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

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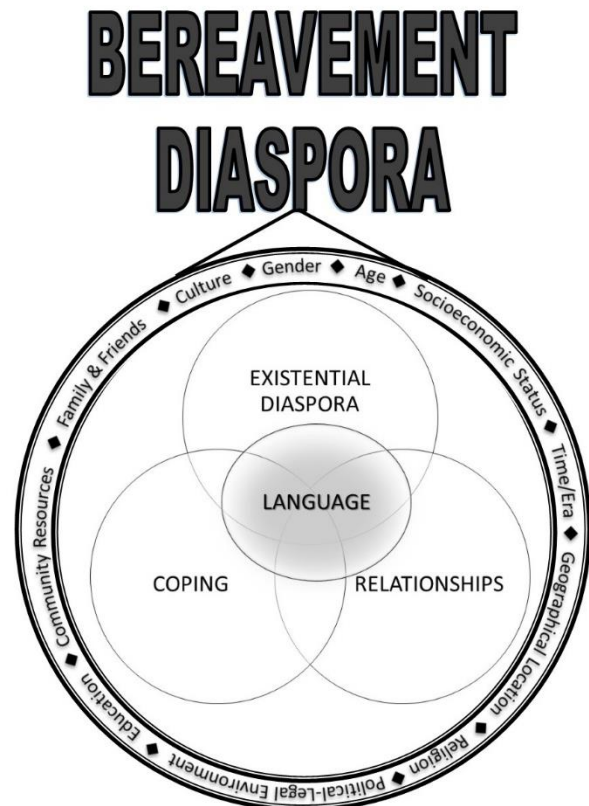
Chapter 9: Bereavement Diaspora and Receptivity

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; Holtslander & 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:

“...*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 ...*” ID: HP: ALO: 3412: F; 39; R1

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>	<p><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...”</i> ID: HP: ALO: 3447: M; 49; R1</p>
<i>Infrastructural issues</i>	<p><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>

	<p><i>Aboriginal families - they know Aboriginal families come - they're mobbed - but they're still not doing it...</i>" ID: HP: ALO: 3412: F; 39; R1</p>
<p><i>Staff technical skills</i></p>	<p><i>"...they are not trained as palliative nurses..."</i> ID: HP: ALO: 3412: F; 39; R1</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

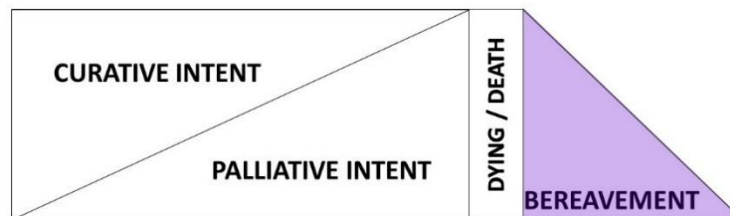
Receptivity factors were previously discussed throughout the previous chapters and were examined through the lens of diaspora. These are outlined in *Appendix E: Overview Bereavement Diaspora Receptivity Issues (Chapters 5-8)*. There were many additional receptivity enablers and barriers that emerged 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.