp; 0-3; R3

McGrath (2013) highlights that receptivity is influenced by an individuals' *desire* and *ability* to utilise support. Likewise, ego depletion thus impacts on an individual's desire and ability to utilise support. As previously discussed, *bereavement diaspora* is an experience that impacts on many personal resources of an individual and ego depletion may impact on their ability to cope. However, as demonstrated in the following participant statement, realisation and insight into the individual's own situation takes time, so their *ability* to reach out for help is compromised:

“...I think maybe that takes a bit of time to get around to - is realising that you have capabilities, 'cause I think you do feel a little bit vulnerable and weak at the beginning...” ID: B: 3072: F; 52; Sp; 6-9; R3

Breen and O'Connor (2011) state that the bereaved may not recognise the need for help. Furthermore, the bereaved may not have the ability to ask for, and receive, help as a result

of being overwhelmed in their grief. Hudson (2006) and Holtslander and Duggleby (2010) highlight how the bereaved often experience exhaustion from their physically and emotionally demanding caregiving experience, with exhaustion continuing for up to six months after the death of their loved one (Holtslander & Duggleby, 2010). Ego depletion is thus a concept that can provide further insights into the drives and motivations of individuals' receptivity to support.

Shame Resilience

As discussed in chapter five, many participants described feelings of embarrassment, vulnerability and fear of being judged. Coping strategies to mitigate against these feelings were discussed in chapter six. Many participants described other strategies utilised to hide vulnerability, as demonstrated in the following participant statements:

"...I don't show a weakness, because everyone thinks I'm strong..." ID: B: 3072: F; 52; Sp; 6-9; R3

"...you're trying to prove a point that yes, you can cope...and some days I would just sob..." ID: B: 3388: F; 69; Sp; 13-18; R3

The need to "...present as coping well through their own resources without the need for help from others..." was identified by McGrath, et al., (2000, p.147) as the 'independence factor' and this was discussed in chapter seven. This need to maintain independence along with minimising experiences reflect the desire not to show vulnerability, as displaying vulnerability may create embarrassment (Pascal et al., 2016). These are factors that influence seeking support, or talking about grief or bereavement experiences with others. Embarrassment, vulnerability, sense of belonging, acceptance and feelings of worth are all concepts that emerged from the findings in this study and were discussed in previous chapters. These concepts are inter-related and are permeated throughout Brown's (2006) concept of shame.

Shame is a complex and multifaced concept which requires further in-depth exploration in relation to receptivity. The ability to transcend shame is through what Brown (2006, p.45) describes as 'shame resilience'. Shame resilience can contribute to further insights on receptivity as help seeking behaviours may be influenced by a person's need to guard against revealing one's vulnerability where they may be "...hurt or harmed physically, mentally or emotionally..."; and "...open to attack, harm or damage..." ("Vulnerable", 2016).

Participants in this study discussed scenarios in which they avoided the risk of showing their vulnerability. Vulnerability is at the core of Brown's (2006, p.48) work on shame resilience and she describes a 'vulnerability continuum' whereby when an individual has insight into their personal vulnerabilities, they demonstrate higher shame resilience than in areas where they have not either acknowledged, or perceived, to be a vulnerability. Elements of the vulnerability continuum form the basis of shame resilience. Shame resilience posited by Brown (2006, p.47-48) is measured along a continuum which comprises four components:

- i) The ability to recognise and accept personal vulnerability
- ii) The level of critical awareness regarding social/cultural expectations and the shame web
- iii) The ability to form mutually empathic relationships that facilitate reaching out to others
- iv) The ability to 'speak shame' or possess the language and emotional competence to discuss and deconstruct shame

The shame web is described by Brown (2006, p.44) as "...a layered, conflicting and competing expectations that are at the core, products of rigid socio-cultural expectations..."

When individuals lack critical awareness, or the skills to deconstruct and contextualise their experiences, and not link their issues within larger socio-cultural contexts, this reinforces the idea that they are flawed or unworthy of acceptance. This may lead

individuals to pathologise their own behaviour and that something is inherently wrong (Brown, 2006). This is a common feature often seen in the bereaved who perceive they are not grieving within the expectations of socially and culturally prescribed ways and this can lead to an increased sense of isolation. Brown (2006) asserts that when individuals recognise the universality of their most private struggles and that these struggles are a shared phenomenon, similar to the concept of *affinity diaspora*, this recognition may contribute to reaching out to others. When participants have awareness of issues or events that leave them vulnerable, they may be more likely to seek support in response to a perceived or actual shame experience.

According to Brown (2006), vulnerability and shame are very closely linked. Receptivity to support may be contingent on an individuals' capacity to manage the reactions of others, in effect, an emotional and psychological resilience to the risk of harm, or repercussions, from disclosing or publicly showing emotions or thoughts, as portrayed in the following participant statement:

"...I find it really hard when I'm in public to control my emotions. But some people have said, "well don't feel embarrassed, don't worry about it." But it's easier said than done - not to feel embarrassed..." ID: B: 3180: F; 70; Sp; 0-3; R3

Discourse on shame including works by Derrida, Freud, Darwin and Satre highlight that feelings of inadequacy and deficiencies arise when revealed to the gaze of another, that is, shame occurs within the context of an audience (Leys, 2009). As Nathanson (1989 cited in Leys, 2009, p.131) states "...what is exposed in the moment of shame is something deeply personal, some particularly intimate sensitive and vulnerable aspect of the self...shame monitors our sense of self..."

Brown (2006, p.45) defines shame as "...an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging..." As

mentioned in chapter five, one participant portrays the notion of shame resilience when she stated, “...you either need help, or you feel you don't need help, or you don't feel worthy of asking for it...” (ID: B: 3371: F; 77; Sp; 7-9; R2). Another participant described a sense of not belonging and ‘feeling like a social pariah’ as she expressed feelings of no longer being accepted or belonging to her local community:

“...I've been told, this world of ours is all for couples, not singles, I find the invitations aren't there like they used to be because I'm by myself. I sometimes think was it because of [A]? Were they inviting [A] and not me? Or inviting us as a couple but now that we're not a couple, I don't get the invitations...”
ID: B: 3110: F; 61; Sp; 19-24; R3

Feelings of worthiness, acceptance and belonging are elements of shame resilience theory (Brown, 2006). Within the constructs of shame, there are three key concepts, namely feeling: trapped, powerless and isolated, which interweave to make shame a complex and powerful emotion which is often difficult to overcome. When individuals feel trapped or powerless, they can experience a sense of isolation (Brown, 2006). Participants in this study described feeling powerless and a sense of hopelessness that they could not do anything to change the situation or lost hope for the future. As highlighted in chapter four, one participant described this sense of being trapped and powerless in the following statement:

“...now all those plans, everything's just gone, everything. Everything we'd planned to do has just gone out the window and I just, I feel empty, there's no plans, there's no future where I had a future before...” ID: B: 3386: F; 53; Sp; 19-24; R1

Brown (2006) posits that the concept of ‘trapped’ is incorporated with two properties, expectations and options. As demonstrated in the previous statement, the participant’s

expectations for the future is now diminished and their options appear diminished as their plans for the future revolved around their relationship with their deceased loved one.

Another key feature of Brown's (2006) definition of shame resilience refers to the need for acceptance and belonging. Participants demonstrated they did not want to jeopardise acceptance by others or a sense of belonging and risk being judged, stigmatised or ostracised as portrayed in the following quotes:

"...I mean there are people that mean well, that's different to people that say, "Oh look at her! Gee she's a nutcase" or whatever..." ID: B: 3180: F; 70; Sp; 0-3; R3

"...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 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

Brown (2006) highlights the innate need to hide painful feelings of fear, confusion, and anger and that there is a desire to hide these feelings for fear of judgement. The following participant described her desire to avoid feeling embarrassed:

"...I find it really hard when I'm in public to control my emotions... some people have said, "...well don't feel embarrassed, don't worry about it..." But it's easier said than done not to feel embarrassed..." ID: B: 3180: F; 70; Sp; 0-3; R3

The notion that this person felt powerless in the social situation from the risk of emotional ambushes which would impact her ability to control her emotions, is reflected in Brown's (2006) concept of powerlessness, where one's choice to be able to go out in public was limited for fear of spontaneous emotional expression. This is demonstrated in the following participant statement:

“...there are times when I think well how should I react to this? Should I show any sort of emotion? I just don't know at times because I'm afraid if I let down my guard and show any emotion, I'll lose control and burst into tears. So it's more a case of maintaining control over my emotions because those emotions are still red raw, and it takes very little for it to slam me like a brick between the eyes...” ID: B: 3725: M; 63; Sp; 7-9; R1

Learning to maintain control is a mechanism for developing shame resilience through “...recognising and accepting personal vulnerability...” and developing “...emotional competence...” (Brown, 2006, p.47-48).

Brown (2006) emphasises that language is central to shame resilience. There is a fluency in the language of shame. There is a need for fluency of language in *bereavement diaspora*. When language is acquired that accurately expresses experiences, it increases understanding however, if there is an inability to identify and name the experience, it often leads to internalisation where an individual does not understand, or know, what is happening to them and thus they perceive it to be bad or that they should not talk about it. This applies to *bereavement diaspora* where there is a discord between the subjective lived experience and the dominant discourse or socio-cultural mores in relation to bereavement. Of note, language fluency demonstrates the language of the lived experience changes over time (Bryan & Albakry, 2015) and this reflects the temporal nature of *bereavement diaspora*. Brown's (2006) shame resilience theory has much to offer in terms of insights into receptivity.

Findings that emerged from this study reflect elements of Brown's (2006) shame resilience theory as discussed throughout chapters five to nine and provide preliminary data that indicate shame resilience may be a receptivity factor worthy of further examination.

Introversion

Bonanno (1999, p.41) cited in Gana and K'Delant (2011, p.128) noted that there had been little in the way of systematic research on the role of personality in bereavement and this statement remains true in contemporary times. Personality disposition has been cited as a likely predictor of grief severity and although there has been some exploration of the role of personality in bereavement, studies have mainly focused on extraversion and neuroticism, two of the Big Five Personality traits. The Big Five Personality is a taxonomy of traits and was developed to represent a "...diverse system of personality description in a common framework..." (John & Srivastava, 2001, p.103). The personalities types, known as the Big Five Personality traits include: 1) extraversion, 2) agreeableness, 3) conscientiousness, 4) emotional stability and 5) openness (John & Srivastava, 2001). Introversion is the opposite of extraversion and is a personality trait portrayed in participant narratives in this study. Introversion has been identified as a receptivity factor in research by McGrath (2013).

Introversion is characterised by inwardly directed psychic energy where there is a stronger drive for cognitive engagement as an inner mental experience, a reflective introspection (Prosser-Dodds, 2013; Kaufman, 2014; Davidson, Gillies & Pelletier, 2015). One participant described how his inner world of thoughts about, and memories of, his deceased wife, brought him comfort and he did not want others to interfere in his moments of introspective remembering as portrayed in the following statement:

"...if people are around you at the time, and you are away with the fairies and thinking of her, you don't really want anybody around you that can come

up - you can be walking down the street and somebody stops in the street to talk to you - you just say g'day and keep going because you've got other things on your mind..." ID: B: 3398; M; 67; Sp; 10-12; R3

Introversion has been associated with being energised by the inner world and a preference for reflection and solitude (Prosser-Dodds, 2013). Introverts often need to reduce social stimuli and re-energise through solitude as demonstrated in the following participant quote:

"...I said to them, "Do me a favour. When the funeral directors been, I want you kids to go home, I need 5 minutes to breath in and breath out and be by myself..." ID: B: 3109; F; 64; Sp; 10-12; R3

Introverts also have a tendency to separate themselves, an inward turning and thinking through their situation or experience, as a way to cope (Prosser-Dodds, 2013; Kaufman, 2014; Davidson, Gillies & Pelletier, 2015). Participants in this study articulated their 'need to mentally process things' as demonstrated in the following statement:

"...I need logical explanations for things, even if they're a bit warped, I need logical explanations and I work them out in my head..." ID: B: 3109; F; 64; Sp; 10-12; R3

As discussed in chapter six, many participant narratives reflected coping strategies consistent with introverted traits, particularly expressing a preference for their own company as epitomised in one of the quotes:

"...I know that sounds awful but I don't need anybody... I enjoy my own peace, my own quiet time..." ID: B: 3373; F; 64; Sp; 13-18; R1

Introversion has been attributed to tendencies of establishing autonomy and independence (Khalil, 2016) and has been found to be higher in people from small rural villages or communities and in ageing populations (Singh, Roy, Zafar & Khan, 2014). The authors speculated the correlation between small communities and higher rates of introversion may be as a result of the social mores of smaller communities. This may also be relevant to rural communities in Australia where stoicism and self-reliance are core values (Filmer, 2002; Gray & Wilker, 2008). Introverts may be more reliant on their internal processes to solve problems independently of other people and this may make them more speculative about the suitability or worth of seeking help, such as counselling (Kakhnovets, 2011), thus influencing receptivity to support as depicted in the following participant statement:

“...I think a lot and process a lot but I don't think counselling is the right thing for me...” ID: B: 3072: F; 52; Sp; 6-9; R3

Introverted behaviours have been examined in the neurobiological sciences using functional Magnetic Resonance Imaging (fMRI), measuring changes in the brain in response to different stimuli (Mobbs, Hagan, Azim, Menon, & Reiss, 2005). The amygdala, a small almond-shaped structure in the brain responsible for fear and pleasure responses are of particular interest. Introverts have been found to have low amygdala threshold for stimulation as they have a higher sensitivity to their environment, thus the introvert regulates their reactivity by introverted behaviours such as introspection and reflection (Davidson, Gillies & Pelletier, 2015). Thus, receptivity may not just be a psychological dimension of intrapsychic drives and motivations, but may have underlying neurobiological influences which adds to the complexity of the concept of receptivity.

Perceived Merit-ability

Receptivity is influenced by a person's perception of how much they view the issue as a 'problem' and that accessing services can alleviate their situation (Zimmer & Chappell, 1999). Convergent findings between the bereaved and health professionals highlight that

receptivity to support is contingent on whether the support is perceived to be of value, is meaningful, worthwhile and purposeful as demonstrated in the following participant statements:

<p><i>(Meaningful)</i> To reduce sense of loneliness and aloneness through providing emotional support</p>	<p><i>"...[to be contacted] on those important days so that person is not left feeling just lonely and forgotten and that no-one's remembered and the person they've lost..."</i> ID: B: 3113: F; 61; Sp; 19-24; R3</p> <p><i>"...just to, to have someone to talk to...think that you're not alone...they haven't forgotten you..."</i> ID: B: 3110: F; 61; Sp; 19-24; R3</p> <p><i>"...you just wouldn't feel so alone then..."</i> ID: B: 3113: F; 61; Sp; 19-24; R3</p> <p><i>"...if you're aware that there's not a lot of family support and network and friends and that around..."</i> ID: B: 3433: F; 60; Child; 13-18; R1</p>
<p><i>(Purposeful)</i> Informational and instrumental support to empower and equip</p>	<p><i>"...I think they would have been my preferred sort of sort of support of practical or emotional, rather than necessarily the counsellor..."</i> ID: B: 3407: F; 44; Child; 7-9; M2</p> <p><i>"...they had this cooking class and they would teach them how to make a stir fry or something practical, so that's a really good idea..."</i> ID: B: 3113: F; 61; Sp; 19-24; R3</p> <p><i>"...if someone came out and, in the initial stages and said "Look, these are the things you need to look at within the next week"..."</i> ID: B: 3072: F; 52; Sp; 6-9; R3</p>

	<p><i>“...the only thing would be like it’s those legal kinds of things...I would have liked them to have given me a list at the time...and maybe check every now and again. Do you need any help? Are you getting through the banking things all right...”</i> ID: B: 3391: F; 69; Sp; 13-18; R3</p>
<p>(Worthiness / Value) Proven value through past interaction or support</p>	<p><i>“...you make some choices about who you're going to go to because they've either met your need in a way that you think is good or worthy and they are somehow professional and there's some connection...”</i> ID: HP: 3345: M; 55; R1</p> <p><i>“...the ability of the staff to make the connection, maintain that connection...it might be seen to be of value because no-one wants to go to someone who's of no value...”</i> ID: HP: 3345: M; 55; R1</p>

Factors such as perception of risk, need for self-efficacy and outcome expectancies have all been identified as influencing receptivity to support (Breitkopf et al., 2014). These factors were evident in participant narratives and highlight the notion that support needs to be meaningful, have purpose and to be provided by someone with value or worth who is competent. Technical skills and desired professional traits were identified by the bereaved as factors that influence receptivity. The characteristics and skill set of professionals influenced the therapeutic alliance and participants discussed when and how they engaged with professionals based on these traits. This notion of reciprocity as an influencing factor in receptivity is dependent on the inter-relationship between the individual and others.

Social Factors

Social factors such as having strong informal support networks, having a busy family or work life and financial security are all features that have been identified in the bereavement literature as influencing individuals accessing support in bereavement.

Informal support networks comprising mostly family, relatives and friends have been demonstrated to provide significant positive social support in bereavement. Professional support was only sought when the bereaved did not wish to burden members in their social support network or when the network was dysfunctional (Benkel, Wijk & Molander, 2009). Receptivity is also influenced by an individual's involvement with a similar service in the past (Bambauer & Prigerson, 2006; Cherlin et al., 2007; Currow, Allen, Plummer, Aoun, Hegarty & Abernathy, 2008; Milberg, et al., 2008; Johnson et al. 2009; McGrath, 2013; Goodridge, Quinlan, Venne, Hunter & Surtees, 2013).

Social receptivity factors such as support from others and reciprocity have been identified in the receptivity literature (McGrath, 2013; Pascal et al., 2016) and were supported by findings in this study. Reciprocity was a key feature in the findings of this study in relation to a broad range of social factors that influence receptivity. Reciprocity encompassed a broad range of contexts including the therapeutic relationship and shared trauma, the role of non-family support and central coordination. These subthemes were findings that emerged from participant narratives in this study. Exploration of these concepts contribute further insights on receptivity to support.

Reciprocity: The Therapeutic Relationship and Desired Professional Traits

Similar to the notion of reciprocity with informal support networks (Pascal et al., 2016), reciprocity between bereaved individuals and health professionals was an important factor influencing receptivity to support. One of the key factors that determined receptivity to support from professionals was the presence of a pre-existing therapeutic relationship and the practitioner's willingness to engage in baring witness to the vulnerability of others and in opening themselves up to their own vulnerability. The following participant statement reflects how the presence of a therapeutic relationship influenced 'who' she would be receptive to support from:

“...the nursing staff are there when he gets treatments over the years, so

they've seen him at his good, they've seen him at his bad, seen him when he's grumpy, seen him when he's happy. You know they become a bit more like a family member rather than just somebody that's caring for him...I had more to do with the palliative care nurses than the counsellor at the hospital, and they had known my dad for some time, so they knew exactly what he was like. I could have a laugh and a joke with them or, and even he could have a laugh and a joke with them. I think they would have been my preferred support of practical or emotional support, rather than necessarily the counsellor because the counsellor didn't have a longer-term relationship with my dad..." ID: B: 3407: F; 44; Child; 7-9; M2

Characteristics or traits were identified by the bereaved that would make them receptive to support from professionals and are under the themes 'technical skills' and 'personality and behavioural traits'. Examples are outlined in the table below and further subthemes and examples are outlined in *Appendix F: Desired Characteristics and Technical Skills of Professionals: Bereaved & Health Professionals*.

TECHNICAL SKILLS that would make the bereaved receptive to support	
Subtheme	Participant Statement
<i>competence</i>	<i>"...[nurse] was [P]'s palliative carer he really, really, liked her. She was just lovely and she just knew the right things to say and do and she understood his personality..."</i> (ID: B: 3113: F; 61; Sp; 19-24; R3)
<i>Willingness to engage</i>	<i>"...having someone come to you who not only knows the situation but understands, is prepared to talk, is prepared to listen, prepared to guide..."</i> ID: B: 3725: M; 63; Sp; 7-9; R1

CHARACTERISTICS OR TRAITS that would make the bereaved receptive to support	
Subtheme	Participant Statement
<i>empathetic</i>	<i>"...they were just absolutely fantastic, empathetic and caring, just amazing..."</i> (ID: B: 3076: M; 52; Child; 4-6; R1)

<i>genuine</i>	“...I felt they were genuine and they really cared...” (ID: B: 3399: F; 65; Child; 13-18; R3)
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Relationship capacities of health professionals such as authenticity, mutuality and synchrony, initiative and responsibility have been identified as key mediators in developing and maintaining a positive therapeutic relationship (Mok & Chiu, 2004). Desired characteristics of palliative care professionals include honesty, good listening skills, connecting at a human level, being gentle, taking time, speaking in the patients’ language and having technical expertise (Masel et al., 2016). Likewise, health professionals identified aspects from subthemes of ‘*technical skills*’ and ‘*traits*’ that they believed would encourage or enhance receptivity to support. Examples are outlined in the table below and further subthemes and examples are outlined in *Appendix F: Desired Characteristics and Technical Skills of Professionals: Bereaved & Health Professionals*.

<i>TECHNICAL SKILLS that would make the bereaved receptive to support</i>	
<i>Subtheme</i>	<i>Participant Statement</i>
<i>don't have expectations re: grieving</i>	“...around knowing or understanding what people feel about their bereavement and how they deal with it and not just expecting them to behave in a certain way...” ID: HP: 2888: F; 42; Rem1
<i>proved their worth in delivering outcomes</i>	“...you make some choices about who you're going to go to because they've either met your need in a way that you think is good or worthy and they are somehow professional... it might also be seen to be of value because no-one wants to go to someone who's of no value ...” ID: HP: 3345: M; 55; R1

<i>CHARACTERISTICS OR TRAITS that would make the bereaved receptive to support</i>	
<i>Subtheme</i>	<i>Participant Statement</i>
<i>non-judgemental</i>	“...I think that for here in particular, we've got to be careful not to make too many assumptions...” ID: HP: 3444: F; 50; Rem1

<i>familiarity engenders a sense of safety</i>	<p>“...<i>Quite often people will come back and say look I’m not coping, what can I do? Where can I go? So they’re familiar with us, and they come back to what they know is familiar...</i>”</p> <p>ID: HP: 3334: F; 43; R1</p>
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When Aboriginal Health Professionals described traits and characteristics at a personal level that would influence receptivity, they identified the following: ‘*approachable*’, ‘*conveys concerns*’, ‘*respectful*’ and ‘*non-judgemental*’. A distinguishing feature in the Aboriginal Health Professional’s narratives was of ‘cultural empathy’ where the Aboriginal community felt an affinity with doctors from other countries who were non-Caucasian, as portrayed in the following participant quote:

<p>“...<i>you get a lot of Aboriginal people say, ‘I spoke to the Indian doctor and the African doctor...’ and I think sometimes people feel that the African doctor sympathise a little bit more with them, like ...it’s similar in our country - it’s just how they’re treated there ...</i>” ID: HP: ALO: 3412: F; 39; R1</p>
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Although Aboriginal participants in this study identified cultural empathy led to a feeling of being empathised with, the same has been identified by African overseas trained doctors where they chose to work with an Aboriginal community because they “...*knew they were black, we thought it would be a good place to work...being black...*” (Gilles, Wakerman, & Durey, 2008, p. 660). This sense of affinity may be conducive to establishing a positive therapeutic alliance.

There were convergent findings across all three cohorts when discussing the therapeutic relationship. The centrality of the therapeutic relationship pre and post death had a significant impact on the palliative care and bereavement experience and is depicted in the following participant statements:

Convergent Findings	Participant Statements
<p>the centrality of the therapeutic relationship is key</p>	<p><i>“That was a decisive moment for me. Aside from anything else, the fact that within 10 minutes she was on my doorstep showed me that she cared. Somebody cared for what I was going through. Without that display of selfless care, it made a huge difference. It really did. I felt that I hadn’t been forgotten...having someone come to you who not only knows the situation but understands, is prepared to talk, is prepared to listen, prepared to guide. Oh, that was a huge help to me...those ladies from palliative. They were fantastic because up until then I felt so terribly alone. That is probably the greatest value that palliative care can offer...her visit was everything...”</i> ID: B: 3725: M; 63; Sp; 7-9; R1</p> <p><i>“...I think if they come back through our service, it’s purely the relationship, and the positiveness of the relationship that they’ve had with perhaps our service or individuals within our service, so the familiarity, the relationships, the knowledge that we exist. Quite often people will come back and say look I’m not coping, what can I do? Where can I go? So, they’re familiar with us, and they come back to what they know is familiar...”</i> ID: HP: 3334: F; 43; R1</p> <p><i>“...If you know them in the community and they know you are there to help they will give they will give you that respect that you’re going to give them...”</i> ID: HP: ALO: 3412: F; 39; R1</p> <p><i>“...the longer you work here the more relationship you build up with these people coming in and out and you do feel something for them...”</i> ID: HP: ALO: 3447: M; 49; R1</p>

The therapeutic relationship has been identified in the empirical literature as a key mediator in positive client outcomes in palliative care and a client’s perception of a strong therapeutic alliance has been demonstrated to contribute to better social and mental wellbeing (Trevino, Maciejewski, Epstein & Prigerson, 2015). However, in the absence of a positive therapeutic relationship and truthfulness by professionals, this has a significant impact on the dying experience and in the subsequent bereavement experience as demonstrated in the statements below:

Convergent Findings	Participant Statements
Pre-death factors	
<p>missed opportunity impacts the bereavement experience</p>	<p><i>“...I just wish I had have had more - someone should have said [S] you’re terminal, you’re dying; we’re going to give you - the state you’re in - so many weeks or whatever; and then I would have spent more time because I thought we were coming home and I would eventually bring him home. So, I was going to organise a mock wedding with the three daughters. I was - I don’t know - there was more things I could have said. It happened so quick...” ID: B: 3369; F; 53; Sp; 13-18; R1</i></p> <p><i>“...the hardest part is that if you are not told that your wife is going to die or your husband’s going to die - you don’t ask all the questions that you should’ve asked like "Darling, have you been happy for thirty-two years?" "Did I do enough for you?" "Do you still love me?" And you don’t get the chance to ask all these questions which would make you feel better, even though she’s died or dying, it would make you feel better to know that she’d been happy, you know? So, if I could’ve got the doctor to sit down with me and say look [T], we don’t have anything that can stop this, we have to put this in the terminal basket, it is not going to come out any other way. So if you need to talk, talk to</i></p>

	<p><i>her - but they didn't! If you can walk away from that hospital bed after she passed away with all the answers - you actually want to hear it from her mouth - and if you can get that done before she passes away, if you can get that done, your bereavement would be half what it was..." ID: B: 3398: M; 67; Sp; 10-12; R3</i></p> <p><i>"...So if they are a late referral and they don't have anything in place and there is financial hardship...that's a huge thing; because if they have got financial stress in bereavement that can be huge for that carer..." ID: HP: 3333: F; 53; R1</i></p> <p><i>"...whilst they were down there, we tried to make it a smoother journey for them following up while they were down there, making sure they got all the support they could...then after he did pass away, I did make contact with the grandmother, and then she required assistance with support letters because the dad was in jail and so was the mum... t was and just trying to assist the parents in being able to go and see the child because they were both in prison..." ID: HP: ALO: 3412: F; 39; R1</i></p>
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A lack of open and honest communication about prognosis or end of life issues and withholding information about disease and prognosis may have detrimental consequences on carers and family members in bereavement (Hancock, et al., 2007). Truth telling is an important factor that influences receptivity. The palliative care literature on truth telling focuses on communication with the dying patient and there is little attention given to the impact on the bereaved when truth telling has not occurred. Participants in this research described the missed opportunities or the impact lack of disclosure has had on their bereavement. A positive therapeutic relationship is founded on trust. Furthermore, disclosure of prognosis "...helps maintain family connectedness, facilitate acceptance of death and helps carers transition from their caring role after death..." (Holdsworth, 2015,

p.839). If a participant loses trust in the health profession, this may influence their receptivity to support after death. As there is a dearth of literature on missed opportunities as a result of lack of truth telling in preparing family members for dying, this is an area requiring further exploration.

Reciprocity: Professionals & Shared Trauma

Palliative care nurses experience their own trauma and transformative growth in the therapeutic alliance (Mok & Chiu, 2004). Just as psychic disruption was prevalent in the narratives of bereaved participants, likewise, it was present in the stories of the health professionals. The emotional intensity experienced by health professionals has been recognised as an inherent part of providing palliative care (Johnson et al., 2011; Chang, Bidewell, Hancock, Johnson & Easterbrook, 2012). Professionals in palliative care often experience the same traumatic reality that affect their patients (Dekel, 2010) and there is a mutual influence of personal experiences with professional responsibilities underscoring the reciprocal nature of the therapeutic exchange (Tosone, Bauwens, & Glassman, 2016). The health professional participant in the following vignette describes their ‘*trauma*’ from attending the funeral of a paediatric patient whose parents decided to go travelling with their child in the time they had left together as a family:

“...I went to the funeral as one of their support systems and his cousin and best mate and his wife had flown up; and I think, it was either her mum and dad, or his mum and dad, and the funeral director and myself. So really, really small; and it was a burial and it was sooo beautiful...the two men were just howling and it was so raw. The funeral director and I were howling...we were all crying...and it was real...and beautiful...and heartfelt, and perfect...” ID: **HP**: 2874: F; 53; Rem1

Palliative care clinicians are often deeply affected by the suffering they witness, however the clinician is both witness and contributor to the distress, with mutual distress occurring

within a dyadic therapeutic alliance. This is a shared traumatic reality, has been referred to as “shared trauma” (Tosone et al., 2003; Tosone, Nuttman-Schwartz & Stephens, 2012; Halpern, 2014). Although much of the literature refers to vicarious and secondary trauma, in the presence of a therapeutic alliance, clinician and patient along with the carer and family share the experience. Palliative care clinicians engage inter-subjectively, holding the vulnerability of others whilst placing themselves in a position where they may feel vulnerable themselves. Thus the concept of shame resilience may not just be a factor influencing receptivity to support by the ‘receiver’ but reflects the shame resilience of the ‘giver’.

Although receptivity is commonly regarded as an intrapsychic phenomenon, the therapeutic alliance reflects inter-connectedness where receptivity has an ‘openness to’ or ‘openness with’ an ‘other’. Hooghe, Neimeyer and Rober (2011) highlight that an individual’s receptiveness is contingent on an ‘other’s’ openness to them. Receptivity is thus an interdependent concept, influenced by factors external to an individual’s intrapsychic state (Robinson, 2006; Hooghe, Neimeyer & Rober, 2011). When health professionals are ‘open to’ placing themselves in positions where they are potentially vulnerable, this ‘symbiotic receptivity’ can provide the foundation of a positive therapeutic alliance and thus has implications for receptivity to support. The notion of symbiotic receptivity requires further exploration to identify facilitators and barriers to support within this dyad.

Reciprocity: The role of non-family support

Participants in this study described the emotional support they received from family and the significant emotional support they received from friends. As stated in chapter seven, one participant, (ID: B: 3111: F; 68; Friend; 13-18; R3), stated they found that a close friend provided necessary emotional support and described that their close friendship was better than the relationship with her children. This example of the value of friendships was

reflected in many participant narratives, which indicated the strengths of the support from non-family sometimes surpassed the support provided by one's 'legal family'.

Participants in this research described the broader spectrum of close or perceived intimate relationships with others that were not family members, or 'legal family'. These relationships were founded on companionship or who they felt comfortable with to disclose their experiences and emotions, or who provided them with emotional, psychological and spiritual nourishment, along with practical support. This broader selected group, which includes pets, are thus considered the 'socio-psychological family'. The notion of reciprocity is a central feature of these types of relationships. An example of how individuals surround themselves with friendships that create a 'socio-psychological' family is portrayed in the following participant quote:

"...I had some young women in town who...I was their second mother, and I used to - very candidly - advise them without being overbearing. I've watched them grow up and they have stayed close to me...and...I have a young friend, a young lady, who I've watched grow up...It's like having a daughter..." ID: B: 2875: F; 81; Sp; 13-18; Rem1

Friends and close friends have been identified as a primary source of support (Riches & Dawson, 2000; Breen & O'Connor, 2011). Other sources of support identified by participants in this study were work colleagues or people encountered through their role in the workplace. The following participant quote portrays the value of informal support networks who are not often considered as important sources of support throughout the bereavement literature, however they provide much needed emotional and psychological support:

"...one of the ways I cope with it, not just with my family unit but...at work, I deal with retailers all through the [region] and they've seen my ugly face for the last 18 years in my present role; so many of them are friends, albeit once

a week, or once a fortnight, and I told them I wasn't here last week because of this, and finding this a bit of a challenge and so on. In their eyes, you become not just someone representing a particular company, you become a human being who is faced with the same challenges or similar challenges to what they are, ups and down of family life and all that sort of thing. You set business aside for 5 or 10 minutes, or half an hour or whatever, and just chat about what's going down. I really think that actually helped me along the way. I mean don't get me wrong, I didn't cry on everyone's shoulders, there was a couple of clients closest to me, 3, 4-5 maybe, who I'd been dealing with for years and they asked about things. If I hadn't turned up on a particular time, or day, I'd tell them straight. I didn't cover it up, and as good decent human beings they are, they expressed ongoing concern, "how's your mum going this week?" and all that sort of stuff. They'd bring forth their own anecdotes, their own challenges in life "When my dad was sick, I did this, and we had that problem" and so on, and you share knowledge, you share experiences..."

ID: B: 3076; M; 52; Child; 4-6; R1

Many people spend significant time in the workplace with co-workers and others with whom they interact and therefore the opportunities to develop friendships provides a wider network for support (Benkel, Wijk & Molander, 2009). Likewise, in small rural communities, members of the local community comprise part of the wider support network. The following participant described the sense of nurturing she felt from individuals and businesses in the local community:

"...I'd go in to IGA to do my shopping and the owner...she always smiles and speaks to me...quite often she'll give me a big hug...the girls in the bank, they all know you, the girls in the newsagent, the chemist, they all knew and quite a few of them said, you know, "we're sorry to hear about [B]". So it's not as if you're alone, you've got the community's sympathy...the girls at the service station... one of them had a little shop in town and she'd pop out, you know, and say "oh, how are you going?" you know. And the girl at the café, she'd

say "and how are you going? You knew you got their sympathy and they know you by your name. You know?" ID: B: 3073: F; 87; Sp; 6-9; R3

Phillips (2015) discusses social capital in rural communities where the norms of reciprocity are formed through trust, civic participation, common purpose and reciprocal social norms. Individuals living in rural communities acknowledge and interact with each other to form social capital, that is, form social relationships in which there is the formation of "...a resource that can be stored and drawn on..." across the community (Falk & Kilpatrick, 2000, p. 92). Social interactions within rural communities has the potential to contribute to the social well-being of community members (Falk & Kilpatrick, 2000) and by the reports of participants in this study, there were reports of feeling a sense of belonging and feeling nurtured by their local community.

Although most research in social support in bereavement has focussed on human relationships, pets also played a key role with some participants in this study in providing emotional nourishment during bereavement. Although there is a significant body of literature on bereavement from pet loss, there is a dearth of literature in relation to the role of pets in bereavement. Participants in this study described their pets as family members and discussed the synergistic role they played in adjusting in bereavement through providing routine, distraction and companionship as demonstrated in the following participant statements:

"...At the wake, when I took the dogs down there, the dog looked for him... I put the photos on the TV, just for my benefit. But the dog's a TV addict, so she watched them as well...And the grand-dogs living here as well too...they're great. We go down the park and throw the ball and we go for little walks and have a look at things, and they're good little guard dogs...I love them" ID: B: 3109: F; 64; Sp; 10-12; R3

“...you do need an animal of some description...I can talk to the cat like I talk to [A]...” ID: B: 3110: F; 61; Sp; 19-24; R3

Fine (2006) describes one study that demonstrated fewer physical and psychological symptoms of distress in spousally bereaved individuals who reported support from, and involvement with, daily routines with their pets. Of interest, dog owners reported the benefits of a sense of normality and routine from daily walking. Additionally, pet owners reported that their pets provided an outlet for emotions such as crying while holding their pets, or in the company of their pets. Emotional expression with their pets provided a cathartic outlet for emotions for which they felt embarrassed about. Likewise, crying with, or talking to their pets, was cathartic and they were sometimes thus more able to control their emotions when in the company of others (Fine, 2006).

There is limited reference or emphasis on the role of friends, social clubs and pets as sources of support in the bereavement literature and these have been referenced for the purpose of this study as the ‘socio-psychological family’. Although people may not have family members living locally or may not receive much support from family due to conflictual dynamics or estrangement, most of the bereaved in this study had a close group of friends or received emotional nourishment from people (and animals) in their network. If the bereaved perceive themselves to have good support either from a small and intimate group of people or larger groups of people, then this may influence their receptivity to support as they may receive the emotional, informational and instrumental support from their informal support networks. Likewise, bereaved who own pets may receive much needed support from their pets and if they are predisposed to introverted traits, pets may provide an outlet for emotional expression and companionship (Fine, 2006).

Centralised Coordination

The bereavement literature discusses at length different ways of coping, however experiences of the bereaved when dealing with practical matters and the impact this has on their psychological, emotional and physical wellbeing is a significant receptivity factor. Participants in this study described challenges when dealing with practical matters and portrayed a sense of “...going from pillar to post in a fruitless and unceremonious manner...” (“From Pillar to Post”, 2016) when having to liaise with different organisations to deal with the deceased’s estate. Although this was discussed at length in chapter six on coping in the *bereavement diaspora*, a key receptivity factor identified by the bereaved and was convergent with the findings of health professionals (both Aboriginal and non-Aboriginal) was having a centralised agent, often described by participants as an identified ‘go to’ person or agency. The role of this agent would be to act as an identified bereavement support officer who could facilitate or coordinate support or empower the bereaved as demonstrated in the participant quotes below:

Convergent Findings	Participant Statements
<p>having an allocated ‘go to’ person</p>	<p>“...maybe there's a go to person...if someone could take control to delegate to the people that can [help] ... it would be nice for one like governing body...” ID: B: 3109: F; 64; Sp; 10-12; R3</p> <p>“...I suppose a one stop shop or I hesitate to say we need to set up another bureaucracy, but an administrator, a bereavement administrator or something like that who has the knowledge...” ID: B: 3076: M; 52; Child; 4-6; R1</p> <p>“...what would be lovely if someone could come in after and say look I'm of this service, this is what you need to do, this is who</p>

	<p><i>you need - because you are a bit shell shocked by it...” ID: B: 3433: F; 60; Child; 13-18; R1</i></p> <p><i>“...I think they need to know that they’ve got someone to go to and how to get to them...” ID: HP: 3444: F; 50; Rem1</i></p> <p><i>“...it’s not common knowledge for that - where to go, where to start and it did take a lot of back and forth movement trying to work out what’s the go...” ID: HP: ALO: 3448: M; 64; R1</i></p>
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As discussed in chapter six, assistance with taking care of matters related to the deceased may help to alleviate some of the stressors (Ogbuagu, 2012). The need for a ‘go to’ person or ‘one stop shop’ was identified by all cohorts in this study. Likewise, the need for bereavement support to be tailored to individual needs was another receptivity factor. The following participant statements portray the need for individualised support:

Convergent Findings	Participant Statements
<p>the need for support to be client-centred and based on individual need</p>	<p><i>“...it’s such a personal thing for different people. Everybody is different and everyone needs something different...” ID: B: 3113: F; 61; Sp; 19-24; R3</i></p> <p><i>“...different people need or respond to different sort of help in their own way...” ID: B: 3407: F; 44; Child; 7-9; M2</i></p> <p><i>“...every situation seems to be quite different in terms of what the need is just trying to think outside the square to provide the support we feel is needed out there...” ID: HP: 3334: F; 43; R1</i></p>

	<p><i>“...AMS are great. Like I say that is in that little resource book they’ve got. They will help with small sort of food donations from the food bank, transport, eulogies; so they do a lot but it’s not just financial but there are organisations out there but it’s just tapping into the resources...”</i> ID: HP: ALO: 3412: F; 39; R1</p>
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The identified need for an agent or agency that can provide a centralised point for support in bereavement, along with the ability to tailor support to individual need indicates a significant receptivity issue that can inform service design and delivery for bereavement support.

Geographical Factors

Receptivity to support in rural areas has nuances that differ to metropolitan contexts. Issues such as tyranny of distance, cost and limited resources have been recognised as impacting on receptivity to support (McGrath, 2013). Rurality has benefits and drawbacks and these are outlined in tables below. The benefits of living in a rural community are portrayed by participants in the following table:

Subtheme	Participant Statements
<i>Sense of belonging</i>	<i>“...couldn't really put community ahead of family but being part of the community - you don't just live in a town. You're actually part of something, and that's been great...”</i> ID: B: 3371: F; 77; Sp; 7-9; R2
<i>feeling nurtured</i>	<i>“...I couldn't go even to the bank and fetch money but the bank Director would come, and give the money - that's the small town - and the shops would send somebody with the food, that was how it is and it's also all the support you get by people just phoning, that's good as well... people were very good...the support from everyone else in the little town, the town was supportive all along...”</i> ID: B: 3111: F; 68; Friend; 13-18; R3

<p><i>country towns are friendly places</i></p>	<p><i>“...You go into town and people say, “hello, how are you?” If you've been away, they say, “how are you going? Where have you been?” I felt happy that I could go to town and people would talk, would say hello and ask how're you going, that type of thing, which you don't get in the city...”</i> ID: B: 3112: F; 75; Sp; 13-18; R3</p>
<p><i>people going that extra mile</i></p>	<p><i>“...I have come home from work and there's a load of wood dumped on the wood heap, when the woods been getting low... I came home from work one day and my lawns and gardens were being done...”</i> ID: B: 3109: F; 64; Sp; 10-12; R3</p> <p><i>“...a pile of firewood turned up one day out the front and it took me about ten days to track down who had dropped it off...”</i> ID: B: 3072: F; 52; Sp; 6-9; R3</p> <p><i>“...I found that people look out for each other a little bit more and even people that didn't know [G] or know me but knew of us or heard of us, we got cards from people and flowers...”</i> ID: B: 3386: F; 53; Sp; 19-24; R1</p>
<p><i>preference for country living and lifestyle</i></p>	<p><i>“...when we retired, we moved to a rural town in Western Australia, an outback town, actually, which we loved...”</i> ID: B: 2875: F; 81; Sp; 13-18; Rem1</p> <p><i>“...we've mainly went to the city for the education of the children but of course once they were off our hands, we headed back to the country again. I like the country...”</i> ID: B: 3112: F; 75; Sp; 13-18; R3</p>
<p><i>awareness of services available</i></p>	<p><i>“...I knew where to go to... I knew who to ask to get things done, if I needed things...”</i> ID: B: 3109: F; 64; Sp; 10-12; R3</p>

	<p><i>“...I didn't know anyone here... I had read things at the surgery, things like paperwork, pamphlets and things like that and a few articles in the local paper when I got here, - the staff that were here [hospice], I knew half of them anyway...”</i> ID: B: 3370: M; 73; Sp; 10-12; R2</p>
<p><i>Shopping encounters</i></p>	<p><i>“...[town] is such a little community, only about 7,000 in the town site and all in all, only about 11,000, I'd bump into them [palliative care staff] in the shopping centre and we'd stop and chat, so I found the team here were quite lovely and quite reassuring as well, you know. I didn't really feel totally alone...”</i> ID: B: 3399: F; 65; Child; 13-18; R3</p>

Participants described feeling a sense of belonging to their community. Participants portrayed an openness to others and any support they provided, such as emotional or instrumental support. The support and willingness to provide support was viewed by participants as one of the benefits of living in a rural community. As discussed earlier, the concept of ‘social capital’ (Falk & Kilpatrick, 2000; Phillips, 2015) refers to a reciprocity between an individual and their community where the ‘community’ is a resource to draw on. The other benefit identified by participants was that they had insight into what resources are available in the local community and where to go for support if required. The downfalls of living in a country town however, are portrayed in the following participant statements:

Subtheme	Participant Statements
<p><i>assumed familiarity by others</i></p>	<p><i>“...Everybody knows everybody. People that you know - but they're not close - come up and offer condolences... you learn to steel yourself...”</i> ID: B: 3109: F; 64; Sp; 10-12; R3</p> <p><i>“...people stop you in the street and say "I'm so sorry to hear" you know... you have to sort of bear up and cope with it...”</i> ID: B: 2875: F; 81; Sp; 13-18; Rem1</p>

<p><i>competition for opportunities</i></p>	<p><i>“...In a country town everybody else is trying hard to get jobs too, so, that was hard...” ID: B: 2875: F; 81; Sp; 13-18; Rem1</i></p>
<p><i>ever changing resource landscape</i></p>	<p><i>“...I had a new GP because they keep turning them over a bit... they do when they're in the rural areas...” ID: B: 2875: F; 81; Sp; 13-18; Rem1</i></p> <p><i>“...We had a problem in [town] because the supermarket was closing down... it took the morning to go to [town 1] or [town 2] to do my shopping...” ID: B: 3111: F; 68; Friend; 13-18; R3</i></p>
<p><i>not private</i></p>	<p><i>“...you can't get away with much in a rural community. If you go in to the [town] supermarket in town here, you'll see a sign by the counter that just about sums it up, and I can't remember the exact wording, but it's something like: "I love living in a small town. If I don't know what I'm doing, someone else is bound to be able to tell me"...” ID: B: 3072: F; 52; Sp; 6-9; R3</i></p> <p><i>“...Everyone knows everything. Everyone knows what's happened...” ID: B: 3111: F; 68; Friend; 13-18; R3</i></p>
<p><i>shopping encounters</i></p>	<p><i>“...some things I found so hard to do like going shopping. You live in a town where you go shopping, you meet the same people at the shop on the same day and I was avoiding those days, go a different day. I would go to town and I was hoping I wouldn't meet anyone I knew...” ID: B: 3371: F; 77; Sp; 7-9; R2</i></p> <p><i>“...people are, sometimes, when you'd do your shopping you would see somebody that you knew and they would avoid you. Whether it was because they didn't know what to say. I found that a little off-putting at first, until I actually sort of made eye contact and actually said hello to them, you know...” ID: B: 3373: F; 64; Sp; 13-18; R1</i></p>

	<p><i>“...It's a bit hard at first because you didn't know if you'd get, you know, tearful or anything like that, but it's a lot easier now...” ID: B: 3370: M; 73; Sp; 10-12; R2</i></p>
<p><i>poignancy of feeling avoided</i></p>	<p><i>“...they've come up [at the funeral] and offered their condolences...I've seen them down the street, the shop or something like that and they've sort of walked past me. I've sort of said "oh g'day [J] or [K]." You know, I don't know if they don't want to know me or don't want to talk.... I don't know...” ID: B: 3370: M; 73; Sp; 10-12; R2</i></p> <p><i>“...they must be still grieving or whatever, but I would've thought I would've had more friends around me - more people - but I didn't. (laughs). It's a funny thing, I didn't. Some people especially women, were chatty when my wife was alive, they'd talk to you in the street, they'd stop and talk; now I don't know what it is, they just say hello and keep going. So I don't know what the mindset is now...and that's another thing, everybody is - instead of coming out and saying what they mean, a lot of people watch what they say. They're going to say something about when [K] was alive and she used to dance and sing in the cool room while she was putting everything away, but they get to that point and say “[K] ...” and then they stop; you actually have to prompt them, [they say] “oh well, I didn't want to bring up bad memories.” Well they're always going to be there and if you've got some good funny ones about my wife when she worked here then hey, I'm interested...” ID: B: 3398: M; 67; Sp; 10-12; R3</i></p>

As discussed in chapter two, the experience of bereavement in rural areas and accessing professional support is challenging due to issues of lack of anonymity, personal and professional boundaries and lack of confidentiality. These issues along with others, are reflected in the empirical literature (Gray, Zide & Wilker, 2000; Giljohann, et al., 2008; Gray & Wilker, 2008; Kosteniuk, Morgan, Bracken & Kessler, 2014). These pose

significant receptivity issues as many rural people may be reluctant to access support due to these factors. Participants described their reluctance to engage professional support due to the potential for seeing the professional, for example, a counsellor, in a social setting, as demonstrated in the following participant statements:

“[the doctor] asked me about it [counselling] - if I wanted to. I guess I'm a little bit apprehensive about it, I suppose because being a, small town, I'll probably see them in Coles next week...” ID: **B**: 3110: F; 61; Sp; 19-24; R3

“...There's something a bit weird about dropping your bundle in front of someone you'll end up having a drink with at the pub as well...” ID: **B**: 3072: F; 52; Sp; 6-9; R3

Lack of privacy was an issue impacting on accessing professional support and is portrayed in the following scenario described by a participant:

“The counsellor would come from [town] on certain days and my son would go in there and he'd see people in the waiting room and he'd say "Mum, they all know I'm going to see somebody and they know me". So, it was, it just doesn't work very well...” ID: **B**: 3072: F; 52; Sp; 6-9; R3

The challenges of maintaining privacy and confidentiality were issues specific to living in rural communities as reflected in health professionals' narratives:

“...I think the only, the only tricky bit for us is really around confidentiality. Because obviously, we have to be very careful from a confidentiality point of view. Often everybody knows everything about everyone (laughs). You know they'll ask you a question and you have to try and phrase it in a way that -

without giving any information over, which is really, really hard...” ID: **HP:**
2888: F; 42; Rem1

Privacy, confidentiality and a blurring of personal-professional roles have been identified in the literature (Gray, Zide & Wilker, 2000; Giljohann et al., 2008; Gray & Wilder, 2008). When examining service utilisation in rural areas, Anderson and Newman (2005) argue that the norms of the community in which an individual lives, may influence the behaviour of the individual to access services. Rurality has been identified as a pre-dispositional factor that influences receptivity (Zimmer & Chappell, 1999) and there were many convergent findings between health professionals and bereaved in relation to living in rural communities and factors that influence receptivity to support.

Rurality as a receptivity issue needs further exploration in terms of where support services should be targeted. As community norms of independence and self-reliance are predominant cultural norms of rural communities (Filmer, 2002; Gray & Wilker, 2008), service design and delivery may be more productive if it is focussed on building the social capital of the local community. A death in the community has a ‘ripple effect’ (Cheers, Darracott & Lonne, 2007) and services that empower and equip communities to support each other when a member or family are bereaved may be more beneficial. This is an area of receptivity further of exploration.

Aboriginal Culture and Receptivity Factors

The discussion in chapter two highlighted the limited empirical evidence in relation to bereavement support to Aboriginal people. There are many cultural factors that influence receptivity and as stated previously, cultural empathy was identified by Aboriginal health professionals as a factor that contributes to a positive therapeutic relationship, thus possibly influencing receptivity. Aboriginal Health Professional participants in this study discussed their professional and personal experiences with providing and receiving

bereavement support. Key receptivity issues were identified throughout their narratives and are discussed below.

Health Literacy

The issue of health literacy in terms of fundamental literacy and numeracy, scientific literacy, community and cultural literacy have been identified as challenging within health promotion in Aboriginal communities where English is the second language, education levels are low or cultural language and worldview differs (Vass, Mitchell & Dhurrkay, 2011). One participant, ID: HP: ALO: 3412: F; 39; R1, talked about a pack that has now been developed that provides information and resources for Aboriginal people on where to go and get help. However, literacy levels came up as an issue and were discussed by participants as demonstrated in the following statements:

“...they very rarely do [read]. You’ve got all the information - when it comes to Indigenous - when it comes to too much information... just straight forward they will look at it - but if you come at them with a big pack they won’t...” ID: **HP: AHW:** 3438: F; 43; Rem1

“...if there is too much writing there - but if it’s pictorial - pictures and all that...” ID: **HP: ALO:** 3448: M; 64; R1

“...lots and lots and lots of different things they probably won’t read...” ID: **HP: ALO:** 3412: F; 39; R1

Provision of any resources to equip and empower individuals to support each other, their local community or themselves, needs to be developed in conjunction with Aboriginal communities and relevant to localised contexts. Cultural safety practices recognise unique

cultural nuances and for any information to be disseminated, or for any practices or health and help seeking behaviours to change, observation of principles for service design and delivery for Aboriginal communities must include cultural respect, seamless care, equity, autonomy/empowerment, trust and non-judgemental care (McGrath & Phillips, 2008c; van den Berg, 2010). Ways to increase health literacy in relation to receptivity to bereavement support is worthy of further exploration.

Organisational Cultural Safety

Key to improving Aboriginal health and wellbeing is the need for organisations delivering services to adopt culturally safe practices (van den Berg, 2010). Cultural safety entails recognising the social, political and economic position of cultural groups and it is incumbent on organisation and professionals to “...respect, support and empower the cultural identity and wellbeing of individuals...” (McGrath & Phillips, 2008a, p.154). Aboriginal health professional participants in this study discussed specific cultural safety issues they have encountered both professionally and personally and these are demonstrated in the following table:

Subtheme	Participant Statement
<i>Capacity issues</i>	<i>“...We have a shortage of beds it’s always a juggling act to try and fit all the people into that room without disturbing the actual hospital and running of it. I mean that can be improved but again it’s space...” ID: HP: ALO: 3447: M; 49; R1</i>
<i>Infrastructural issues</i>	<i>“...we’ve got a family room - relatives room, and it’s a room there just with lounge chairs and a coffee table where relatives can sit if someone is unwell or being transferred... There was too many people coming and going [Aboriginal family members]. Now I identified this as an issue and asked them why can’t there be an external door attached to that family room... it’s just not culturally appropriate. They just don’t recognise the fact that - they know</i>

	<p><i>Aboriginal families - they know Aboriginal families come - they're mobbed - but they're still not doing it..." ID: HP: ALO: 3412: F; 39; R1</i></p>
<p><i>Staff technical skills</i></p>	<p><i>"...they are not trained as palliative nurses..." ID: HP: ALO: 3412: F; 39; R1</i></p>
<p><i>Staff lack of insight and sensitivity to Aboriginal culture</i></p>	<p><i>"...when my father passed he was very popular and everyone wanted to come. It was just an overcrowding of the ward and then the nurse stepped in and said, "that's it! We've got to control this!" So they get in there and say, "only immediate family" ID: HP: ALO: 3447: M; 49; R1</i></p> <p><i>"...In Aboriginal culture, immediate family is everyone..." ID: HP: ALO: 3412: F; 39; R1</i></p> <p><i>"...when it comes to numbers, you know, we might have 50 people queueing up there to see our loved one and they're non Aboriginal people too - coming and going - but it's hard to control..." ID: HP: ALO: 3448: M; 64; R1</i></p> <p><i>"...you know we've got remote communities right close by and when they come in, they come in by droves...they come in by packs. We've had graduated nurses - just young grads they just come out and they send them to [town] - and until they get told and explained, "look love, regardless they are going to come in by truckloads. This is our closest community and they are going to come in by droves..." ID: HP: AHW: 3438: F; 43; Rem1</i></p> <p><i>"...when you have a nurse coming in and saying, "there is too many people; your kids are running amok; you people need to stop."</i></p>

	<i>That's when people get on the back foot and say, "hang on, what respect do you have? We're here grieving, or about to, and you're coming in with an attitude..."</i> ID: HP: ALO: 3412: F; 39; R1
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Aboriginal family structure and kinship ties are central to Aboriginal identity and the experience of illness, death and subsequent mourning practices (*sorry business*) is a community and communal experience (McGrath & Phillips, 2008b; O'Brien et al., 2013). Some behaviours of health professionals which diminish demean or disempower Aboriginal people, families and community create culturally unsafe practices (McGrath & Phillips, 2008b). The attitudes and behaviours of health and other professionals are receptivity issues and may likely influence receptivity to support.

One participant described their confidence and skills in providing support to their community in their professional role and that they draw on personal experiences to guide how they support others as demonstrated in the following quote:

<i>"...we all know personally how to be and how to grieve with our family and how we would want someone professional to act towards us and our families. So we would sort of try and be there for those people. But we have had no training - it's basically just the experience that we bring to our roles [the Aboriginal way] and being local and being known and respected in the community. So that's basically what we've got and that's all we can offer... We don't need a lot of training but we need guidance I think, as well, in our roles..."</i> ID: HP: ALO: 3412: F; 39; R1
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Cultural safety is thus not only about enhancing culturally competent skills of medical, nursing, allied health and other professionals but of up-skilling and equipping Aboriginal people to enhance their skills in supporting Aboriginal patients and families. Aboriginal people are a minority cultural group who often experience a sense of cultural isolation when accessing mainstream services (O'Brien et al., 2013). However, culturally

competent care done in collaboration with Aboriginal staff can enhance awareness and improve culturally congruent practices. This is demonstrated in the following participant quotes which demonstrate the need for awareness of kinship and family ties, identification of, and working with, an identified spokesperson:

“...What you do in your life time, in our life, in our ways, people don’t have to be family. They can be really, really close and they have got a place in the line...and they have to be given that respect by people that they’re with...and I think the nurses and that should talk to someone in the family – [to find out] who’s who in the zoo...” ID: **HP: ALO:** 3448: M; 64; R1

“...Trying to have that spokesperson from the word go and a second person. You get those two people - get that liaison going it filters down and everyone plays their part. But if it’s not initially done, it could get out of hand. People get upset and if you get a large group upset, it takes away that thing of what we’re there for...” ID: **HP: ALO:** 3448: M; 64; R1

In observing cultural safety throughout clinical practice, health professionals can enhance cultural identity and wellbeing and may promote openness to further support if required in the future. The influence of previous experiences with health professionals has been identified as a receptivity factor in the empirical literature (Goodridge, Quinlan, Venne, Hunter & Surtees, 2013) and is reflected in the following participant statement:

“...most families when they are in that situation, because they’ve either had experience at [palliative care unit] before, or they have heard the good work that they do over there, they will try and expedite that person being transferred over there. And of course it all depends on bed availability over there as well. People recognise that that’s a facility that can accommodate them best. It’s so much more nicer than what it is in a hospital here, and that’s the experience...” ID: **HP: ALO:** 3412: F; 39; R1

Cultural safety is a key receptivity issue in the health care setting. Integral to enhancing cultural safety in health care environments in Australia is to recognise the unique value Aboriginal Australians have to our past, present and future (van den Berg, 2010). The value of Aboriginal people in their role in preserving the land, empowering and looking after their own communities through their own work roles and guiding and educating the non-Aboriginal professionals and community, can create more culturally safe support and care. Working in partnership with the Aboriginal people can lead to improved health and wellbeing when it meets local needs and is informed by local cultural nuances. The following participant describes the unique differing stance of Aboriginal people and their *sorry business*:

“...we all want equality in life and to be treated the same, but on such things like this you can't - there is always going to be a difference, and the way that things should be, and how different it is from [non-Aboriginal people] - we all grieve, we all need support. But just with the Aboriginal community compared to the non-Aboriginal community, things are just still done so differently and always will be. And all we can do is just continue to learn...”

ID: **HP: ALO:** 3447: M; 49; R1

If Aboriginal people feel worthy as individuals, are not denigrated for being Aboriginal, are treated as equals and not patronised, the “...*human kindness shown by hospital staff is remembered with gratitude...*” (van den Berg, 2010, p.137). Health and other professionals and organisations as a whole, impact on receptivity to support for Aboriginal Australians and this is an area requiring further exploration.

Melding of Personal-Professional Worlds

The nature of being an Aboriginal health professional is such that the personal and professional worlds meld and this was demonstrated throughout participant narratives.

The following statements provide insight to the experience of Aboriginal people living within their community where they are approached out of hours as part of their professional role:

“...your job is never ended here - you get a knock on the door at 6 or 7 o'clock at night because you are local, and they know where you live because they haven't had the chance to sort of catch up with you, and they will [knock on your door] and just...” a cup of tea?” ... My job never stops when I walk out of that door at 4 o'clock, because I am local.” ID: **HP: AHW:** 3438: F; 43; Rem1

Aboriginal Health Workers (AHW's) and Aboriginal Liaison Officers (ALO's) often experience barriers working within health services due to a lack of understanding or undervaluing of their role. Mitchell and Hussey (2006, p.529) state that Aboriginal health professionals “...have usually lived in the community they work in and have developed lasting relationships...” There are often expectations on Aboriginal health professionals in the local community to be readily accessible and available and they may be accessed for support, or they may be ostracised due to belonging to a different clan. Negotiating the challenges of living within one's own local community can put additional stress on Aboriginal health professionals' physical, psychological and emotional wellbeing. One Aboriginal health worker described accessing the staff of the local mental health team to debrief to ensure her own self-care, so her ability to respond to the needs of others is not diminished as demonstrated in the following statement:

“...when you mention mental health, they think - I tell them – “I go there, I've got that much - I've got to get it off - whatever is said in that room stays in that room and I've got to get it off because if I come to work tomorrow I won't want to come to work - I will be screaming at work you know. Or I just walk through the door and I just bawl my eyes out...” ID: **HP: AHW:** 3438: F; 43; Rem1

This participant is the only specialist palliative care Aboriginal health worker in Western Australia and is receptive to psychological and emotional support. Self-care of staff in palliative care is advocated for, and actively encouraged, in recognition of the nature of stressful work in caring for the dying person and their families (Breiddal, 2012; Stodart, 2015). However, the culture of needing permission to self-care in other generalist or acute environments may not encourage receptivity to support. This is demonstrated in the following statement by one of the Aboriginal Liaison Officer participants:

“...a lot of the time you are binded, so you can’t talk about a lot of things - we’re all grieving the same, but if you’ve got added pressure at work and sometimes I suppose, if you need that confidentially too - you would have to ask for it I suppose...” ID: **HP: ALO:** 3412: F; 39; R1

Emotional and psychological burden within employment has been identified as a factor contributing to burn out in health care professionals (Kravits, McAllister-Black, Grant & Kirk, 2010). If Aboriginal health professionals experience under-valuing of their role and low job satisfaction in an environment that does not recognise, or foster, a culture of self-care, this will impact on their receptivity to support in their role, leading to burnout and lowered retention rates of Aboriginal staff. The reticence of the previous participant when stating “...you would have to ask for the support...” indicates that self-care and actively seeking out support is not an expectation, or indeed actively advocated for by organisations. Threat of loss to professional integrity has been identified as a contributing factor influencing staff receptivity to support (Keene, Hutton, Hall & Rushton, 2010). This culture of not help-seeking in the professional role reflects the same features that characterise shame resilience of seeking help.

Browne, Thorpe, Tunny, Adams and Palermo (2013, p.457) state that because the Aboriginal Health Worker workforce in Australia is small, “...workforce development needs to involve a range of actions...” One successful program has been a mentoring program between allied health and aboriginal health professionals, creating an

environment of reciprocity, of mutual learning and support that fosters personal and professional development (Browne, et al., 2013). Receptivity via a mentorship program may contribute to enhanced personal and professional development and does not have the associated stigma with help seeking behaviours when accessing psychological support. Promotion of a permissive ‘self-care’ culture within organisations is a receptivity factor. If support is couched in terms of professional development, or mentoring, and not psychological assistance via an Employee Assistance Program for counselling, this may change attitudes and behaviours in receptivity to support by the professionals.

Convergent and Divergent Findings Across the Cohorts

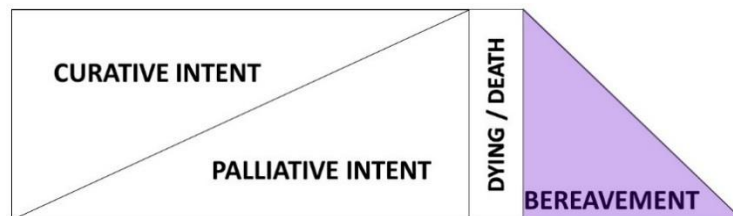
Receptivity factors were previously discussed throughout the previous chapters and were examined through the lens of diaspora. These are outlined in *Appendix E: Overview Bereavement Diaspora Receptivity Issues (Chapters 5-8)*. There were many additional receptivity enablers and barriers that emerged in the data and there was convergence between health professionals and bereaved participants. Due to the exhaustive list and variability in facilitators and barriers, receptivity issues identified by all cohorts are outlined in tables in *Appendix G: Receptivity Enablers and Barriers to Bereavement Support*. Although there were predominantly convergent findings on issues that encourage or deter receptivity to support, the most significant divergence finding was between the health professionals’ expectations of their role and the bereaved expectations of bereavement support provided by health professionals. Bereaved participants thought ongoing support by the palliative care service would put extra burden on the staff and did not have an expectation that bereavement support is an intrinsic part of the palliative care model. Bereaved participants discuss their thoughts on bereavement support from palliative care services in the following quotes:

“...I think it’s a really big ask of - you know for the palliative care people to have to continue... I think that’s a really big ask of them to do that...” ID: **B**: 3433; F; 60; Child; 13-18; R1

“...I felt like they're just so busy they, they're busy doing their thing, they don't want to, they don't need me adding extra work to their, their workload thing...” ID: **B**: 3386: F; 53; Sp; 19-24; R1

There is a dual imperative on palliative care services to balance meeting the needs of the bereaved whilst remaining cost effective (Aoun, Breen, O'Connor, Rumbold & Nordstrom, 2012). Palliative care models demonstrate that bereavement support is an intrinsic feature of palliative care service provision as depicted in the following diagram:

Figure 26: Curative-Palliative Model of Palliative Care and Bereavement



Health professional participants described a sense of responsibility and obligation to provide follow up support in bereavement as portrayed in the following statements:

“...from my point of view, bereavement is an add-on and that we're expected to know how to support people from a bereavement point of view... we're not just there to look after the dying, it's all the other stuff that goes along with it...being able to put people in contact with support processes or provide that [bereavement] support yourself. It's so vital...” ID: **HP**: 2888: F; 42; Rem1

“...you've got to factor it [bereavement support] in with your time constraints with what resources you have...Sometimes bereavement does tend to get pushed back a little bit...” ID: **HP**: 3389: F; 54; R3

The divergent findings between health professionals' expectations of providing bereavement support and the bereaved having no expectations of actually receiving bereavement support is a significant receptivity issue. The sense from the narratives of bereaved participants in this study indicate that there was a lack of awareness that bereavement support is embedded within the model of palliative care (Frager, 1976) and this is not made explicit to the bereaved in most circumstances. Thus, the bereaved may not be receptive to support because they were unaware that bereavement support is an intrinsic feature of palliative care service models.

Agnew, Mangkletow, Haynes and Jones (2011) highlight that the bereaved are often passive recipients in the current delivery of bereavement support as they are often not aware that they are being assessed for being 'at risk' of depression or other psychological condition and unaware that information or data is being collected about them, thus bereavement programs are 'done to them'. There needs to be working agreements between the palliative care service and the bereaved that promotes clarity regarding consent, service delivery, duty of care, assessment methods, care planning, confidentiality and complaints procedures (Agnew, et al., 2011). However resources within the health care system are often not homogenously dispersed so people living in rural, regional or remote areas often do not have the same resources that are available in metropolitan settings (Anderson & Newman, 2005). Resources are a mitigating factor that influence receptivity. Public policy aims to ensure equitable distribution of services however in rural areas, this is not the reality. Individuals living in rural areas may not access services due to the sole reason of the longer distances they may need to travel (Anderson & Newman, 2005).

Examining receptivity to bereavement support from palliative care services can help inform the design and development of services and programs (McGrath, 2013). In exploring bereavement support in rural contexts, it can provide insights on how to guide stewardship of resources in ways to meet the needs of the bereavement within the constraints of limited resources in rural areas. The enhancement of social capital may be an area to focus service design as people may be receptive to education on supporting

bereaved individuals and families. Likewise, placing the onus of centralising or coordinating practical, informational and psychological support may be better placed under the auspice of a group or organisation in the local community, again building the social capital of the local community. This would alleviate the burden on resource-poor palliative care services.

Conclusion

Receptivity to bereavement support is contingent on a multitude of factors at individual, social, geographical and cultural levels. The findings from this research indicate specific individual factors of ego depletion, shame resilience, introversion and perceived meritability of support are receptivity issues. Although ego depletion and introversion are referenced in the extant receptivity literature, this chapter explored these concepts further to provide deeper insights. Social factors discussed in this chapter include factors such as reciprocity in relation to the therapeutic alliance, along with the role of support from non-family were identified as receptivity issues. Likewise, centralised coordination to mediate the impact of the stressors of dealing with the deceased estate and tending to practical matters have been identified by participants in this study as receptivity issues. Much of the literature on the nuances of living in rural communities was supported by participant narratives in this study and discussed as part of geographical factors and receptivity. Insights from an Aboriginal cultural perspective also highlighted receptivity issues and were explored in this chapter.

Key receptivity issues from the findings in this study and the literature were discussed in this chapter and are outlined in *Appendices E and F*. The interdependence of individual, social and geographical features all impact receptivity to support. The next chapter will conclude this thesis with an exploration of implications for practice and research.

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 *memorialscape*s 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 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.

INDIVIDUAL FACTORS & RECEPTIVITY	
Intrapersonal	Interpersonal
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:

INDIVIDUAL FACTORS	
Intrapersonal	Interpersonal
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	Desire for sociability
Attitude	Social role within a family and non-family system
Drives and Motivation	
Cognition	
Behaviours	
Knowledge	
Experiences	

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:

SOCIAL FACTORS & RECEPTIVITY
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 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.

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**Appendix A: Human Research Ethics Committee Approval
Documentation.**


HUMAN RESEARCH ETHICS COMMITTEE

ETHICAL CLEARANCE
CERTIFICATE

This certificate generated on 24-03-2014.

This certificate confirms that protocol 'Full Review: Exploring the concept of 'receptivity' to bereavement support: Implications for palliative care services in rural, regional and remote country WA' (GU Protocol Number HSV/38/13/HREC) has ethical clearance from the Griffith University Human Research Ethics Committee (HREC) and has been issued with authorisation to be commenced.

The ethical clearance for this protocol runs from 21-10-2013 to 30-12-2015.

The named members of the research team for this protocol are:

Dr Pim Kuipers
Dr Pamela McGrath
Mrs Philippa Blackburn

The research team has been sent correspondence that lists the standard conditions of ethical clearance that apply to Griffith University protocols.

The HREC is established in accordance with the *National Statement on Ethical Conduct on Research Involving Humans*. The operation of this Committee is outlined in the HREC Standard Operating Procedure, which is available from www.gu.edu.au/or/ethics.

Please do not hesitate to contact me if you have any further queries about this matter.

Rick Williams
Manager, Research Ethics
Office for Research
Bray Centre, N54 Room 0.15 Nathan Campus
Griffith University
Phone: 07 3735 4375
Facsimile: 07 373 57994
Email: rick.williams@griffith.edu.au



11th December 2013

Mrs Pippa Blackburn
2c Wilson St
Carey Park
BUNBURY WA 6230

Dear Mrs Blackburn

Project Title: *Exploring the concept of 'receptivity' to bereavement support: implications for palliative care services in rural, regional and remote Western Australia*

HREC Reference: 2013:32

The ethics application for the project referenced above was reviewed by the WA Country Health Service Board Research Ethics Committee at its meeting on the 14th November 2013. It has been approved and the following documents have been approved for use in this project.

Documents
<ul style="list-style-type: none">▪ Information Sheet: Individuals who are Bereaved: 28th October 2013▪ Consent Form for Bereaved Patients: 28th October 2013▪ Information Sheet for Health Professionals: 28th October 2013▪ Consent Form for Health Professionals: 28th October 2013▪ Promotional Flier: 28th October 2013▪ FLOWCHART: WA Country Health Service (WACHS) anticipated recruitment process: 28th October 2013▪ Question Bank: 28th October 2013

Approval of this project from the WA Country Health Service Board Research Ethics Committee EC00261 is valid to December 2015 and on the basis of compliance with the 'Conditions of HREC Approval for a Research Project' (attached).

The nominated participating site(s) in this project is/are:

- WACHS - Great Southern
- WACHS – South West
- WACHS – Midwest
- WACHS – Kimberley
- WACHS – Goldfields
- WACHS – Pilbara
- WACHS - Wheatbelt

[Note: If additional sites are recruited prior to the commencement of, or during the research project, the Coordinating Principal Investigator is required to notify the HREC. Notification of withdrawn sites should also be provided to the HREC in a timely fashion.]



Government of **Western Australia**
WA Country Health Service

A copy of this ethical approval letter must be submitted by all site Principal Investigators to the Research Governance Office or equivalent body or individual at each participating institution in a timely manner to enable the institution to authorise the commencement of the project at its site/s.

This letter constitutes ethical approval only. This project cannot proceed at any site until separate site authorisation has been obtained from the CE, or delegate, of the site under whose auspices the research will be conducted at that site.

The WA Country Health Service Board Research Ethics Committee is registered with the Australian Health Ethics Committee and operates according to the NHMRC National Statement on Ethical Conduct in Human Research and International Conference on Harmonisation – Good Clinical Practice.

Should you have any queries about the HREC's consideration of your project, please contact the Ethics Executive Officer of the WA Country Health Service Board Research Ethics Committee on research.ethicscommittee@health.wa.gov.au or mobile ph 0417 068 594.

The WA Health Research Governance Policy & Procedures 2012, Standard

Operating Procedures and standard forms are available from the WACHS Research

Ethics Committee Internet Page

www.wacountry.health.wa.gov.au/researchethicscommittee or from the Ethics Executive Officer of the WA Country Health Service Board Research Ethics Committee.

Yours sincerely

Professor Samar Aoun

Chairperson

WA Country Health Service Board Research Ethics Committee

Working together for a healthier country WA

Our Values: Community | Compassion | Quality | Integrity | Justice



1st November 2013

Dear Pippa,

RE: HREC Reference number 519

Title: “Exploring the concept of ‘receptivity’ to bereavement support. Implications for palliative care services in rural, regional and remote Western Australia”

Thank you for submitting the above research project which was considered by the WAAHEC at its meeting held on 17th October 2013

I am pleased to advise that the WAAHEC has granted approval of this research project. WAAHEC approval is granted from 17th October 2013 pending your agreement of the following conditions:

1. Conditions

- The WAAHEC will be notified, giving reasons, if the project is discontinued before the expected date of completion.
- The Coordinating Investigator will provide an annual report to the WAAHEC and at completion of the study in the specified format. This form can be found on the AHCWA website (www.ahcwa.org).
- The approval for studies is for three years and the research should be commenced and completed within that period of time. Projects must be resubmitted if an extension of time is required.
- Publications that arise from this research are to be provided to the WAAHEC for review prior to submission for dissemination.
- That the Aboriginal and Torres Strait Islander community are formally acknowledged for their contribution to this research project.

2. Amendments

If there is an event requiring amendments to be submitted you should immediately contact ethics@ahcwa.org for advice.

Western Australian Aboriginal Health Ethics Committee



AHCWA
Aboriginal Health Council
of Western Australia

Should you have any queries about the WAAHEC's consideration of your project please contact ethics@ahcwa.org.

The WAAHEC wishes you every success in your research.

Kind regards

Chelsea Bell
For
Tammy Prouse
Chair, WAAHEC

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, *NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. The process this HREC uses to review multi-centre research proposals has been certified by the NHMRC.

Appendix B: Participant Information Sheets & Bereaved & Health Professionals

*“Exploring the concept of ‘receptivity’ to bereavement support:
Implications for palliative care services in rural, regional and
remote country WA”*

INFORMATION SHEET: INDIVIDUALS who are BEREAVED

Who is conducting the research?

Student: Pippa Blackburn

School of Human Services and Social Work, Griffith
University, Qld 0434 824 894 /
pippa.blackburn@gmail.com

Supervisors:

Associate Professor, Dr Pamela McGrath - Senior Research Fellow,
Centre for Community Science, School of Human Services and Social
Work, Griffith University Qld

Associate Professor, Dr Pim Kuipers - Research Fellow, Centre for
Community Science, School of Human Services and Social Work
Griffith University Qld

Associate Professor, Dr Caroline Bulsara - Brightwater Centre
Manager and **Adjunct Research Fellow University of WA,** Associate
Professor Notre Dame University, Research Fellow Curtin University
and Adjunct Lecturer Edith Cowan University WA

The ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If you have any concerns or complaints about the ethical conduct of the research project, please contact the Manager, Research Ethics on 3735 54375 or research-ethics@griffith.edu.au. Alternatively, you may wish to contact the WA Aboriginal Health Council Ethics Officer on 9227 1631 or email chelsea.bell@ahcwa.org.

This research is being undertaken for the purpose of obtaining a Doctor of Philosophy and this study has been approved by the Griffith University Human Research Ethics Committee.

Why is the research being conducted?

Bereavement care is often provided by health and Palliative Care services in Western Australia. We're keen to speak to you about your bereavement experiences to help improve services in this area. For this study we are particularly interested about rural experiences and whether people in rural areas are receptive to support.

We are using the term 'receptivity' and for the purpose of this research it means:

“the range of factors (individual, social and geographical) that affect an individual’s desire or ability to receive or engage with supportive care services designed to meet his or her needs”

Bereavement support provided by health and palliative care services is generally delivered in an ad hoc manner and may involve telephone calls, visits at home, sending cards or letters or inviting individuals and families to remembrance services. We need more evidence to better inform the development of bereavement programs and help us to make a more tailored approach to meet individual needs. We believe that understanding bereavement in rural, regional and remote Western Australia is a highly important topic. We hope that you will provide us with a greater understanding of what is required in a health and/or palliative care bereavement program, at what times support is required and by whom. We want to know how we can better support bereaved people in country WA and the information you provide will help inform the development of relevant, individualised and responsive bereavement programs.

We would like to invite you to participate in a study that aims to explore the experience of bereavement support in rural, regional and remote country Western Australia. We have asked you to participate in this study as we are inviting a diverse range of individuals who represent a range of backgrounds, geographically, socially and economically. The researcher is keen to talk to you about your experience to help us understand bereavement needs in country WA. It is anticipated that individuals will have different experiences and so all insights will be valued and appreciated.

If you decide to take part in this study it is important that you understand its purpose and what is involved in your participation. Please read the following pages, which will provide you with information about the study.

What you will be asked to do

As a participant in the research you will be asked to engage in an interview on the topic of bereavement. An interview simply means an interviewer will talk informally with you about your experience. There are no right or wrong answers and the interviewer will be interested to hear of your experience in your own words and in your own way. The interview will be conducted either face to face, over the telephone or via Skype, and is likely to last approximately one hour to one and a half hours. However, it is entirely at your discretion what you choose to share of your experience with the interviewer.

The basis by which participants will be selected or screened

We will be interviewing individuals about their personal experience with bereavement, specifically to the death of a loved one who was receiving care from a health care or palliative care service. You have been identified through the service which cared for your loved one. We will also be interviewing health professionals who provide bereavement support. The focus of this project is the lived experience of bereavement in rural, regional

and remote Western Australia. Participants over the age of 18 years will be invited to participate.

The expected benefits of the research

Participation in research by the bereaved has been found to be a positive and therapeutic experience as participants appreciated the opportunity to tell their story and they felt that the research may also be helping others in some way. Although participants acknowledged that it can evoke distress, many have reported it to be a positive experience. However, it is possible that there may be no direct benefit to you from participation in this study. You are in control of the information you want to provide and the topics you are prepared to discuss. While there is no guarantee that you will benefit, the knowledge gained from your participation may help others in the future. A summary of the findings from the study will be mailed out to you at the completion of the work.

Risks to you

We are aware of the potential of discussing your loss may stimulate uncomfortable thoughts and feelings and we hope to ease the impact by assuring you that our intentions are to understand your experiences without judgement. We are aware of the sensitive and personal nature of this topic, and assure you that all information will be held in the strictest confidence. Similarly, you are free to withdraw from the interview at any time should you decide that the experience is uncomfortable. It may be possible to reschedule should you choose to do so. Any information about you will be de-identified when coding and writing up results and any descriptions that can identify a person through the process will be eliminated through making global statements that further deidentifies participants.

Your confidentiality

Statements made during the interview will be digitally recorded and transcribed word for word. Any statements can later be withdrawn. Confidentiality will be respected and once your recorded interview has been transcribed and de-identified the audio will be deleted. Your name will be given a code number and your interview will be identified by the code number and not your name. Any paper copies of information will be stored in separate, locked filing cabinets off campus at the office of the principal investigator. Any information that is stored on the computer will be password protected. The only people with access to the information will be the researchers working on this project. The information will be kept for five (5) years and will then be destroyed (shredded or deleted).

Your comments may be used in research publications, conference presentations, reports, lay publications, and media releases. Although your comments may be used in publications, there will be no way to link your statements with yourself. The data collected from participants will be de-identified, encrypted and stored under secure conditions at

Griffith University and can only be accessed by the immediate research team. Data security and storage procedures are subject to external audit under Griffith University Human Research Ethics Committee.

Privacy Statement – disclosure

The conduct of this research involves the collection, access and/or use of your identified personal information. As outlined elsewhere in this information sheet, while some of the information you provide in interviews may appear in publications or reports, it will not be linked to your personal details and not be identifiable to you. This is occurring with your consent. Any additional personal information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded, except where you have consented otherwise. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/privacy-plan> or telephone (07) 3735 4375.

Your participation is voluntary

Participation is entirely voluntary and you may withdraw from this study at any time, for whatever reason. Choosing not to take part in this research will incur no loss of benefit in any way in relation to you. The interview will be conducted at your own pace and any issues that are difficult to talk about will be addressed in a sensitive and respectful manner. The questions are open ended and you are in control of what is said. If at any time during the interview you become distressed, you can terminate the interview or ask for some time before continuing with the interview.

Questions / further information

For further questions about the research project please feel free to contact the investigator listed with her contact details in the introduction to this project sheet.

Thank you for taking the time to read this project description.

Feedback to you

If you would like a copy of the summary of results at the completion of this project, please complete the request form at the bottom of the consent form.

What next?

As you have expressed interest in the research and have consented to being contacted by the researcher, Pippa will contact you shortly. You will be given a chance to discuss the study, any implications for participating and make a decision if you want to participate. If

you decide to participate, Pippa will arrange an interview time convenient to yourself. If you require further information please do not hesitate to contact the research team on (07) 3374 1792.

If at any time after the interview you feel distressed and wish to speak to someone, the following organisations can be contacted:

Lifeline 13 11 44

Lifeline provides access to crisis support, suicide prevention and mental health support services. **Website:** <http://www.lifeline.org.au/>

Rural Link 1800 552 002

Is a specialist after hours mental health telephone service for all rural communities in Western Australia (from 4:30pm to 8:30am).

Website:

http://www.mentalhealth.wa.gov.au/getting_help/Emergency_help/emergency_rural.aspx

BeyondBlue 1300 22 4636

The *beyondblue* support service provides advice and support via telephone 24/7 (just call 1300 22 4636), daily web chat (between 4pm-10pm) and email (with a response provided within 24 hours). **Website:** <http://www.beyondblue.org.au/>

*“Exploring the concept of ‘receptivity’ to bereavement support:
Implications for palliative care services in rural, regional and remote
country WA”*

INFORMATION SHEET: Health Professionals

Who is conducting the research?

Student: Pippa Blackburn
School of Human Services and Social Work, Griffith University, Qld. 0434 824 894 /
pippa.blackburn@gmail.com

Supervisors: Associate Professor, Dr Pamela McGrath - Senior Research Fellow, Centre for
Community
Science, School of Human Services and Social Work, Griffith University Qld
Associate Professor, Dr Pim Kuipers - Research Fellow, Centre for
Community Science, School of Human Services and Social Work Griffith
University Qld
Associate Professor, Dr Caroline Bulsara - Brightwater Centre Manager
and Adjunct Research. Fellow University of WA, Adjunct Senior Lecturer
Notre Dame University, Research Fellow Curtin University and Adjunct
Lecturer Edith Cowan University WA

This research is being undertaken for the purpose of obtaining a Doctor of Philosophy and this study has been approved by the Griffith University Human Research Ethics Committee. For any concerns or complaints about the ethical conduct of the research please contact the Manager, Research Ethics, Griffith University on 3735 4375 or research-ethics@griffith.edu.au.

Why is the research being conducted?

This research aims to explore perspectives from health professionals who provide bereavement support to individuals and families in their local communities in rural, regional and remote Western Australia. Bereavement care is often provided by health and Palliative Care services in Western Australia and for this study, we are particularly interested about your bereavement experiences to help improve services in this area. We are particularly interested about rural peoples’ experiences and whether people are receptive to support. We are using the term ‘receptivity’ and for the purpose of this research it means:

“the range of factors (individual, social and geographical) that affect an individual’s desire or ability to receive or engage with supportive care services designed to meet his or her needs”

Bereavement support provided by health and palliative care services is generally delivered in an ad hoc manner and may involve telephone calls, visits at home, sending cards or letters or inviting individuals and families to remembrance services. We need more evidence to better inform the development of bereavement programs and help us to make a more tailored approach to meet individual needs. We believe that understanding bereavement in rural, regional and remote Western Australia is a highly relevant topic and we hope that you will provide us with a greater understanding of your experiences in providing bereavement support to families who have had a loved one die whilst under the care of your service. Not much is known about health professionals thoughts about people being receptive to bereavement care in country WA. The information you provide will help inform the development of relevant, individualised and responsive bereavement programs.

We would like to invite you to participate in a study that aims to explore the experience of bereavement support in rural, regional and remote country Western Australia. We have asked you to participate in this study as we are inviting health professionals from a range of backgrounds and disciplines and it is anticipated that individuals will have different experiences and so all insights will be valued and appreciated.

If you decide to take part in this study it is important that you understand its purpose and what is involved in your participation. Please read the following pages, which will provide you with information about the study.

What you will be asked to do?

As a participant in the research you will be asked to engage in an interview on the topic of bereavement. An interview simply means an interviewer will talk informally with you about your experience. There are no right or wrong answers and the interviewer will be interested to hear of your experience in your own words and in your own way. The interview will be conducted either face to face, over the telephone or via Skype and is likely to last approximately one hour to one and a half hours. However, it is entirely at your discretion what you choose to share of your experience with the interviewer.

The basis by which participants will be selected or screened

We will be interviewing health professionals about their experiences in providing bereavement support specifically to those who have had a loved one die who was receiving care from your health care or palliative care service. The focus of this project is the experiences of bereavement support in rural, regional and remote Western Australia. Participants over the age of 18 years will be invited to participate.

The expected benefits of the research

While there is no direct benefit to you, the knowledge gained from your participation may help others in the future through informing health care services in the development and delivery of bereavement programs. We hope you will appreciate the opportunity to have your ideas, experiences and concerns recorded as part of this research. You are in control of the information you want to provide and what you are prepared to discuss. It is hoped that the research will provide gains in knowledge, insights and understanding of health professionals' perspectives in providing bereavement support. A summary of the findings from the study will be mailed out to you at the completion of the work.

Risks to you

We are aware of the potential of discussing your experiences of working with patients and families may stimulate uncomfortable thoughts and feelings and we hope to ease the impact by assuring you that our intentions are to understand your experiences without judgement. We acknowledge the sensitive and personal nature of this topic, and assure you that all information will be held in the strictest confidence. Similarly, you are free to withdraw from the interview at any time should you decide that the experience is uncomfortable. It may be possible to reschedule should you choose to do so. Any information about you will be de-identified when coding and writing up results and any descriptions that can identify a person through the process will be eliminated through making global statements that further de-identifies participants.

Your confidentiality

Statements made during the interview will be digitally recorded and transcribed word for word. Any statements can later be withdrawn. Confidentiality will be respected and once your recorded interview has been transcribed and deidentified the audio will be deleted. Your name will be given a code number and your interview will be identified by the code number and not your name. Any paper copies of information will be stored in separate, locked filing cabinets off-site by the principal investigator. Any information that is stored on the computer will be password protected. The only people with access to the information will be the researchers working on this project. The information will be kept for five (5) years and will then be destroyed (shredded or deleted).

Your comments may be used in research publications, conference presentations, reports, lay publications, and media releases. Although your comments may be used in publications, there will be no way to link your statements with yourself. The data collected from participants will

be de-identified, encrypted and stored under secure conditions at Griffith University and can only be accessed by the immediate research team. Data security and storage procedures are subject to external audit under Griffith University Human Research Ethics Committee.

Privacy Statement – disclosure

The conduct of this research involves the collection, access and/or use of your identified personal information. As outlined elsewhere in this information sheet, while some of the information you provide in interviews may appear in publications or reports, it will not be linked to your personal details and not be identifiable to you. This is occurring with your consent. Any additional personal information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded, except where you have consented otherwise. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/privacy-plan> or telephone (07) 3735 4375.

Your participation is voluntary

Participation is entirely voluntary and you may withdraw from this study at any time, for whatever reason. Choosing not to take part in this research will incur no loss of benefit in any way in relation to you. The interview will be conducted at your own pace and any issues that are difficult to talk about will be addressed in a sensitive and respectful manner. The questions are open ended and you are in control of what is said. If at any time during the interview you become distressed, you can terminate the interview or ask for some time before continuing with the interview.

Questions / further information

For further questions about the research project please feel free to contact the investigator listed with her contact details in the introduction to this project sheet.

Thank you for taking the time to read this project description.

The ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If you have any concerns or complaints about the ethical conduct of the research project, they should contact the Manager, Research Ethics on 3735 54375 or research-ethics@griffith.edu.au.

Feedback to you

If you would like a copy of the summary of results at the completion of this project, please complete the request form at the bottom of the consent form.

What next?

As you have expressed interest in the research and have consented to being contacted by the researcher, Pippa will contact you shortly. You will be given a chance to discuss the study, any implications for participating and make a decision if you want to participate. If you decide to participate, Pippa will arrange an interview time convenient to yourself. If you require further information please do not hesitate to contact the research team on (07) 3374 1792.

If at any time after the interview you feel distressed and wish to speak to someone, the following organisations can be contacted:

Lifeline **13 11 44**

Lifeline provides access to crisis support, suicide prevention and mental health support services. **Website:** <http://www.lifeline.org.au/>

Rural Link **1800 552 002**

Is a specialist after hours mental health telephone service for all rural communities in Western Australia (from 4:30pm to 8:30am).

Website:

http://www.mentalhealth.wa.gov.au/getting_help/Emergency_help/emergency_rural.aspx

BeyondBlue **1300 22 4636**

The *beyondblue* support service provides advice and support via telephone 24/7 (just call 1300 22 4636), daily web chat (between 4pm-10pm) and email (with a response provided within 24 hours). **Website:** <http://www.beyondblue.org.au/>

**Appendix C: Consent: Information Sheets Outlining Process:
Bereaved & Health Professionals**

*Exploring the concept of 'receptivity' to bereavement support:
Implications for palliative care services in rural, regional and remote
country WA"*

CONSENT FORM: Individuals who are Bereaved

Research Team

Student: Pippa Blackburn

School of Human Services and Social Work, Griffith University, Qld.
0434 824 894 / pippa.blackburn@gmail.com

Supervisors: **Associate Professor, Dr Pamela McGrath** - Senior Research Fellow, Centre for Community Science, School of Human Services and Social Work, Griffith University, Qld.

Associate Professor, Dr Pim Kuipers - Research Fellow, Centre for Community Science, School of Human Services and Social Work, Griffith University, Qld.

Associate Professor, Dr Caroline Bulsara - Brightwater Centre Manager / Adjunct Research

Fellow University of WA, Associate Professor Notre Dame University, Research Fellow Curtin University and Adjunct Lecturer Edith Cowan University, WA.

Contact for Ethical Concern: For any concerns or complaints about the ethical conduct of the research please contact the Manager, Research Ethics, Griffith University on 3735 4375 or research-ethics@griffith.edu.au. All complaints will be treated in confidence, investigated fully and you will be informed of the outcome. For further questions about the research project please feel free to contact the investigator listed with her contact details in the introduction to this project sheet. Thank you for taking the time to read this consent description.

As outlined in the attached project description, you are invited to participate in a preliminary study which aims to explore the experiences of bereavement support in rural, regional and remote country Western Australia. We're keen to speak to you about your bereavement experiences to help improve services in this area. We are particularly interested about rural experiences and whether people are receptive to support. We are using the term 'receptivity' and for the purpose of this research it means: *the range of factors (individual, social and geographical) that affect an individual's desire or ability to receive or engage with supportive care services designed to meet his or her needs"*

We believe that understanding bereavement in county Western Australia is a highly relevant topic and we hope that you will provide health and palliative care services with a greater understanding of what is required to include in a bereavement program, at what times support is required and by whom.

The purpose of this form is to give you information on your ethical rights associated with your participation in this research.

As a participant in this research you will be asked to engage in an interview on the topic of bereavement in country areas of Western Australia. An interview simply means that an interviewer will talk informally with you about your experience. There will not be a long list of questions to answer or a lengthy questionnaire to fill in. Instead, the interviewer will be interested to hear of your experience in your own words and in your own way. Should you feel the need for direction; the interviewer will be able to help the discussion with relevant questions. The interview will be conducted either face to face, over the phone or via Skype at a time of your choice and is likely to last one hour to one and a half hours. However, it is entirely at your discretion what you choose to share of your experience with the interviewer. You are free to withdraw from the interview at any time should you decide that the experience is uncomfortable. It may be possible to reschedule should you choose to do so.

Participation is voluntary and you can withdraw from the study at any time. Statements made during the interview will be de-identified, recorded and transcribed. Choosing not to take part in this research will incur no loss of benefit in any way in relation to you or the university.

Total confidentiality will be respected and your interview will be de-identified, encrypted and stored in a secure location. Confidentiality will be respected and once your recorded interview has been transcribed and de-identified the audio will be deleted. Your comments may be used in research publications, conference presentations, reports, lay publications or media releases. Although your comments may be used in publications, there will be no way to link your statements with yourself. The data collected from the participants will be de-identified, encrypted and stored under secure conditions at Griffith University and can only be accessed by the immediate research team. Data security and storage procedures are subject to external audit under Griffith University Human Research Ethics Committee.

The conduct of this research involves the collection, access and/ or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 5585.

If, for any reason you wish to discuss this research further then the investigator (as listed at the beginning of this consent form) for the project will be happy to talk to you. **If you want to**

discuss any aspect of the study with someone who is not directly involved, please contact the Griffith University Human Research Ethics Committee Secretariat on (07) 37354106.

Consent Procedure:

Before you participate in the research we need to ensure and record that you have fully understood your rights and consent to participate. Consent for your participation in this project is verbally recorded before the commencement of the interview. Before the interview commences, the interviewer will read the following:

"For purposes of informed consent this conversation needs to be audio recorded. If at any time you do not wish to participate or give your consent to participate in this study; this audio recording will be permanently deleted. Do you wish to continue?"

If you agree the interviewer will begin the audio recording:

"You have been asked to participate in a study conducted by Griffith University, Queensland, to help us better understand your experience of bereavement and bereavement support in rural, regional and remote Western Australia.

This study has been approved by Griffith Universities Human Research Ethics Committee. Participation is voluntary and you can choose to cease participation in this study at any time and for any reason and without consequence."

"Your responses are held in total confidentiality."

- "Could you please state your full name?"

"For us to record your consent could you please indicate with a yes or no that:

- I understand that for any concern I can contact the Manager, Research Ethics, Griffith University Office of Research on 07 37355585.

- I freely give my consent to participate in this study. "

Once you have given your consent the researcher will commence the interview.

If at any time after the interview you feel distressed and wish to speak to someone, the following organisations can be contacted:

Lifeline 13 11 44

Lifeline provides access to crisis support, suicide prevention and mental health support services. **Website:** <http://www.lifeline.org.au/>

Rural Link 1800 552 002

Is a specialist after hours mental health telephone service for all rural communities in Western Australia (from 4:30pm to 8:30am).

Website:

http://www.mentalhealth.wa.gov.au/getting_help/Emergency_help/emergency_rural.aspx

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The *beyondblue* support service provides advice and support via telephone 24/7 (just call 1300 22 4636), daily web chat (between 4pm-10pm) and email (with a response provided within 24 hours). **Website:** <http://www.beyondblue.org.au/>

*“Exploring the concept of ‘receptivity’ to bereavement support:
Implications for palliative care services in rural, regional and remote
country WA”*

CONSENT FORM: Health Professionals

Research Team

Student: Pippa Blackburn
School of Human Services and Social Work,
Griffith University, Qld 0434 824 894 /

Supervisors: pippa.blackburn@gmail.com

Associate Professor, Dr Pamela McGrath - Senior Research Fellow, Centre for Community Science, School of Human Services and Social Work Griffith University, Qld.

Associate Professor, Dr Pim Kuipers - Research Fellow, Centre for Community Science, School of Human Services and Social Work Griffith University, Qld.

Associate Professor, Dr Caroline Bulsara - Brightwater Centre Manager and Adjunct Research Fellow University of WA, Associate Professor Notre Dame University, Research Fellow Curtin University and Adjunct Lecturer Edith Cowan University, WA.

Contact for Ethical Concern: For any concerns or complaints about the ethical conduct of the research please contact the Manager, Research Ethics, Griffith University on 3735 4375 or research-ethics@griffith.edu.au. All complaints will be treated in confidence, investigated fully and you will be informed of the outcome. For further questions about the research project please feel free to contact the investigator listed with her contact details in the introduction to this project sheet. Thank you for taking the time to read this consent description.

As outlined in the attached project description, you are invited to participate in a preliminary study which aims to explore the perspectives of health professionals in relation to your thoughts about bereavement care and support in rural, regional and remote country Western Australia. We're keen to speak to you about your experiences to help improve services in this area. We are particularly interested about rural experiences and whether people are receptive to support. We are using the term 'receptivity' and for the purpose of this research it means: *“the range of factors (individual, social and geographical) that affect an individual's desire or ability to receive or engage with supportive care services designed to meet his or her needs”*

We believe that understanding bereavement in county Western Australia is a highly relevant topic and we hope that you will provide us with a greater understanding of the needs and thoughts of health professionals in relation to the provision of bereavement support.

The purpose of this form is to give you information on your ethical rights associated with your participation in this research.

As a participant in this research you will be asked to engage in an interview on the topic of bereavement in country areas of Western Australia. An interview simply means that an interviewer will talk informally with you about your experience. There will not be a long list of questions to answer or a lengthy questionnaire to fill in. Instead, the interviewer will be interested to hear of your experience in your own words and in your own way. Should you feel the need for direction; the interviewer will be able to help the discussion with relevant questions. The interview will be conducted either face to face, over the phone or via Skype at a time of your choice and is likely to last one hour to one and a half hours. However, it is entirely at your discretion what you choose to share of your experience with the interviewer. You are free to withdraw from the interview at any time should you decide that the experience is uncomfortable. It may be possible to reschedule should you choose to do so.

Participation is voluntary and you can withdraw from the study at any time. Statements made during the interview will be de-identified, recorded and transcribed. Choosing not to take part in this research will incur no loss of benefit in any way in relation to you or the university.

Total confidentiality will be respected and your interview will be de-identified, encrypted and stored in a secure location. Confidentiality will be respected and once your recorded interview has been transcribed and de-identified the audio will be deleted. Your comments may be used in research publications, conference presentations, reports, lay publications or media releases. Although your comments may be used in publications, there will be no way to link your statements with yourself. The data collected from the participants will be de-identified, encrypted and stored under secure conditions at Griffith University and can only be accessed by the immediate research team. Data security and storage procedures are subject to external audit under Griffith University Human Research Ethics Committee.

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If, for any reason you wish to discuss this research further then the investigator (as listed at the beginning of this consent form) for the project will be happy to talk to you. **If you want to discuss any aspect of the study with someone who is not directly involved, please contact the Griffith University Human Research Ethics Committee Secretariat on (07) 37354106.**

Consent Procedure:

Before you participate in the research we need to ensure and record that you have fully understood your rights and consent to participate.

Consent for your participation in this project is verbally recorded before the commencement of the interview. Before the interview commences, the interviewer will read the following:

"For purposes of informed consent this conversation needs to be audio recorded. If at any time you do not wish to participate or give your consent to participate in this study; this audio recording will be permanently deleted. Do you wish to continue?"

If you agree the interviewer will begin the audio recording:

"You have been asked to participate in a study conducted by Pippa Blackburn, PhD Student with Griffith University, Queensland, to help us better understand the experience of bereavement and bereavement support in rural, regional and remote Western Australia."

"This study has been approved by Griffith Universities Human Research Ethics Committee. Participation is voluntary and you can choose to cease participation in this study at any time and for any reason and without consequence."

"Your responses are held in total confidentiality."

- "Could you please state your full name?"

"For us to record your consent could you please indicate with a yes or no that:

- I understand that for any concern I can contact the Manager, Research Ethics, Griffith University Office of Research on 07 37355585.

- I *freely give my consent to participate in this study. "*

Once you have given your consent the researcher will commence the interview.

If at any time after the interview you feel distressed and wish to speak to someone, the following organisations can be contacted:

Lifeline 13 11 44

Lifeline provides access to crisis support, suicide prevention and mental health support services. **Website:** <http://www.lifeline.org.au/>

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Appendix D: Schedule of Interview Questions: Bereaved, Health Professionals and Aboriginal Health Professionals

The following interview schedules are a pool of questions that evolved as part of the iterative process for interviewing participants.

A. Sample Bereaved Prompt Questions:

PROMPTER QUESTIONS: BEREAVED
CAN YOU TELL ME ABOUT YOUR BEREAVEMENT EXPERIENCE?
Who did you turn to for support during this time and what was your experience with the support?
Did you feel the need for professional bereavement support?
Did you use other sources of help available e.g. resources / groups / technologies?
Were there people in your networks who said something that was helpful? If so, what did they say? Did this influence your bereavement? In what way?
What were the hardest aspects about dealing with your grief?
Some people have made a really conscious or intentional effort to take care of themselves in bereavement, looking after their own needs. Can you tell me if you have experienced this and if so, what have you done to look after yourself?
Some people have talked about their experiences in dealing with institutions such as banks, phone companies etc. what has been your experience, if any, with these? Did you seek support in dealing with these practical matters?
An interesting concept I have come across in interviews is the notion of 'banking' support where people try to do things for themselves so that they don't ask for help but when they do finally ask for help, they have 'banked' up requests so they don't feel so guilty asking for support. Is this something you have experienced?
Some people have talked about how they get selective with who they talk to, that their grief is, or becomes, a private thing. Is this something you have experienced?
Some people have talked about their experiences during very 'dark times' during their bereavement and have felt like they no longer wish to be here and have had suicidal thoughts. Is this something you have experienced?
If so, is there anything you think professionals could do that could help people from getting to that point, or to help people when they are experiencing these thoughts and feelings?

Some people I have talked with have used humour a bit. Have you used humour to help you in your bereavement? If so, has it helped and what does humour mean to you?
Participants who are still working have talked about the benefits and drawbacks with work; what have your experiences been?
Has living in a rural/regional/remote area had an influence on your bereavement experience? Has this influenced seeking support?
What has been the major impact of your bereavement? <i>*this question was included to ascertain the impact and to see if this may be correlated with receptivity to support</i>
What has surprised you in your bereavement?
What do you think would be good for palliative care services to provide in terms of bereavement support?
Are there particular times where you think assistance or support in your bereavement may have been helpful?
Is there anything you would like to share with others that might help their engagement with getting support?
What pearls of wisdom or message would you like to share with others in rural/regional/remote areas?

B. Sample Health Professionals Prompt Questions

PROMPTER QUESTIONS: HEALTH PROFESSIONAL
COULD YOU TELL ME A LITTLE BIT ABOUT YOUR WORK IN BEREAVEMENT SUPPORT?
Health professionals talk about risk in bereavement. What is your understanding of this and how do you assess?
If someone was considered as being 'at risk', what do you do?
What do you think the bereaved require for support?
Are there things bereavement support doesn't include that you think might be helpful for the bereaved?
What are the things that you think encourage the bereaved to get help from professionals?
What are the things that you think deter or prevent the bereaved from getting help from professionals?
Do you have any ideas about innovative or different ways to reach bereaved people?

How do you manage the dual imperative of having to provide bereavement support and not having the additional resources and support to do it?
Many people talk about their experiences in dealing with institutions such as banks etc. in bereavement. What do you think the experiences are for the bereaved with these?
Many of the bereaved have talked about some kind of 'replenishment' of themselves in bereavement where they make an intentional and conscious effort to look after their own needs. Have you encountered this in your experience and if so, what have you observed?
Many bereaved have used humour throughout interviews. Have you observed the use of humour in the bereaved and what role do you think humour might play?
Some participants have talked about the role of technology in their bereavement such as inheriting digital assets, online accounts, social media etc. Have you had any experiences around this or what are your thoughts around this?
Is there something about living in rural, regional or remote areas that influences a person's bereavement?
What has surprised you about the bereaved?
What are some of lessons you have learned from the bereaved?

C. Sample Aboriginal Health Professionals Prompt Questions

PROMPTER QUESTIONS – ABORIGINAL HEALTH PROFESSIONALS
COULD YOU TELL ME A LITTLE BIT ABOUT YOUR WORK IN BEREAVEMENT SUPPORT?
Health professionals talk about risk in bereavement. What is your understanding of this and how do you assess?
If someone was considered as being 'at risk', what do you do?
What do you think the bereaved require for support?
Are there things bereavement support doesn't include that you think might be helpful for the bereaved?
What are the things that you think encourage the bereaved to get help from professionals?
What are the things that you think deter or prevent the bereaved from getting help from professionals?

Do you have any ideas about innovative or different ways to reach bereaved people?
How do you manage the dual imperative of having to provide bereavement support and not having the additional resources and support to do it?
people talk about their experiences in dealing with institutions such as banks etc. in bereavement. What do you think the experiences are for the bereaved with these?
Many of the bereaved have talked about some kind of 'replenishment' of themselves in bereavement where they make an intentional and conscious effort to look after their own needs. Have you encountered this in your experience and if so, what have you observed?
Many bereaved have used humour throughout interviews. Have you observed the use of humour in the bereaved and what role do you think humour might play?
Some people I have talked with, talked about some of the issues with technology and how some of the younger ones are posting things on Facebook after someone has died and how this has been upsetting to some of the elders in their local community. Are you aware of or have you experienced anything like this?
Is there something about living in rural, regional or remote areas that influences a person's bereavement?
What has surprised you about the bereaved?
What are some of lessons you have learned from the bereaved?

Appendix E: Overview of Receptivity Issues (Chapters Five to Eight) through the diaspora lens.

Although some receptivity issues may be referred to in the extant receptivity literature, the new contribution of issues were framed within concepts from the diaspora discourse. The following tables provide an overview of receptivity issues that were examined through the lens of diaspora. McGrath (2013) identified three key receptivity factors, individual, social and geographical and receptivity issues will be categorised within these factors outlined in the tables below.

Chapter Five: *Existential Diaspora in the Bereavement Diaspora*

<i>Existential Diaspora in the Bereavement Diaspora</i>	
What is in the receptivity empirical literature?	NEW CONTRIBUTION Findings in this study that influence receptivity using concepts from the diaspora discourse
<p>INDIVIDUAL</p> <ul style="list-style-type: none"> × Vulnerability: (self): do not want to expose to others. Creates embarrassment and shame. × Vulnerability: (others): others don't like to be exposed to the vulnerability of others so shut them down, distract them or minimise × Reciprocity: being open to others and others being open to the individual in terms of their thoughts, feelings and behaviours in a non-judgemental way × Independence factor: trying to do things on their own first before seeking help. Asking for help a sign of weakness; is a perceived threat to one's ability to cope independently × Determination and will: drives and motivation – 	<p>INDIVIDUAL</p> <ul style="list-style-type: none"> × <i>Existential isolation</i>: A sense that people do not really understand the inner, subjective world of the individual × <i>Disruption</i>: Private internal world: too profound to make sense of, and to let others in. Sometimes feel they are going crazy so fear being judged × <i>Disruption</i>: Private internal world: not wanting others to impose their thoughts, feeling, experiences and interpretations and 'expert' advice × <i>Disruption and displacement</i>: sense of disconnect from self so difficult to connect with others; not sure where they fit in the world anymore; others can't make sense of it until the person can × <i>Existential diaspora</i>: can create a cognitive and emotional anaesthesia in early period post death – <i>inability</i> to seek support or creates block to recognising and utilising support × <i>Lived tensions</i>: struggle between wanting to be open and share with others and desire to keep thoughts and feelings private × <i>Syncopated temporality</i>: rupture in time or lifespan; developmental milestones yet to be met

<p>ability and desire to seek support</p> <ul style="list-style-type: none"> × Minimisation × Self-determination: activities to promote emotional and social independence × Self-efficacy: reducing stigma – seeking professional help may be seen as shame inducing and there is a risk to being labelled as having a mental illness or not experiencing a ‘normative’ response to grief <p>SOCIAL</p> <ul style="list-style-type: none"> × Reciprocity: do not wish to burden others or cause emotional or cognitive stress; want to protect informal networks × Relationships: positive relationships (informal and formal networks) fosters safety and security and psychological safety for disclosure 	<p>may be impetus for support needs = receptivity changes throughout lifespan</p> <ul style="list-style-type: none"> × <i>Displacement</i>: Vulnerability and the concept of <i>shame resilience</i>: shame inducing activities ie. counselling; asking for help; showing vulnerability. Shame resilience: avoid or manage shame inducing activities × <i>Double Consciousness</i>: Yearning and Nostalgia: an enduring feature of grief; reconciling here (present) and there (past); may be made to feel something abnormal or maladaptive about grief response in contemporary complicated grief discourse × <i>Transcendence: Memory</i>: openness to sharing of memories or activities/objects that encourage continued bonds × <i>Affinity diaspora</i> as a concept: a sense of connection with others who are bereaved. × <i>Linguistic influences</i>: language in the dominant discourse does not fit with subjective experience ie. alexithymia: unable to find the words to describe the subjective experience <p>SOCIAL</p> <ul style="list-style-type: none"> × <i>Linguistic influences</i>: co-creation or shared narratives of experience or the deceased fosters connection and continued bonds × <i>Linguistic influences</i>: language connects inner, outer and transcendent worlds. The language of others influences engagement × <i>Embodied diaspora</i>: spatialised habits and memories within the domestic space not recognised in bereavement discourse × <i>Deathscapes</i>: risk of being pathologised for having ‘shrines’ of deceased belongings in the home × <i>Deathscapes</i>: ‘virtual’ memorialsapes where the deceased continue as social actors in the lives of bereaved × <i>Therapeutic Relationship</i>: pre-existing therapeutic relationship with professionals; particularly if they cared for or knew loved one.
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Chapter Six: Coping in the *Bereavement Diaspora*

Coping in the <i>Bereavement Diaspora</i>	
What is in the empirical literature?	NEW CONTRIBUTION Findings in this study that influence receptivity using concepts from the diaspora discourse
<p>INDIVIDUAL</p> <ul style="list-style-type: none"> × Timing: push-pull factors at different times; receptivity to support differs across time × Dealing with practical matters × Self-efficacy: reducing stigma: intimate others reduce stigma and loss of power and control × Self-efficacy: positive self-efficacy reduced desire to seek support × Introversion × Independence factor: internationalisation as a way to cope; maintains independence × Independence factor: perceived threat to success or power if admits to vulnerability or seeks help × Pre-existing mental health conditions and previous experiences with service providers × Keeping busy × Accessibility of resources and support eg. IT, internet × Exhaustion <p>SOCIAL</p> <ul style="list-style-type: none"> × Reciprocity: Do not want to burden family and friends × Exhaustion and hyperactivity: normalising the range of responses and coping; inability or little 	<p>INDIVIDUAL</p> <ul style="list-style-type: none"> × <i>Lived tension</i>: maintaining independence with recognising vulnerability; receptivity changes at different times × <i>Hybridity</i>: become a different person to different people in different situations: <i>selectivity</i>: receptive to receive support from some while providing support to others; fear of being ostracised from others if talk about grief, bereavement or the deceased × <i>Socio-political</i> ‘situatedness’: impact of dealing with practical matters; legislation, organisational activities - may require help seeking for informational or practical support; ‘organisation fatigue’ × <i>Time</i>: extensive time and labour required to deal with administrative practical matters; deadlines to meet with practical matters; constraints with leave from work; may be receptive to informational and practical support × <i>Time</i>: risk of pathologised or non-normative grief responses after ‘expected time-frames’ however this is impacted by the time it takes to deal with practical matters <p>SOCIAL</p> <ul style="list-style-type: none"> × <i>Gender</i> socialisation: determines help seeking behaviours × <i>Power</i> dynamics: retain versus relinquish; who is safe and who is not to relinquish one’s power to; disclosing inner thoughts opens oneself up to vulnerability and perceived loss of power × Power dynamics: family adjustment (role conflicts or attitudes) may be impetus for family or member receptivity to support × <i>Affinity diaspora</i>: relationships and feeling a sense of connection with others; others not judgemental; legitimacy of others who have experienced bereavement; influence receptivity

<p>desire to seek help if exhausted</p>	<p>to sharing grief and bereavement experiences with others</p> <ul style="list-style-type: none"> × <i>Embodied Diaspora</i> (spatialised): changing or retaining habitual inter-relational spatialised habits; may be judged by others × <i>Embodied diaspora</i> (somatised): replenishing mind, body and soul; attending to health needs may influence receptivity × <i>Deathscapes</i>: holding on to and converting belongings; creating ‘memorialscape’- private versus public; receptivity influenced by receptiveness of others × <i>Humour</i>: humour oriented communication and facilitated reflection or memories may influence receptivity; response by professionals and others to use of humour by bereaved × <i>Death etiquette</i>: fear of being judged for going against social norms
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Chapter Seven: Relationships in the *Bereavement Diaspora*

Relationships in the <i>Bereavement Diaspora</i>	
What is in the empirical literature?	NEW CONTRIBUTION Findings in this study that influence receptivity using concepts from the diaspora discourse
<p>INDIVIDUAL</p> <ul style="list-style-type: none"> × Expectations of outcome of support × Pre-existing mental health conditions × perception those with legitimate or authoritative knowledge and experience more <p>SOCIAL</p> <ul style="list-style-type: none"> × Reciprocity: Interdependent relationships within family unit; resources within social support network already burdened × Reciprocity: dis-synchrony of grieving within family unit 	<p>INDIVIDUAL</p> <ul style="list-style-type: none"> × <i>Displacement</i>: feeling of alienation from local community and informal support networks; may influence receptivity to professional support <p>SOCIAL</p> <ul style="list-style-type: none"> × <i>Power</i>: family role perception and values; differential power dynamics as social roles change within family unit; may lead to difficulties in adjustment thus individual family member(s) may be receptive to supporting vulnerable family members × <i>Hybridity</i>: values, belief systems and attitudes socialised within family unit change over time relational to experiences; a desire to maintain integrity of family unit may influence receptivity × <i>Hybridity</i>: keeping personal and workplace separate; maintain a persona at work which may be different with family and close friends in the

<ul style="list-style-type: none"> × Reciprocity: Interdependent relationships with other informal support networks ie. friends, social clubs: support can be positive or negative × Reciprocity: perception of impact or risk on members within family identified as impetus for being receptive to support × Reciprocity: review of and changes to friendships; receptivity selective to support × Scheduling conflicts × Time: social support maintained by family but diminishes over time with friends. 	<ul style="list-style-type: none"> home environment; individual, workplace and employees influence receptivity × <i>Socio-political</i>: compassionate workplaces may make employees more open to seeking support if workplace culture supports this; may also be more hospitable for bereaved when attending an organisation in relation to attending to practical matters × <i>Displacement</i>: no longer among mixed gendered informal support networks; may influence receptivity to mixed gender activities or leisure and social club networks × <i>Affinity diaspora</i>: linking bereaved with others who are bereaved to feel connection and reduce sense of aloneness may influence receptivity × <i>Affinity diaspora</i>: little attention in empirical bereavement literature given to the role of friends, acquaintances, social or service clubs; feel connection with others with whom they perceive an intimate relationship
<p>GEOGRAPHICAL</p>	
<ul style="list-style-type: none"> × Geographical dispersion × Geographical issues: social or community context in which support is situated × Availability and accessibility of resources 	<ul style="list-style-type: none"> × <i>Affinity diaspora</i>: informal social support networks may be receptive to support that empowers and equips them to support a bereaved loved one × <i>Socio-cultural</i>: generational influences ie. older generation may be less receptive to support × <i>Socio-cultural</i>; age related resources ie. capabilities versus needs eg. elderly may have less resources or capabilities to attend to practical matters × <i>Socio-cultural</i>: education level may influence receptivity × <i>Socio-political</i>: bureaucracies and organisational processes influence receptivity × <i>Socio-cultural</i>: gender socialisation influences help seeking behaviours × <i>Deathscapes</i>: virtual memorialscape enfranchise disenfranchised griever; can also foster <i>affinity diaspora</i> connecting bereaved within a virtual community thus an influencing factor in role of receptivity × <i>Transcendence</i>: role of informal networks in anniversaries fostering continued bonds; a collective 'affinity' diaspora
	<p>GEOGRAPHICAL</p>

	<ul style="list-style-type: none"> × <i>Embodied diaspora</i>: ‘home space’ - changes or keeping the same × <i>Deathscapes</i>: collective community grief may influence receptivity if public memorials/scapes done collaboratively and consensually
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Chapter Eight: Language in the *Bereavement Diaspora*

Language in the <i>Bereavement Diaspora</i>	
What is in the empirical literature?	NEW CONTRIBUTION Findings in this study that influence receptivity using concepts from the diaspora discourse
<ul style="list-style-type: none"> × Discourse/terms eg. closure; moving on; acceptance influence receptivity × Labels for grief and bereavement to describe ways of coping, tasks of mourning etc. developed through professional discourses 	<ul style="list-style-type: none"> × <i>Displacement</i>: marginalised as others do not understand inner world; language used can open up or shut down the bereaved × <i>Socio-cultural</i>: language created within the society of the individual × <i>Socio-political</i>: professional discourses maintain their power through ascribing the language of a phenomenon; tools used for assessment are embedded with the language of the discipline and the cultural context within which it is developed × <i>Language</i>: can enfranchise or disenfranchise × Diaspora promotes the language of the person and compels others to be open to the world of the bereaved

Appendix F: Desired Characteristics of Professionals: Bereaved and Health Professionals

The following tables describe the desired characteristics of professionals that influence receptivity according to a) bereaved participants and b) health professional participants.

a) Bereaved Participant Statements:

CHARACTERISTICS and TECHNICAL SKILLS of PROFESSIONALS: BEREAVED PARTICIPANTS	
<i>TECHNICAL SKILLS</i>	<i>TRAITS</i>
<p>Experienced <i>"...she's a gorgeous lady, she's very understanding and had lots of experience..."</i> ID: B: 3180: F; 70; Sp; 0-3; R3</p> <p>Competent <i>"...just discussing it, with somebody who has clinical knowledge..."</i> ID: B: 3072: F; 52; Sp; 6-9; R3</p> <p><i>"...there needs to be, certainly more palliative care nurses, with really good training..."</i> ID: B: 3180: F; 70; Sp; 0-3; R3</p> <p><i>"...[nurse] was [P]'s palliative carer he really, really, liked her. She was just lovely and she just knew the right things to say and do and she understood his personality..."</i> ID: B: 3113: F; 61; Sp; 19-24; R3</p> <p>acknowledges what you've been through <i>"...just an acknowledgement of the fact that you know what they've been going through..."</i> ID: B: 3391: F; 69; Sp; 13-18; R3</p> <p>has insight i) into bereavement; <i>"...someone who understands..."</i> ID: B:</p>	<p>Non-judgemental <i>"...someone to talk to who you know understands, who you know is not going to say "Oh for goodness sake get your act together" that kind of thing..."</i> ID: B: 3180: F; 70; Sp; 0-3; R3</p> <p><i>"...well I'm happy with home but I think sometimes with people I have my little shrine set up and sometimes they - it depends on [the person] -</i> ID: B: 3369: F; 53; Sp; 13-18; R1</p> <p>Empathetic <i>"...there's that connection, there's a connection....it's a good thing..."</i> ID: B: 3433: F; 60; Child; 13-18; R1</p> <p><i>"...they were just absolutely fantastic, empathetic and caring, just amazing..."</i> ID: B: 3076: M; 52; Child; 4-6; R1</p> <p>Genuine <i>"...I felt they were genuine and they really cared..."</i> ID: B: 3399: F; 65; Child; 13-18; R3</p> <p>Caring <i>"...Somebody cared for what I was going through..."</i> ID: B: 3725: M; 63; Sp; 7-9; R1</p>

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

ii) into deceased

"...She's good to talk to because she sort of understands and she knew [N]. I find a comfort if I'm talking to people who knew [N], rather than just talking to someone who I know but they didn't know [N], because they can kind of relate more..." ID: B: 3180: F; 70; Sp; 0-3; R3

iii) into family composition & dynamics (including pets)

"...I certainly think if the palliative care nurses, they're there when the family member passes away so they kind of know what's happening, different people [family members] are going to handle things differently..." ID: B: 3407: F; 44; Child; 7-9; M2

iv) into palliative care

"...At [hospice] the nurses couldn't have done more for me and my family, they were absolutely amazing. Now the advantage is they're all trained in a special way, because I believe it's a special calling to be that kind of a nurse, not everyone could do it. But I couldn't have had, as horrible as it was, I could not have had a better experience of the nurses and the care and the love and all that. And that's how it should be. ID: B: 3180: F; 70; Sp; 0-3; R3

Willingness to engage

"...having someone come to you who not only knows the situation but understands, is prepared to talk, is prepared to listen, prepared to guide..." ID: B: 3725: M; 63; Sp; 7-9; R1

Good listener

"...sometimes you just want someone to talk to who you know understands..." ID:

"...I just felt that the team here were very supportive and very caring and I really did appreciate that..." ID: B: 3399: F; 65; Child; 13-18; R3

humour

"...they were always come in with a smile and a joke and a laugh..." ID: B: 3400: M; 70; Sp; 13-18; R3

Open

"...they were good, open people..." ID: B: 3400: M; 70; Sp; 13-18; R3

"...Someone that, one I feel very comfortable, would understand where I'm coming from..." ID: B: 3072: F; 52; Sp; 6-9; R3

Selfless care

"... Without that display of selfless care it made a huge difference. It really did. I felt that I hadn't been forgotten..." ID: B: 3725: M; 63; Sp; 7-9; R1

Supportive

"...they were very supportive, they, you know I was able to take my time, have a cup of tea..." ID: B: 3407: F; 44; Child; 7-9; M2

Treats you like a human being

"...human being point of view - empathy from someone and to still be as caring..." ID: B: 3076: M; 52; Child; 4-6; R1

Honest

"...you want the truth..." ID: B: 3398: M; 67; Sp; 10-12; R3

Truth telling

"... You've got to tell them. You have to tell me that they're loved one is dying. You have to tell them to get all the answers to all the questions that are in

B: 3180: F; 70; Sp; 0-3; R3

Facilitates reminiscence

“...they were very supportive, they, you know I was able to take my time, have a cup of tea and couple of the nurses that worked a lot with my dad were there to talk to, and then we used humour there to, so you know reminiscing a little bit and just I guess be there as a bit of a sounding board, and they did that very well..” ID: B: 3407: F; 44; Child; 7-9; M2

Recognise grief is as important as disease and goes on for longer

“...nurses specialise in that area...grief is as important an issue as any kind of disease...” ID: B: 3180: F; 70; Sp; 0-3; R3

Responsive and productive

“...the fact that it was suddenly offered, the care and consideration and help with my emotional chaos that was a turning point more than almost anything else...” ID: B: 3725: M; 63; Sp; 7-9; R1

“...palliative care, they were very good. They came around within half an hour of my father dying and also the GP came around as well, very promptly which was very reassuring and spent a long time with my mother which was great...” ID: B: 3399: F; 65; Child; 13-18; R3

Someone who can normalise things

“...that's what you really need. It's good if you have issues by telling you it's normal if this happens...” ID: B: 3111: F; 68; Friend; 13-18; R3

“...it's making me a bit more comfortable, and thinking well even though there's nothing normal, I suppose most people like to think that they're a little bit

your mind...” ID: B: 3398: M; 67; Sp; 10-12; R3

Chatty

“...they [palliative care staff] are very friendly and chatty and open to, if you wanted to have that discussion with them...” ID: B: 3407: F; 44; Child; 7-9; M2

Someone with a smile on their face

“...I'd want someone with a smile on their face for a start. Someone who comes in and says well good morning and how are we today...” ID: B: 3388: F; 69; Sp; 13-18; R3

<p><i>normal... ” ID: B: 3180: F; 70; Sp; 0-3; R3</i></p> <p>Timely <i>“...you want a timely response, if you had someone like that, that was offering to help you out with things...” ID: B: 3072: F; 52; Sp; 6-9; R3</i></p> <p>Willing to explore and investigate their experiences <i>“...maybe someone who understands....I s'pose it wouldn't hurt to actually investigate the personal beliefs and needs of everybody...” ID: B: 3072: F; 52; Sp; 6-9; R3</i></p>	
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b) Health Professional Participant Statements

CHARACTERISTICS of PROFESSIONALS: PROFESSIONAL PARTICIPANTS	
<i>TECHNICAL SKILLS</i>	<i>TRAITS</i>
<p>confidence <i>“...their level of confidence to deliver that [bereavement support] ...” ID: HP: 3444: F; 50; Rem1</i></p> <p>don't have expectations re: grieving <i>“...around knowing or understanding what people feel about their bereavement and how they deal with it and not just expecting them to behave in a certain way...” ID: HP: 2888: F; 42; Rem1</i></p> <p>knowledge of family and previous deaths and experiences <i>“...it makes them feel like that person was not just a name - wasn't just another number and they were special - that they were cared for by people who knew their name and who knew the individual names of the family even though there were 50 of us - they knew the main ones you know that kind of thing and things like that...”</i></p>	<p>non-judgemental <i>“...I think that for here in particular, we've got to be careful not to make too many assumptions...” ID: HP: 3444: F; 50; Rem1</i></p> <p><i>“...I think you've got to be really, really careful to respect that and not judge it [humour] for one thing...” ID: HP: 3444: F; 50; Rem1</i></p> <p>not wanting to be intrusive <i>“...we haven't got a blanket approach, but, it really depends on the relationship with the family. If we've had a good relationship with the family and they've invited us...” ID: HP: 2888: F; 42; Rem1</i></p> <p>respectful of family dynamics and of social roles within family unit <i>“...some want how to talk to their family or how to get their family through it and</i></p>

ID: HP: ALO: 3412: F; 39; R1

good skills:

i) listening

“...Listening. Rule number one...” ID: HP: 2874: F; 53; Rem1

ii) interpersonal

“...building the trust and rapport is ideal...” ID: HP: 2874: F; 53; Rem1

“...I think it's very important that developing rapport and trust...” ID: HP: 3444: F; 50; Rem1

“...Relationship, yeh - if you've had a good relationship with the team or the team established a good relationship with them and that's some are going to come down to the quality of the people you've got working in the job and I guess how they maintain the relationship...” ID: HP: 3345: M; 55; R1

iii) knowledge of bereavement

“...GP's aren't always very good at it (laughs) at bereavement stuff because they've had no training in it...” ID: HP: 2888: F; 42; Rem1

“...the professionals, training, skills, education around bereavement. I think the professionals understanding in their role, they need to have a clear understanding of where do I sit with this in my role. Is this actually an expectation in my role, their level of confidence to deliver that and I guess where they are at that point in time too...” ID: HP: 3444: F; 50; Rem1

proved their worth in delivering outcomes

“...they see that you were there, you know, trying to guide and end of life

concerned about their loved ones or their loved ones having concern about them or they're concerned about their family and how they're coping and things like that - what to do around those sort of things...” ID: HP: 3345: M; 55; R1

she had a 10 year old Downs Syndrome boy who was her son, but not her husband's child, but for all intents and purposes he was dad to this boy, and she wanted everything nicely signed, sealed and delivered for this boy's future before she died, but she died much faster than anticipated and things weren't in place. So she had wanted him to be the boys' legal guardian and she wanted finances and that set up for him, for the future. And all that was stipulated in a very complex Will she had drawn up, but it didn't cover this boy's needs, so I became involved on that capacity. But she'd been away in hospital for quite some time and she'd been absent from his life for several months, so he didn't realise how sick she was and didn't have an understanding of what was going on, and then she came back and he was at school when she became terminal, and the hospital and Dad were wondering whether to have him at the hospital when she was dying, and I encouraged them to please go and get him from school, to at least give him the opportunity to be there. And they thankfully did and he didn't want to be by mum's bedside, but he stood in the doorway as she passed away... I had tried to work with dad, not only on the guardianship issue so there was a whole lot of legal and financial stuff and support issues around this boy, but also working with dad on trying to create a memory box or some sort of tangible thing that this boy could turn to when he was feeling that he needed to be

planning...and...practical. You know, equipment and...service provision and respite. All of those parts of the job were hopefully being put in place when they could be. When the person was dying and then so the bereaved see you over time...”
ID: HP: 2874: F; 53; Rem1

“...I think the team would have to be seen as fairly accessible and worthwhile following up with or worthwhile going back to...” ID: HP: 3345: M; 55; R1

“...you make some choices about who you're going to go to because they've either met your need in a way that you think is good or worthy and they are somehow professional... it might also be seen to be of value because no-one wants to go to someone who's of no value ...”
ID: HP: 3345: M; 55; R1

willing to explore and investigate the bereaved experiences

“...to give them a space and permission to raise what ever they want to talk about in terms of their grief ...” ID: HP: 2874: F; 53; Rem1

is not prescriptive; guided by client

“...to give them a space and permission to raise what ever they want to talk about in terms of, you know, their grief, ah, it's a gift...” ID: HP: 2874: F; 53; Rem1

“...I think it's important to ask people too. If you can establish early on what is usual maybe for that person and the family and their culture and then if you want to be say from a service perspective and be prescriptive about it, maybe that's what part of you do is you try and capture what that person expects its going to look like for them...” ID: HP: 3444: F; 50; Rem1

closer to mum. And dad wasn't very in tune with this, but thankfully a teacher was, and through discussions with the teacher, she created a little book based on, just a little kids book that she then cut and pasted pictures of mum and the boy in to and it just told the story about how mum had fallen ill, had been sick and then had died and gone up to the stars and how he missed her; and this little boy carries...” ID: HP: 3334: F; 43; R1

remembers likes and dislikes

“...when you know someone then you know what they liked and didn't like...and the dog that still pines for her. You know, we talked about the dog and how the dog was coping in grieving and then that was also a symbol of how the family was doing and because I got to know them so well, over time, I'd see them at the shop and you know....you'd form those connections in small country towns that you may not in other places...” ID: HP: 2874: F; 53; Rem1

engenders a sense of safety in bereaved

“...Quite often people will come back and say look I'm not coping, what can I do? Where can I go? So they're familiar with us, and they come back to what they know is familiar...” ID: HP: 3334: F; 43; R1

human connection

“...the clients that I did connect with and did provide bereavement support to, it was about supporting them in the journey. So not only when their loved one was dying and then did die, but also afterwards, so for them it felt, hopefully, well, that's the feedback I got that they were supported... what they were saying

embrace educative role (to communities, informal support networks and other professionals)

“...I definitely think it should be a broader approach. The community approach I think, which is, being, you know, making people aware about bereavement and what, what services are out there and how they can access them, would, would be really good because at least, you know, they'd know where to go if they thought that their family member wasn't coping, or that, or that they felt themselves weren't coping, they knew where to go next...” ID: HP: 2888: F; 42; Rem1

“...promoting community awareness of bereavement essentially and information...” ID: HP: 2888: F; 42; Rem1

to me was that follow up, that connection and that ongoing nature of the connection, they found incredibly supportive...” ID: HP: 2874: F; 53; Rem1

“...I think if they come back through our service, it's purely the relationship, and the positiveness of the relationship that they've had with perhaps our service or individuals within our service, so the familiarity, the relationships, the knowledge that we exist...” ID: HP: 3334: F; 43; R1

“...So I think connection is a big thing for me. Now I think that's a Social Work thing. I really do, I think that's a Social Work thing but I think it's a human thing as well....So I think, yeh, connection and the ability of the staff to make the connection, maintain that connection... and there's some connection. So I think connection is a big thing for me” ID: HP: 3345: M; 55; R1

provides quality care and concern is trustworthy

“...Sometimes it can be a very short process and a more recent one that I wasn't involved in - it was so intense in the few short days that they've gone from having a healthy parent to dying a few short days. Even if that's managed well and we haven't had a long relationship, but it's been intense so they're able to make contact... it's the quality of it really. Normally the quality of that initial contact, getting the conversations right...” ID: HP: 3389: F; 54; R3

Appendix G: Receptivity Enablers and Barriers to Bereavement Support

The following table outlines enablers and barriers to bereavement support as identified by all three cohorts. Preferred characteristics of health professionals that contribute to a positive therapeutic relationship were discussed in chapter nine. Convergent and divergent perspectives are outlined in the tables below. Participants are reflected in the following coloured asterisks: *Bereaved *Health Professionals *Bereaved Aboriginal Health Professionals.

ENABLERS: Findings from all three cohorts

RECEPTIVITY ENABLERS: BEREAVEMENT SUPPORT PROGRAM	
<p>PRE-EXISTING THERAPEUTIC RELATIONSHIP with family***</p> <ul style="list-style-type: none"> • When there has been perceived successful anticipatory planning ** • For clinical care* • For psychosocial care* • Truth telling that loved one was dying* • Getting conversations right prior to death* • With palliative care service ** • Familiarity of team* • Good positive rapport* • Therapeutic relationship makes the bereaved feel safe* • Human connection** • Quality of care and concern* • Trust** • Staff need to be approachable* • Already known in community so will be accessed* <p>MATCHING: *** Client with staff (prefer palliative care team member) * Compatibility with bereaved*</p> <p>VOLUNTEERS: to assist with practical matters*</p> <p>COSTS:</p> <ul style="list-style-type: none"> • Little* • None* 	<p>SKILLED STAFF***</p> <ol style="list-style-type: none"> i) Clinical ** ii) Counselling ** <ul style="list-style-type: none"> × Provide clinical debrief ** iii) Spiritual* iv) Knowledge of <ul style="list-style-type: none"> × Grief, loss and bereavement* v) Experience working with: <ul style="list-style-type: none"> × Grief, loss and bereavement* vi) Assessment*** <ul style="list-style-type: none"> × Assess early on what is usual for person, family, culture & spirituality** × Awareness of previous deaths and their experiences** vii) Self-awareness* <ul style="list-style-type: none"> × Insight into own stuff* <p>Clarity of role*</p> <p>DEDICATED BEREAVEMENT PERSON: *** Coordination: Having a ‘go to’ person***</p> <ul style="list-style-type: none"> • Link bereaved in with each other in local community* • Someone who can mobilise community resources ** • Someone who can put a barrier between debtors & family** • Someone who can be a repository for all accounts etc. for a 3 to 4-month period until probate goes through* • Someone who can coordinate linkage with other services*

RECEPTIVITY ENABLERS: BEREAVEMENT SUPPORT PROGRAM

PRINCIPLES of PROGRAM:

Guided by the individual (client directed) ***
 Not prescriptive (time frames etc.) **
 needs to be readily available; don't need to chase after it *
 needs to be accessible*

PREFERRED PROVIDER:

Palliative care team members to provide bereavement support*

- To initiate contact **
- Need to be accessible (team/staff)*
- Consent*
- Has insight into family and deceased (knowing likes & dislikes; family composition) ***
- Continuity of contact/care*
- Not having a universal 'blanket' approach (explore what person expects bereavement support will look like for them) *
- Open door policy*
- Skillset of staff*
- Support and educate informal networks too*

PURPOSE:

- needs to be meaningful**
 - × *to feel you haven't been forgotten**
 - × *to reduce sense of being along**
- needs to have purpose**
 - × *to support aged / elderly**
 - × *to support those with limited support networks**
- to provide reassurance*
- to normalise experiences**
- to be private and confidential**
- needs the bereaved to guide it**
- Processes need to be made explicit: **
 - × Consent **
 - × Expectations*
 - × Goals*
- Informing them what it's about, for and processes ie. contact etc. **

PREFERRED CONTACT:

- Face to Face **
- Phone ***
 - × *Anonymity**
 - × *In own time**
 - × *Not intrusive**
- Skype*
- Website – Vlogging / Blogging / SNS*
- Texting / email*
- Regular*
- semiformal*

PREFERRED VENUE:

- Clinic*
- "comfort zones" eg home*
- Home **
- Flexible depending on client*
- A 'one-stop-shop'***
 - × *Independent of 'conflict of interest'**
 - × *Not a big bureaucracy; community run; more intimate specialised service for everything bereavement**
- To assist with practical and information *
 - × *Advocacy**
 - × *Notifications**
 - × *Paperwork**

RECOMMENDED TARGET GROUP for SUPPORT:

- elderly*
- nominated by deceased prior to death**
- others in family who may need it; not necessarily N.O.K*
- single people*
- those living alone*
- those who are socially isolated*
- those overwhelmed emotionally**
- those overwhelmed with practical tasks*

RECEPTIVITY ENABLERS: BEREAVEMENT SUPPORT PROGRAM

PREFERRED SCHEDULING AND TIMING:

Scheduling*

- Impromptu and opportunistic*
 - × *From friends**
 - × *From palliative care service**
- In client's time (convenience) *
- Not feeling like being squeezed into busy staff schedule*
- Not feeling rushed*
- Not restricted to finite number of visits*
- Not prescriptive*
- Schedule firm appointments*
 - × *Gives motivation to have shower; put on clothes and get out of house**
 - × *Palliative care to book and diarise dates – commitment motivates**
- Night time (for therapeutic groups) *
- Open door policy ***
- Assist to attend appointments as may have other responsibilities*

Timing*

- Initial stages post death*
 - × *After the initial shock and grief but still fairly close after death**
 - × *To provide guidance, information, next steps**
- Optimal time markers for contact post death*
 - × *Immediately post death to collect equipment and answer questions**
 - × *1-2 weeks **
 - × *1 month **
 - × *4-6 weeks**
 - × *3 months**
 - × *6 months**
 - × *12 months**
 - × *Anniversary dates – birthdays; date of death; wedding**

Length of Time*

- For the first year*
- For the first 2 years *
- Open ended ***

INFORMATIONAL SUPPORT:

- Awareness of what's available – list of community resources*
- Checklist of who to notify*
- DVD about grief from others' perspectives and experiences (normalises) *
- Want a conversation or someone to talk to – not just handed pamphlets*
- Websites: *
- where to go to get support / assistance / information*
- what to do ie. dealing with deceased estate*
- what to expect with grieving*
- connecting with others*
- Let them know the service is still there to support if/when required*

INSTRUMENTAL SUPPORT:

- Basic serves: laundry, cleaning, carpets shampooed
- Chopping wood*
- Cooking*
- Financial ***
- Legal ***
- Someone to help with notifications and fill out forms ***
- Referral to other agencies **
- Attend to health care needs*
- Practical support with child care needs*
- Catching up with things neglected during caregiving*
- Assistance to learn new household tasks*
 - ✓ *Animal care**
 - ✓ *Maintenance of property**
 - ✓ *Small farm operation**

COMPLEMENTARY THERAPIES

- 3-4 times post death*
- Volunteer beautician*

RECEPTIVITY ENABLERS: BEREAVEMENT SUPPORT PROGRAM

EMOTIONAL SUPPORT:

Counselling*

- Up-skill nurses to provide*
- Prefer palliative care team members*
- Opportunity for clinical debrief with staff*
- Forward looking & backwards exploring*
- Normalising experience*
- Up-skilling of GP's*
- Acknowledge the different ways of coping*
- Acknowledge what the carer has been through*
- Affirming it will take time and they'll be ok*
- Active listening*
- Providing a 'holding space'*
 - ✓ *let them lead what they want to talk about**
 - ✓ *privileging the relationship and the 'holding space'**
 - ✓ *support to explore their understanding**
- validating frustrations and hurts*
- provide reassurance*

Spiritual support*

Informal support networks*

- Don't want to burden with emotional needs – would prefer to access to palliative care team members*
- Preferred to access for support*
- Support networks to assist with memorialisation activities*
- To provide companionship on anniversaries*

Peer to Peer*

- Informal cuppa's*
- Peer support groups*
- Having someone to accompany on 1st group*
- Mixed gendered groups*
- Very small groups or low numbers*
- Same disease specific groups *

Have a trained facilitator*

ACKNOWLEDGEMENT from palliative care service*:

- Card**
- Memento**
- Staff attend funeral*

RURALITY

- Geographically closer to resources*
- Availability of resources (days/times) *
- Nature of resources available*
- Remote area nurses*
- Spiritual leaders eg. pastor, minister etc.*
-

BARRIERS: Findings from all three cohorts

RECEPTIVITY BARRIERS: BEREAVEMENT SUPPORT PROGRAM	
<p>INDIVIDUAL FACTORS: PERSONALITY</p> <ul style="list-style-type: none"> ● Introverted* <ul style="list-style-type: none"> × Private person** × Not open** × Stubborn* × Don't want people interfering with your thoughts* × Private world of grief* ● Hiding vulnerability** <ul style="list-style-type: none"> × Maintaining face* × Putting on a brave face* × Trying to prove can cope* × Don't talk about it – fear breaking down* × Self-deception* × Don't want to feel embarrassed* × Hard to admit support needed* ● Imposition* <ul style="list-style-type: none"> × Don't want to be a burden on others* × Don't want to impose on others* ● Independence factor*** <ul style="list-style-type: none"> × Self-determination** × Self-reliance* × Self-efficacy** × Don't want help from others* × Don't like to be fussed over* × Did not feel needed professional support* × Prefer to do by self* × Capabilities* <ul style="list-style-type: none"> ✓ Amazing* ✓ Can cope* ✓ Not shy* ✓ Self sufficient* ✓ Strong* ✓ Tough* ✓ Resilient** ● Perception* <ul style="list-style-type: none"> × Fear of Stigma*** ✓ Mental health label*** 	<ul style="list-style-type: none"> ● Expectations* ● Overwhelmed* ● Faith is a source of support** ● Attitude* <ul style="list-style-type: none"> × Feel driven to do on own* × Prefer to handle everything by self* × Likes feeling sense of achievement* × Felt should do by self* × Anti-help/assistance* ● Worthiness* <ul style="list-style-type: none"> × Feeling worthy of help* × Did not feel reaching out for help justified* × Don't feel worthy* × Minimisation* × Everyone has their own problems* × Someone else might need it more* ● Asking for help* <ul style="list-style-type: none"> × A sign of weakness** × Don't want to do it constantly* × Feel guilty for asking* × Find it very hard to ask for it* × Hate having to ask* × Just did not occur to reach out* × Not in nature to ask* × Reluctant* ● Health* <ul style="list-style-type: none"> × Physical illness* <p>BEHAVIOURAL FACTORS</p> <ul style="list-style-type: none"> ● Coping patterns* <ul style="list-style-type: none"> ● Increased alcohol intake** ● Keeping busy* ● Health* ● Exhaustion* ● Physical illnesses* ● In 'survival mode'* ● Influenced by upbringing - stoicism*

RECEPTIVITY BARRIERS: BEREAVEMENT SUPPORT PROGRAM

BEHAVIOURAL FACTORS cont...

- *Bottle things up**
- *Denial – don't want to acknowledge death**
- *Resistant to support**
- *Resigned to chronic sorrow & enduring grief*
- *Exhaustion and depleted personal resources**
- *'organisation fatigue'**

SOCIAL FACTORS

- *Busy Lifestyle***
 - × *Scheduling conflicts***
 - × *Other responsibilities ***
 - × *Work commitments***
- *Costs**
 - × *Services cost**
 - × *Cost to travel to services**
 - × *Prefer to pay for service than ask for favours**
- *Gender*
 - × *socialisation**
 - × *Conscious of having another male in the house**
- *Informal support****
 - × *Need 'concrete' offers**
 - × *Nobody asks***
 - × *Very supportive; did not need to look elsewhere****
 - × *Well supported by community; did not need to ask for other help***
 - × *Community nosy/intrusive; wanted to keep to own business**
 - × *Families are best placed to support each other****
 - × *Self-efficacy of family unit**
 - × *Prefer to talk to friends****
 - × *Church community****
- *Expectations**
 - × *Imposed by others***
 - ✓ *Get on with your life**
 - ✓ *Would cope**

SOCIAL FACTORS continued:

- ✓ *Doesn't need help; able to cope on own**
- ✓ *'normal' grief**
- ✓ *Others judgemental**
- ✓ *Of timeframes**
- × *Imposed by self***
 - ✓ *Have to be strong for kids**
 - ✓ *Have to get through it**
- *Self Censuring***
 - × *Don't want to bore people**
 - × *Don't want to drive people away**
 - × *People don't understand so won't talk to them**
 - × *Others may think it odd – continued relationship with deceased**
 - × *Unhelpful things people say**
 - × *Things people say shut bereaved down**
 - × *Wife's death compared to death of pet dog**
 - × *Traditional communities have own resources**
 - × *'Virtual communities' support*
Cultural practices***

GEOGRAPHICAL FACTORS

- *Costs***
 - × *Cost of services & living high***
 - × *Of fuel to travel high**
- *Resources & Services**
 - × *Ever changing resource landscape****
 - × *GP's rotate; keep changing***
 - × *Not available locally****
 - × *Limited in rural areas***
 - × *Specialist services don't exist in rural areas***
 - × *Non-existent***
- *Lack of confidentiality & privacy***
 - × *Will see counsellors at shop or pub**
 - × *Lack of privacy**
 - × *Everyone knows everyone**
 - × *Everyone knows what's happened**

RECEPTIVITY BARRIERS: BEREAVEMENT SUPPORT PROGRAM

GEOGRAPHICAL FACTORS continued...

- × *The community 'monitors' the bereaved**
- Social Isolation*
 - × *Live too far out of town – no-one visits**
- Tyranny of distance**
 - × *Resent having to travel so far for services etc. **
- Rural Culture
 - × *Rural apathy to attend memorial**
 - × *Rural 'social collateral'**

BEREAVEMENT SUPPORT / PROGRAM

- Was not aware it existed**
- Don't know what's available**
- Lack of advertising/promoting**
- Did not seem to have purpose*
- Centralised*
- Metrocentric – lacked insight to rural nuances*
- Lack of funding for services locally*
- Limited numbers to access group support*
- Range of support available restrictive*
- Skeleton staff*
- Not readily accessible*
- Don't know where to go*
- Restricted by commitments of role*
- Not targeted to right person*

PRE-DEATH FACTORS

- No truth telling*
 - × *Missed opportunities with loved ones**
- Relationship with health professionals**
 - × *Shut down by palliative care nurse*
- The Acute Care Setting***
 - × *Staff in hospitals elusive**
 - × *Staff in hospitals avoid you**
 - × *Small rooms when person dying**
 - × *Doesn't cater to cultural issues**
- No links with others in same boat for post support*
- Previous experiences – knew what to do and expect*

PRE-DEATH FACTORS continued...

- Previous experience with Western health care bad*
- Late referrals impact*
- Poor communication between metro and rural services*

STAFF

- Expect a 'normative' grieving response*
- Do not have skills/insight to bereavement***
- Recommended to go on anti-depressants ('sad, not depressed!') *
- Personalities not warm or compassionate*
- Previous bad experiences – lose trust / faith**
- Not specialised*
- No compassion*
- No longer accessible*
- Part time availability*
- Not good communicators*
- Poor listening skills*
- Lack of confidence*
- Lack of experience*
- Lack of training*
- Use old models of grief and loss*
- Professionalism gets in the way of humanness*
 - attitude*
 - high turnover*

THERAPEUTIC RELATIONSHIP*

- No connection*
- Non-existent **
- Distrust of health professionals*
- Don't want to add burden on already busy staff**
- Poor experiences pre-death*
- Age – perception of health professionals – too young looking = no value*

RECEPTIVITY BARRIERS: BEREAVEMENT SUPPORT PROGRAM

THERAPEUTIC RELATIONSHIP

continued...

- Cultural incongruence**
- Cultural ignorance**
- Miss 'cultural cues'**
- Non-English speaking background**
- Organisational infrastructure does not cater to cultural need*

STRUCTURE

- Duration not long enough*
- Long wait times for counselling*
- Finite number of contacts*
- Group programs*
- Feel helpless in the pain of others in a group*
- Not facilitated by qualified staff*
- Not having a firm/set appointment*
- Venue not convenient*
- Counselling*
 - × *Can't see how counselling can help**
 - × *Counselling exacerbates the experience**
 - × *Previous experiences negative**
 - × *Uncertain if the help will have any value***
 - × *Seen as threatening**

RESOURCES

- Paraphernalia*
- handed out too late*
- too prescriptive*
- Absent of personal stories*
- Too 'textbooky'*
- Information overload ('showbag' approach)*

CONTACT:

- Emails / texts – *impersonal**
- Letters / fliers – *too repetitive**
- Memorial service – *feels like another funeral***
- Not having person to person contact a deterrent*
- Not a 'social networky' type of person*
- Phone contact**
 - × *Did not find comfort**
 - × *Found threatening**
 - × *Hard to talk on the phone**
 - × *Found it invasive**
- Intrusive**
 - × *not invited***
 - × *Too much contact**
 - × *Unsolicited contact***
- Timing*
 - × *Not ready for it**
 - × *Not convenient**
 - × *Too late**
- Wanting to initiate contact by self*
- Cold calling*

MATCHING

- Incompatible**
- Not sure why matched with volunteer**
- Felt obliged to engage*
- Did not know the process to change if unhappy with nominated person*
 - × *Resented being put in a position of requesting another person**