

Theses

2017

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

Pippa Blackburn

Follow this and additional works at: <http://researchonline.nd.edu.au/theses>

 Part of the [Nursing Commons](#)

COMMONWEALTH OF AUSTRALIA
Copyright Regulations 1969

WARNING

The material in this communication may be subject to copyright under the Act. Any further copying or communication of this material by you may be the subject of copyright protection under the Act.

Do not remove this notice.

Chapter 2: Setting the Context

Introduction

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

Grief, Loss and Bereavement

Clarifying the concepts: Grief and Bereavement

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

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

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

Bereavement Research

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

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

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

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

Impact of bereavement on family and community

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

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

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

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

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

Theoretical perspectives of grief and bereavement

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

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

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

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

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

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

pathologised reactions and behaviours and introduced the notion that continuing bonds with the deceased could be adaptive or healthy coping. This is a significant change to historical practices in working with the bereaved where people are no longer expected to ‘de-cathect’ or forget about the deceased, but instead are encouraged and supported to maintain a relationship with the deceased that emotionally relocates them but continues (Klass, Silverman & Nickman, 1996). Process models such as the Dual Process Model (DPM) of coping in bereavement recognise the many concurrent stressors bereaved individuals contend with while attending to their grief. The DPM has key features of loss-orientated activities (that encourage grieving through affective, cognitive and behavioural means) and of restoration-oriented activities (which facilitate re-engagement in tasks, relationships and living). The bereaved adapt in bereavement through adopting dynamic coping strategies and processes that oscillate between loss and restoration oriented activities (Rubin, 1999; Stroebe & Schut, 1999). Hence bereavement should be viewed as a complex interplay between many mediators: cognitions, emotions, behaviours, social milieus and spirituality as well as physiological changes in the brain and body (Gundel, O’Conner, Littrell, Forth & Lane, 2003; Najib, Lorberbaum, Kose, Bohning & George, 2004; Freed & Mann, 2007; Coan, 2010).

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

Bereavement Support in Palliative Care

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

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

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

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

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

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

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

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

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

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

International perspectives on bereavement support in palliative care

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

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

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

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

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

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

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

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

Bereavement assessment in palliative care

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

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

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

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

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

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

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

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

Bereavement in Rural Western Australia

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

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

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

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

Bereavement and Aboriginal people

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

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

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

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

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

Support needs of the bereaved

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

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

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

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

Receptivity and Bereavement

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

Exploring the concept

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

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

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

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

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

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

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

Receptivity Definition

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

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

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

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

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

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

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

Receptivity to bereavement support

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

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

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

Conclusion

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

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