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Psychosocial and bereavement support for family caregivers of palliative care patients: A review of the empirical literature

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Chapter 1. Introduction to family caregiving in the context of palliative care

1.1 Palliative care in Australia

Palliative care is defined as specialised health care and practical support for people with a terminal illness and their families. This care may be provided in the home, an aged-care facility or other residential facility and in hospice or hospital settings (Palliative Care Australia, 2003). Specialist palliative care services involve consultative and ongoing care for patients and family caregivers during the patient's illness and in bereavement. It is estimated that specialist palliative care services are involved in the care of approximately 37.5% of all people expected to die in Australia each year (Palliative Care Australia, 2005). According to Macleod (2008) the services typically provided by specialist palliative include:

- assessment, advice and care for patients and families
- specialist in-patient facilities (in hospices or hospitals)
- intensive co-ordinated home support (e.g. community nursing)
- medical, psychosocial and emotional support and care in the home
- day care facilities with a range of services (e.g. physical, psychological and social interventions)
- advice and support to all people involved in patient's care
- bereavement support services for caregivers and families following the patient's death
- education and training in palliative care.

These services should be provided by specialist teams that include palliative medicine and palliative care nurse specialists, as well as professional support from physiotherapists, occupational therapists, art and music therapists, psychologists, social workers and those able to provide spiritual support (Macleod, 2008).

Due to social and economic demands on health care services, there is major encouragement for home care and a home death (Aoun & Kristjanson, 2005; Kellehear, 2009). While it is estimated that one third of terminally ill patients die at home, it is reported that In Australia and the UK, up to 90% of terminally ill patients spend the majority of their time in the home (Palliative Care Australia, 1998; Robbins, 1998). Community based palliative care services are established on the basis of availability of care from family, friends or the community (Palliative Care Australia, 2005). It has been shown that the absence of a family caregiver can reduce the likelihood of being cared for in the home and dying in the home (Grande, Addington-Hall, & Todd, 1998).

Family caregivers of palliative care patients shoulder a plethora of responsibilities including personal hygiene, medical care, emotional support, financial and legal tasks, household duties, patient advocacy and consultation with health professionals. It is widely acknowledged that without this input from caregivers the quality of patients' end-of-life care would be compromised (Stetz & Brown, 1997). As public health costs rise, populations age and health care shifts from institutions to the community, palliative care is shifting into the home with longer patient survival time in the terminal phase (Candy, Jones, Williams, Tookman, & King, 2009). This can place considerable burden on caregivers who are vulnerable and lack adequate resources to sufficiently prepare for this complex role (Aoun & Kristjanson, 2005).

1.2 Support for the primary caregiver and family

P. Hudson and Payne (2009b) have outlined several reasons why governments and health and social care agencies should offer support to family caregivers:
- caregivers are profoundly affected by the patient's terminal illness
- caregivers are responsible for numerous tasks
- caregivers are prone to physical and psychological morbidity

- caregivers are financially disadvantaged
- caregivers have limited exposure to death and dying
- caregivers are pivotal in achieving 'successful' home care
- caregivers are often excluded from information and care planning
- caregivers can become socially isolated
- caregivers commonly report unmet needs.

The World Health Organisation (WHO) advocates that palliative care should improve the quality of life of patients and their families facing problems associated with terminal illness (World Health Organisation, 2002).

Palliative care services are ideally placed to provide support to caregivers and family members of terminally ill patients. Service providers are often in close contact with families and have the opportunity to build rapport and trust over a period of time. The potential benefit of obtaining support from a specialist palliative care program was shown in a US cohort study whereby 30,838 elderly couples were retrospectively matched on the basis of whether or not the decedent was the recipient of hospice care. Findings showed that the surviving spouse of decedents who received hospice care were less likely to fall ill and die during bereavement than spouses of decedents who did not receive hospice care (Christakis & Iwashyna, 2003).

Within Australian health policy standards it is explicitly acknowledged that the needs of primary caregivers and family members should be considered as an integral component in the provision of specialist palliative care services (P. Hudson & Payne, 2009b). Furthermore, it is deemed best practice for this duty of care to extend into the phases of post-patient death and bereavement (Palliative Care Australia, 2005; Relf, Machin, & Archer, 2008). In recent years, the importance of developing and identifying support interventions for caregivers involved in terminal care has been recognised by a number of health care agencies and research bodies (Candy, et al., 2009; Eagar et al., 2007; Palliative Care Australia, 2004). Despite the evidence of caregiver burden, there are minimal evidence based strategies or interventions to ensure effective delivery of support to caregivers and families of palliative care patients.

While the national standards for palliative care services endorse this principle in many countries (Relf, et al., 2008), it is not always feasible to provide care for all family members of a palliative care patient. In an effort to set realistic objectives in the provision of palliative care, it has been recommended that support should focus on the needs of primary caregiver(s) in the first instance and where resources allow, the entire family (P. Hudson & Payne, 2009b; Relf, et al., 2008).

Primary caregivers) usually provide primary support for the patient at all levels of need. They may be the patient's spouse, child, another family member or a friend. Although the primary caregiver may be supported by other caregivers, they generally assume primary responsibility for the co-ordination and provision of care and support to the patient (Palliative Care Australia, 2005).

1.3 The literature review

The purpose of this report was to review the literature related to family caregivers of palliative care patients (published in the last decade). The specific objectives of this review were:

(1) To outline the experiences, impact and needs of family caregivers during care provision for their relative and into bereavement.

(2) To review evidence based psychosocial and bereavement support interventions for family caregivers of palliative care patients.

(3) To provide a basis for the development of best practice guidelines for health professionals in order to assist them to respond to the psychosocial and bereavement needs of family caregivers of palliative care patients.

1.3.1 Outline of review

Part one of this review describes the experiences, impact and needs of caregivers of palliative care patients. A comprehensive review of support interventions for caregivers of palliative patients is also presented. Part two of this review focuses on the impact of bereavement on caregivers following the death of the person previously under their care. The risk factors for complicated bereavement, needs of the bereaved caregivers and a review of bereavement interventions is presented.

1.3.2 Process of identifying and reviewing literature

(1) Given the aim of the current literature review was to obtain recent findings in palliative care and caregiving research, a systematic search of key electronic databases (EMBASE, PsycINFO, MEDLINE and CINAHL) was conducted to source literature published since 2005. Cochrane reviews were examined separately. The electronic searches were limited by the following inclusion criteria:

- published between 2005 and 2009
- published in English language
- containing studies with populations of adult caregivers who are caring for adult patients (adult was defined as over the age of 18 years).

The following is a list of the terms employed in the electronic search:

(a) Palliative care / terminal care / hospice care / terminally ill / terminally ill patients / palliative therapy / palliative nursing / hospice nursing / death and dying / bereavement;

(b) Caregivers / caregiver burden / caregiver / caregiver support; and

(c) Palliative care / terminal care/ hospice AND caregivers/family/grief/death/bereavement AND support/Interventions/therapy.

(2) To obtain an overview of literature published between the years 2000-2005, we relied on key reviews and other seminal articles, reports and texts. These publications were sourced through the electronic search and from recommendations by the study investigators. This method of 'reviewing the reviews' has been previously used and described in other major literature reviews (Center for Advancement of Health, 2004). The key papers identified for this purpose are presented in Table 1.

Table 1: Key literature reviews utilised in the current report (2000-2009)

Literature reviews of caregiving in the context of palliative care		
Authors	**Title**	**Time frame of review**
Given, Given & Kozachik (2001)	Family support in advanced cancer	No limits stated
Harding & Higginson (2003)	What is the best way to help caregivers in cancer and palliative care? A Systematic literature review of interventions and their effectiveness.	From database inception to 2001
Ingleton, Payne, Nolan & Carey (2003)	Respite in palliative care: A review and discussion of the literature	
Hudson (2004a)	A critical review of supportive interventions for family caregivers of patients with palliative-stage disease.	1985 to 2001
Kristjanson & Aoun (2004)	Palliative care for families: Remembering the hidden patients.	No limits stated
Aoun, Kristjanson, Currow & Hudson (2005)	Review article: Caregiving for the terminally ill: at what cost?	No limits stated
McMillan (2005)	Interventions to facilitate family caregiving at the end of life	No limits stated
Andershed (2006)	Relatives in end-of-life care- part 1: a systematic review of the literature the five last years, January 1999-February 2004	Jan 1999 to Feb 2004
Eager et al. (2007) - Centre for Health Service Development	Effective caring: a synthesis of the international evidence on caregiver needs and interventions. Vol One: The Report	No limits stated
Hanratty, Holland, Jacoby & Whitehead (2007)	Review article: Financial stress and strain associated with terminal cancer – a review of the evidence.	From database inception to June 2006
Kirchhoff & Faas (2007)	Family support at end of life	From database inception to 2006
Lloyd-Williams (2003)	Psychosocial issues in palliative care (edited book)	
Candy, Jones, Williams, Tookman & King (2009) – The Cochrane Collaboration	Interventions for supporting informal caregivers of patients in the terminal phase of a disease.	From database inception to present
P. Hudson & Payne (2009b)	Family caregivers in palliative care (edited book)	

Literature reviews of grief and bereavement		
Authors	**Title**	**Time frame of review**
Centre for Advancement of Health (2004)	Report on bereavement and grief research	1985 through to publication
Forte, Hill, Pazder & Feudtner (2004)	Bereavement care interventions: a systematic review	From 1966 to 2003
Kristjanson, Lobb, Aoun & Monterosso (2006)	A systematic review of the literature on complicated grief	1990 to 2005
The Joanna Briggs Institute (2006)	Literature review on bereavement and bereavement care	1990 through to publication
Stroebe, Schut & Stroebe (2007)	Health outcomes of bereavement	From 1997 onwards
Stroebe, Hansson, Schut & Stroebe (2008)	Handbook of bereavement research and practice (edited book)	
Agnew, Manktelow, Taylor & Jones (2009)	Bereavement needs assessment in specialist palliative care: a review of the literature	No information on review process
Lobb, Kristjanson, Aoun, Monterosso, Halkett & Davies (2010)	Predictors of complicated grief: A systematic review of empirical studies.	1990-2007 + seminal work published pre 1990

2.1 A profile of family caregivers of palliative care patients

Within the context of home care, it appears primary caregivers are most often women (68% to 77%) who are caring for their male partners (Fleming et al., 2006; Gill, Kaur, Rummans, Novotney, & Sloan, 2003). Female patients tend to be cared for by their daughters or daughters-in-law (Visser et al., 2004). Studies show that the average age range of people who die at home and those who care for them is between 60 to 70 years. It is estimated that one third of caregivers are employed, while many stop working temporarily or decrease their hours of work to provide care in the home (Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004; P. Hudson, Aranda, & Kristjanson, 2004a). Overall, home care for terminally ill patients occurs mostly when the patient lives with a spouse or partner (Carlsson & Rollison, 2003; Ferrario, et al., 2004; Grande, et al., 1998).

A recent Australian study found that adult caregivers of palliative care patients were predominantly female, born in Australia and married with children. The average age of caregivers was 57 years. The majority of caregivers were not in the workforce, but interestingly, over 35% of caregivers had reduced or stopped work in order to provide care. Overall, 48% of caregivers were caring for their spouse, 37% were caring for a parent, 5% were caring for a child and approximately 5% were caring for a friend, sibling or other relative (P. Hudson, Thomas, Trauer, Remedios, & Clarke, In Press).

Abernathy et al. (2009) sought to identify caregiver sub-populations from the Health Omnibus Survey, a large health study conducted in South Australia. Among people bereaved through terminal illness, it was found that nearly 30% of respondents had provided care prior to death. Caregivers reported providing the following activities: 'day-to-day hands-on-care' for 5-7 days per week (32%), 'day-to-day hands-on-care for 2-4 days per week' (40%) and 'rare hands-on-care' for one or less days per week (28%). On average, caregivers reported providing this care over 21 months. Active caregivers (hands-on caregivers) were mostly female, older and more closely related to the patient. They were also more likely to be widowed, have a reduced level of employment and lower income profiles compared to non-active caregivers.

Despite the prevalence of female caregivers shown in palliative care studies, Hauser and Kramer (2004) assert that the contribution of male caregivers should not be underestimated. Male spouses primarily care for their female spouse with chronic disease and male caregivers account for 30% of caregivers to older adults (Kramer & Thompson, 2002; Turner & Catania, 1997). Men are also the main caregivers for up to 41% to 53% of persons with acquired immunodeficiency syndrome. Hauser and Kramer (2004) appeal for recognition of the socio-cultural expectations for men to be confident, in control and independent; and the difficulties this may pose in caregiving roles.

2.2 Reasons for caregiving

There are a range of reasons why caregivers may take on the role of caring for a palliative care patient (P. Hudson & Payne, 2009b). There are potential positive outcomes associated with caring for someone with whom there is a relational bond including enhanced family relationships; a greater sense of purpose; and the opportunity to find meaning at a difficult time in life (Grbich, Maddocks, & Parker, 2001; Robbins, 1998; Yates & Stetz, 1999). However, for some caregivers there may be little choice in the matter; they may feel obligated to take on roles they are not comfortable to assume or for which they do not feel capable (P. Hudson & Payne, 2009b; Yates & Stetz, 1999).

Caregivers who are genuinely motivated to undertake the caregiving role tend to report less burden.(Nolan, Grant, & Keady, 1996; Stajduhar & Davies, 2005) investigated the factors influencing family members' decisions for palliative home care. The authors found that when caregivers were uninformed or indifferent about caregiving in the home, they were more likely to feel unprepared and put their own needs aside. Caregivers seemed to cope better when decisions were negotiated and when

they felt they had a choice in the matter. Being given a choice to provide care appears to be an important determinant of caregiving willingness (Burridge, Winch, & Clavarino, 2007).

According to Burridge et al. (2007), the concept of caregiving reluctance is an unrecognised and uncommon topic of research. Caregiving reluctance has been defined as resistance, aversion or oppositional thoughts; or feelings related to the decision to provide care (Burridge, et al., 2007). It is argued that while caregiver reluctance and burden may be related, the two are conceptually distinct. A significant difference is that caregiver reluctance may not be as readily acknowledged as burden or it may be concealed by other dominating factors such as conflict, financial strain or social expectation. In their review of the issue, Burridge et al. (2007) clearly demonstrated that whether covert or overt, the impact of caregiving reluctance may be underestimated.

Caregiving reluctance has been found to have important implications including deterioration of the caregiver-patient relationship, reduced quality of care for patients and increased likelihood of institutionalisation (Burridge, et al., 2007). The consequences of caregiving reluctance require serious consideration by health professionals. A survey of caregivers showed that lack of choice constituted 35% of the reasons for taking on a caring role (Australian Bureau of Statistics, 2004; Burridge, et al., 2007). These findings indicate that caregiving willingness cannot be assumed in palliative care; assessment of caregiving reluctance is therefore required.

2.3 The caregiving role

To a great extent, the role and demands of caregiving will depend on the setting of care (home versus in-patient units). Caring in the home can involve complex physical and medical care tasks including the assessment and management of symptoms, hygiene care, administration of medications and consultation with health professionals (P. Hudson, 2004a).

When care at home is not possible, caregivers may still actively deliver care to patients in medical, surgery or oncology units, intensive care units or in-patient palliative care units (Ferrell, Borneman, & Thai, 2009). While physical and medical care tasks are the responsibility of health professionals who staff in-patient units, caregivers often assume the responsibilities of providing comfort, emotional support, financial administration, patient advocacy, decision making, practical and social support and coordination of care (Stajduhar & Cohen, 2009). For many caregivers, these duties are assumed in addition to the usual roles and responsibilities they previously held, such as work and community commitments.

2.4 Impact of caregiving

Studies of palliative care patients have identified several sources of stress for caregivers, such as the uncertainty of treatment, lack of knowledge regarding patient care, difficulties in accessing services, financial burdens, lack of support, changes in paid employment and worries associated with an unknown future (Andershed, 2006; Aoun & Kristjanson, 2005). Many caregivers must also manage secondary stressors resulting from (1) emotional reactions from the patient and other family members; (2) family conflict; (3) work role conflict; and (4) financial strains (Hauser & Kramer, 2004). Furthermore, it has been well-noted that caregivers must carry the dual responsibility of assisting the patient to prepare for death while coming to terms with their own grief and sense of impending loss (Candy, et al., 2009). For a number of caregivers, this may be their first major exposure to the many issues related to death and dying (P. Hudson, 2004a).

2.4.1 Physical and medical care responsibilities

The physical and medical demands of caring for a person with a terminal illness are often substantial and burdensome (Andershed, 2006; Kristjanson & Aoun, 2004). Many caregivers report that the provision of personal hygiene and the administration of medications are particularly confronting (Andershed, 2006). In one study the physical demands of the role were found to increase substantially in the last three months with increased patient needs being the strongest predictor of caregiver burden (Brazil, Bedard, Willison, & Hode, 2003). Research also suggests that the impact of caregiving may vary according to disease, with caregivers of advanced cancer patients reporting greatest concern over

managing physical care and treatments (Hauser & Kramer, 2004; Stetz & Brown, 1997). According to Given, Given, and Kozachik (2001) the most pressing concerns for caregivers of palliative care patients are related to maintaining comfort, managing equipment and reporting changes in the patient's status.

2.4.2 Psychological impact

Alongside the physical demands of caregiving, are the emotional and psychological demands. Caregivers report emotional distress from feelings of loneliness, fear, guilt, helplessness and lack of control over everyday life (S. Payne, Smith, & Dean, 1999). Several studies show that caring for terminally ill patients is associated with fatigue, sleeping problems, depression, anxiety and burnout (Barg et al., 1998; Schulz et al., 2004; Thomas, Morris, & Harman, 2002). Despite demonstrated psychological burden among caregivers, limited information exists on the prevalence of mental health problems (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005).

A study of 153 caregivers of patients with advanced cancer showed that over 50% of caregivers had depression scores at or near the cut-off for clinical depression. Depression was highest among female caregivers, caregivers aged 45 to 54 years, caregivers who were adult children of patients and caregivers who were employed. The number of patient symptoms was also positively related to depression (Given et al., 2004). In a US multi-site, longitudinal study of 200 caregivers of advanced cancer patients, 13% of caregivers were found to meet DSM-IV criteria for a psychiatric disorder and 25% had accessed treatment for mental health concerns since the patient's diagnosis. The prevalence of psychiatric disorders was as follows: panic disorder, 8.0%; major depressive disorder, 4.5%; post-traumatic stress disorder, 4.0%; and generalised anxiety disorder, 3.5% (Vanderwerker, et al., 2005).

High levels of psychological distress were found in an Australian study of caregivers who were providing informal care to a person receiving palliative care. Psychological distress is a multifactorial, unpleasant emotional experience of psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with effective coping (International Association of Hospice and Palliative Care, 2009). Based on the Hospital Anxiety and Depression Scale (HADS; (Zigmond & Snaith, 1983), 44% of caregivers were found to experience probable caseness for depression and anxiety. Using a more conservative cut-off of 14, 20% of caregivers were highly likely to have an anxiety disorder and 10% were highly likely to have a depressive disorder. Furthermore, mental health risk factors such as sleeplessness, multiple stressors, cumulative loss and previous mental health problems were associated with a greater prevalence of psychological distress at the time of caregiving. Anxiety and depression among caregivers was predicted by higher levels of sleeplessness, caregiver esteem, greater impact on caregivers' schedule, greater impact on caregivers' health and lower levels of optimism (P. Hudson, et al., In Press).

2.4.3 Caregiver health burdens

Multiple studies show that many caregivers have their own health problems; these may worsen or be exacerbated as a result of providing care (Eagar, et al., 2007; Kristjanson & Aoun, 2004). Within the context of palliative care it has been found that up to 75% of primary caregivers of terminally ill patients have their own chronic health problems (Briggs & Fisher, 1999). Kristjanson and colleagues (1996) demonstrated that family members of palliative care patients experience deteriorating health and rate their health as significantly poorer compared to ratings found in a normal population (Kristjanson & Aoun, 2004). In a separate study it was shown that relatives of patients in palliative care scored lower ratings of physical health and quality of life than relatives in curative care (Weitzner, McMillan, & Jacobsen, 1999). Further to these concerns are findings in the general caregiving literature that indicate caregivers with physical, psychological and social vulnerabilities have an increased risk of early mortality compared to non-caregivers (Christakis & Iwashyna, 2003; Schulz & Beach, 1999).

2.4.4 Social burdens

According to Kellehear (2009), social isolation is one of the most widely self-reported problems associated with family caregiving. One contributing factor may be the need to reduce hours of paid work, social outings and recreational outings in order to provide adequate care. A second factor is the extent of support provided by the extended circle of family and friends. Soothill, et al. (2003) reported

that although a number of caregivers have friends and relatives who live nearby, only a minority offer support and assistance. It is suggested that people in wider social circles may themselves struggle to know what support services to offer to those caring for a patient who is nearing death (Kellehear, 2009). Finally, while extended family may be a major source of support for caregivers, it cannot be assumed that interactions are always positive. The blend of traditional roles with care responsibilities can result in changes to family dynamics, presenting new challenges for families and at times generating conflict (Hauser & Kramer, 2004). This can jeopardise support and effective communication between caregivers and their support circle.

2.4.5 Financial burdens

The financial burden experienced by caregivers of terminally-ill patients is well documented. It is estimated that over 25% of caregivers experience financial hardship resulting from prior financial difficulties, limited work hours, cessation of work and/or retirement (Kellehear, 2009; Stajduhar & Cohen, 2009). In some families there may be loss of two incomes, those of the patient and the caregiver. Additional costs associated with care may include purchase of equipment, bedding, home alterations, medical bills, rental equipment, respite, hygiene supplies and pharmaceuticals (Kristjanson & Aoun, 2004). Caregiving can also increase standard living costs through greater energy expenditure in the home, increased travel expenses and the need to rely on ready-made or take-away meals (Glendinning, 1992; Holzhausen & Pearlman, 2000; Tibble, 2005). The consequences of financial hardship as a result of care have reportedly included the forced selling of assets, an additional or increased loan or mortgage and the need for additional employment (Emanuel, Fairclough, Slutsman, & Emanuel, 2000).

2.5 Positive and protective factors in caregiving

While research suggests that caregiving can be burdensome on health and well-being, there is also evidence to show that the majority of family caregivers will not develop clinically significant levels of psychological distress (Zhang, El-Jawahri, & Prigerson, 2006). P. Hudson and Payne (2009a) advocate the importance of recognising that caregivers need support without pathologising the caregiving role. They argue that the common portrayal of family caregiving as an inherently burdensome experience may inadvertently imply that there are no or few positive aspects associated with the role. In fact, some studies have reported that relatives in palliative care describe caring as a valuable experience associated with feelings of satisfaction, gratitude and pleasure (Andershed, 2006; P. Hudson, 2004b).

According to Andershed (2006), positive and valuable aspects of caregiving during terminal illness involve meaningful time with the dying person; feeling appreciated as a caregiver; and gaining new insight in self-awareness and relationships with others. Caregiving was identified as a significant way to demonstrate love and give back what caregivers had previously received from the relationship with the patient. Providing care was also seen as an opportunity to share the time that remained, to be present at death and importantly, to say goodbye (Andershed, 2006).

Proot et al. (2003) developed a model describing the vulnerability of caregivers in palliative care as a continual balance between burden and capacity. It is acknowledged that caregivers face increased vulnerability through burdens such as provision of physical care, restricted activities, fear, death and lack of support. It is also recognised that caregivers demonstrate considerable capacity by continuing previous activities, remaining hopeful, keeping control, experiencing satisfaction and receiving support. The authors assert that maintaining balance between the experiences of burden and capacity is a key factor in handling challenging care situations.

Protective or vulnerability-decreasing factors have also been identified in the literature (Eagar, et al., 2007). Studies have shown that the following factors can decrease vulnerability for burnout among caregivers of cancer and palliative care patients:

- continued involvement in previous commitments, such as work
- setting limits on involvement, for example, refusing to give injections
- receipt of good support from family, friends and professionals

- continuation of valued activities and interests (e.g. physical exercise and social outings)
- a generally optimistic outlook towards life.

Interestingly, a number of studies found that continued involvement in valued activities despite workload was an effective coping strategy for dealing with the stress of caregiving (Eagar, et al., 2007). Finally, personal attributes such as sense of coherence, inner strength and fighting spirit were also found to buffer the stress associated with caregiving (Andershed, 2006).

2.6 A theoretical model to understand the caregiver experience

The theoretical model most widely advocated in family caregiver research is the stress-processing framework derived from the psychological literature on cognitive processing, stressors and coping (Hauser & Kramer, 2004; P. Hudson, 2003; S. Payne & Rolls, 2009). The transactional model of stress and coping first proposed by Lazarus and Folkman (1984) has provided the basis for conceptualising caregivers' and families' responses to supporting a terminally ill person (P. Hudson, 2003). The model is based on the theoretical premise that a person's response to stress results from their cognitive appraisal of a situation as threatening to their well-being and/or their efforts to cope. The process is seen to be transactional as the person and the environment are in a continual dynamic and reciprocal relationship (Lazarus & Folkman, 1984).

P. Hudson (2003) has provided an expanded structure of the transactional stress and coping framework that enables better application of the model in the context of palliative care. The proposed framework was developed from Folkman's (1997) refinement of the original model, which was based on extensive work undertaken with family caregivers of terminally ill AIDS patients. Hudson's modification to this revised framework is based on the event of referral to a palliative care service.

P. Hudson's (2003) revised conceptual framework of stress and coping incorporates Lazarus and Folkman's original model with the inclusion of key variables to be considered in caregiving experiences. Sustained in the revised framework is the premise that an individual's subjective appraisals and perceived resources are the determinants of whether an event is stressful. Furthermore, this is understood as a continuing reinterpretation of the perceived threat based on primary appraisals (events), secondary appraisals (coping resources) and reappraisals. In this way, there is an appreciation of the ever changing circumstances of caregiving and the enduring nature of progressive illness as well as bereavement.

In the revised model there is also acknowledgement of potential positive psychological states and outcomes that may occur through positive reappraisal, revised goals, spiritual beliefs or positive events. As research has shown, family caregivers report that caring for a person with terminal illness can be associated with both positive and negative experiences (Proot, et al., 2003). Finally, the refined model highlights the key variables that are influential in caregivers' appraisal of events, their assessments of coping resources and perceptions of resolution (P. Hudson, 2003).

Overall, the transactional model of stress and coping is advocated as a useful theoretical framework for understanding caregiver experiences and designing therapeutic interventions. While the model has been criticised for the focus on individual coping and the limited attention to socio-cultural and systemic influences, it is generally considered to be the most applicable framework for understanding caregiving to date. P. Hudson's (2003) expansion of the transactional stress and coping model demonstrates the theoretical applicability of the framework in palliative caregiving research.

2.7 Chapter summary: Caregivers of palliative care patients

- End of life caregivers are generally aged between 60-70 years of age; women caring for their male partner; and unemployed.

- The contribution and vulnerability of male caregivers is suspected to be underestimated and unrecognised in palliative care studies.

- A high proportion of caregivers have their own chronic health problems.

- Caregivers of palliative care patients face complex and challenging tasks including physical and medical patient care, consultation with health professionals and management of end-of-life issues.

- Psychological burdens of care include fatigue, sleeping problems, weight loss, depression, anxiety and burnout.

- Social burdens associated with caregiving include isolation, reduced social contact and poor social support.

- Financial burdens may result from costs associated with caring, prior financial difficulties, limited work hours, cessation of work and/or retirement.

- Caregivers carry the dual responsibility of assisting the patient to prepare for death while coming to terms with their own grief and sense of impending loss.

- Caregiving at the end of life has been associated with physical health burdens, psychological burden, social burden and financial burden.

- Caregivers who are reluctant to care or feel they have little choice in caregiving face a greater risk of caregiving burden and poor caregiving outcomes.

- Risk factors for caregiving burden include higher levels of caregiver esteem, financial difficulties, greater impact on schedules, greater impact on health, lower levels of support and pessimistic thinking.

- Many caregivers report positive and valuable experiences associated with providing care including feeling appreciated; gaining personal satisfaction; and spending meaningful time with the dying person.

- Protective factors that decrease caregiver vulnerability for burden and burnout include:

  - continued involvement in previous commitments

  - setting limits on caring involvement

  - adequate support from personal networks and professionals

  - participation in valued activities and interest

  - a generally optimistic outlook towards life.

- A theoretical model that assists in understanding the caregiving experience is the stress-processing framework derived from the psychological literature on cognitive processing, stressors and coping.

In recent years greater attention has been given to the unmet needs of caregivers of terminally ill patients. Findings from major literature reviews consistently show that caregivers report a greater need for information and knowledge; improved communication with health professionals; better preparation for patient death; and more support from health professionals and health services (Andershed, 2006; Aoun & Kristjanson, 2005; Docherty et al., 2008; Eagar, et al., 2007). Furthermore, caregivers' needs for assistance and support regarding the physical demands of care, decision-making aspects of care, financial costs of care and spiritual and cultural aspects of care are frequent discussion points in the literature. These findings are summarised below.

3.1 Information and knowledge

Caregivers consistently express the need for information on topics related to the patient's illness, symptoms, treatment and care (Andershed, 2006). According to Aoun and Kristjanson (2005), caregivers desire information about the provision of practical care such as strategies to relieve patient discomfort; explanations about patient diagnosis and prognosis; recognition of caregiver emotional responses; and direction regarding access to practical aids such as walking frames, wheel chairs and hospital beds. The provision of this information has been recognised as a central form of support for caregivers.

In some studies, families reported that information was difficult to retrieve from health professionals requiring them to persist in asking questions (Andershed, 2006). Other studies indicated that information could be withheld through gate-keeping, meaning that various persons (either staff, patient, or relative) could keep important information from other parties involved in caregiving. Issues related to death and dying are difficult topics to broach for many families and therefore poor communication, secrecy and gate-keeping can be significant impediments to appropriate clinical management in palliative care.

Parker et al. (2007) reviewed international studies and reported prognostic and end-of-life information was important for patients and caregivers from several countries, including non-English speaking countries. There was a tendency for most patients to prefer less detailed information about issues compared to caregivers. However, both caregivers and patients expressed the need for clear information at all stages of the disease process. Patient and caregivers wanted information to be offered at the time of diagnosis or soon after but they also wanted to negotiate the content and extent of this information.

Families may be active or passive in the seeking of information; health professionals need o communicate effectively and ensure adequate information is provided. P. Hudson, Aranda and McMurray (2004) identified three types of barriers that families must overcome in order to seek information: communication process barriers, health system barriers and family-related barriers (P. Hudson, Aranda, & Kristjanson, 2004b). Health professionals need to be aware of these potential barriers and assist families to obtain the information they need.

Studies reported variation in the views of patients and caregivers with respect to the accessibility and dissemination of information (Docherty, et al., 2008). Views ranged from consistent information between both parties (with caregiver access to additional information with patient permission) to caregiver preference for full access to information in recognition of the caregiving role. To accommodate these differences, health professionals may need to consider the relationship and communication patterns between patients and caregivers as well as preferences regarding ownership of information (Clayton, Butow, & Tattersall, 2005 ; Docherty, et al., 2008; Terry, Olson, Wilss, & Boulton-Lewis, 2006).

Together, the findings of these reviews highlight the fact that caregivers have specific information needs that require recognition and understanding. The provision of adequate information and

knowledge has the potential to empower caregivers to function better in this complex role. Information provision appears to be a central coping resource for caregivers of terminally ill patients (Andershed, 2006; Docherty, et al., 2008).

3.2 Practical support

Caregivers report the need for greater assistance with the physical demands of caregiving (Andershed, 2006; Hauser & Kramer, 2004). A study of service preferences found that caregivers would have liked more support from house-keeping services, caregiver respite, in-home nursing care, personal care services and self-help or support groups (Brazil et al., 2005). An Australian study of caregivers supported by a palliative care service found that further assistance was desired in the provision of information, in-home respite, household tasks and financial support (Zapart, Kenny, Hall, Servis, & Wiley, 2007).

Docherty et al. (2008) found that caregivers' needs for practical information were greatest in relation to issues surrounding pain management, addiction and medication tolerance. The authors emphasise the need for caregivers to be given sufficient information, education and training in administration, dosage and titration of dosage to treat increasing symptoms. Pain management was found to be a significant concern for caregivers, particularly among older caregivers and those with less education.

Two systematic reviews on the practical needs of informal caregivers providing home-based palliative care (Bee, Barnes, & Luker, 2008; P. L. Hudson, 2006) suggested that health providers often have unrealistic expectations regarding the extent to which family caregivers may be comfortable undertaking practical nursing tasks. Research consistently showed that caregivers needed more support and information related to practical tasks such as special equipment, nursing care, home care and other aspects of care (Bee, et al., 2008). It was found that when caregivers felt that support was accessible from a 24-hour nursing service, family caregivers' anxieties regarding care responsibilities were greatly reduced (Field & McGaughey, 1998; V. Wilson, 1999). However, caregivers who reported poor availability of staff were more likely to feel unsupported and document more negative caring experiences (Jones, Hansford, & Fiske, 1993).

3.3 Communication

Communication and the relationship between caregivers and health professionals were identified as key determinants in the adequacy of information provision (Docherty, et al., 2008). Dissatisfaction with communication was found in a number of studies, particularly in relation to the level of detail of the information provided and the limited opportunities for meetings or discussions (Docherty, et al., 2008). Where poor communication was experienced, relatives often reported feeling isolated, disillusioned, frustrated and distressed. This was also found to impact on their ability to handle situations (Andershed, 2006).

Parker et al. (2007) reported that patients and caregivers had specific preferences for style of communication. It was found that patients and caregivers wanted a trusted health professional, who provided information in small amounts, without professional jargon. They wanted their health professionals to encourage questions and check their understanding of the discussion. Preferences regarding having another person present were also mentioned as an important aspect of communication. Overall, patients and caregivers wanted health professionals to 'show empathy, care, compassion and honesty, as long as the honesty was balanced with sensitivity and hope' (Parker, et al., 2007). The importance of sustaining hope when communicating with terminally ill patients and their families has been discussed in great depth in a systematic review by (Clayton et al., 2008).

Cultural differences also impact on the communication between families and health professionals. Studies show that withholding information is the norm in some cultures where it is

believed that discussions about dying could precipitate the patient's death. In such cases it was common for families and health professionals to know more than the patient (Andershed, 2006). Language difficulties require consideration, especially in situations where family members were involved in translation. Concerns have been raised with regard to the power of individuals to withhold information (Andershed, 2006; Docherty, et al., 2008).

3.4 Decision-making

Decision making is an important responsibility that can be burdensome for families and caregivers. End-of-life decisions are fraught with broader issues of death and dying, which can be emotionally distressing for families. Caregivers often feel unprepared for the task and can suffer from a lack of support or coaching from health professionals and other family members. Studies suggest that specific interventions are needed to support caregivers in the decision-making role through open communication, spiritual and cultural support, emotional and practical support and continuity of care (Andershed, 2006; Eagar, et al., 2007; Kirchhoff & Faas, 2007).

3.5 Preparedness needs

There are two concepts of preparedness that will be discussed in this section: (1) preparedness for caregiving and (2) preparedness for patient death. Preparedness for caregiving refers to caregivers' readiness for care tasks and the demands of the role (P. Hudson, 2003). It is not an assessment of a caregiver's adequacy to provide care but rather a subjective perception on the part of the caregiver. Caregivers who feel unprepared for the caregiving role are at greater risk of caregiving burden, whereas caregivers who feel well prepared in terms of support, skills and knowledge have been found to have decreased levels of depression (Archbold, Stewart, Greenlick, & Harvath, 1990; P. Hudson, 2003; Nolan, et al., 1996). Health professionals can better prepare caregivers for caregiving tasks through the provision of information and training.

Preparedness for a patient's death is an important factor that impacts on terminal caregiving and bereavement. Preparedness is defined as the degree to which a caregiver perceives he/she is ready for the death (Hebert, Prigerson, Schulz, & Arnold, 2006). It has been noted that preparedness for death is distinct from being informed of prognosis, death acceptance and forms of anticipatory grief. Rather, preparedness for death is thought to be a multidimensional concept that encompasses medical, psychosocial, spiritual and practical dimensions of readiness. Therefore, perceptions of preparedness for death are unique, meaning 'different things to different caregivers' (Hebert, Prigerson, et al., 2006) p.1166).

Recent research reveals that caregivers who perceived they were unprepared for death were more likely to experience greater depression, anxiety and complications in bereavement (Barry, Kasl, & Prigerson, 2002; Yates & Stetz, 1999). Hebert and colleagues (2006) have demonstrated that ethnicity, education, income, pain and discomfort experienced by the patient and pre-bereavement depression are all related to preparedness. Interestingly, duration of caregiving has not been found to be associated with preparedness. Another significant factor that has been found to impact on perceptions of preparedness is the quality of communication between caregivers and health providers. In one study, communication about death, dying and bereavement as well as psychosocial support, were the strongest predictors of caregivers' awareness of a terminal prognosis (Hebert, Prigerson, et al., 2006; Valdimarsdottir, Helgason, Furst, Adolfsson, & Steineck, 2004).

3.6 Health care service needs

The need for a supportive relationship with health providers has been shown to be important to families and caregivers (Andershed, 2006). Family members who felt unsupported by health providers reported feeling uninvolved, misguided and poorly prepared for the caregiving role. In several studies this was described as 'being in the dark', meaning that relatives were involved in the situation but were left to find their own ways to care, manage and support the patient.

The development of a trusting and supportive relationship between families and health professionals is perceived as the professional's responsibility (Andershed, 2006). In situations where this occurred, relatives and authors described the supportive attitude of the professional in terms such as trust, love, patience, presence, continuity, taking time, caring about, listening, answering questions and seeing the family's needs (Milberg, Strang, Carlsson, & Borjesson, 2003; Mok, Chan, Chan, & Yeung, 2003; S. A. Wilson & Daly, 1999). A trusting relationship between the family and health providers was also recognised as a key element in the identification of ethical dilemmas and family problems (Andershed, 2006).

Docherty et al. (2008) found caregivers frequently sought a personal relationship with health professionals as a means of communicating their needs, including the need to freely discuss the patient's illness and confide difficult issues or concerns. A positive relationship between health professionals and families was characterised as those in which families were well-informed and experienced a meaningful involvement based on mutual trust, respect, openness, sincerity and cooperation. Some studies emphasised the importance of partnership and collaboration, while others described the importance of family-centred care (Andershed, 2006).

3.7 Personal needs

As highlighted in Chapter 2, caregiving can have a major impact on caregivers' personal well-being and quality of life. Juarez et al. (2008) report that caregivers showed similar levels of distress and disruptions to physical, psychological, social and spiritual dimensions of quality of life as the patients in their care. While caregiver distress is widely recognised and efforts have been made by the World Health Organisation to promote caregiver well-being (Sepulveda, Marlin, Yoshida, & Ullrich, 2002), the personal needs of caregivers can easily be neglected (Osse, Vernooij-Dassen, Schade, & Grol, 2006). There are a number of reasons put forward for this assertion. The first is that caregivers may be reluctant to draw attention to their own problems as they believe the patient's needs come first. Second, health professionals need to continually re-assess caregivers' needs in order to establish how best to intervene and provide support. Professionals may lack time, resources and tools to undertake structured assessments. Furthermore, it is argued that access to resources and provisions of support must be available to address the needs of caregivers when they are identified (Osse, et al., 2006). A review of supportive interventions for caregivers will be undertaken in Chapter 4 of this literature review.

3.8 Financial needs

The economic burden of caregiving has been identified as a significant issue for caregivers of palliative care patients. In a random audit of clinical notes for informal caregivers it was found that the primary need of caregivers was for financial assistance and advice regarding welfare benefits (Harding & Leam, 2005). Findings from cost-estimate studies indicate that families may require financial assistance to cover costs that include the purchasing of medications, home care supplies, rental equipment, transportation and respite services (Aoun & Kristjanson, 2005). Aoun and Kristjanson (2005) assert that the needs of caregivers have been long ignored in economic policies, resulting in marginalisation of caregivers in the social welfare system.

According to Kristjanson and Aoun (2004) family caregivers may be reluctant to disclose their financial concerns, or they may feel guilty about raising financial matters when the patient is dying. Preoccupation with financial problems may even lead to family conflict and distraction from the patient's care needs (Kristjanson et al., 1998). It is suggested that health professionals address the issue of financial needs through a simple question about how families are coping with financial changes or pressures consequent to the illness (Kristjanson & Aoun, 2004). This provides an opportunity for family members to discuss their concerns and allows health professionals to identify resources or make an appropriate referral.

Hanratty et al. (2007) conducted a review of the evidence on financial stress and strain associated with terminal cancer. A total of 24 papers were identified from 21 studies published in English between 1980 and 2006. Financial stress was reported in all 13 studies from the USA

but there was a dearth of data on financial stresses from studies in other countries. According to (Hanratty, et al., 2007), inquiries about financial stressors and strain should be a regular part of assessment and research in family caregiving.

3.9 Spiritual and cultural needs

Spiritual and cultural support are considered important care needs in palliative care; however, some studies indicate that health professionals express discomfort or lack of knowledge or skill in addressing these issues (Kirchhoff & Faas, 2007). Studies of minority and cultural groups suggest patients and families need healthcare professionals to understand socio-cultural traditions and norms, including burial preferences and spiritual practices (Docherty, et al., 2008). Recognition and assessment of spiritual and cultural needs are a component of palliative care that can easily be neglected in relation to other competing care needs.

One of the difficulties in the provision of spiritual support is the various meanings attached to the word 'spiritual'. According to Speck (2004), while the terms spiritual and religious may overlap in some contexts, they should be differentiated in health care. R. Hudson (2009) defines 'spiritual' as the essence of life, where the 'spirit' refers to the breath that sustains life. It is emphasised that spirit is not something separate from the body, rather body and spirit are profoundly connected and inter-related. R. Hudson (2009) asserts that it is impossible for health care professionals to have detailed knowledge of the diverse cultures, faiths and/or religious beliefs of patients and family caregivers. It needs to be acknowledged that there will be individual variation within the same cultural or spiritual perspectives. According to R. Hudson (2009) it is important to ask questions such as 'Do you have any particular religious/spiritual beliefs that help you in this situation?' Another example might be, 'I am not familiar with your cultural beliefs and practices. Would it be all right to ask you a few questions to help my understanding?' Questions such as these enable health professionals to make an initial assessment and determine whether referral or intervention is required.

3.9 Chapter summary: Caregiver needs in palliative care

- The literature consistently shows that caregivers report the following needs:
    - greater information and knowledge
    - improved communication with health professionals
    - better preparation for patient death
    - more support from health professionals and health services

- Additional support needs identified in the literature include:
    - greater assistance with the physical demands of care
    - greater financial assistance and advice
    - more support in decision-making processes
    - greater effort in the provision of spiritual and cultural support

- Caregivers want more detailed information on the following topics:
    - patient's illness, symptoms, treatment and prognosis
    - strategies to relieve patient discomfort
    - access to practical aides
    - pain management, addiction and medication tolerance
    - common emotional responses among caregivers.

- Patients and caregivers may have differing views on the accessibility and dissemination of information. Caregivers want more opportunities for communication with health professionals.

- Caregivers differ in their capabilities to access information and may need health professionals to take the lead in communication and ensure adequate information is provided.

- Poor communication, gate-keeping and secrecy are significant impediments to family-centred palliative care.

- Health professionals need to be sensitive to the specific communication needs of families from culturally and linguistically diverse backgrounds.

- Caregivers who feel unprepared for caregiving are at greater risk of experiencing burden. Health professionals can assist in preparing caregivers for caregiving tasks through the provision of information and training.

- Caregivers who feel unprepared for the patient's death are at greater risk of poor bereavement outcomes. Health professionals can better prepare caregivers by ensuring communication about dying and bereavement and by providing psychological support.

- Satisfaction with health care services results when families report a trusting and supportive relationship with health care providers.

- The personal, financial, spiritual and cultural needs of caregivers can be neglected as the focus is often on the well-being and care of the patient. It is recommended that health professionals directly inquire about these aspects of caregiver well-being.

4. Supportive interventions for caregivers of palliative care patients

4.1 Published reviews

While it is widely recognised that caregivers of palliative care patients have informational and psychosocial needs, there is limited knowledge regarding the types of interventions likely to be effective in meeting these complex needs. In the last decade, researchers have attempted to identify effective interventions for caregivers of palliative patients through systematic or critical reviews of research in this area.

4.1.1 Studies of interventions for caregivers of cancer and palliative care patients

One of the earliest systematic reviews of interventions for cancer and palliative care patients was conducted by Harding and Higginson (2003). Key databases were searched for reported interventions from 1966 to 2001, and the evidence was graded according to the rigour of study design and analysis. The review identified 22 relevant papers; nine of which were services specific to caregivers. Of these nine interventions, only six had been evaluated. A range of intervention models were identified including home care, respite care, social networks and activities, problem-solving and education, one-to-one therapy and group work. Harding and Higginson (2003) reported that there was a small body of evidence suggesting the effectiveness of interventions for caregivers of cancer and palliative care patients. However, the bulk of the evidence was based on study designs graded as moderate to weak in rigour.

P. Hudson (2004a) and McMillan (2005) undertook separate critical reviews of supportive interventions for caregivers of palliative care patients. P. Hudson (2004a) reviewed published literature from the years 1985 to 2001 and reported a paucity of evidence based interventions for caregivers of palliative care patients. Studies of interventions for caregivers of non-palliative care patients were found to be of a higher standard; however, intervention effects were rare. McMillan (2005) reviewed literature published from the years 1984 to 2004, and similarly reported that interventions with a specific focus on the needs of caregivers of palliative care patients was a neglected area of research.

Due to the lack of data on the relevance of interventions for caregivers of palliative care patients, findings from previous reviews have been based on general caregiving populations or caregivers of cancer patients (Harding & Higginson, 2003; P. Hudson, 2004a; McMillan, 2005). According to this evidence, interventions for caregivers were found to fall into three categories: (1) education-focused; (2) support-focused; or (3) a combined focus on education and support (McMillan, 2005). Evaluations of these interventions show modest evidence for interventions that are multi-component in design (e.g. support and education versus support alone); individualised as opposed to group focused; and goal oriented in approach (P. Hudson, 2004a). Three randomised controlled trials showed that interventions with a combined focus on social activity, education and support were significantly beneficial to caregivers (Harding & Higginson, 2003; McMillan, 2005).

4.1.2 Studies of respite services for caregivers of palliative care patients

Ingleton et al. (2003) conducted a systematic review of the literature on the nature and efficacy of respite services for caregivers of palliative care patients. A total of 28 papers published prior to 2003 were found to directly relate to adult respite in specialist palliative care. The papers comprised descriptive accounts of respite programs, reasons for referral or an analysis of the impact of respite on the patient. There were no empirical studies on the effects of respite interventions among caregivers of palliative care patients. An examination of the themes and issues presented in the papers revealed inherent problems in evaluations of respite care as a result of ambiguous definitions, flaws in methodology and disregard of caregivers. The term 'respite' was found to describe both a service and an outcome, with reasons for referral varying

between 'respite for caregivers' and 'symptom control for patients'. There was also considerable variation in the types and locations of services, which included inpatient care, specialist day care and home-based respite care. Ingleton et al. (2003) reported that while documentation of referrals revealed that respite for caregivers was a common reason for respite admissions, it was unclear whether respite interventions were beneficial to caregivers.

Harding and Higginson (2003) reported that respite services were well regarded by some caregivers of cancer and palliative care patients; however high costs, burnout among respite workers and ambivalent attitudes among caregivers were also found to be significant impediments. Other studies show that while the number of respite services are said to have increased, service uptake has continued to be low suggesting that what is available is inconsistent with caregivers' needs (Morarity & Levin, 1998; Zarit, Gaugler, & Jarrott, 1999). Ingleton et al. (2003) suggested there was preliminary evidence to indicate respite services have the potential to benefit caregivers. However, the bulk of this evidence had been generated from caregivers of people with long-term illnesses such as dementia. Ingleton et al. (2003) cautioned against reliance on the literature from non-palliative caregiving populations as the applicability of findings may not correspond to situations of death and dying.

4.1.3 Intervention studies in mixed caregiver populations

Eagar et al. (2007) reviewed Australian and international literature on interventions for caregivers in a variety of circumstances . It was reported that research evaluations and systematic reviews have failed to yield conclusive information on the effectiveness of caregiver support interventions. The data reviewed suggested that services do not have an impact on overall caregiver burden and there was little known about the effective 'dose' of support interventions or the best time for their delivery (Eagar, et al., 2007). Possible explanations offered for these negative findings were inappropriate outcome measures; non-specific goals that do not target needs; and ineffective research evaluation designs (Ducharme, Lebel, Lechance, & Trudeau, 2006).

Despite the limitations of the research reviewed, Eagar et al. (2007) noted that interventions aimed towards problem-solving and cognitive restructuring showed demonstrable effects on caregiver well-being. Also, interventions based on an individual approach were more likely to have significant effects than those based on group approaches. The bulk of caregiver intervention studies were based on caregivers of people with dementia and therefore the evidence was found to be strongest for this group. The review showed little evidence of systematic differences in the needs of caregivers based on illness populations and circumstances surrounding care (Eagar, et al., 2007).

4.2 Review of interventions for caregivers of terminally ill patients (2000-2009)

The reviews outlined in the previous section have relied on intervention data from cancer and general caregiving populations prior to 2005. These findings highlight a paucity of interventions for caregivers of palliative care patients. Given the intense experiences of caring for someone with a terminal illness, there is a need for interventions with a specific focus on caregivers of palliative care patients. In light of recent evolvement in the field of palliative care, a systematic review of the literature was undertaken to identify further developments in the design and implementation of interventions for caregivers of patients with advanced, terminal illness.

A literature search was undertaken in Medline, CINAHL, EMBASE and PsychINFO databases to obtain all relevant intervention studies published between 2000 and 2009. More details of these searches are provided in section 1.3 of this report. Intervention studies were also sourced from the published reviews and evaluations summarised in the previous section.

The following inclusion criteria were adopted in the current review:
(1) English language publications.
(2) Study populations of adult caregivers of terminally ill or palliative care patients.

(3) Studies of psychosocial or education based interventions employed pre-patient death.

Studies were excluded for the following reasons: (1) interventions were patient-focused rather than caregiver-focused; (2) interventions were designed to support caregivers during bereavement; and (3) study populations were caregivers of patients with non-life threatening disease or potentially life threatening disease.

To remain consistent with Harding and Higginson's (2003) review, studies were evaluated according to the same grading system (Cancer Guidance Subgroup of the Clinical Guidance Outcome Group, 1996). The evidence was graded based on the rigour of study design and analysis. This system is shown below in Table 2.

Table 2: Grading criteria for review of caregiver intervention studies

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Grade I (Strong evidence)
Random Controlled Trials (RCT) or review of RCTs
- IA Calculation of sample size and accurate standard definition of appropriate outcome variables
- IB Accurate and standard definition of appropriate outcome variables
- IC Neither of the above

Grade II (Fairly strong evidence)
Prospective study with a comparison group (non-randomised controlled trial, good observational study or retrospective study that controls effectively for confounding variables)
- IIA Calculation of sample size and accurate, standard definition of appropriate outcome variables and adjustment for the effects of important confounding variables
- IIB One or more of the above.

Grade III (Weaker evidence)
Retrospective or observational studies
- IIIA Comparison group, calculation of sample size, accurate and standard definition of appropriate outcome variables.
- IIIB Two or more of the above
- IIIC None of these.

Grade IIII (Weak evidence)
Cross-sectional study, Delphi exercise, consensus of experts

A total of 15 studies were selected for the purposes of this review. These are presented in grading order (highest to lowest) in Table 3. The goals of interventions included education, psycho-social support, caregiver coping, training in patient-care, sleep promotion and facilitation of family meetings. Six studies were randomised controlled trials (RCTs); three with high quality graded evidence (Haley, 2008; P. Hudson, Aranda, & Hayman-White, 2005; Keefe et al., 2005) and three that met criteria for the highest quality graded evidence in design (McMillan & Small, 2007; McMillan et al., 2006; K. Walsh et al., 2007). There were two prospective studies with comparison groups that met criteria for fairly strong levels of graded evidence (Carter, 2006; Harding et al., 2004). However, both these studies had relatively small samples of caregivers. Five studies were pre-post in design without comparison groups and all were graded weaker in evidence (Duggleby et al., 2007; P. Hudson et al., 2008; P. Hudson, Thomas, Quinn, & Aranda, 2009; Kwak, Salmon, Acquaviva, Brandt, & Egan, 2007; S. Walsh & Schmidt, 2003). Finally, two studies were qualitative in nature with semi-structured interviews and were therefore graded as weak evidence according to the defined grading criteria (Harding, Leam, Pearce, Taylor, & Higginson, 2002; Milberg, Rydstrand, Helander, & Friedrichsen, 2005).

Among RCTs with the highest graded evidence, all were interventions that focused on providing psycho-social support to enhance caregivers' well-being and efficacy in delivering care (McMillan & Small, 2007; McMillan, et al., 2006; K. Walsh, et al., 2007). The outcomes of these trials produced mixed findings in relation to caregivers. A psycho-educational program for caregivers demonstrated a significant, favourable effect on caregivers' perceptions of caregiving rewards (P. Hudson, et al., 2005). A support intervention was found to improve caregivers' quality of life, their perceived burden of patients' symptoms and their perceived burden of care tasks (McMillan, et al., 2006). The same intervention also showed benefit to patients through lower reports of symptom distress (McMillan & Small, 2007). However, an evaluation of a separate psychosocial support intervention indicated no significant benefit to caregivers in the intervention group compared to those in the control group (K. Walsh, et al., 2007).

Two RCTs were graded slightly lower in evidence due to lack of power calculations. Nevertheless, both studies provide good quality evidence that caregivers can benefit from interventions. One study showed that a partner-guided pain management training intervention was associated with significantly higher ratings of caregiver self-efficacy for helping patients control pain and other symptoms (Keefe, et al., 2005). Another study of a counselling and support group intervention showed positive effects on depression levels of caregivers of patients with Alzheimer's disease (Haley, 2008).

Among two prospective intervention studies with comparison groups, only one showed significant benefit to caregivers. Carter (2006) found that a brief behavioural sleep intervention produced greater improvements in sleep quality and depression in the caregiver intervention group compared to the control group. However, Harding et al. (2004) reported that a short-term intervention promoting self-care had no significant benefit to caregivers' psycho-social health or well-being. A qualitative study with caregivers who participated in the latter intervention revealed that caregivers valued the following aspects of the intervention: validation of feelings, identification with other caregivers, opportunities for questions and provision of support to others (Harding, et al., 2002).

The pre-test/post-test studies without comparison groups all showed favourable results of the interventions. P. Hudson et al. (2008) reported that a psycho-educational group program had significant positive effects on caregivers' preparedness, competence, reward ratings and informational needs . P. Hudson et al. (2009) found that a training program for nurses in the facilitation of family meetings was positively associated with caregivers' reports of having their needs met. Kwak et al. (2007) reported a significant increase in caregivers' levels of comfort, closure and satisfaction following the attendance of a caregiver support program. Lastly, Walsh and Schmidt (2003) found that a telephone support intervention had psychological benefits for participating caregivers. However, due to attrition the data is based on a sample of five caregivers. These studies were graded weaker in evidence due to the lack of comparison groups.

Two studies with qualitative data suggest that caregivers perceived psychosocial support interventions as beneficial. Duggleby et al. (2007) conducted a pre-post test study of a program intended to promote hope among caregivers. The study sample size precluded statistical analyses, however qualitative responses indicate the program was received favourably. Milberg et al. (2005) found that regular support group sessions for family caregivers of palliative care patients were also perceived as beneficial when follow-up evaluations were conducted. All participants reported that they would recommend a support group to others in a similar situation.

Overall, the evaluation studies conducted in the last decade show very promising results of interventions for end-of-life caregivers. In particular, four of five RCTs showed that psycho-educational support interventions and pain management training had beneficial outcomes for caregivers. Nevertheless, it should be mentioned that two studies (one randomised controlled trial (? RCT) and one prospective study) failed to show significant benefit to caregivers. A number of studies with favourable treatment effects utilised interventions that targeted specific

needs of caregivers, such as therapy for sleep deprivation and training in problem-solving skills. This design strategy has been recommended in previous systematic reviews and may be the reason for the positive outcomes found in recent studies.

Studies with lower graded evidence also showed favourable trends in outcomes of interventions for caregivers. While these designs are limited by less rigorous approaches, such studies have their place in the future development of high-quality, systematic designs in empirical research.

For instance, a number of studies identified in this review examined novel intervention approaches for end-of-life caregivers such as facilitation of family meetings and partner training in pain management. These designs should be commended in taking a family-centred approach through the inclusion of patient, caregivers and family members, and therefore warrant further investigation. The findings from this review suggest that while there are no established evidence based interventions for end-of-life caregivers, there is evidence of more rigorous effort in the design, implementation and evaluation of interventions

In a comprehensive review of the literature on effective interventions for caregivers of palliative care patients, Grande and Ewing (2009) concluded that existing research had failed to reliably demonstrate efficacy in interventions for caregivers. According to the authors, 'lack of a firm empirical and conceptual base, combined with general challenges of palliative care research and inadequate design' (p. 3), has been the major barriers to high quality research and positive outcomes. Grande and Ewing (2009) contend that research studies have largely been limited by a lack of randomised controlled designs, small samples, varied interventions and a non-specific focus on caregivers. Based on reviews of the research to date (Eagar, et al., 2007; P. Hudson, 2004a) it is recommended that future work in this area focus on the following issues:

- clear definition and operation of intervention goal
- clear theoretical framework
- separate and specific assessment of caregivers needs
- greater focus on preventative intervention approaches
- facilitation of the positive aspects of caregiving
- development of valid and reliable measures in caregiver assessment
- better understanding of the 'active' components of interventions
- identification of optimal components and potential barriers to effectiveness
- optimal empirical design of evaluations.

While there is a great need for higher quality research in this area, the studies identified in the present review indicate that such issues are being addressed in more recent research. Furthermore, the need for attention to this area is being realised through a more focused effort in the development of intervention studies and comprehensive research reviews (Candy, et al., 2009; Grande & Ewing, 2009). Through greater international collaboration and continued empirical investigation, the establishment of effective and reliable interventions for caregivers of palliative care patients may well be on the way.

Table 3: Intervention studies for family caregivers of palliative care patients published between 2000- 2009

Reference and grade of evidence	Study population	Intervention description	Evaluation design	Outcome variables	Findings
P. Hudson et al. (2005) IA	106 caregivers of patients receiving home-based palliative care	A psycho-educational intervention delivered via 2 home visits and 2 phone calls by a nurse. This was supplemented with a guide book and audio tape. Program content included preparation, information, caregiver needs, psychosocial support, respite, future planning and goals.	RCT following eligibility assessment. Trial arms were (1) standard palliative care and (2) standard care + intervention. Data collected at baseline, five weeks later and eight weeks following patient death.	*Preparedness for caregiving *Caregiver competence *Rewards of caregiving *Anxiety and depression *Mastery *Self-efficacy	A significant positive effect of the intervention was found in perceptions of caregiving rewards. No other significant treatment effects were found.
McMillan et al. (2006) IA	A consecutive sample of 354 family caregivers of community palliative care patients	COPE Intervention: problem-solving/coping skills intervention with 4 components: creativity, optimism, planning and expert information	RCT following inclusion assessment. Trial arms were (1) Usual care group (n=109); (2) Usual care + 3 support visits (n=109); and (3) Usual care + 3 visits to teach intervention (n=111). Data collection was at baseline, 1 wk post- intervention and 2 weeks post-intervention	*Caregiver quality of life *Symptom Assessment *General Caregiver *Caregiver Demands	At 30-day follow-up, the intervention showed significantly improved quality of life, burden of patients' symptoms and caregiving task burden compared to the other two conditions. There were no changes in caregiving mastery or coping.
McMillan & Small, (2007) IA	329 hospice homecare patients and their caregivers	COPE Intervention: problem-solving/coping Skills intervention with 4 components: creativity, optimism, planning and expert information	RCT following inclusion assessment. Trial arms were (1) Control/usual care group; (2) Usual care + 3 support visits; and (3) Usual care + 3 visits to teach intervention. Data collection was at baseline, 1 wk post- intervention and 2 weeks post-intervention	*Pain intensity *Dyspnea intensity *Constipation assessment *Symptom assessment *Hospice quality of life	Symptom distress was significantly decreased in the patient group whose caregivers received COPE training. There were no significant differences for any other target variables.

Reference and grade of evidence	Study population	Intervention description	Evaluation design	Outcome variables	Findings
Walsh et al. (2007) IA	271 informal caregivers of patients in palliative care	Six visits by caregiver advisors to meet needs of caregivers and provide additional support to palliative care services. Domains covered were: patient care, physical health needs, respite, future planning, psychosocial issues, relationships with health professionals and finances	RCT following baseline assessment. Trial arms were usual care from specialist palliative care service (n=134) and intervention (n=137). Follow-up was at 4, 9 and 12 weeks.	*Psychological distress *Caregiver strain *Caregiver quality of Life *Bereavement assessment	Scores on GHQ fell below the threshold of 5/6 in a third of caregivers in both arms at all follow-up points. No significant differences between groups were found on any outcome measures.
Keefe et al (2005) IB	78 advanced cancer patients eligible for hospice care and their partners	A cognitive-behavioural, partner-guided pain management training intervention over three (45 to 60 min) sessions in patient's homes. The aims of the intervention were (1) education, (2) pain management and (3) coping skill maintenance. Written materials, a videotape and audiotapes were also provided.	RCT: Following a pre-treatment phone assessment, patients and partners were randomly assigned to either the intervention or standard care. Post-treatment evaluations were conducted by phone and/or mail a mean of 7.56 days following completion.	*Pain assessment *Functional assessment *Self-efficacy in chronic pain assessment *Mood	Partners who received the intervention reported significantly higher levels of self-efficacy for helping the patient control pain and other symptoms. There was non-significant trend for partners to report lower levels of caregiver strain.
Haley et al. (2008) IB	254 spousal caregivers of Alzheimer's patients who had experienced the death of their spouse during participation in the New York University Caregiver Intervention Project	Caregiver intervention included (a) 2 individual and 4 family counselling sessions; (b) a weekly support group; and (c) Ad-hoc counselling upon request. The usual care arm received standard care, which included counselling upon request.	RCT – Prior to death of spouse, caregivers were randomly assigned to the intervention (n=122) or usual care (n=132) and baseline measures were taken. Participants were followed up every 4-6 months prior to patient death and either 1 or 2 years after patient death.	* Depression	Caregivers in intervention group had significantly lower depression symptoms compared to those in usual care both before and after bereavement. These effects were more marked among caregivers whose spouses were not nursing home placed.
Carter (2006) IIB	30 adult caregivers of advanced cancer patients with at least a 6-month life expectancy who were not enrolled in hospice services	A brief behavioural sleep intervention for family caregivers that included stimulus control, relaxation, cognitive therapy and sleep hygiene training in two 1 hour sessions. The control group received body mechanics training in two 1	Repeated measures experimental design with intervention group (n=15) and control group (n=15). Data collected at baseline, 3 & 5 weeks, and 2, 3, and 4 months post baseline.	* Sleep Quality *Sleep monitoring *Sleep logs *Depression *Caregiver quality of life	Improvement in both groups but intervention group showed greater improvements in sleep quality and depression scores than controls. Quality of life scores were similar across groups.

hour sessions.

Reference and grade of evidence	Study population	Intervention description	Evaluation design	Outcome variables	Findings
Harding et al. (2004) IIB	73 family caregivers of patients receiving home-based palliative care.	Short-term intervention in group format aimed to promote self-care by combining informal teaching with group support in six weekly sessions of 90 minute duration.	Pre-post design: Intervention (n=36) and comparison group (n = 37) Three time points: baseline, 8 wks from baseline and 5 months from baseline Semi-structured interviews at 8 weeks from baseline	*Palliative outcomes *Patient performance *Burden *Coping *General health *State anxiety	Group intervention had no significant effect on any outcome variables post-intervention or at follow-up. Qualitative data showed caregivers valued talking to others and sharing experiences.
Hudson et al. (2009) IIIB	20 family caregivers of patients in palliative care, 18 health professionals and 4 patients	Nurses received training on the facilitation of family meetings based on clinical practice guidelines. Family meetings were conducted with caregivers and follow-up phone calls were made.	Pilot study: Pre-post survey design. & Focus group Three time points: before meeting, after meeting and two days after meeting.	*Family needs *Pre/post meeting questionnaire *Family meeting evaluation forms *Qualitative data from focus groups	Caregivers reported a significant increase in having their needs met from TI to T2 and T3. Professionals and patients reported meetings were well facilitated.
Hudson et al. (2008) IIIB	156 primary family caregivers of patients with advanced cancer receiving palliative care	Caregiver Group Education Program: a psycho-educational intervention (3 sessions over 3 weeks) that covered (1) the caregiver role; (2) strategies for self-care; and (3) strategies for patient care. Delivered by health professionals.	Pre-post survey design Three time points: commencement of program, upon completion and two weeks later.	*Caregiver competence *Preparedness for caregiving *Family needs *Rewards of caregiving	Significant positive effects of the intervention were found for caregiving preparedness, competence, rewards and informational needs.
Kwak et al. (2007) IIIB	2025 end-of-life family caregivers who volunteered to participate in the study	The Hospice Experience Model of Care program was delivered by 142 trainers in 5 sessions. The program included 7 modules: life affairs; community relationships; personal relationships; love; acceptance of end-of-life; and bereavement.	Pre-post survey design: Pre-surveys were administered at the end of the first session and post-surveys were completed at the end of the last session.	*Comfort with caregiving *Caregiver closure *Caregiver satisfaction	Significant improvement was found in all 3 outcomes. Program length made a difference for improvement in comfort with caregiving and closure but not in caregiver gain.

Reference and grade of evidence	Study population	Intervention description	Evaluation design	Outcome variables	Findings
Duggleby et al. (2007) IIIC	10 family caregivers of people with advanced cancer	Living with Hope program delivered via a home visit. The program consists of a 17-min video and a daily journaling activity.	A mixed method concurrent triangulation, pre-and post-test design. Quantitative and qualitative data collected at baseline, prior to program delivery. Data also collected at two post-treatment time points (1 and 2 weeks post-treatment).	* Hope *Quality of Life *Qualitative open-ended evaluation questions	The sample size precluded statistical analyses although mean scores on both measures did increase. Qualitative data was said to be very positive in evaluation of the program.
Walsh & Schmidt (2003) IIIC	14 caregivers recruited but only 5 completed study due to patient death	A 4 week telephone support intervention modified for caregivers of hospice patient. Based on 'tele-care II intervention, which uses a tele-care workbook to provide information related to palliative care. The information was delivered via teleconferencing with a nurse.	Pre-post study. Data collected prior to intervention and post intervention (if patient had not died).	*Caregiver burden *depression *social support *end-of-life reactions	Caregivers who completed the full study were found to experience decreased depression, despair and disorganisation as the patient's condition worsened.
Harding et al.(2002) IIII	40 family caregivers participated but only 21 were evaluated	As described in Harding et al. (2004)	Qualitative study with semi-structured interviews	Topics in interviews addressed motivation for attending, format, participation, content, information and benefits gained.	Attendees reported that identifying with other caregivers, validating feelings, asking questions, and providing support were valuable outcomes.
Milberg et al. (2005) IIII	19 of 22 family caregivers of patients receiving palliative home care	Weekly support groups run over 6 or 7 weeks for approximately 1.5 hours. All led by health professionals (social worker and physiotherapist). There were prepared topics such as 'psychological responses' and 'community resources' but the aim was to promote flexibility in discussion topics.	Follow-up evaluations of the support group were conducted via four tape-recorded focus group interviews (13 members participated) and a questionnaire (completed by 19 members).	Interview questions regarding perceptions of support group. Thematic analysis of focus group data	The majority of caregivers reported favourably on participation in the focus groups and said 'recommend it to other caregivers'. Themes that emerged from focus groups were: reasons for group participation; group composition; group leader; meaningful dialogue; sense of cohesion; and post-session reflections.

4.3 Chapter summary: Supportive interventions for caregivers of palliative care patients

4.3.1 Published reviews

- In general caregiving populations, interventions for caregivers were found to fall into three categories:
    1. Education-focused.
    2. Support-focused.
    3. A combined focus on education and support.

- Studies based on general caregiving populations or caregivers of cancer patients, provide modest evidence for the effectiveness of interventions that are:
    - multi-component in design
    - individualised as opposed to group focused
    - goal oriented in approach.

- There is preliminary support for the effectiveness of respite care for caregivers of chronically ill patients.

- In a recent review of Australian and International literature of caregiver interventions it was reported that studies had failed to yield conclusive information on the effectiveness of caregiver support interventions. Nevertheless, it was acknowledged that studies of interventions geared towards problem-solving and cognitive restructuring had demonstrated more promising findings (Eagar, et al., 2007).

4.3.2 Studies of interventions for caregivers of terminally ill patients

- A total of 15 separate studies were identified as evaluations of interventions for caregivers of terminally ill patients published between 2000 and 2009.

- Among RCTs with the highest graded evidence, one psychosocial support intervention was found to benefit caregivers and patients. However, a separate psychosocial support intervention indicated no significant benefit to caregivers' quality of life.

- Three RCTs were graded slightly lower but all provided evidence that caregivers received significant benefits compared to control groups. These interventions were:
    - a psychosocial-education program for caregivers
    - a partner-guided pain management intervention
    - a counselling support group.

- Among two prospective intervention studies with comparison groups, only one showed significant benefit to caregivers: a brief behavioural sleep program for caregivers. A short-term intervention promoting self-care had no significant benefit to caregivers' psycho-social health or well-being.

- The pre-post design studies without comparison groups all showed favourable results of interventions, however the studies were graded weaker in design. These studies were:
    - a psycho-educational group program
    - a training program for health professionals in the facilitation of family meetings
    - caregiver support program.

- Two qualitative studies reported favourable responses from caregivers following:
    - a program to promote self-care
    - a program to promote hope among caregivers.

- The separate studies of interventions for caregivers of palliative care patients show very promising results. In particular, four of five RCTs showed that psycho-educational support interventions and pain management training had beneficial outcomes for caregivers.

- The findings from this review suggest that while there are no established evidence based interventions for caregivers of palliative care patients, there is evidence of more rigorous effort in the design, implementation and evaluation of interventions.

Bereavement refers to the objective experience of loss through death (Center for Advancement of Health, 2004). In the context of palliative care, the significance of bereavement is two-fold: on the one hand, it marks the endpoint of patient care and the effort towards achieving "a good patient death"; on the other hand, it is a time to offer bereavement care and support to families and caregivers. As previously acknowledged, one of the fundamental distinctions of bereavement in palliative care is that 'the same people who become bereaved are those who have provided care and companionship through the final illness of the dying person' (S. Payne & Rolls, 2009). Part two of this report will focus on the bereavement experiences of caregivers following the death of the person previously under their care.

5.1 General concepts in bereavement research

Research and clinical practice in the fields of grief and bereavement have burgeoned in recent decades, and an understanding of the general concepts and issues in the literature is therefore warranted (Stroebe, et al., 2008). This chapter will outline general concepts in the bereavement literature and highlight recent research in various bereaved populations. The chapters that follow will discuss issues and concerns related to the experience of caregiver bereavement with a specific focus on palliative care.

5.1.1 Common terms in the literature

According to Stroebe et al. (2001), the discourses of bereavement have meant that terms may be used interchangeably with varied meaning. The following definitions are in accordance with major literature reviews and bereavement texts. Bereavement is widely accepted 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, Bonnano, Malkinson, & Rubin, 2003). Grief is defined as a more specific phenomenon that primarily applies to the emotional (affective) reaction to loss through death. It is regarded as a natural and normal experience that can involve physical, cognitive, emotional and social manifestations (Center for Advancement of Health, 2004; Stroebe, et al., 2008). Another term that is distinguished in bereavement literature is mourning. Mourning is described as the social expression or acts expressive of grief that are often shaped by cultural, religious or societal norms (Stroebe, et al., 2008; The Joanna Briggs Institute, 2006).

5.1.2 The experience of normal grief

While there is consensus that grief is a normal experience following major loss, there has been much hesitance on the part of researchers to define normal grief (Stroebe, et al., 2008). According to Stroebe et al. (2008) this is due to the complexity in the manifestation of grief, which can encompass emotional responses, psychological changes, behavioural changes and physiological responses (Stroebe, et al., 2008). Furthermore, there are a myriad of variations in the experience of grief due to cultural differences, social norms, personality traits and the circumstances of the death (see Table 4). In the first year of bereavement, the most common areas of disruption are cognitive disorganisation, dysphoria, health deficits, and disruption in social and occupational functioning (Bonnano & Kaltman, 2001). Given such factors Stroebe et al. (2008) suggest that 'normal grief could be defined as an emotional reaction to bereavement, falling within expected norms, given the circumstances and implications of the death, with respect to time course and/or intensity of symptoms'.

Normal grief or uncomplicated grief has been described as a process that is dynamic, pervasive and highly individualised (Cowles, 1996). Thus, discussions of normal grief validate the physical, psychological, behavioural and social turmoil that accompany uncomplicated grief (Corless, 2006). Importantly, reviews of the evidence suggest that the experience of intense grief reactions do not necessarily lead to poor outcomes and the majority of bereaved people will recover from their loss within a reasonable time frame (Center for Advancement of Health, 2004; The Joanna Briggs Institute, 2006). Definitions of 'recover' and what constitutes 'reasonable' also vary in the literature with acknowledgement that these will differ from individual to individual (The Joanna Briggs Institute, 2006).

The key element that appears to delineate the experience of normal grief is the time frame and intensity of the grieving process. In general, normal grief is described as an acute reaction of deep sorrow, which subsides in a period of weeks or months whereupon renewed engagement and interest in life occurs. The loss is slowly integrated into the bereaved person's life and the pain associated with the loss begins to lessen (Lobb, Kristjanson, Aoun, & Monterosso, 2006). According to Worthington (1994), the process of recovery may involve brief periods of relapse that improve with time until the individual adjusts to the loss. For those individuals who struggle to adjust to their loss, the grief process can become problematic and result in a reduced quality of life (The Joanna Briggs Institute, 2006).

Table 4: Manifestations of grief

Manifestations of grief			
Physical	**Cognitive**	**Emotional**	**Behavioural**
Headaches	Sense of depersonalisation	Anger	Impaired work performance
Dizziness	Inability to concentrate	Guilt	Crying
Exhaustion	Sense of disbelief and confusion	Anxiety	Withdrawal
Muscular aches	Idealisation of the deceased	Sense of helplessness	Avoiding reminders of the deceased
Sexual impotency	Search for meaning of life and death	Sadness	Seeking or carrying reminders of the deceased
Loss of appetite	Dreams of the deceased	Shock	Overreactivity
Insomnia	Preoccupation with image of deceased	Yearning	Changed relationships
Feelings of tightness or hollowness	Fleeting visual, tactile, olfactory, auditory hallucinatory experiences	Numbness	
Breathlessness		Self-blame	
Tremors		relief	
Shakes			
Oversensitivity to noise			

Source: Corless (2006)

5.1.3 Prolonged grief disorder

In a minority of bereaved persons (10% to 20%), a normal grief adjustment does not occur and debilitating grief is experienced for an extended period. Prolonged Grief Disorder (PGD) is the term used to describe grief that continues in intensity, beyond a time frame in which some form of adjustment is expected and to an extent that is significantly disruptive to a person's life (Smith, Kalus, Russell, & Skinner, 2009). It has been shown that people who suffer from PGD have the greatest risk for adverse health effects (Lobb, et al., 2006).

In recent literature the term PGD has replaced the term 'complicated grief', which encompassed a multitude of descriptive variations from normal grief including chronic grief and delayed, inhibited or absent grief. Delayed, inhibited or absent grief has been characterised by minimal or no grieving response in early bereavement, while delayed or inhibited grief has been characterised as an intense grieving response experienced at a later time (Lobb, et al., 2006; Stroebe, et al., 2008).

According to Smith et al. (2009),there is consensus that symptoms of PGD fall into two categories: (1) symptoms of distress, such as longing for the deceased, loneliness and preoccupation of thoughts of the deceased; and (2) symptoms of traumatic distress, such as feelings of disbelief, anger, shock and detachment from others (Prigerson & Jacobs, 2001a). Further development of this model has resulted in a proposed set of diagnostic criteria for PGD as shown in Table 5 (Prigerson, Vanderwerker, & Maciejewski, 2008).

Recent reviews of the PGD literature state that the issue of importance in differentiating between normal grief and PGD is the time frame and intensity of the symptoms. That is, the set of grief symptoms outlined in Table 5 are identified as (1) persistent (beyond 6 months post-death, regardless of when those six months occur in relation to the loss) and (2) severe (marked intensity or frequency). The importance of a six month delay in diagnosing PGD is highlighted in order to allow normal grief symptoms to subside and identify those individuals who are unusually distressed (Kristjanson, et al., 2006; Lobb, et al., 2006; Ray & Prigerson, 2006). While there is evidence that PGD does occur in small proportions of bereaved populations, further work and discussion will determine whether PGD will be included in forthcoming editions of the Diagnostic and Statistical Manual of Mental Disorders (Stroebe, et al., 2008).

Table 5: Proposed diagnostic criteria for Prolonged Grief Disorder

Criteria	Description
Criterion A	Yearning, pining, longing for the deceased Yearning must be experienced at least daily over the past month or to a distressing or disruptive degree
Criteria B	In the past month the person must experience four of the following eight symptoms as marked overwhelming or extreme. 1. Trouble accepting the death. 2. Inability trusting others since the death. 3. Excessive bitterness or anger about the death. 4. Feeling uneasy about moving on with one's life (e.g. difficulty forming new relationships). 5. Feeling emotionally numb or detached from others since the death. 6. Feeling life is empty or meaningless without the deceased. 7. Feeling the future holds no meaning or prospect for fulfilment without the deceased. 8. Feeling agitated, jumpy or on edge since the death.
Criterion C	The above symptom disturbance causes marked dysfunction in social, occupational or other important domains
Criterion D	The above symptom disturbances must last at least 6 months

From (Prigerson, et al., 2008)

5.1.4 Anticipatory grief

According to Rando (2000), anticipatory grief is the phenomenon encompassing mourning, coping, interaction, planning and psychological reorganisation that are stimulated and begun in part in response to the impending loss of a loved one and the recognition of associated losses in the past, present and future (p.29). There has been much controversy over the concept and definition of anticipatory grief and there is need for more research to clarify debates surrounding this complex and multidimensional phenomenon (Clukey, 2008; Fulton, 2003). While some investigators maintain that the experience of grief prior to death is not plausible (Parkes, 1983), others recognise that some family caregivers may experience grief-like symptoms in anticipation of the patient's death (Zisook, Irwin, & Shear, 2009).

At the time of impending death many losses, changes and transitions can occur in families such as re-allocation of roles, resource management and changes in family dynamics (Strauss, 1984). In an effort to define the constituents of anticipatory mourning, Clukey (2008) conducted qualitative interviews with nine bereaved caregivers who had not received hospice services. Based on study findings it was reported that anticipatory mourning involved a dynamic set of processes that include (1) realisation that death is imminent; (2) caretaking of the dying person; (3) the act of being physically present; (4) finding meaning in the experience; and (5) transitions in the relationship with the dying person. Further research is needed to verify these processes of anticipatory grief in large-scale study populations.

The anticipatory grief hypothesis suggests that individuals who have the opportunity to psychologically prepare themselves for the loss of a loved one may have a reduced risk for difficulties after the death (Burton et al., 2008). Research findings on the anticipatory grief hypothesis remain inconclusive. While some researchers propose that this theory is particularly relevant to the experience of caregiver bereavement (Schulz, Newsom, & Fleissner, 1997), few studies have examined the phenomenon prior to the patient's death (Tomarken et al., 2008).

Pre-death prolonged grief symptoms may include yearning or longing for the person to be as they were before the illness (Prigerson & Maciejewski, 2006). Tomarken et al. (2008) reported that in a sample of 250 caregivers of terminally ill cancer patients, caregivers under the age of 60 had significantly higher levels of pre-death prolonged grief than caregivers 60 years and older. Significant predictors of pre-death prolonged grief were the severity of stressful life events and pessimistic thinking. P. Hudson et al. (In Press) also examined pre-death prolonged grief among 302 caregivers of palliative care patients. It was found that 15% of caregivers met cut-off criteria for pre-loss prolonged grief around the time patients were admitted to palliative care. Predictors of pre-death prolonged grief were higher levels of caregiver esteem, lack of family support, impact on caregivers' health, bereavement dependency and lower levels of optimism (P. Hudson, et al., In Press).

5.2 Health outcomes following bereavement

In a recent review of health outcomes of bereavement it was reported that there is rigorous evidence to show bereavement is associated with an increased risk of mortality from varied causes, including suicide (Stroebe, et al., 2008). The majority of this research has been conducted in the area of spousal bereavement and subgroup differences show sex differences and age differences. Generally, widowers (with married same-sex counterparts) have a greater risk of mortality than widows (compared with married same-sex counterparts). Studies also indicate that younger bereaved spouses have a greater mortality risk than older bereaved spouses. However, some caution is recommended regarding the latter finding as institutionalised individuals are sometimes excluded from large-scale samples (Stroebe, et al., 2008).

The same review also reported that bereaved persons are more likely to have physical health problems, particularly earlier in bereavement. Bereaved persons have also been found to have higher rates of disability, medication use and hospitalisation than non-bereaved persons. Interestingly, studies suggest that many bereaved persons with intense grief might fail to consult with a doctor although the need for assistance is evident (Stroebe, et al., 2008).

5.2.1 Mental health problems

Bonnano et al. (2008) report that 10% to 15% of bereaved individuals suffer chronic distress and depression for years after the loss, while others experience acute distress and depression from which they recover in approximately one or two years. The differentiation between grief and depression is not always clear due to the overlap in symptom classification. As highlighted by (Middleton, Burnett, Raphael, & Martinek, 1996), bereaved people can experience considerable symptoms of depression and yet still be coping adaptively.

In the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) an episode of depression is defined as the experience of five (or more) symptoms of depression during the same two-week period, which represents a change from previous functioning. At least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure. Other symptoms of depression include insomnia or hypersomnia; fatigue or loss of energy; feelings of worthlessness or excessive guilt; and recurrent thoughts of death or suicide ideation. It is further specified that depression is not an appropriate diagnosis where the symptoms are better accounted for by bereavement.

There is wide opinion that bereaved individuals with pre-existing depression or other psychopathology are more likely to experience severe reactions (Bonnano, et al., 2008; Stroebe, et al., 2007). Bereavement studies indicate that among bereaved individuals who experience depression, 25% to 45% show mild levels of depressive symptoms and 10% to 20% show clinically significant levels of depression. A study of bereaved spouses showed that the rate of anxiety disorders during the first year of bereavement was 44%. This was significantly greater than prevalence rates in the community (Jacobs et al., 1990). In circumstances where there has been trauma surrounding a death, bereaved individuals may develop post-traumatic stress disorder. Rates of post-traumatic stress disorder have been found to range from 5% to 10% in bereaved populations (Barry, Kasl, & Prigerson, 2001; Zisook & Schuchter, 1991).

While mental health problems such as depression and anxiety can be co-morbid with prolonged grief disorder, there is now sufficient evidence to indicate that prolonged grief disorder symptoms are distinct from other mental health disorders (Boelen & Prigerson, 2007). Therefore it is recommended that assessments of mental health disorders are not substituted for the assessment of prolonged grief symptoms as cases of prolonged grief disorder would be missed by reliance on the psychiatric disorders currently found in the DSM-IV (Boelen & Prigerson, 2007; Zhang, et al., 2006).

5.2.2 Resilience

There is evidence that some individuals exhibit resilient responses to bereavement. For these individuals grief reactions are short-lived and a relatively stable trajectory of healthy functioning continues throughout bereavement (Bonnano, et al., 2008; Ray & Prigerson, 2006). Traditional views of the grieving process regarded prolonged absence of grief as abnormal or pathological. It was thought that individuals exhibiting minimal or no distress following bereavement either lacked a meaningful relationship with the deceased or were experiencing an inhibition in the grieving process. There was an assumption that this group of bereaved people required professional assistance to resolve their latent grief (Bonnano, et al., 2008; Ray & Prigerson, 2006).

In the last decade, prospective research has provided compelling evidence that resilience to loss represents an empirically distinct outcome trajectory of bereavement. Furthermore, studies have shown that resilience during bereavement is more prevalent than generally assumed (Bonnano, et al., 2008). According to (Bonnano, et al., 2008), the Changing Lives of Older People (CLOC) study presented strong evidence for the prevalence of resilience following bereavement. Bonanno et al. (2002) used data from this large prospective study on widowhood to identify the most common or typical trajectories of adjustment to loss across time (three years pre-death to 18 months post-death). The study showed that close to half the sample were characterised by a stable low distress profile that began prior to their spouse's death and continued with relatively few grief symptoms in bereavement. There was no evidence for delayed grief reactions. Bonanno et al. (2008) report that several other studies provide

convergent evidence for resilience in bereavement under varying circumstances including premature death of a spouse mid-life, loss of a child mid-life and loss of a homosexual partner through AIDS.

5.3 Theoretical models of grief and bereavement

Stress process models are increasingly used as the theoretical basis for studying both caregiving and bereavement (Burton, et al., 2008). Within the stress process model, there are two hypotheses regarding the adjustment process: (1) resource depletion theory and (2) relief theory. The depletion theory suggests that prolonged caregiving is a chronic stressor that depletes personal and social resources, leaving the caregiver vulnerable to negative outcomes in bereavement. The relief theory also suggests that caregiving is stressful; however, it is proposed that the reduction in caregiving burden following the death of care recipients results in improved mental and physical bereavement outcomes (Burton, et al., 2008; Li, 2005).

Post-modern theoretical models of grief and bereavement draw on the stress process framework and incorporate assessment of both personal risk factors and coping styles in bereavement assessment (Agnew, et al., 2009). Such models include the Dual Process Model, the Integrative Risk Factor Framework and the Range of Response to Loss Model (Agnew, et al., 2009; Machin, 2001; Stroebe, Folkman, Hansson, & Schut, 2006; Stroebe & Schut, 1999). The commonality in these models is that grief is recognised as an active, fluctuating process in which there is oscillation between experiences of loss and restoration. In this way, the process of grieving incorporates both avoidance and confrontation of the loss. Further exploration of current models of grief will be examined in section 7.1.1 Bereavement Assessment.

5.4 Chapter Summary: A review of bereavement concepts

- The term bereavement refers to the objective experience of loss through death. The term grief refers to the subjective experience of the emotional reaction to loss through death.

- A normal grief reaction is delineated by the time frame and intensity of the grieving process. It is described as an acute reaction of deep sorrow, which subsides in a period of weeks or months. The process of recovery may involve brief periods of relapse that improve with time.

- Prolonged Grief Disorder (PGD) is the term used to describe grief that continues in prolonged intensity, beyond a time frame in which some form of adjustment is expected and to an extent that is significantly disruptive to a person's life.

- Anticipatory grief is the phenomenon encompassing the process of mourning, coping, interaction, planning and psychological reorganisation that are stimulated and begun in part in response to the impending loss of a loved one.

- Studies show that caregivers of palliative care patients can have significant levels of pre-loss prolonged grief during the period of caregiving. Predictors of pre-loss prolonged grief among caregivers include stressful life events, higher levels of caregiver esteem, lack of family support, impact on health, bereavement dependency and pessimistic thinking.

- Research suggests that vulnerable populations of bereaved individuals are at a greater risk of mortality, physical health problems and mental health problems than non-bereaved individuals.

- There is evidence that some bereaved individuals exhibit resilient responses to loss. These grief reactions are short-lived and a relatively stable trajectory of healthy functioning continues through bereavement.

Chapter 6. Caregiver bereavement

6.1 The impact of bereavement on family caregivers

Several studies indicate that the majority of caregivers are able to adjust reasonably well following the death of the person they cared for. Brazil et al. (2003) interviewed 151 bereaved family caregivers to examine bereavement experiences. The most frequently reported symptoms reported by caregivers were sleeplessness, followed by 'nerves' or depression, loss of appetite and other symptoms including pain and weight gain. Nearly 50% of caregivers reported experiencing none of the four symptoms, while 22% reported one symptom, 18% reported two symptoms and 11% reported three or more symptoms. Eighty-nine percent of caregivers felt things were going reasonably well and 60% felt they had come to terms with their relative's death. Fifty-seven percent of the caregivers reported that they did not look forward to things the way they used to and loneliness was a problem. It was found that mental health status was the strongest predictor of poorer adjustment, followed by caregivers' relational status (caregivers who were also spouses had poorer outcome). It was also found that friends and relatives played an important role in assisting the bereavement process.

P. Hudson (2006) followed up 45 family caregivers two months after their relative's death and found that 74% of caregivers reported they were 'okay' or 'good' at the time of data collection. Just over a quarter of caregivers reported they were not coping well after the death of their relative and more than one third expressed feelings of loneliness and/or sadness since the death. Thirteen percent of caregivers reported feeling tired or exhausted and almost 10% reported feeling a sense of relief following the patient's death.

A qualitative study of bereavement experiences of 30 caregivers showed that caregivers' self reported distress on the Global Severity Index decreased significantly between caregiving and bereavement (Waldrop, 2007). Although the number of symptoms also reduced between caregiving and bereavement this was not significant; analyses indicated that the intensity of distress decreased and was significantly different at both time points. Qualitative responses indicated that sleep disruptions and fatigue were commonly experienced in the first year of bereavement. Most participants reported relief from previously exacerbated symptoms and only a small number reported the onset of new symptoms. The majority of caregivers reported relief from the physical burden of providing care. Psychologically, caregivers reported overwhelming emotional responses triggered by a variety of occurrences such as feeling flooded with emotion or a sense of being back in the caring situation (Waldrop, 2007).

6.2 Long-term adjustment to bereavement among caregivers

In Hudson et al's. (In Press) longitudinal study of 302 Australian caregivers of palliative care patients, caregivers were followed up at six months post-death and 13 months post-death. Six months into bereavement it was found that, using self report checklists with validated cut-off scores, 18% of caregivers were likely to have an anxiety disorder, 14% were likely to have a depressive disorder and 13% were likely to have prolonged grief disorder. It was also found that 15% of caregivers had significant symptoms of demoralisation and 28% were likely to meet the criteria for post-traumatic stress disorder. At 13 months post-bereavement, levels of anxiety, depression, prolonged grief disorder, and demoralisation were similar (17%, 13%, 11% and 17% respectively), while levels of post-traumatic stress had decreased considerably (18%). Hudson et al. (In Press) found that the best predictor of distress at 6 months and 13 months post-death was distress pre-death (on entry to palliative care) and that other significant predictors of distress were no longer significant when pre-death distress was accounted for.

A prospective study of 668 Taiwanese caregivers of terminally cancer patients was conducted to investigate determinants of complicated grief (Chiu et al., 2009). Patients had received either in-patient hospice care or shared care hospice consultation. Primary caregivers were interviewed by telephone on average 8.9 months after the patient had died. Chinese variations of the Inventory of Complicated

Grief (ICG) were modified for the Taiwanese setting and were used to establish cases of complicated grief. It was found that 33% of bereaved caregivers met criteria for complicated grief as measured by the ICG. Logistic regression showed that risk factors for complicated grief were female gender, spousal relationship, parent-child relationship, lack of religious belief, unavailable family support and history of mood co-morbidity. Factors that protected caregivers from complicated grief included longer duration of caring, medical disease history in the carer and patients being cared for on the hospice ward. A limitation of this study was the exclusion of caregivers with a history of drug abuse or a diagnosed psychiatric disorder.

Ferrario et al. (2004) followed up caregivers of advanced cancer patients in bereavement. One hundred and eleven caregivers completed questionnaires while caring and then at three, six and 12 months in bereavement. Repeated measures analyses showed a significant decrease in anxiety from time one (while caring) to time four (12 months post patient's death). Depression symptoms significantly decreased from baseline to three months post patient's death and then significantly increased at 12 months post patient's death. Between the third and twelfth month in bereavement there was a significant decrease in life satisfaction scores and a significant increase in caregiver mourning scores. The results did not appear to be influenced by gender or duration of disease. Regression analyses showed that a spousal relationship was highly predictive of bereavement maladjustment at 12 months. When this variable was removed, older age and emotional burden also predicted bereavement maladjustment.

Gilbar and Ben-Zur (2002) assessed aspects of bereavement in 69 widowed caregivers of cancer patients. Caregivers were interviewed at three months to one year following the death of patients. Scores on the Brief Symptom Inventory indicated that collectively caregiver's scored highest on symptoms of depression, anxiety, phobic anxiety and general severity of psychological symptoms. A path analytic model showed that gender and age contributed directly to distress and present grief, while past grief and burden contributed to general severity of psychological symptoms and psychosocial adjustment. Gilbar and Ben-Zur (2002) reported that being female, older and experiencing grief in the past were factors that contributed to levels of current distress and grief in the sample of widowed spouses.

6.3 Prolonged grief disorder and depression

6.3.2 Trajectories of grief and depression in general bereavement

Bonanno et al. (2002) conducted a pivotal investigation of depression and chronic grief trajectories using prospective data from the Changing Lives of Older Couples study (CLOC). The CLOC study followed a baseline sample of 1,532 older married people from the US and identified a sample of 205 individuals whose spouse had died during the study. These individuals had been interviewed three years prior to the death of their spouse and re-interviewed at six, 18 and 48 months post-loss. Bonanno et al. (2002) used this data to classify bereaved spouses as changing, staying the same, or improving from pre-bereavement to 18 months post bereavement. Five distinct trajectories of grief and depression were identified as shown below in Table 6.

Table 6: Trajectories of grief and depression following bereavement

Pattern of grief	Prevalence	Characteristics
Common grief or recovery	11%	Low pre-loss depression and high post-loss depression at six months with improvement by 18 months
Stable low distress or resilience	46%	Low pre-and post-loss depression at six months and 18 months
Depression followed by improvement	10%	High pre-loss depression and low post-loss depression at six months and 18 months
Chronic grief	16%	Low pre-loss depression and high post-loss depression at six months and 18 months
Chronic depression	8%	High pre-loss depression that persists at six months and 18 months

According to Bonanno et al (2002) the 46% of bereaved individuals who experienced stable low distress both pre and post-loss represent a population of individuals with a genuine form of resilience. Those individuals who had low pre-loss depression and high post-loss depression at six months with improvement by 18 months were thought to represent a common grief reaction or recovery. A group of individuals (10%) were found to experience high pre-loss depression and low levels of depression post-bereavement. The reasons for the high levels of pre-loss depression were unclear. Among the remaining individuals, 16% were regarded as chronic grief sufferers (low pre-loss depression and high post-loss depression at six and 18 months) and 8% were regarded as chronic depression sufferers (high pre-loss depression that persisted at six and 18 months).

6.3.3 Trajectories of depression in caregiver bereavement

A number of studies have investigated such depression trajectories in populations of bereaved caregivers. Aneshensel, Botticello and Yamamoto-Mitani (2004) investigated depressive symptoms pre- and post-bereavement using five-year data from a longitudinal study of 291 spouses and adult children who were caring for someone with Alzheimer's disease. Bereaved individuals were found to report highest depression symptoms during the first year following bereavement, which then dropped significantly in the second year and remained fairly stable in years three and four until further declining in year five. Trajectory analyses identified four distinct groups with varying patterns of bereavement adjustment within the entire sample as shown in Table 7 (Aneshensel, et al., 2004).

Table 7: Trajectories of grief and depression in caregiver bereavement

Pattern of grief	Prevalence	Characteristics
Repeatedly symptomatic	63%	Repeated depression symptoms that were present and regularly occurring, albeit infrequently.
Temporarily distressed	18%	High symptom levels of depression during the first year that improve substantially in year two. Improvement is slower thereafter.
Repeatedly unsymptomatic	11%	A near absence of depressive symptoms throughout bereavement
Repeatedly distressed	8%	Considerable depression both early and late in bereavement

Taken from (Aneshensel, et al., 2004)

Overall, Aneshensel et al. (2004) concluded that caregivers with fewer symptoms pre-bereavement tend to maintain these states post-bereavement (Aneshensel, et al., 2004) while emotionally distressed caregivers tend to become more distressed in bereavement. Risk factors for poor outcome were role overload in caregiving and lower income. Protective factors were self-esteem and socio-emotional support.

Li (2005) examined the trajectory of depressive symptoms for wife and daughter caregivers during the transition from caregiving to bereavement. Hierarchical linear modelling was used to analyse longitudinal data collected from 157 wife and daughter caregivers over a period of approximately four and a half years. On average, wife and daughter caregivers experienced increasing depressive symptoms as their care recipients were closer to death, highest depressive symptoms immediately after the death and decreasing symptoms thereafter. Wives were found to have higher and more fluctuating depression levels than daughters. Factors associated with higher levels of depression in caregivers were feelings of overload, burden and dissatisfaction with support. Further, caregivers of recipients with more problematic behaviours had higher depression levels than caregivers of elders with fewer problems.

6.4 Chapter summary: Caregiver bereavement

- Several studies indicate that the majority of caregivers adjust reasonably well after the death of the person they cared for.

- Studies indicate that caregivers report a range of feelings in bereavement including loneliness, sadness, apathy, relief and overwhelming feelings of being back in the situation.

- Frequently reported symptoms in the first year of bereavement were sleep problems, nervous tension, depression, loss of appetite and pain.

- Mental health status and caregiver's relational status were strong predictors of poor adjustment in early bereavement. Other risk factors included female gender, older age, grief in the past and emotional burden.

- Longitudinal studies of grief trajectories indicate that mental health problems such as anxiety and depression tend to subside by 18 months post-loss. However, a proportion of bereaved people (approximately 20%) continue to remain significantly distressed and symptomatic years after the death.

- A five-year study of bereaved caregivers of Alzheimer's disease patients showed four trajectories of grief and bereavement: repeatedly symptomatic (63% of caregivers), temporarily distressed (18% of caregivers), repeatedly unsymptomatic (11% of caregivers) and repeatedly distressed (8% of caregivers) (Aneshensel, et al., 2004).

- Risk factors for poor bereavement outcome in longitudinal studies were role overload during caregiving, lower income and dissatisfaction with support.

7.1 What is bereavement needs assessment

In epidemiological and health research, a risk factor is defined as an aspect of a person's condition, lifestyle or environment that increases the probability of occurrence of a disease (International Association of Hospice and Palliative Care, 2009). Within the context of bereavement, risk refers to the 'extent to which a person is susceptible to adverse outcomes associated with loss of someone significant through death' (Centre for Palliative Care, 2000) p.8). Risk factors are therefore characteristics of bereaved people and features of their situation that may increase the probability of vulnerability (Relf, et al., 2008). These factors can be used to determine decisions about who may be most at risk for poor bereavement adjustment and/or prolonged grief disorder. Furthermore, studies indicate that bereavement interventions only make a measurable difference to those bereaved persons with high levels of vulnerability or risk (Relf, et al., 2008). Therefore, undertaking an assessment of bereavement risk can identify those individuals who are most likely to benefit from bereavement services. According to Centre for Palliative Care Education and Research (2000), there are two questions that should guide the determination of risk:

- What factors affect vulnerability to negative bereavement outcomes?
- What factors impede or promote adjustment to the bereavement experience?

7.1.1 Theoretical underpinnings of bereavement assessment
According to Agnew et al. (2009), post-modern theoretical developments postulate the need for an integrative approach to bereavement assessment, in which both risk factors and coping styles are examined. Recent theoretical frameworks give recognition to this integrative approach in various ways. Models of Coping identified by Lazarus and Folkman (1984) emphasised the use of pre-existing coping mechanisms in the face of stress and in the appraisal of the situation. Later work by Folkman (1997) gave recognition to the positive states experienced by caregivers of terminally ill patients and the role of positive psychological states was incorporated into the original stress and coping model (P. Hudson, 2003). The Dual Process Model and Cognitive Stress Theory highlights the need to understand the interaction between loss and restorative factors in the process of grieving. It is suggested that in the process of adjustment following bereavement, there is oscillation between experiences of loss and experiences of restoration (Hansson & Stroebe, 2007; Stroebe & Schut, 1999). The Range of Response to Loss Model (Machin, 2001) proposes that responses to loss fall across three broad states: overwhelmed, controlled and resilient. Consistent with other major theoretical frameworks, Machin's model suggests that resilience reflects the ability to move or oscillate between experiencing grief and controlling emotions in order to manage everyday life (Relf, et al., 2008).

7.2 Bereavement risk factors for caregivers of palliative care patients

In the last decade there has been much effort to identify the risk factors for prolonged grief disorder. Lobb et al. (2010) conducted a systematic review of this research and reported that the predictors for prolonged grief disorder prior to death include previous loss, exposure to trauma, a previous psychiatric history, attachment style and the relationship to the deceased. Risk factors for prolonged grief disorder associated with the death were reported to include violence; quality of caregiving; quality of the dying experience; close relationship to the deceased; marital closeness and dependency; and lack of preparation for the death. It was noted that perceptions of social support, in addition to cognitive appraisal and high distress at the time of death, also played a significant role in adjustment after the death (Lobb, et al., 2010). Risk factors that have been shown to be most relevant and important for caregivers are discussed below.

7.2.1 Characteristics of the bereavement
Personality traits such as trait anxiety, neuroticism and a pessimistic outlook have been found to be associated with emotional burden in bereavement (The Joanna Briggs Institute, 2006). A study of caregivers of terminally ill spouses revealed that those with higher levels of depression and burden pre-

death and who reported positive aspects of caregiving pre-loss were found to be at greater risk of prolonged grief disorder (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006).

Age and gender also appear to be associated with bereavement outcome. Females have been shown to have significantly greater psychological distress than males (Ferrario, et al., 2004; Gilbar & Ben-Zur, 2002). The research findings in relation to age and bereavement are somewhat contradictory (The Joanna Briggs Institute, 2006). It has been found that older caregivers tend to have poorer psychological and physical health in bereavement, while younger people react to bereavement with greater shock and emotional intensity (Brazil, et al., 2003; Ferrario, et al., 2004). In the general bereavement literature, there is evidence of a greater mortality risk to younger bereaved people who have lost a spouse (Stroebe, et al., 2007). Finally, studies also suggest that insufficient economic resources are a significant risk factor for poor bereavement outcomes among caregivers (Aneshensel, et al., 2004; Relf, et al., 2008).

According to Lobb and Kristjanson et al. (2010), insecure attachment styles are a significant risk factor for complicated grief. Bereaved adults who had experienced life adversities such as childhood separation anxiety, death of a parent and childhood abuse were more likely to experience symptoms of prolonged grief disorder in bereavement (Silverman, Johnson, & Prigerson, 2001; Vanderwerker, Jacobs, Murray-Parkes, & Prigerson, 2006). Also, excessive dependency in the relationship to the deceased and as a general personality trait, has been shown to be an independent risk factor for prolonged grief symptoms (van Doorn, Kasl, Beery, Jacobs, & Prigerson, 1998).

7.2.2 Situational factors in caregiving

Studies show that situational factors during the delivery of patient care can impact on bereavement outcomes. Perceptions of greater problems in caregiving and feelings of burden while delivering care are associated with poorer bereavement outcomes (Ferrario, et al., 2004; Grande, Farquhar, & Barclay, 2004; Li, 2005). Caregivers who report more problematic behaviours (e.g. swearing or dressing inappropriately) in care recipients have also been found to have higher depression levels than caregivers of recipients with fewer problematic behaviours (Li, 2005). Furthermore, Wright et al. (2008) reported that in their study of 332 palliative care patients, more aggressive medical treatment prior to death was associated with a higher risk of major depression among bereaved caregivers.

7.2.3 Relationship with deceased

A number of studies show that caregivers who were married to the deceased person have a greater risk of poorer bereavement outcomes compared to those with other relational ties (Brazil, et al., 2003; Ferrario, et al., 2004; Li, 2005). Generally, the loss of a close relationship, such as that of a spouse, parent or child is associated with greater risks to health (Relf, 2004). A study by Kelly et al. (1999) suggests that lower levels of intimacy are also associated with an increased likelihood of bereavement distress. Metzger and Gray (2008) examined caregivers' end-of-life communication and level of interaction with a dying relative as a predictor of bereavement adjustment. It was found that caregivers who engaged in a greater degree of communication through expressions of love, affection and closeness were more likely to have features of prolonged grief disorder.

7.2.4 Family functioning

In-depth research on the influence of family functioning on bereavement suggests the ways families function as a unit has a significant impact on bereavement adjustment (Kissane et al., 2006; Kissane, McKenzie, Mckenzie, Forbes, & al., 2003). Studies indicate that cohesion, expressiveness and conflict are important parameters in discriminating adaptive families from dysfunctional families. Families at risk are those who fall into the categories of (1) hostile, where there is high conflict, poor cohesion and poor expressiveness; and (2) sullen, where there is moderate conflict, cohesion and expressiveness but high levels of muted anger. Kissane and colleagues recommend routine screening of family functioning in palliative care services (Kissane, et al., 2006).

7.2.5 Lack of preparation for death

Lack of preparation for death has been shown to be a risk factor for poor bereavement outcomes among family and caregivers of palliative care patients (Center for Advancement of Health, 2004). Barry et al. (2002) found that lack of preparedness among caregivers was associated with complications in grieving at baseline, four months post-death and nine months post-death. A study of caregivers of dementia patients showed that despite having provided care for a median of three years, 23% of caregivers felt unprepared for the death of their relative (Hebert, Dang, et al., 2006). Those who felt unprepared had greater symptoms of depression, anxiety and prolonged grief disorder at six months post-loss. Ethnicity, lower levels of education, lower levels of income and higher levels of depression pre-death were positively associated with perceptions of being unprepared for death. In contrast, the amount of pain the care recipient was perceived to experience was positively related to preparedness.

7.3 Factors that facilitate bereavement adjustment

7.3.1 Palliative care

Some research shows that enrolment in a palliative care service is associated with better bereavement adjustment. A US cohort study of 30,838 elderly couples showed that the surviving spouse of decedents who received hospice care were less likely to fall ill and die during bereavement than spouses of decedents who did not receive hospice care (Christakis & Iwashyna, 2003). In a separate study of 174 caregivers, it was found length of hospice enrolment impacted on caregiver bereavement (Teno, Gruneis, Schwartz, Nanda, & Wetle, 2007). Caregivers of patients enrolled with a hospice within three or fewer days of death (24%) were significantly more likely to have major depression disorder at follow-up than caregivers of patients enrolled with a hospice earlier in the course of their terminal illness (9%). Similarly, Kris et al. (2006) reported that caregivers of patients with a very short hospice enrolment were more likely to be diagnosed with major depressive disorder at 13 months post-loss.

Abernethy et al. (2008) utilised the Health Omnibus Study of 4,400 households in South Australia, to evaluate the association between specialised palliative care services and long-term caregiver outcomes. Long-term caregiver outcomes were assessed qualitatively as the degree to which the caregiver was able to adapt and return to a new equilibrium after the death. It was found that caregivers were more able to 'move on' with their lives when specialised palliative care services were involved in the patient's care.

Other studies have found no difference between hospice and standard care (Grande, et al., 2004). Grande et al. (2004) reported that a hospice at home service had no significant impact on caregivers' bereavement outcomes. Rather, caregivers' perceptions of inadequate terminal support for patients, inadequate practical and psychosocial support for themselves and high symptom severity were associated with worse caregiver bereavement outcomes. In this same study, home deaths were associated with better bereavement support and better physical health post-bereavement than inpatient deaths.

7.3.2 Positive self-perceptions

In studies of general bereaved people, positive outcomes have been found to relate to self-perceptions that include feeling stronger, wiser, more mature and independent, having a better understanding of others and feeling more patient, tolerant, empathic and courageous. More positive perceptions about life changes since the loss, for example the perception that relationship with others has been strengthened as a result of the loss, have also been associated with positive outcomes (Affleck & Tennen, 1996; Calhoun & Tedeschi, 1989-90).

7.3.3 Social support

There is consistent evidence that caregiver grief is greatly influenced by social context; that is, the social environment, relationships with significant others and the degree of support available (Brazil, et al., 2003; Stroebe, et al., 2007; Waldrop, 2007). The majority of studies indicate that high levels of

social and emotional support may buffer bereavement distress (Center for Advancement of Health, 2004; Kelly et al., 1999; Kissane, 2003). A recent study of the predictors of well-being among bereaved former hospice caregivers indicated that lower levels of social activities, smaller social networks and lower satisfaction with support were related to higher levels of depression (Burton, et al., 2008).

7.4 Bereavement assessment in practice

According to the National Institute for Clinical Excellence (NICE) Guidance for the Supportive and Palliative Care for Adults with Cancer, it is recommended that cancer network organisations strive to implement reliable methods of screening and assessing bereavement outcomes based on the three component model of bereavement support in the NICE Guidance as specified below in Table 8 (National Institute for Clinical Excellence, 2004).

Table 8
Three Component of Bereavement Support in the NICE Guidance Manual

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Component 1 Grief is normal after bereavement and most people manage without professional intervention. Many people, however, lack understanding of grief after immediate bereavement. All bereaved people should be offered information about the experience of bereavement and how to access other forms of support. Family and friends will provide much of this support, with information being supplied by health and social care professionals providing day-to-day care to families.

Component 2 Some people may require a more formal opportunity to review and reflect on their loss experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers/befrienders, self-help groups, faith groups and community groups will provide much of the support at this level. Those working in Component 2 must establish a process to ensure that when cases involving more complex needs emerge, referral is made to appropriate health and social care professionals with the ability to deliver Component 3 interventions.

Component 3 A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist counselling/psychotherapy services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist needs of bereaved children and young people (being developed as part of the National Service Framework on children and not covered here).

Taken from (National Institute for Clinical Excellence, 2004).

Based on the NICE guidelines, bereavement support should be offered in response to an assessment of the needs of an individual. It is widely recognised that palliative care organisations are ideally placed to provide assessment and support to individuals who show an increased risk of complicated grief (Agnew, et al., 2009). While most palliative care agencies undertake some form of bereavement assessment, methods can vary from clinical judgement, formal bereavement assessment and written checklists of risk factors. To provide some guidance in the assessment of bereavement risk among family members of palliative care patients, the Centre for Palliative Care Education and Research (2000) developed the following guidelines:

- Family members should be involved in assessment of risk of complicated bereavement outcomes.
- Complicated bereavement risk assessment forms part of the palliative care team's duty of care and is a process requiring input from a range of professionals involved in the care of the patient and family.
- Complicated bereavement risk assessment should commence at the point of referral to palliative care, and continue through care provision, patient death and early bereavement.
- Complicated bereavement risk assessment requires structured documentation, review in team meetings and the use of family assessment.
- Complicated bereavement risk assessment involves four key categories of information: the illness terminal care and the nature of the death; characteristics of the bereaved; interpersonal

relationships including family functioning; and characteristics of the deceased (Centre for Palliative Care, 2000).

7.4.1 A review of bereavement tools

Agnew et al. (2009) undertook a review of bereavement assessment tools to determine their suitability for use within bereavement services and hospice settings. The review of the literature identified two groups of assessment: (1) ongoing assessment from the time of patient admission through to early bereavement; and (2) post-bereavement assessment to determine between normal and complex grief.

Three tools were identified as commonly used in the first group of assessment (admission to early bereavement). The Bereavement Risk Index (BRI); (Parkes, 1993), a professional assessment based on observation and family contact, was found to be the most commonly used assessment tool across the UK. While the BRI has been criticised for its poor reliability and the tendency for the assessment to remain incomplete, it has been widely adapted for use within specialist palliative care settings (Agnew, et al., 2009). The Family Relationships Index (Moos & Moos, 2002) was highlighted as a validated screening tool to identify dysfunctional families and those at risk for poor bereavement outcome. However, Agnew et al. report that it is uncertain how many services offer family focused grief therapy, for which the tool was specifically designed. The Matrix of 'Range of Responses to Loss Model' (Relf, et al., 2008) was the third tool identified as having potential for wide implementation in palliative care settings. The Matrix provides a framework to assess an individual's risk for poor outcome by identifying existing vulnerability factors and coping responses. Agnew et al. (2009) contend that the Matrix strengths are its basis on modern theoretical concepts, applicability to diverse populations and involvement of service users. A full display of the Matrix of Range of Response to Loss Model can be seen in Appendix 1.

For the assessment of complex grief later in bereavement when an individual presents for support, Agnew et al. identified the following three tools: the Inventory of Traumatic Grief (ITG); (Prigerson & Jacobs, 2001b); the Texas Revised Inventory of Grief (TRIG); (Faschinbauer, Zisook, & DeVaul, 1987); and the Adult Attitude to Grief Scale (AAG); (Machin, 2001). According to Agnew et al. (2009) the ITG and the TRIG are the most widely tested tools to differentiate between normal and complex grief states. However, they are thought to be complex to use and therefore may not be appropriate in all bereavement settings. Agnew et al. assert that the AAG scale may be most appropriate for assessing need in a hospice bereavement support service as is user friendly, brief and encourages active engagement on the part of service users.

As shown in the study by Agnew et al. (2009), in order for bereavement services and hospices to conduct reliable and continuous bereavement needs assessment, further research is necessary to develop knowledge of the tools and methods to be utilised for evidence based practice (Agnew, et al., 2009). Only then can bereavement needs assessment be conducted in an integrative approach that includes 'the investigation of coping styles and risk factors, in line with more recent theoretical developments' (Agnew, et al., 2009) p.4.

7.5 Chapter summary: Bereavement Needs Assessment

- Bereavement risk factors are characteristics of bereaved people and features of their situation that may increase the probability of vulnerability.

- Undertaking an assessment of bereavement risk can identify those individuals who are most likely to benefit from bereavement services. Two key questions are:
    1. What factors affect vulnerability to negative bereavement outcomes?
    2. What factors impede or promote adjustment to the bereavement experience?

- Bereavement risk factors for caregivers of palliative care patients can be categorised by the following: characteristics of the bereaved, situational factors in caregiving, the relationship with the deceased, family functioning and lack of preparation for death.

- Factors that facilitate bereavement adjustment include early enrolment to palliative care service, positive perceptions and social support.

- Bereavement support should be offered in response to an assessment of the needs of the individual.

- Guidelines for the assessment of bereavement risk among family members of palliative care patients were compiled by the Centre of Palliative Care (2000).

- Bereavement tools commonly utilised in bereavement services and hospice settings include:
    Assessment at admission to early bereavement:
    1. The Bereavement Risk Index (BRI; Parkes, 1993)
    2. The Family Relationship Index (FRI; Moos & Moos, 2002)
    3. The Matrix of Ranges of Responses to Loss Model (Relf, Machin, et al., 2008)

    Assessment of complex forms of grief
    1. The Inventory of Traumatic Grief (ITG; Prigerson & Jacobs, 2001)
    2. Texas Revised Inventory of Grief (TRIG; Fachinbauer et al., 1987)
    3. Adult Attitude to Grief Scale (AAG; Machin, 2001)

Chapter 8. Bereavement services in palliative care

8.1 An overview of services

Bereavement support is a key component of hospice and palliative care services in many Western countries (O'Connor, Abbott, Payne, & Demmer, 2009). However, there is great variation in the nature and extent of these services. Bereavement support can range from telephone calls and the provision of written information, to one-to-one counselling and group therapy. Other support services that may be offered include volunteer befriending, social activities, self-help groups, memorial services and drop-in events (Relf, et al., 2008; Roberts & McGilloway, 2008). According to Relf et al. (2008) many services offer a range of support services to all families, with a more proactive focus on the provision of one-to one support to those who are considered more vulnerable.

8.1.1 Australian palliative care services
Two studies were identified that investigated Australian palliative care and hospice bereavement services (Abbott, O'Connor, & Payne, 2008; Mather, Good, Cavenagh, & Ravenscroft, 2008). Mather et al. (2008) sent bereavement service surveys to 324 palliative care centres identified from the Australian Palliative Care National Directory 2004. From the 236 centres that participated (73%), 95% were found to provide bereavement follow-up, with similar rates in metropolitan and regional areas. Among the 13 centres that did not provide bereavement support, four indicated that they intended to expand their services and offer such programs in the future. Among the 88 non-participating centres, two services had closed palliative care provision, 23 (27%) were metropolitan based and 63 (73%) were regional based (Mather, et al., 2008).

Mather et al's (2008) survey showed that 83% of participating palliative care centres offered support to the families and significant others of all patients who were enrolled in their service. The forms of bereavement support included phone calls (86%), individual sessions and visits (84%), letters (55%) and memorial services (66%). The timing of first contact in bereavement was found to be quite early, with the majority of centres advocating a policy of making contact with significant persons within two weeks of death. Only a small percentage of centres had a designated bereavement coordinator or counsellor. In most centres bereavement care was shared among various staff including social workers, nurses, pastoral care workers, bereavement co-ordinators or counsellors. Bereavement risk assessments were conducted in 69% of centres, but were more common practice in metropolitan centres than in regional centres (80% versus 65%). Multidisciplinary team and staff member opinion were also adopted forms of risk assessment (Mather, et al., 2008).

Mather et al (2008) concluded that bereavement support is a standard part of palliative care services in Australia, with a high prevalence in both metropolitan and regional centres. According to the authors, the report highlighted the need for bereavement services to be accounted for in staff budgeting as the coordination and delivery of services are often the responsibility of staff who are involved in other aspects of palliative care. Further highlighted was the need for collaborative research to improve bereavement services to families of patients in palliative care.

In the study by Abbott et al (2008), 510 eligible adult palliative care services were identified in Australia. Data were obtained from 143 organisations (a response rate of 28%). The percentage of organisations that actively offered bereavement services was unstated. It was found that the many bereavement services had been established some time after the palliative care organisation commenced and had been operating between five to 15 years. The majority of services provided phone calls from bereavement personnel with literature or materials on grief or memorial services. It was found the most common first priority bereavement service offered was face-to-face support, the second priority service was the provision of written material and the third priority service was memorial services. The majority of organisations reported providing bereavement services to all bereaved persons, with only three indicating they provided services to 'high risk' individuals only. Services were typically offered by nurses or a part-time bereavement co-ordinator. Barriers to providing bereavement services were reported to be the models of bereavement support used, the lack of a formal risk assessment and personnel and

funding constraints. A study limitation was the lack of information regarding non-participating organisations.

8.1.2 International comparisons of palliative care services

O'Connor, Abbott et al. (2009) compared the findings from surveys of bereavement services conducted in Australia, the UK and the USA. The most common forms of services across the three countries were telephone calls and mailed literature. Individual, face-to-face support was most commonly used in the UK, but was not among the three most common forms of support in the USA and Australia. An informal assessment process was used in the majority of American and Australian services, but was only utilised in less than half of UK services. In all countries, services wanted to extend their bereavement support by providing more groups or offering additional counselling and resources. Common barriers identified in all countries were low numbers of paid staff, variations in specialist training, insufficient levels of funding, and the lack of the use of validated bereavement assessment tools. Australian and US surveys indicated that less than 5% of the hospice and palliative care budget was allocated to bereavement services. O'Connor et al. (2009) assert that more guidance is needed on what constitutes an acceptable bereavement support program for a hospice or palliative care service.

8.2 Service use and service needs

A randomised , cross-sectional, state-wide population-based survey of 6034 people in South Australia was used to investigate bereavement help-seeking following an expected death (Currow et al., 2008). A third of the sample had experienced an expected death of someone close to them in the last five years. It was found that 13% sought help for their grief from one or more: friend or family member (10.7%), grief counsellors (2.2%), spiritual advisers (1.9%), nurses or doctors (1.5%). Twenty-five respondents indicated they would have valued help with their grief but did not seek help (Currow, et al., 2008). Regression analyses identified the following significant factors related to professional help seeking: provision of intense caregiving, lack of part-time or full-time work and the perception of being unable to move on with life. Use of a palliative care service was not found to be a significant contributing factor.

A prospective cohort study of 161 family caregivers of hospice patients in Connecticut was the basis for tracking utilisation of bereavement services (Cherlin et al., 2007). Approximately 30% of family caregivers were found to use bereavement services in the first year of their loss, with the majority of caregivers utilising services in the first six months. The factors associated with utilisation of bereavement services were being a spouse caregiver, having major depressive disorder at study enrolment, witnessing highly distressing events associated with the patient's death, having greater availability of instrumental support and end-of-life communication with a physician prior to the patient's death. The majority of caregivers (70%) who did not use services reported that bereavement services were not needed or were not perceived to be helpful. For these caregivers, the support from friends and other networks was perceived to be sufficient. Limitations of the research were loss to follow-up and a lack of information on participant's psychological history.

Roberts and Gilloway (2008) evaluated a hospice-based bereavement support service in Ireland through the distribution of a postal survey to 517 bereaved clients. A total of 243 people (47% RR) completed the survey and the majority were found to be satisfied with the services. The data showed that 81% of respondents who were asked about bereavement follow-up had received some form of contact, usually via a telephone call from a nurse. Approximately two thirds of people found these contacts to be helpful. The majority of respondents (87%) who were invited to attend a memorial service reported that they did attend. Respondents reported that their reasons for attending were comfort, assistance in coping with grief and to honour their deceased relative or friend. Those who did not attend memorial services indicated that it would be too painful or unhelpful at the time, they were reluctant to return to the hospice, the service was too soon after their loss, the religious nature of the service was unappealing and/or it was too inconvenient. With regard to bereavement information evenings, one third of respondents indicated attending this event. Most were satisfied with the content and support provided. Those who did not attend the information evening gave similar reasons to those who chose not to attend the memorial service.

A Swedish study by Milberg and colleagues (2008) evaluated the perceived needs of family members following the death of their relative who was enrolled in a palliative care service. The study was cross-sectional and targeted family members three to nine months after the patient's death. Two hundred and forty-eight family members responded (RR 66%) to a postal questionnaire, with 46% indicating a perceived need for bereavement follow-up. The most favoured point of time for bereavement follow-up was between two to six months into bereavement. A personal home visit from a staff member known to the family was the preferred method of contact for most people. Of the 86% of family members who received a bereavement follow-up, most reported that it was 'good' or 'very good'. It was found that family members wanted to talk about what happened during the palliative phase of care (e.g. if the patient suffered or not). Family members expressed the need to discuss their present situation, their feelings of loneliness and the future. The follow-up reportedly made family members feel that their needs were valued and recognised. It was also found to be valuable as a means of discussing family members' feelings of guilt.

8.3 Context of care

According to Holtslander (2008) the bereavement needs of caregivers has been a neglected and marginalised area of hospice development in policy, research and evidence based practice. It is reported that while hospice and palliative care organisations advocate that bereavement support is integral to their service, bereavement services can vary immensely depending on the geographic population, community resources and differences in approach. As such it is reported that the majority of bereavement services remain severely limited as a result of lack of time, infrastructure, qualified personnel and low allocation of resources (Holtslander, 2008).

Given the negative bereavement outcomes experienced by bereaved caregivers, Holtslander (2008) warns that the loss and grief of bereaved palliative caregivers can become a public health issue in itself. According to the National Consensus Project for Quality Palliative Care (2004) bereavement support should be made available for at least 12 months, or as long as needed after the death of patients, with the ultimate goal being successful transition and reintegration into society following the caregiving experience (Ferris et al., 2002). Reid et al. (2006) advocate that bereavement services work best when they are integrated within a continuum of care for family caregivers beginning with pre-bereavement support and continuing support throughout the bereavement process. Holtslander (2008) contends that further research into the effectiveness, efficiency and equity of bereavement support programs is needed to improve bereavement services for palliative caregivers during bereavement.

8.4 Chapter summary: Bereavement services in palliative care

- Bereavement support is provided by many hospice and palliative care services in Western countries.

- Bereavement support can range from telephone calls and the provision of written information, to one-to-one counselling and group therapy. Other support services that may be offered include volunteer befriending, social activities, self-help groups, memorial services and drop-in events.

- An Australian study found that 95% of 236 palliative care centres provided bereavement follow-up, with similar rates in metropolitan and regional areas (Mather, et al., 2008).

- Bereavement care was shared among various palliative care staff. A small proportion of palliative care centres had a bereavement co-ordinator or bereavement counsellor (Mather, et al., 2008).

- Bereavement risk assessments were conducted in 69% of centres and were more common in metropolitan areas (Mather, et al., 2008).

- In a separate Australian study it was shown that barriers to providing bereavement services were utilised models of support, lack of formal risk assessment, lack of personnel and funding constraints (Mather, et al., 2008).

- A study comparing bereavement services in Australia, UK and USA showed the most common forms of support were telephone calls and mailed literature (O'Connor, et al., 2009).

- Common barriers to providing bereavement support in Australian, UK and USA were low numbers of paid staff, variations in specialist training, insufficient levels of funding and lack of validated bereavement assessment tools (O'Connor, et al., 2009).

- Studies indicate that approximately 30% of family caregivers seek professional help from a bereavement service and close to 50% of family caregivers perceived a need for bereavement follow-up.

- Factors associated with accessing bereavement support are being a spouse caregiver, having major depressive disorder at study enrolment, witnessing highly distressing events associated with the patient's death, having greater availability of instrumental support and end-of-life communication with a physician prior to the patient's death.

- The majority of bereaved family members who access bereavement support report feeling satisfied with the support received.

- While hospice and palliative care organisations advocate that bereavement support is integral to their service, many services remain severely limited due to lack of time, infrastructure, qualified personnel and low allocation of resources.

- It is recommended that bereavement services need to provide an integrated continuum of care for family caregivers beginning with pre-bereavement support and continuing support for at least 12 months into bereavement.

Chapter 9. Bereavement support interventions

Bereavement interventions have been conceptualised within the framework of primary, secondary and tertiary approaches (Stroebe, et al., 2007). Primary or universal interventions are those in which professional support is available to all bereaved individuals irrespective of whether there is clinical need for intervention. Secondary or selective interventions are designed for bereaved individuals who are regarded as more vulnerable to the risks of bereavement based on screening or clinical assessment. Both primary and secondary interventions provide a public health approach by attempting to prevent chronic or long-term grief-related problems (Currier & Holland, 2007). Tertiary or indicated interventions are those that provide therapy for prolonged grief disorder, grief-related pathology, or post-traumatic disorders, which are usually evident longer after bereavement (Currier & Holland, 2007; Stroebe, et al., 2007). This review will focus on evaluated data of various psychosocial interventions for the bereaved, with a particular focus on caregivers and family members of deceased palliative care patients.

9.1 Primary Interventions

The bulk of research indicates that the provision of bereavement interventions to all bereaved persons is unlikely to be of benefit in terms of diminishing grief related symptoms (Center for Advancement of Health, 2004; Stroebe, et al., 2007). Currier, Neimeyer et al. (2008) conducted a meta-analysis of 61 controlled bereavement intervention studies. Controlled studies were defined as those that compared bereaved persons who received a grief intervention with bereaved persons who did not receive any active intervention or treatment. Based on findings from the meta-analysis, it was concluded that primary interventions failed to produce better outcomes than would be expected by the passing of time.

Other data suggest that primary bereavement interventions may be unhelpful to bereaved persons; they impede normal grief processes (S. Payne & Rolls, 2009). Neimeyer (2000) conducted a meta-analysis of 23 studies of grief therapy published between 1975 and 1998. It was found that participants with uncomplicated grief did not receive measurable positive effect from grief therapies on any outcome variable. Furthermore, close to 50% of participants were found to suffer as a result of treatment (Center for Advancement of Health, 2004).

More recent research indicates that primary interventions may be helpful in certain circumstances and sub-populations (Stroebe, et al., 2007). Schut, Stroebe et al. (2001) reviewed 16 studies of primary bereavement interventions and concluded there was little evidence to support their effectiveness for bereaved adults. This review was updated by Schut and Stroebe (2005), in which four new studies of primary bereavement interventions were found to yield more positive results. Schut and Stroebe (2005) attributed this finding to the utilisation of self-selection procedures (i.e. the bereaved person requested help rather than help being offered) and the provision of intervention services later in bereavement (after several months or years). It was also found that there were better results in people with prior mental health problems, adult and young females and children.

According to Currier and Holland (2007), the benefit of primary interventions may be masked by methodological problems such as short-term follow-up assessments that fail to capture longer term benefits. Currier, Neimeyer et al. (2008) argue that pre-loss primary interventions may be more appropriate for caregivers, who often begin to process their loss before the actual death and have greater access to qualified health professionals at this time. There is some support for this proposal from two older studies that showed bereaved individuals who received pre-loss support and counselling through palliative care services were less impaired than control participants at follow-up across a variety of domains such as somatic symptoms, anger and anxiety (Cameron & Parkes, 1983; Parkes, 1979).

9.1.1 Pre-loss primary interventions for Alzheimer's caregivers

The potential benefits of pre-loss primary interventions have been demonstrated in two separate studies of caregivers of patients with Alzheimer's disease. As reported in section 4.2 (above), a randomised trial showed that a support intervention for 254 Alzheimer's caregivers significantly lowered depressive symptoms both before and after bereavement compared to that of controls who received usual care (Haley, 2008). The intervention involved counselling sessions (both individual and family sessions) tailored to meet the needs of the caregiver, as well as participation in a weekly support group. A third component of the interventions was 'ad hoc' counselling, available to caregivers at any time during participation in the study. According to Haley et al., the beneficial impact of enhanced caregiver support early in caregiving can lead to long-term improvements in both mean depression levels and recovery from depression symptoms, persisting beyond the patient's death and often for many years later. Furthermore, an examination of depression patterns revealed that caregiver resilience (non-clinical levels of depression scores at any point in the study) was more common among recipients of the intervention (60%) than those in the control condition (42.9%). While gender and baseline depression were controlled covariates in the analytic model, statistical comparisons showed a higher proportion of severe dementia cases randomly assigned to the control group. This was not factored into the analyses and may have confounded the results of the study.

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) study was a multisite randomised study of caregiver interventions that included psycho-education, behavioural interventions, environmental modifications and support (Holland, Currier, & Gallagher-Thompson, 2009). Data from the REACH study were used to investigate the efficacy of interventions (delivered during the phase of active caregiving) in preventing heightened bereavement symptomatology among 224 family caregivers who experienced the death of the person they were caring for during the course of the study. It was found that active interventions showed a significant effect on normal grief symptoms, a trend toward improvement on complicated grief symptoms and little effect on depressive symptoms at 18 month follow-up. Previous analysis of the impact of REACH interventions failed to show a significant reduction in depression symptoms for those still in the active caregiving role (Gitlin et al., 2003). These findings support the premise that long-term follow-up is warranted to assess the impact of primary interventions for caregivers. Differential treatment effects were observed in the study, in that cognitive-behavioural strategies were most effective at reducing levels of complicated grief, information and emotional support were most effective for normal grief, and environmental modification (e.g. increasing social support) were most effective for depressive symptoms. A limitation of these findings was that differential effects were examined through correlational analyses rather than randomisation.

9.2 Secondary Interventions

The overall evidence suggests that secondary interventions for individuals at risk for complications in bereavement are generally more effective than primary interventions. However, reviews of the research show effects are modest and there are indications that improvements are temporary (Center for Advancement of Health, 2004; H. Schut & Stroebe, 2005). In Currier et al.'s (2008) meta-analysis of bereavement interventions it was concluded that while interventions with higher risk grievers provided some benefit at post-treatment, the gains were relatively small and failed to yield statistically significant results at follow-up.

9.2.1 Family focused therapy

An empirically evaluated secondary intervention for families of palliative care patients is family focused grief therapy (FFGT). Based on over 15 years of research, this secondary preventative grief therapy begins during a terminal illness and continues following the patient's death (Kissane & Lichtenthal, 2008). Families who are considered to be at risk of bereavement maladjustment are screened using the Family Relationships Index (Moos & Moos, 1981). This scale classifies families according to five typologies: supportive, conflict resolvers, hostile, sullen or intermediate. Supportive and conflict resolving families are considered to be functioning well, while hostile and sullen families are considered to be poorly functioning. Intermediate families are those who demonstrate moderate cohesiveness with a tendency for psychosocial morbidity when under stress, such as bereavement. Therapy is initially conducted with the patient, the patient's family and caregivers. Typically, three to four sessions will

occur before the patient dies and the family then continue meeting with the therapist during bereavement. The goals of therapy are to foster family relational functioning and mutual support, encourage the sharing of grief and promote adaptive coping. Having the patient present in the initial sessions of therapy ensures the patient's wishes are known to the family and sets the foundation for a strong alliance with the therapist (Kissane & Lichtenthal, 2008).

A randomised controlled trial of family focused grief therapy was conducted in Melbourne, Australia (Kissane, et al., 2006). The Family Relationships Index was used to screen 257 families of cancer patients enrolled in a palliative care service. The screening process identified 183 families at risk of poor bereavement adjustment and of these, 81 participated in the trial. The cohort included 41 intermediate families, 21 sullen families and 19 hostile families. Randomisation in a 2:1 ratio assigned 53 families to intervention and 28 to a control condition. The controlled condition was usual care by the palliative care team with counselling when deemed necessary. Assessments were conducted at baseline, and six and 13 months after the patient's death. Results showed that family focused grief therapy had a modest effect, with a reduction in general distress over 13 months and significant reductions in distress and depression among the 10% of family members with high baseline scores. These gains were not accompanied by improvements in social functioning. Family focused therapy was found to be most beneficial for sullen families and modestly beneficial for Intermediate families. Importantly, hostile families appeared to benefit from therapy through reduced conflict at six months, but this was found to be reversed at 13 months follow-up. The authors caution that hostile families may be best treated individually.

9.3 Tertiary Interventions

While reviews of bereavement interventions have found only limited support for the effectiveness of primary and secondary interventions, investigations of tertiary interventions have yielded far more favourable results. Currier et al.'s (2008) meta-analysis of bereavement interventions demonstrated that targeting bereaved persons who showed indication of poor bereavement adaptation (tertiary interventions) promoted significantly greater benefit than universal or selective interventions. The mean effect size of tertiary interventions at post-treatment was significantly higher than that found for studies of primary interventions ($p =.02$) or secondary interventions ($p =.05$). The results at long term follow-up showed similar effects; tertiary interventions had significantly greater benefit than primary interventions ($p =.01$) or secondary interventions ($p =.01$). The authors claim that these findings converge with reports from others in the field (Jordan & Neimeyer, 2003; H. Schut & Stroebe, 2005), suggesting that bereavement interventions are of benefit to bereaved persons with indicated problems.

The following review of tertiary interventions is based on general populations of bereaved adults. According to Stroebe et al. (2007), studies of psychotherapeutic bereavement interventions published before 2001 indicate modest but lasting effects on symptoms of pathology and grief (Stroebe, et al., 2007). These interventions included individual and group therapy, psychoanalytic therapy and cognitive and behaviour therapy. While there are a range of psychiatric disorders that may occur following bereavement, more recent intervention studies have tended to focus specifically on the alleviation of depression and prolonged grief disorder.

9.3.1 Depression
Reviews of bereavement intervention studies consistently report that standard pharmacological treatments for depression are equally effective in bereavement related depression (Forte, et al., 2004; Hensley, 2006; Zhang, et al., 2006). A major study in this field was an investigation of the individual and combined effects of drug and psychological therapy. Reynolds et al. (1999) conducted a randomised, placebo-controlled double-blind trial of nortriptyline (a tricyclic antidepressant) and interpersonal therapy among 80 bereaved adults over the age of 50 with Major Depressive Disorder. Following the 16-week trial, it was found that interpersonal therapy alone had a remission rate of 29% (5 of 17 patients); nortripyline alone had a remission rate of 56% (14 of 25 patients); and interpersonal therapy in combination with nortriptyline had a remission rate of 69% (11 of 16 patients). The placebo arm of the trial showed that 45% of patients (10 of 22) had spontaneous remission. All conditions resulted in low

rates of relapse. These findings suggest that the combination of drug therapy and interpersonal psychotherapy may be the most effective treatment response for bereavement related depression.

9.3.2 Prolonged grief disorder

While pharmacological intervention has been shown to be effective for bereavement related depression, it has not proven effective in treating symptoms of PGD (Reynolds, et al., 1999; Zygmont, Prigerson, Houck, Miller, & Shear, 1998). In the clinical trial by Reynolds and colleagues (Reynolds, et al., 1999), it was reported that there was no significant improvement in the intensity of grief symptoms from drug therapy alone, interpersonal therapy alone nor the combination of the two.

In terms of psychotherapeutic interventions for PGD , the Traumatic Grief Treatment (TGT) has yielded the most promising evidence (Harkness, Shear, Frank, & Silberman, 2002; Shear, 2005). TGT involves psycho-education about normal grief and PGD; promotion of adaptive coping strategies for loss and restoration; and a focus on personal life goals. In addition, traumatic symptoms of grief are addressed using repeated story-telling and confrontation exercises modified from imaginal and invivo exposure used in therapies for post-traumatic stress disorder (Shear et al., 2001).

Shear et al. (2005) conducted a prospective, randomised clinical trial to compare the efficacy of TGT with standard interpersonal therapy. A total of 95 bereaved persons who met criteria for PGD as measured by the Inventory for Complicated Grief (Prigerson, Maciejewski, Reynolds, Bierhals, & Newsom, 2005) were assigned to receive 16 sessions of traumatic grief therapy (n=49) or interpersonal psychotherapy (n=46). Participants were permitted to continue with antidepressant medication if use was stabilised and managed by the study pharmaco-therapist. Findings showed that both therapies resulted in significantly reduced symptoms of PGD. However, the response rate for TGT (51%) was significantly greater than that of interpersonal therapy (28%). Further, time to response was significantly faster for TGT.

Reviewers of TGT postulate the clinical importance of Shear et al's research and advocate further randomised clinical trials. A disadvantage in Shear et al's (2005) research study is the inability to discern which aspects of the therapy are most effective as the therapeutic strategies employed are quite eclectic (Ray & Prigerson, 2006). Another concern that has been raised is the effectiveness of TGT in cases where trauma symptoms are less pronounced and complications in grief are related to issues of attachment, separation, loss and re-attachment. It has been suggested that other therapies addressing these issues may be more appropriate in such cases; for instance, integrated cognitive dynamic techniques or interpretive and supportive therapies. Research evidence to support the effectiveness of these techniques is needed (Ray & Prigerson, 2006; Zhang, et al., 2006).

A study by Wagner et al. (2006) combined cognitive behavioural interventions with narrative approaches in an internet-based treatment for prolonged grief disorder. The intervention group completed a series of carefully tailored writing assignments with therapist feedback. Writing themes included recalling painful details of the loss; integrating positive memories of the person into present life; fostering meaning from the loss; and redefining identify and new life goals. At post-intervention the intervention group were significantly improved on a variety of dimensions compared to the waitlist control, particularly in measures of intrusive thoughts and avoidance (effect sizes were up to 1.5 at post-intervention and up to 1.6 at follow-up). Limitations of the study were (1) reliance on Horowitz et al's (1997) criteria of prolonged grief disorder; (2) lack of face to face contact with a therapist; (3) exclusion of participants with co-morbid depression (Smith, et al., 2009). Nevertheless, the use of narrative techniques provides some support to the work by Neimeyer and others (R.A Neimeyer, 2004; R.A. Neimeyer, Prigerson, & Davies, 2002) who postulate the importance of facilitating the process of reorganisation of meaning. Future empirical work is needed to further link theoretical conceptualisations and treatment approaches in this area (Smith, et al., 2009).

9.4 Chapter Summary: Bereavement support interventions

- Bereavement interventions are conceptualised within the framework of primary, secondary and tertiary approaches.

- Primary or universal interventions are those in which professional support is available to all bereaved individuals irrespective of clinical need.

- Secondary or selective interventions are those provided to bereaved individuals who are thought to be vulnerable or 'at risk' based on screening or clinical assessment.

- Tertiary or indicated interventions are those provided to bereaved individuals who present with prolonged grief disorder, grief-related pathology or post-traumatic disorders.

- Generally research suggests that the provision of primary or universal interventions is unlikely to be helpful in resolving grief. However, more recent research indicates that primary interventions may be helpful for certain circumstances and populations.

- A number of studies have demonstrated that primary interventions can benefit caregivers, who often begin to process their loss before the actual death and have greater access to health professionals at this time.

- Secondary interventions have been found to be more effective than primary interventions for individuals at risk for complications in bereavement. Nevertheless, reviews of the research show that the effects are models and in some cases improvements are temporary.

- An empirically evaluated secondary intervention for families of palliative care patients is family focused grief therapy (FFGT). A randomised controlled trial showed that family focused grief therapy had a modest effect, with a reduction in general distress over 13 months and significant reductions in distress and depression among the 10% of family members with high baseline scores.

- Investigations of tertiary interventions demonstrate that they are substantially more effective than universal or selective interventions. That is, targeting bereaved persons who showed indication of poor adaptation was more likely to provide therapeutic benefit than targeting all bereaved persons or those who are thought to be 'at risk'.

- A combination of pharmacological and interpersonal therapy has been found to be effective in the treatment of bereavement related depression.

- Drug therapies have not been shown to be effective in the treatment of prolonged grief disorder. Traumatic Grief Treatment (TGT) has shown promising results in reducing symptoms of PGD.

Chapter 10: Conclusions and recommendations

- Caregivers of palliative care patients face complex and challenging tasks including physical, medical, financial, legal and emotional aspects of caregiving. While many caregivers report that caregiving provides positive and valuable experiences, a high proportion of caregivers report considerable burden on their own physical health, psychological well-being, financial welfare and social life. It is recommended that the assessment of caregivers' needs and well-being become routine in palliative care.

- Greater recognition of the factors that increase or decrease caregivers' vulnerability for burden is advocated. Risk factors for psychological burden include sleeplessness, higher levels of caregiver esteem, financial difficulties, greater impact on schedules, greater impact on health and pessimistic thinking. Protective factors that decrease caregivers' vulnerability for burden include involvement in previous commitments, setting limits and boundaries, adequate personal and professional support, participation in valued activities and an optimistic outlook on life.

- Caregivers consistently report the need for more information and knowledge, particularly in relation to the patient's illness, symptoms, treatment and prognosis. A number of caregivers report feeling unprepared for caregiving, which can increase the risk for burden and burnout. Health professionals can assist in preparing caregivers for the caregiving task through the provision of detailed information and training.

- Poor communication with health professionals is a common complaint among caregivers. Caregivers want more opportunities for communication with health professionals and differ in their capabilities of accessing information. Health professionals may need to take the lead and ensure adequate information is provided. Gate-keeping and secrecy are also important issues that need to be addressed in communication with caregivers and family members.

- Caregivers report the need for better preparation for the patient's death. Health professionals can better prepare caregivers for the patient's death by ensuring adequate communication about dying and bereavement and through the provision of psychological support.

- Caregiver interventions aimed towards problem-solving and cognitive restructuring have shown more promising findings in systematic reviews. Interventions for caregivers of palliative care patients that have been shown to be helpful include sessions to enhance problem-solving or coping, provision of psycho-social support, pain management training, behavioural sleep therapy and group psycho-educational programs. It is recommended that such intervention strategies be incorporated in standard provisions of psychosocial support to caregivers.

- Caregivers of palliative care patients can have significant levels of pre-loss prolonged grief during the period of caregiving. Predictors of pre-loss prolonged grief among caregivers include stressful life events, higher levels of caregiver esteem, lack of family support, impact on health, dependency on the care recipient and pessimistic thinking. These presentations should be identified in bereavement risk assessments.

- Bereavement risk factors include characteristics of the bereaved person, situational factors in caregiving, the relationship with the deceased person, poor family functioning and lack of preparation for death. Factors that facilitate bereavement adjustment include early enrolment to palliative care, positive perceptions and social support.

- In undertaking bereavement assessments it is important to identify factors that increase vulnerability to negative bereavement outcomes as well as those that promote adjustment. Bereavement support should be offered in response to an assessment of needs of each individual. Organisations should consider the use of bereavement and grief assessment tools.

- Research indicates that the majority of caregivers adjust reasonably well following the death of the person they were caring for. Mental health problems and a close relationship to the patient

are strong predictors of poor adjustment in early bereavement. Other risk factors are female gender, older age, grief in the past and emotional burden. These factors should be noted when contact is made with caregivers or family members in early bereavement.

- Studies indicate that approximately 50% of family caregivers perceive a need for bereavement follow-up. Barriers to the provision of bereavement support in hospice and palliative care organisations include lack of time, infrastructure, qualified personnel and low allocation of resources. Greater attention to the importance of bereavement services is needed from governments, health departments and organisations.

- Longitudinal studies indicate that mental health problems among bereaved caregivers tend to subside by 18 months post-loss. However approximately, 20% of bereaved people continue to remain significantly distressed and symptomatic. Risk factors for poor bereavement outcome in longitudinal studies were role overload during caregiving, lower income and dissatisfaction with support.

- While research suggests that the provision of primary or universal interventions is unlikely to be helpful in resolving grief, a number of studies have demonstrated that primary interventions can benefit caregivers. Caregivers often begin to process their loss before the actual death and have greater access to health professionals at this time. Therefore, interventions that target caregivers can also have a positive benefit in bereavement.

- An empirically evaluated secondary intervention for distressed families of palliative care patients is Family Focused Grief Therapy. Services with suitable staff and resources are encouraged to consider this family intervention. Other therapies found to benefit caregivers include psycho-educational support, information sessions and training in caregiving, and behavioural strategies for sleep management.

- Research has demonstrated that tertiary bereavement interventions are more effective than universal or selective bereavement interventions. A combination of pharmacological and interpersonal therapy has been found to be effective in the treatment of bereavement related depression. Traumatic Grief Treatment has shown promising results for the treatment of prolonged grief disorder.

- Overall, the present literature review presents the complex journey that many caregivers face in providing care for a palliative care patient and coping with loss in bereavement. While it must be acknowledged that caregivers perceive the benefits of providing care, many caregivers also struggle with their own personal health issues and the difficulties associated with providing care in the palliative phase of illness. It is important that palliative care services identify and assess caregivers' needs early in the caregiving phase, to ensure adequate support and referral in caregiving and through to bereavement.

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Overwhelmed + Vulnerable	Vulnerability	*Controlled + Vulnerable*
Feelings: Continual and/or high levels of distress. **Thoughts:** Preoccupied with the loss. Views self as a victim of circumstances. **Behaviours:** Confused, unpredictable. **Life perspective:** Generally negative outlook. **Social support:** Perceives support as lacking or makes poor use of it.	**Personal capacity reduced**, e.g by physical or psychological problems, difficulty in dealing with past stresses. **Circumstantial risk heightened** by concurrent factors, e.g difficult death, caring for children, elderly parents, relationship/ financial/housing problems.	**Feelings:** High anxiety about losing control or expressing strong feelings. **Thoughts:** Has difficulty in accepting reality. Cognitive defences may not effectively control emotions. **Behaviours:** Finds it hard to cry. Temper or irritation under pressure. **Life perspective:** Believes in being strong but struggles to maintain this. **Social support:** Reluctant to make use of support or disclose personal needs.
Overwhelmed Powerful emotions are central.	O/V V C/V O Core dimensions of grief C O/R R C/R	**Controlled** The desire to (re)establish control is central.
Overwhelmed + Resilient	Resilience	*Controlled + Resilient*
Feelings: Experiences feelings but not continually dominant. **Thoughts:** Able to understand and acknowledge impact of loss. **Behaviours:** Generally functions well. **Life perspective:** Has hope for the future even when currently distressed. **Social support:** Uses available support well.	**Personal capacity** – Inner resources are adequate to meet the demands of the loss, e.g positive past experience, confidence, hopeful outlook. **Circumstantial factors** are positive, e.g events surrounding death, support available, additional demands manageable.	**Feelings:** Not visible **Thoughts:** Thinks clearly re strategies to manage loss. **Behaviours:** Functions practically and effectively. **Life perspective:** Believes in importance of being strong. **Social support:** Makes few demands on social support.