

Title: The meaning and experience of bereavement support: A qualitative interview study of bereaved family caregivers

Author 1: Emma Kirby

UNSW Scientia Fellow, Australian Research Council DECRA Fellow and Senior Research Fellow - Sociology
School of Social Sciences, Level 3 Goodsell Building, University of New South Wales, Sydney, NSW 2052 Australia.

Emma.kirby@unsw.edu.au

Author 2: Katherine Kenny

Postdoctoral Research Fellow – Sociology
School of Social Sciences, University of New South Wales, Australia
k.kenny@unsw.edu.au

Author 3: Alex Broom

Professor of Sociology
School of Social Sciences, University of New South Wales, Australia
a.broom@unsw.edu.au

Author 4: John MacArtney

Qualitative Researcher
Health Experiences Research Group, University of Oxford, United Kingdom
john.macartney@phc.ox.ac.uk

Author 5: Phillip Good

Director of Palliative Care, St Vincent's Private Hospital Brisbane
Associate Professor, Mater Research Institute
The University of Queensland, Brisbane, Australia
Phillip.good@svha.org.au

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Abstract

Objectives: Experiences of bereavement can be stressful and are frequently complicated by emotional, familial and financial issues. Some – though not all – caregivers may benefit from bereavement support. While considered standard within palliative care services in Australia, bereavement support is not widely utilised by family caregivers. There is little research focused on the forms of bereavement support desired or required by family caregivers, how such care is viewed, and/or how bereavement support is experienced. This study examined the experiences of bereaved family caregivers and their impressions of and interactions with bereavement support.

Methods: This paper reports on one aspect of a broader study designed to explore a range of experiences of patients and caregivers to and through palliative care. Focusing on experiences of bereavement, it draws on qualitative, semi-structured interviews with 15 family caregivers of palliative care patients within a specialist palliative care unit of an Australian metropolitan hospital. The interviews for this stage of the study were initiated 3-9 months after an initial interview with family caregiver, during which time the palliative patient had died, and covered family caregivers' experiences of bereavement and bereavement support. Interviews were digitally audio-recorded and transcribed in full. A thematic analysis was conducted utilising the framework approach wherein interview transcripts were reviewed, key themes were identified and explanations developed.

Results: The research identified four prevalent themes: (1) socio-cultural constructions of bereavement support as for the incapable or socially isolated; (2) perceptions of bereavement support services as narrow in scope; (3) the 'personal' character of bereavement and subsequent incompatibility with formalised support, and; (4) issues around the timing and style of approaches to being offered support.

Significance of Results: Systematic pre-bereavement planning, and careful communication about the services offered by palliative care bereavement support centres, may improve receipt of support among bereaved family caregivers in need.

Keywords

Bereavement, support, family caregivers, qualitative, palliative

Introduction

Bereavement has long been acknowledged as one of life's most stressful experiences, (Holmes & Rahe, 1967; Stroebe et al., 2007) with family caregivers prone to a range of physical and psychological problems and health outcomes (Groven et al., 2005; Girgis et al., 2006; Hudson, 2006; Lobb et al., 2010; Hudson et al., 2011). Studies have shown that bereavement, and bereavement-related grief, increases the risk of mortality (Stroebe & Stroebe, 1993; Bowling, 1994; Hart et al., 2007; Buckley et al., 2012), and has also been linked to depression, anxiety, insomnia, cognitive function, and work and relationship difficulties (Groven et al., 2005; Hardison et al., 2005). Bereaved individuals may experience a loss of identity, change in their roles and responsibilities within the family, or social isolation (Aoun et al., 2005; Stoltz et al., 2004). Given the links between bereavement, health and quality of life more broadly (Rebollo et al., 2005), the presence of bereavement support services within health settings, particularly palliative care, is unsurprising (Forte et al., 2004). Yet, research within and outside Australia has indicated both a lack of uptake in formal bereavement services among family caregivers, and the lack of a sufficient evidence base upon which to develop policy and practice (Hudson, 2006; Abbott et al., 2008; Mather et al., 2008; Breen, 2012). While a range of guidelines for bereavement support services has been developed in Australia (Hall et al., 2012; Hudson et al., 2010, 2012) and internationally (Kerslake et al., 2014; Tol et al., 2014), a growing body of work has highlighted the challenges for

bereavement support services in accessing caregivers who have been assessed as in need of support, including difficulties maintaining contact following the patient's death and subsequent underutilization of support services by the bereaved (Cherlin et al., 2007; Lichtenthal et al., 2011; Breen et al., 2014; Aoun et al., 2015). Little is known about why bereaved family caregivers choose not to engage with support services (Cherlin et al., 2007). At the same time, there have been calls for qualitative studies that explore the kinds of support and types of services desired and valued as helpful by bereaved family caregivers (Jordan & Neimeyer, 2003; Diamond et al., 2012). In this paper, we use the term family caregiver to describe any kin or non-kin relative, friend, or person with a significant relationship to the deceased person, and to whom they provided support or assistance approaching the end of life (Hudson & Payne, 2009). Our aim in this study was to systematically examine family caregivers' accounts of their bereavement experiences using qualitative interviews, including their views on and interactions (or, alternatively, lack of interaction) with palliative care bereavement support services.

Palliative care and bereavement support

Within palliative care, the family is considered to be the unit of care (WHO, 2002; Aoun et al., 2005; Hudson et al., 2012). Such a focus on improving quality of life for the patient *and* their family includes preparing for death and post-death support/follow-up (Steinhauser et al., 2000; Hudson et al., 2012). Provision of bereavement support is

considered to be standard within palliative care (Abbott et al., 2008; Mather et al., 2008), yet it is also acknowledged to be the least developed facet of Australian palliative care services, as indeed in comparative contexts internationally (Payne, 2001; Agnew et al., 2010; Breen et al., 2014; Sealey et al., 2015). In addition, the evidence base to guide practice and program development is lacking, arguably resulting, in the Australian context at least, in variability in terms of the support services offered across and between palliative care centres (Mather et al., 2008; Breen et al., 2014). Bereavement support in palliative care units in Australia is coordinated by a range of health professionals including nurses, social workers, pastoral care workers and volunteers (Mather et al., 2008). Types of support vary, but commonly include follow-up phone calls, home visits, memorial services, counselling, provision of information/resources, and referral to other support agencies (Mather et al., 2008). Less is known about the extent to which bereavement care engages family caregivers, the forms of support desired or required by family caregivers, or how such care is experienced. Indeed, previous studies have noted the need for further research, especially qualitative studies, in order to further our understandings of family caregivers' experiences of bereavement and to improve service provision for patients and families (Diamond et al., 2012, Forte et al., 2004; Mather et al., 2008; Breen et al., 2014; Sealey et al., 2015).

Family caregivers and bereavement

Although bereavement is a stressful life experience, the majority of individuals will manage with the support of family, friends and the community (Stroebe et al., 2007). However, research has revealed that a substantial number of family caregivers require support. One study found that around half of bereaved family members expressed a need for bereavement follow-up (Milberg et al., 2008), and others have estimated that 10-20% of family caregivers experience ongoing and significant psychiatric distress as a result of their loss (Lobb et al., 2010; Prigerson et al., 1995; Aoun et al., 2015). While some researchers have argued for caution against medicalising or pathologising “normal” grief experiences (Friedman, 2012; Bandini, 2015), it is clear that for a proportion of family caregivers, bereavement will present complex and variable challenges that call for support or intervention from health and social care professionals (Milberg et al., 2008; Hudson & Breen, 2009; Breen, 2012). In addition, family caregivers may experience a considerable burden of care approaching the end of life (Aoun et al., 2005), resulting in emotional suffering (Stoltz et al., 2004), and difficulties associated with identity and role transitions, namely from caregiver to bereaved. While family caregivers experiencing bereavement-related difficulties are likely to benefit from targeted interventions, they are also less prone to seek out supportive services (Currier et al., 2008; Lichtenthal et al., 2011; Sealey et al., 2015). Bereavement may be a key time during which to offer support to family caregivers given that two of the

barriers to service uptake have now ended: the time-consuming activities of providing care (Colombo et al., 2011) and the reticence among family caregivers to discuss their own need for support in front of their relative (Hudson, 2013). Thus, there is a clear need for potentially vulnerable family caregivers to be identified by bereavement support services.

Assessing bereavement and support needs for family caregivers

A key problem for bereavement support services lies in the character of bereavement experience; bereavement is often experienced privately, as a personal or individual process which can be shaped by various and ongoing emotions or circumstances (Milberg et al., 2008; Sealey et al., 2015). Grieving privately, at home, can compound social isolation, and is difficult for health services to gauge (Hudson, 2006; Agnew et al., 2011). In this way, pre-bereavement risk-assessment or care planning can be effective, while staff have face-to-face contact with family caregivers (Sealey et al., 2015). While a range of bereavement risk-assessment tools have been developed (Forte et al., 2004; Currier et al., 2008; Sealey et al., 2015), the implementation of such tools within Australian palliative care settings is uneven (Mather et al., 2008; Aoun et al., 2015; Sealey et al., 2015). Moreover, research has highlighted the challenges in measuring or assessing the likelihood of a family caregiver needing (or benefitting) from support services (Milberg et al., 2008; Hudson et al., 2010; Agnew et al., 2011;

Aoun et al., 2015). It is difficult to predict who will need support services, when or at which point(s) they will need support, or indeed how and when offers of support are most likely to be accepted (Milberg et al., 2008; Hudson et al., 2010; Agnew et al., 2011; Breen et al., 2014; Aoun et al., 2015). The experiences of bereaved caregivers thus need to be systematically examined in order to provide a more comprehensive understanding of the factors which may shape engagement with bereavement support services.

Methods

This paper reports on one aspect of a broader study designed to explore a range of experiences of patients and caregivers to and through palliative care (MacArtney et al., 2015a; MacArtney et al., 2015b; MacArtney et al., 2016; Broom et al., 2016). Given the sensitivity of the research, face-to-face interviews were chosen as a feasible and effective method for documenting experiences of care at the end of life (Steinhauser & Barroso, 2009; Broom & Kirby, 2013; MacArtney et al., 2015a; MacArtney et al., 2015b; MacArtney et al., 2016; Broom et al. 2016). Focusing on experiences of bereavement, this paper draws on semi-structured interviews conducted with 15 bereaved Australian family caregivers of patients (avg. patient age = 84) cared for at a specialist palliative care unit in Queensland, Australia. The unit offers a 'patient and family support service', consisting of social workers, nurses, pastoral care personnel

and counsellors, offering the following support: information cards/brochures, follow-up phone calls, individual counselling (within the hospital or at home), group counselling, memorial services, assistance with burial/cremation arrangements (when applications for funding to support costs are needed), and referral to psychological/psychiatric services, both prior to, and following the person's death. After we obtained both university and hospital ethics approval, caregivers (pre-bereavement) were approached by their treating clinician, who explained the study aims and methods. The researchers then contacted family caregivers to confirm their participation, arrange an initial interview, and obtain formal written consent. From the original family caregivers interviewed (n=67), 48 volunteered to be contacted for a follow-up interview 3-9 months later. We were later able to contact 21 of the caregivers, 2 of whom had moved away from the region, and 4 of whom declined to be interviewed. These post-death interviews were conducted most often in participants' homes and focused on: experiences of the transition from palliative care to the experience of the post-death/bereavement period and reflections on formal and informal support offered, accepted/declined, and received. Interviews lasted between 20-60 minutes, were digitally recorded and transcribed in full.

Analysis

Data analysis took place both during the qualitative fieldwork during July 2013 - October 2014, and was revisited over 5 months in 2016. We employed the framework approach of qualitative data analysis, utilising NVivo 11 software, which involves the following steps: (1) *Familiarisation*: the researchers reviewed the transcripts. (2) *Identification of framework*: key themes were identified around which the data were organised. (3) *Indexing*: application of themes to text. (4) *Charting*: use of headings and sub-headings to build up a picture of the data as a whole. (5) *Mapping and interpretation*: in which associations were clarified and explanations worked towards (Pope et al., 2006) Three research team members independently coded the data, and these separate analyses were then cross-checked to uncover related and/or deviant cases/themes, and to develop an overall interpretation of the data. Once a theme was identified in the transcripts, interviews were searched for related comments using constant comparison in order to further develop themes (Ezzy, 2002). In this way the richness of the data was retained, while interrelated events could be mapped. Analytical rigor was augmented by constant comparison and searching for negative cases during code and theme development (Fitzpatrick & Boulton, 1996; Pope et al., 2006).

Results

A summary of participants' characteristics is included in Table 1. 13 participants recalled offers of bereavement support, 11 of whom declined. Here we report on the

emergent themes from our systematic analysis of the interviews. It was clear from the interviews that some caregivers felt more ‘in need’ of support than others. Indeed, the meaning and character of support varied across the participant group. Despite these variations, our analysis revealed four predominant themes: (1) socio-cultural constructions of the character of bereavement support; (2) the perceived limited scope of bereavement support services; (3) the ‘personal’ experience of bereavement, and; (4) timing and approaches to providing support.

‘I’m a capable person’: Socio-cultural constructions of bereavement support

The caregivers we interviewed provided detailed accounts of their understanding of formalised bereavement support, in terms of both the services offered by the palliative care centre, and the idea of bereavement support more broadly. That is, such support was understood by the majority of participants as synonymous with counselling or ‘talking to someone’. Moreover, counselling was associated by the majority of participants with being only for the weak or socially isolated. While all participants acknowledged the potential for post-death counselling to be useful or therapeutic, it was described predominately as being for people who were not coping or ‘falling apart’. This theme was particularly prevalent among the (adult) children of the deceased (as opposed to spousal or other family caregivers). As the indicative quotations in Table 3 show, several participants felt that counselling was unnecessary for them as they were

‘strong’, ‘capable’ or ‘able to cope’. Some of the participants felt that counselling would be more appropriate for those without family, as the absence of family members with whom to talk and grieve may result in needing to talk to a professional. However, other participants stressed the personal nature of their grief, suggesting that bereavement was something to process ‘on your own’.

The (perceived) scope of bereavement support

Another predominant theme within the interviews was the perceived limited scope of bereavement support. That is, the notion that bereavement support focuses on the psycho-social aspects of bereavement rather than practical aspects such as organising funerals or developing new skills/roles formerly handled by the deceased person. Our analysis revealed a clear demand for post-death assistance with practical tasks, and we heard frequent accounts from participants around ‘not knowing what to do’, or how to complete the various bureaucratic, financial or organisational tasks associated with death. As the indicative quotations in Table 4 demonstrate, the months immediately following bereavement were usually dominated by a range of decisions and tasks which family caregivers did not necessarily feel well-prepared to complete. Yet, for the majority of participants, they did not feel that the hospital bereavement support included such assistance. Furthermore, and as shown in Table 4, the participants directly linked their ability to cope more broadly with their ability to manage the required practical

tasks. The majority of participants talked about the emotional stress and strain experienced as a result of their unfamiliarity with various practical, legal or financial processes at such a difficult time. Indeed, we heard frequent accounts of such practical difficulties serving to compound emotional distress, grief and loss.

The 'personal' experience of bereavement

The third theme to emerge from our analysis was the view among participants that the bereavement experience was personal, individual, and unique. For these participants, the specificities of cancer experience, tumour types and relationship to the deceased served as points of differentiation that mitigated against anyone else being able to 'understand what they were going through'. Comments like 'everyone is different' and that 'it's different for every individual' were frequently expressed (see Table 5). This presumed uniqueness of the bereavement experience was a persistent barrier to bereavement support uptake among participants. That is, participants talked about finding it difficult to see the potential benefit of bereavement support, as every circumstance was different. We did hear occasional counter-narratives, for example one participant recounted the benefit of interacting with others who she considered to be 'in the same boat'. Importantly, though, she too expressed initial hesitation to participate in a group session because she considered her coping to be personal and individual. Overall, the analysis identified a tendency towards understanding bereavement as an individualised

experience. Such views were inextricably linked to the ways by which support was offered or approached, and the timing of such offers of support, as we discuss below.

Stereotypical grief, untimely help and delayed recognition: Timing and approaches to providing support

The question of when a person would be ‘ready’ to talk, think, or begin to process their grief and loss was central to participants’ accounts of their bereavement experience. While some participants talked about coping well, others said they were still struggling months later. Indeed, we saw a continuum of coping relative to time. That is, at similar durations of weeks or months post-death, there was little to no consistency across participants in terms of coping, managing the deceased’s affairs, and associated stress or strain. This raises questions around when best to approach family caregivers with offers of bereavement support services, how best to approach them, and when to avoid approaching them, so as to avoid alienating those in need. Our analysis also revealed how individuals’ experiences of bereavement and general hesitance about formal support services is coloured by widely shared social assumptions and stereotypes about grieving – namely that bereavement is private, and necessarily entails feelings of sadness and loss. Participants were reluctant to publicly air their feelings and were similarly hesitant to express sentiments that might not resonate with stereotypical grieving. In other words, some participants felt relief or release at the death of a family

member, but questioned the acceptability of expressing such feelings. The quotations in Table 6 highlight the need for sensitivity in terms of family dynamics and context and a flexibility of approach in offering bereavement support services.

Discussion

The findings presented here provide timely insight into the lived experience of bereavement and support. It is important to note here that during the interviews we heard very positive accounts of the quality of bereavement support, both in terms of offers and experiences of support from the palliative care service. It is not our intention in this paper to question the quality or effectiveness of the support offered by formal services. Rather, we hope that our findings are helpful for health professionals in better understanding experiences of support from the perspectives of family caregivers themselves.

Accounts of bereavement as personal, along with ideas of being ‘strong willed’ or (emotionally) ‘stronger than others’, highlight individualised forms of resistance to, or avoidance of, pathologising discourses (Bandini, 2015). Acknowledging participants’ desire for practical support (other than psycho-therapeutic interventions), we argue, better locates our finding of the need for support outside of concerns about the pathologisation of grief. Bereaved family caregivers face manifold challenges beyond

grief and loss. Several participants talked about the financial stress they faced (or were facing) due to care-related costs, and for some, ceasing employment in order to fulfill the caregiver role. Participants often expressed a desire for assistance in areas such as funeral and estate planning and legal/financial matters as they were particularly burdensome tasks in the weeks and months following bereavement (Steinhauser et al., 2000). This insight offers support to Grande et al. (2004) whose randomized controlled trial of the impact of a hospice at home program in the UK on bereavement outcome found poorer early bereavement experiences among carers who felt they were offered inadequate practical support. The intensity of these logistical requirements early in the bereavement period raises the question of when to approach bereaved family caregivers with offers of support. For these participants, the days following bereavement were talked about as being incredibly busy, filled with practical tasks. As such, participants were ‘too busy’ to think about how they were coping, and thus not well placed to engage with the idea of accepting psychological or emotional bereavement support.

This study has several highlights that may be relevant for practice. Previous Australian research has shown that bereavement follow-up occurs within 2 weeks in around 70% of centres (Mather et al., 2008). However, our findings support the suggested guidelines for supporting family caregivers (Hudson et al., 2012) by establishing contact at around one month post-death, and again around 6 month post-death. We suggest that family

caregivers may be more likely to accept support if follow-up – particularly offers of counselling or group sessions – occurs after these periods. Our findings also highlight the importance of bereavement support as a transitional process (Field et al., 2007), where family caregivers will likely benefit from 1) assistance in preparing for and carrying out practical tasks, 2) on-going support that begins before bereavement (Roulston et al., 2016), and extends further into the bereavement period and, 3) better communication around the character and scope of bereavement services, including referral to or collaboration with other agencies. Health professionals should also be mindful about the language and tone they use when offering bereavement support. Family caregivers may be experiencing mixed emotions, particularly in contexts of family discord or dysfunction, where terms such as ‘loved one’ may alienate caregivers potentially in need of support.

Finally, our findings highlight a tension between the socio-cultural construction of bereavement support as for the weak or socially isolated and participant’s concurrent desire for practical assistance with the logistical tasks following the death of a relative. Our findings suggest that a productive way out of this tension may be the expanded use of bereavement volunteers in developing community capacity to provide bereavement ‘assistance’ (see Diamond et al., 2012; Field et al., 2007, Breen et al., 2015). As Breen

et al., (2015, p.5) have noted, '[w]hile most bereaved people do not require professional counseling, all would benefit from appropriate information and compassion'.

This study has various limitations. Our sample of 15 caregivers, while appropriate in size for a qualitative study, only captures the experiences of family caregivers of people with cancer, at one moment in time at different points in the months post-death, in one hospital palliative care unit. As such, despite providing indications of themes and theoretical insights likely to resonate across other contexts, our findings cannot be generalised to other settings. However, we argue that the significant rapport built with participants' pre-bereavement resulted in highly valuable and rich data in an area of research which is widely acknowledged to be difficult to access (Stroebe & Stroebe, 1990; Payne & Field, 2004). Further research focused on experiences of bereavement support beyond cancer and among caregivers from culturally and linguistically diverse backgrounds is needed to improve service provision.

The findings presented here add to the growing corpus of research focused on improving bereavement support in palliative care (Hudson & Payne, 2009; Breen, 2012; Breen et al., 2014; Aoun et al., 2015). Bereavement support services may be perceived as limited to counselling or group therapy, potentially concealing the various other forms of support and resources offered. In turn, counselling may be associated with

being only for the weak or socially isolated, or only appropriate for those who have lost *loved* ones, limiting the potential of bereavement support to assist family caregivers in need. In summary, the findings highlight the need for diversity in support services, and the importance of continuity of care throughout the bereavement experience. Further qualitative and/or intervention-based research focused on the practice of bereavement support programs run by palliative care services is needed to better understand carer needs, and continue to develop and deliver effective supportive services in Australia.

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References

- Abbott, J., O'Connor, M. & Payne, S. (2008). An Australian survey of palliative care and hospice bereavement services. *Australian Journal of Cancer Nursing*, 9(2), 12–17.
- Agnew, A., Manktelow, R., Haynes, T., et al. (2011). Bereavement assessment practice in hospice settings: Challenges for palliative care social workers. *British Journal of Social Work*, 41(1), 111-130.
- Agnew, A., Manktelow, R., Taylor, B., et al. (2010). Bereavement needs assessment in specialist palliative care: A review of the literature. *Palliative Medicine*, 24(1), 46-59.
- Aoun, S.M., Breen, L.J., Howting, D.A., et al. (2015) Who needs bereavement support? A population based survey of bereavement risk and support need. *PLOS ONE*, 10(3), e0121101.
- Aoun, S.M., Kristjanson, L.J., Currow, D.C., et al. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine*, 19(7), 551-555.
- Bandini, J. (2015). The medicalization of bereavement: (ab)normal grief in the DSM-5. *Death Studies*, 39(6), 347-352.

Bowling, A. (1994). Mortality after bereavement: An analysis of mortality rates and associations with mortality 13 years after bereavement. *International Journal of Geriatric Psychiatry*, 9(6), 445-459.

Breen, L.J. (2012). The effect of caring on post-bereavement outcome: Research gaps and practice priorities. *Progress in Palliative Care*, 20(1), 27-30.

Breen, L.J., Aoun, S.M., O'Connor, M., et al. (2014). Bridging the gaps in palliative care bereavement support: An international perspective. *Death Studies*, 38(1), 54-61.

Broom, A., Kirby E., Kenny K., et al. (2016). Moral ambivalence and informal care for the dying. *The Sociological Review*, 64(4), 987-1004.

Broom, A., & Kirby, E. (2013). The end of life and the family: hospice patients' views on dying as relational. *Sociology of Health and Illness*, 35(4), 499–513.

Buckley, T., Sunari, D., Marshall, A., et al. (2012). Physiological correlates of bereavement and the impact of bereavement interventions. *Dialogues in Clinical Neuroscience*, 14(2), 129-139.

Cherlin, E.J., Barry, C.L., Prigerson, H.G., et al. (2007) Bereavement services for family caregivers: how often used, why, and why not. *Journal of Palliative Medicine*, 10(1), 148–158.

Colombo, F., Llena-Nozal, A., Mercier J., et al. (2011) *Help Wanted?: Providing and Paying for Long-Term Care*, OECD Publishing, Paris.

Currier, J.M., Neimeyer, R.A. & Berman, J.S. (2008). The effectiveness of psychotherapeutic interventions for bereaved persons: A comprehensive quantitative review. *Psychological Bulletin*, 134(5), 648-661.

Diamond, H., Llewelyn, S., Relf, M. & Bruce, C. (2012). helpful aspects of bereavement support for adults following an expected death: Volunteers' and bereaved people's perspectives. *Death studies*, 36(6), 541-564.

Ezzy, D. (2002). *Qualitative analysis: Practice and innovation*. London: Routledge.

Field, D., Payne, S., Relf, M., et al. (2007). Some issues in the provision of adult bereavement support by UK hospices. *Social Science & Medicine*, 64(2), 428-438.

Fitzpatrick, R. & Boulton, M. (1996) Qualitative research in health care: the scope and validity of methods. *Journal of Evaluation in Clinical Practice*, 2(2), 123–130.

Forte, A.L., Hill, M., Pazder, R., et al. (2004). Bereavement care interventions: A systematic review. *BMC Palliative Care*, 3(1), 3.

Friedman , R.A. (2012). Grief, depression, and the dsm-5. *New England Journal of Medicine*, 366(20), 1855-1857.

Girgis, A., Johnson, C., Currow, D., et al (2006) *Palliative Care Needs Assessment Guidelines*. Newcastle, NSW: The Centre for Health Research & Psycho-oncology.

Grov, E.K., Dahl, A.A., Moum, T., et al. (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology*, 16(7), 1185-1191.

Hall C., Hudson P. & Boughey A., (2012) *Bereavement support standards for specialist palliative care services*. Department of Health, State Government of Victoria, Melbourne.

Hardison, H.G., Neimeyer, R.A. & Lichstein, K.L. (2005). Insomnia and complicated grief symptoms in bereaved college students. *Behavioral Sleep Medicine*, 3(2), 99-111.

Hart, C.L., Hole, D.J., Lawlor, D.A., et al. (2007). Effect of conjugal bereavement on mortality of the bereaved spouse in participants of the renfrew/paisley study. *Journal of Epidemiology & Community Health*, 61(5), 455-460.

Holmes, T.H., & Rahe, R.H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research*, 11(2), 213-218.

Hudson, P.L. (2006). How well do family caregivers cope after caring for a relative with advanced disease and how can health professionals enhance their support? *Journal of Palliative Medicine*, 9(3), 694–703.

Hudson, P. (2013) Improving support for family carers: Key implications for research, policy and practice. *Palliative Medicine*, 27(7), 581 – 582.

Hudson, P.L., Payne, S. (2009) The future of family caregiving: Research, social policy and clinical practice. In: *Family Carers in Palliative Care: A guide for health and social*

care professionals, Hudson P., Payne, S. (eds), pp. 277-303. Oxford: Oxford University Press.

Hudson, P., Remedios, C., Zordan, R., et al. (2010). *Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients*. Centre for Palliative Care, St Vincent's Hospital Melbourne: Melbourne, Australia.

Hudson, P., Remedios, C., Zordan, R., et al. (2012). Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *Journal of Palliative Medicine*, 15(6), 696-702.

Hudson, P.L., Thomas, K., Trauer, T., et al. (2011). Psychological and social profile of family caregivers on commencement of palliative care. *Journal of Pain and Symptom Management*, 41(3), 522-534.

Hudson, P.L., Trauer, T., Graham, S., et al. (2010). A systematic review of instruments related to family caregivers of palliative care patients. *Palliative Medicine*, 24(7), 656-668.

Jordan, J. R. & Neimeyer, R. A. (2003). Does grief counseling work?. *Death studies*, 27(9), 765-786.

Kerslake, D., Chaplin, D., Hartley, J. & Wadey, A., (2014). New Bereavement Care Service Standards. *Bereavement Care*, 33(1), 28-32.

Lichtenthal, W.G., Nilsson, M., Kissane, D.W., et al. (2011). Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatric Services*, 62(10), 1225-1229.

Lobb, E.A., Kristjanson, L.J., Aoun, S.M., et al. (2010). Predictors of complicated grief: A systematic review of empirical studies. *Death Studies*, 34(8), 673-698.

MacArtney, J.I., Broom, A., Kirby, E., et al. (2016). Locating care at the end of life: burden, vulnerability, and the practical accomplishment of dying. *Sociology of Health and Illness* 38(3), 479–492.

MacArtney, J.I., Broom, A., Kirby, E., et al. (2015a). On resilience and acceptance in the transition to palliative care at the end of life. *Health*, 19(3), 263-279.

MacArtney, J.I., Broom, A., Kirby, E., et al. (2015b). The liminal and the parallax: living *and* dying at the end of life. *Qualitative Health Research*. Epub ahead of print: 10 December 2015.

Mather, M.A., Good, P.D., Cavenagh, J.D., et al. (2008) Survey of bereavement support provided by Australian palliative care services. *Medical Journal of Australia*, 188(4), 228-230.

Milberg, A., Olsson, E.C., Jakobsson, M., et al. (2008). Family members' perceived needs for bereavement follow-up. *Journal of Pain and Symptom Management*, 35(1), 58-69.

Payne, S. (2001). Bereavement support: Something for everyone? *International Journal of Palliative Nursing*, 7(3), 108.

Payne, S. & Field, D. (2004). Undertaking bereavement research: Sensitivities and sensibilities. *Grief Matters*, 7(3), 52–56.

Pope, C., Ziebland, S., Mays, N. (2006). Analysing qualitative data. In: *Qualitative Research in Health Care* (3rd ed.), Pope, C., & Mays, N. (eds), pp. 63–81. Oxford, UK: Blackwell Publishing.

Prigerson, H.G., Maciejewski, P.K., Reynolds, C.F.3rd, et al. (1995). Inventory of complicated grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*, 59(1-2), 65-79.

Rebollo, P., Alonso, J., Ramon, I., et al. (2005). Health-related quality of life during the bereavement period of caregivers of a deceased elderly person. *Quality of Life Research*, 14(2), 501-509.

Roulston, A., Campbell, A., Cairnduff, V., et al. (2016) Bereavement outcomes: A quantitative survey identifying risk factors in informal carers bereaved through cancer. *Palliative Medicine*, Epub ahead of print: 11 May 2016.

Sealey, M., Breen, L.J., O'Connor, M., et al. (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliative Medicine*, 29(7), 577-589.

Steinhauser, K.E. & Barroso, J. (2009). Using qualitative methods to explore key questions in palliative care. *Journal of Palliative Medicine*, 12(8), 725-730.

Steinhauser, K.E., Clipp, E.C., McNeilly, M., et al. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132(10), 825–832.

Stoltz, P., Uden, G. & Willman, A. (2004). Support for family carers who care for an elderly person at home - a systematic literature review. *Scandinavian Journal of Caring Sciences*, 18(2), 111-119.

Stroebe, M.S., Schut, H. & Stroebe, W. (2007) Health outcomes of bereavement. *Lancet* 370(9603), 1960–1973.

Stroebe, M.S. & Stroebe, W. (1990). Who participates in bereavement research? A review and empirical study. *OMEGA - Journal of Death and Dying*, 20(1), 1-29.

Stroebe, M.S., & Stroebe, W. (1993). The mortality of bereavement: a review. In: *Handbook of bereavement: theory, research, and intervention*, Stroebe, M.S., Stroebe, W., & Hansson, R.O. (eds), pp. 175–195, New York: Cambridge University Press.

Tol, W.A., Barbui, C., Bisson, J., et al. (2014) World Health Organization Guidelines for Management of Acute Stress, PTSD, and Bereavement: Key Challenges on the Road Ahead. *PLoS Med*, 11(12): e1001769.

World Health Organisation (WHO). (2002). *National cancer control programmes: Policies and managerial guidelines*, 2nd ed. Geneva: WHO.