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

Pippa Blackburn

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## Chapter 7: Relationships in the *Bereavement Diaspora*

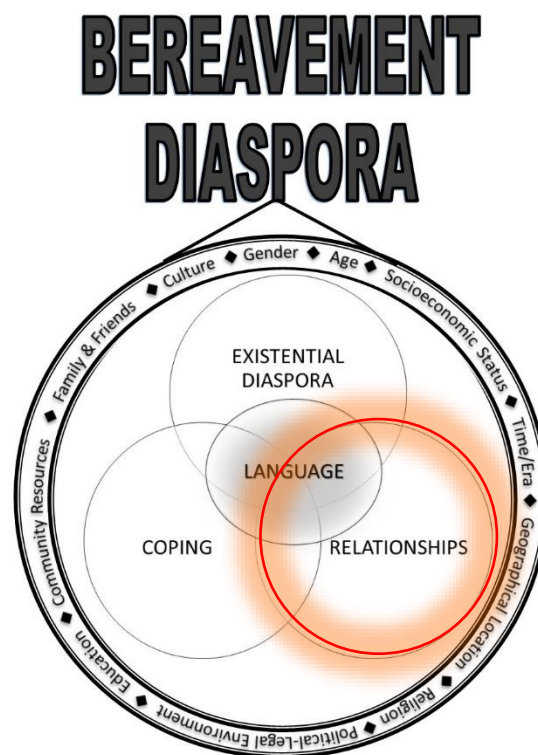
### Introduction

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

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

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

Figure 21: *Bereavement Diaspora: Relationships*

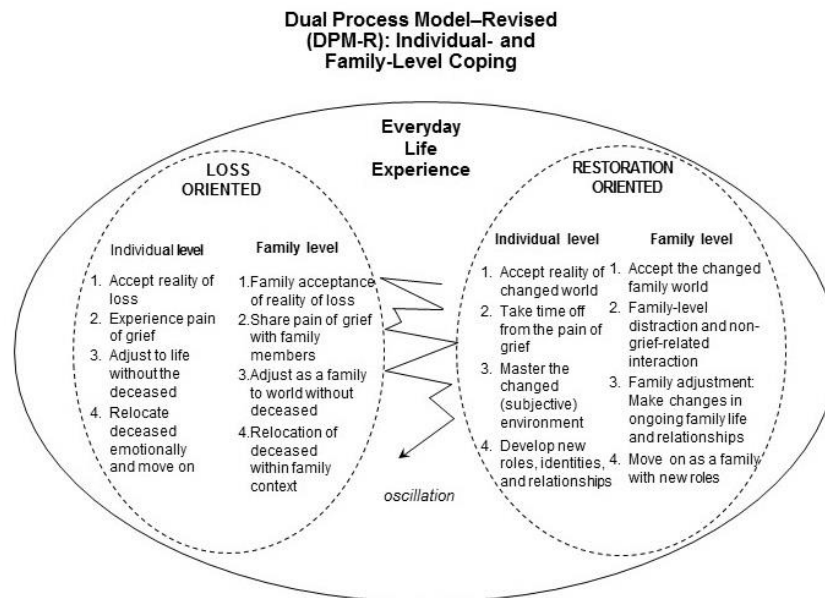


Understanding the role of interdependent relationships in the *bereavement diaspora* can provide insights into how or why people seek help during grief. The diaspora discourse contributes integration of family and community to the situatedness of being-in-the-world and coping in the *bereavement diaspora*.

### Relationships: A Mediator in the Bereavement Experience

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

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



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

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

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

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

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

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

**a) *Bereavement Diaspora: Connection with others***

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

***b) Hybridity: Changing roles in relationships and family identity***

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

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

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

***d) Displacement: Collective grief***

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

*e) Embodied diaspora and transcendence: Ongoing presence of deceased*

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

*f) Deathscapes: Shared sacred spaces*

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

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

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

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

### **Implications of Relationships in the Bereavement Diaspora and Receptivity**

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

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

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

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

*a) Bereavement Diaspora: Connection with others*

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

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

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

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

#### ***b) Hybridity: Changing relationships and family identity***

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

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

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

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

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

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

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

***d) Displacement: Collective grief***

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

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

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

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

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

***e) Embodied diaspora and transcendence: Ongoing presence of deceased***

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

***f) Deathscapes: Shared sacred spaces***

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



## Conclusion

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

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