

# **An overview of bereavement literature:**

a basis for Phase 2 of the EAPC Bereavement Taskforce Project

---

EAPC Bereavement Taskforce Steering Committee, 2016



## Contents

<b>Background</b> .....	<b>3</b>
<b>SECTION ONE Understanding Bereavement and Grief</b> .....	<b>4</b>
Definition and concept of grief.....	4
The grieving process .....	4
Grief trajectories .....	5
When is bereavement a more serious concern? .....	5
Description of prolonged grief disorder/complicated grief.....	6
<b>SECTION TWO Supporting bereaved people</b> .....	<b>8</b>
Models of bereavement care .....	8
A ‘public health’ model.....	8
NICE model .....	10
Assessment.....	12
Developing bereavement support within palliative care .....	13
<b>Conclusion</b> .....	<b>14</b>
<b>APPENDIX ONE</b> .....	<b>15</b>
<b>References</b> .....	<b>16</b>

## Background

This narrative literature review was conducted in 2016 and was designed to provide a context to the work of the European Association for Palliative Care Bereavement Taskforce. It is set out in two parts – understanding bereavement and supporting bereavement. The review has been used (together with surveys of palliative care services in Europe, discussions at Congress and the deliberations of an Expert Advisory Group) as the basis for a Delphi survey. The Delphi survey was distributed to Palliative Care services across Europe in February 2016. The Delphi survey is for separate publication and has identified a consensus for the development of bereavement support in palliative care in Europe. Further details will be made available on the EAPC website.

### **Co-Chairs**

Orla Keegan, Head of Education & Bereavement, Irish Hospice Foundation, Dublin, Ireland

Irene Murphy, Director of Bereavement & Family Support Services, Marymount University Hospice, Cork

### **Taskforce Committee**

Inger Benkel, Social Worker PhD, Palliative Department. Gothenburg University Hospital, Gothenburg, **Sweden**

Joaquim T. Limonero García , PhD, Facultat de Psicologia , Campus de la UAB , Barcelona, **Spain**

Marilyn Relf, PhD, Bereavement Care Lead, Sir Michael Sobell House, Oxford, **England**

Dr Mai-Britt Guldin, Palliative Care Team, Aarhus University Hospital, Aarhus, **Denmark**

### **Expert Advisory Group**

Mr John Birrell, Dr Susan Cadell, Dame Barbara Monroe, Prof Henk Schut

Previous taskforces members Dr Mairant Lacasta, Dame Barbara Monroe

- **We also thank partners for their support** Irish Hospice Foundation, All Ireland Institute of Hospice and Palliative Care, Irish Association for Palliative Care, Association of Bereavement Coordinators (UK)

## SECTION ONE Understanding Bereavement and Grief

### Definition and concept of grief

Grief can be understood as a normal reaction that occurs following bereavement (Limonero, 1996), According to the seminal works of Freud (1917/53), Bowlby (1981), Parkes (1983) and Worden (2009) it comprises thoughts, emotions and behaviours connected to the loss or its anticipation. In this sense, grief is a psychological process that allows the person to adapt to the loss and the new reality. Most bereaved individuals adjust to life without the person who has died without severe emotional, psychological or physical problems (Bonanno, 2002), but a small proportion, less than 10%, experience severe difficulties and develop health problems (Stroebe, Schut and Stroebe, 2007; Prigerson et al, 2009; Shear (2015)).

### The grieving process

Grief manifests in a number of ways: cognitive (e.g., disbelief-unreality, confusion, visual or auditory hallucinations); affective (such as sadness, apathy, depression, anxiety, hostility, anger or frustration), physiological (such as e.g. shortness of breath, palpitations, headache, lack of energy, sleep disturbances) and behavioural (such as/e.g. Talking to the deceased, sensing or 'seeing' the deceased, hyper or hypo activity, seeking distractions, social withdrawal). These grief experiences are all considered normal (Lacasta et al, 2014; Richardson, 2006).

Grief is not a state; rather it is a dynamic process where the person will experience a series of changes over time related to their experience of loss and the coping mechanisms they use to adjust to that loss (Neimeyer, 2000). Most recently Neimeyer (2016) sets out the 'situated' nature of grief, and reinforces the idea that grief/ grieving is an activity. He emphasises how the search for meaning (interpretivist context) as well as the requirement for communication, speaking, sharing and story (communicative context) add to the individual and the developmental characteristics of grief. The situated nature of grief may also describe the impact of family relationships on bereavement outcome, as reported by Stroebe & Schut, 2015. 'Bereavement is experienced within a social and cultural context and is influenced by customs and beliefs (Azulay, 2000). How people express grief is influenced by their cultural beliefs as well as their individual personality and their social and

psychological history. Therefore, grief is different for each person. When someone dies, a unique and individual process of grieving begins.

### Grief trajectories

While grief is often experienced as a very stressful and emotionally painful process, grief trajectories are diverse and the intensity and duration vary reflecting the nature of the loss, the relation to the deceased person and a range of other factors (Boerner et al., 2013). Early work suggested that grief has a predictable emotional trajectory leading from distress to recovery and that successful adjustment depended on individuals' 'working through' grief or undertaking 'grief work'. More recent research shows that the duration of grief is highly variable and evidence has failed to support the notion that grief is necessarily a complex process. In addition, the absence of distress is no longer necessarily seen as pathological (Bonnano, 2002). However, prolonged high levels of distress indicate that there are adjustment difficulties (Thomas et al, 2014; Prigerson et al 1995; Prigerson et al, 2002) and are a cause of concern.

The intensity of grief may depend on mediating factors: the type of relationship with the deceased (the intensity and meaning of the emotional relationship), the circumstances of the death (the degree of distress experienced by the bereaved person during the illness and death), personal resources (physical and psychological health, personality and coping strategies), the quality of family and social resources, and external stressors (economic, concurrent loss), (Raphael, 2001; Thomas et al, 2014; Worden, 2009; Stroebe et al, 2006). There is also growing interest in recent years in identifying and exploring positive outcomes to bereavements, described by Bonnano (2004) as resilient coping; by Stroebe as integrative coping (2006) and by Cadell et al, as post-traumatic growth (2006).

It is considered that grief is accommodated when the person can talk about the loss without experiencing intense negative emotional reaction, such as anxiety. But generally, bereaved people re-engage in pleasurable activities and reattach to significant others (Jordan and Litz, 2014). Shear (2015) summarises adaptation as follows "*The intensity of grief diminishes as the finality and consequences of the loss are understood and future hopes and plans are revised*".

### When is bereavement a more serious concern?

It has been noted that a small but substantial minority of people experience persistent, severely distressing and even disabling symptoms of grief. Longitudinal studies have

identified a characteristic trajectory of complicated grief with persistent distress and chronic grief symptoms. Stroebe and colleagues defined the syndrome as:

A clinically-significant deviation from the (cultural) norm in either (a) the time course or intensity of specific or general symptoms of grief and/or (b) the level of impairment on social, occupational, or other important areas of functioning. (Stroebe et al., 2008)

In the literature the syndrome has been termed complicated grief (CG) (Shear, 2015) and/or prolonged grief disorder (PGD). CG/PGD is estimated to have prevalence in bereaved population of 7-12% (Prigerson et al., 2009).

### Description of prolonged grief disorder/complicated grief

The experience of complicated/prolonged grief has been defined as an incapacitating disorder characterised by intense feelings of grief which last longer than expected given social and cultural norms. Characteristics are described as:

- The reaction is a consequence of the death of a significant person
- persistent longing/yearning for the deceased
- intense feelings of emotional pain, meaninglessness and/or loneliness which do not abate
- preoccupation with the loss and/or the deceased or death/dying
- difficulty accepting the death
- excessive avoidance of reminders of the loss
- difficulty moving on from the loss (acquiring new friends or interests)
- Impairment in daily life, social, occupational and relational functioning

An important characteristic of the syndrome is that symptoms do not wane (Shear, 2015) and last for at least six months and sometimes, years (Prigerson, 2009)

PGD has been shown to be a disabling condition psychometrically distinct from other psychological responses such as depression and anxiety disorders including post-traumatic stress disorder (Bonanno et al., 2007; Prigerson et al, 2009). Bereavement complications can be understood by considering bereavement to be a stressor that can trigger the onset of both physical and mental disorders such as clinical depression, posttraumatic stress disorder, anxiety and sleep disorders all of which require identification and treatment (Hall 2014). However, at the time of writing neither the DSM (Diagnostic & Statistical Manual) nor the ICD (International Classification of Diseases, WHO) have accepted consistent terminology or diagnostic criteria for such complications. A new construct, 'Persistent Complex Bereavement Disorder' (PCBD) was included as a condition that merits further study in DSM 5. A syndrome called 'Prolonged Grief Disorder' (WHO, 2012) has been proposed for inclusion in the International Classification of Disease -11, similar to the original proposal for the DSM-5.

Aoun et al (2015) researched a community sample of bereaved people in Australia and described levels of need which reflect varying levels of intensity up to and including the small and most vulnerable group, i.e. those experiencing complicated or debilitating grief.

We have described grief in its various manifestations as influenced by a range of variables which are personal, cultural and situational. Contemporary knowledge about grief has been integrated into 'tiered' models which are gaining credence - situating grieving individuals on a continuum of experience and by extension, need. The models suggest that while all people grieve, the majority of people do not suffer disruptive distress of a prolonged nature and go on to accommodate their grief. Two such models of note are Bonanno's (2008) trajectories identifying the majority of widowed older people's experience as being one of resilience, while small proportions experienced a disruptive, enduring grief. His model importantly showed grief reactions in the context of previous (ie. pre-bereavement) psychological functioning as his research was longitudinal in nature. More recent work has broadly confirmed these patterns (Galatzer Levy, 2012). Similarly, Aoun (2015) showed three levels of grief response in a community sample which also varied in prevalence.

## SECTION TWO Supporting bereaved people

Support for bereaved people is a core part of palliative care (WHO, 2002) and services have largely developed in response to a demand for continuing support rather than from a robust evidence base (Field et al, 2007). In general, complicated grief, which affects a minority of mourners, has been the focus of much of the research on identifying bereavement needs and effective interventions (Neimeyer, 2014). Methodologically rigorous evaluations of more general bereavement support are limited (Schut et al, 2005) and in particular the efficacy of outreach services remains to be proven (Currier et al, 2008). Most people manage bereavement with support in the bereavement process from their own networks (Benkel et al 2009, McGrath 2010, Breen et al 2011, Gear 2014). However, bereavement is also associated with risks to health and well-being and a substantial minority of bereaved people may need or seek help after bereavement. (Prigerson et al 2001, Stroebe et al 2005; Love 2007; Currier et al 2008; Guldin et al 2012; Aoun et al 2015).

### Models of bereavement care

In this section we describe two models which consistently emerged in our review of the literature. Firstly, the public health model based on reviews of bereavement research from different sectors in the US, Europe and Australia (Schut and Stroebe, 2005; Aoun et al, 2012, 2015; Currier et al, 2008) and secondly, the UK National Institute for Clinical Excellence guidelines for palliative and supportive care derived from a systematic review conducted in 2004 (NICE, 2004).

#### A 'public health' model

All bereaved people benefit from compassion as well as information, assurance and good communication. These are natural human and community-based responses rather than formal service responses per se (Stroebe and Schut, 2005; Wittouck, 2010; Aoun, 2012) and may be referred to as '*Universal*'. Bonanno's longitudinal studies showed the majority of older widowed people were classified as 'resilient' (Bonanno, 2002). Consequently, more formal support services such as counselling are not shown to be effective universal services (Parkes, 1983, Stroebe and Schut 2005).



Some bereaved people may benefit from follow up contact with trained volunteers and/or professional-led support services and these services. This level of service response could be described as 'Selective; following the public health schema. These may be offered to people who are observed to have particular risk factors because of aspects of their personal or social situation, or relating to the illness and death of the patient. Again Bonanno's (2002) work identified approximately 17% of a widowed cohort who encountered problems which may require enhanced support.

Effective interventions to prevent complicated grief have not yet been established through research evidence (Wittouk et al, 2010). The review conducted by Wittouk and colleagues argues however that we should not conclude that complicated grief *cannot* be prevented – rather that it is difficult to research. Existing research studies are of varied quality, they examined a range of techniques/ interventions and account neither for other potential impacts such as accelerated recovery, or for the fact that large individual impacts may have been experienced but are not visible in the group analysis. (Wittouk et al, 2010).

A small proportion of bereaved people require psychotherapeutic intervention and these services are termed '*Indicated*' when people are diagnosed as having significant complications which require intervention – i.e. that a treatment is indicated that will meet their needs. Shear et al (2013) estimates the prevalence of complicated grief as 7%; Bonanno (2002) had found a similar proportion (9%) of widowed older people experiencing what he termed 'chronic depression'.

Universal, selective and indicated categorisations are the preferred terms for this document. It should be noted that they relate broadly to the language of public health which refers to primary treatments (preventive and available to all); secondary treatments (targeted to those identified, or who identify themselves, as being at increased risk) and tertiary treatments aiming to treat people experiencing symptoms/ problems. Schut et al (2005) and Stroebe et al (2007) use these terms relative to bereavement.

A public health approach seeks to ensure that people get the help that is appropriate to their level of need. This approach has been incorporated into some clinical guidelines, including the evidence-based standards for bereavement care developed by Hall et al in Australia (Hall et al, 2012). These standards recommend that bereavement care be provided in a targeted way.

Increasingly it is recommended that people's strengths and resilience should also be included in assessment, an approach favoured by Relf et al (2010), as more comprehensive than focusing on risk factors alone); Stroebe et al, 2006, Relf et al, 2010 and Agnew, 2011).

## NICE model

The UK National Institute for Clinical Excellence (Nice, 2004) included bereavement care provision in its review of evidence to underpin guidance for palliative care services. NICE recommended a tiered or layered model similar to the Public Health approach. Three components or levels to bereavement care were defined. The schema proposed by NICE (2004) for locating the needs of mourners in a three-tiered model has been a dominant influence on the planning of bereavement care in the UK and elsewhere (Guldin et al, 2015). The schema was based on a systematic review of the research evidence existing at that time.

Component one proposes that 'all bereaved people should be offered information about the experience of bereavement and how to access support. Family and friends will provide much of this support, with verbal and written information being supplied by health and social care professionals providing day-to-day care to families.'

Component two states that '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' i.e. volunteer services or 'befrienders, self-help groups, faith groups and community groups' may be involved. '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'.

Finally, level three services refer to 'specialist mental health services, psychological support services, specialist counselling/psychotherapy services, specialist palliative care services and general bereavement services' for the minority of people requiring such specialist intervention.

Figure one below summarises the features of both these bereavement support models and includes approximate prevalence of bereaved people at each level.

Figure one: Bereavement need and associated service response by public health level and NICE components (adapted from Aoun et al, 2012 and Aoun et al 2015))

Level of public health intervention	NICE Components	Type of support	Support provided by	Target population & level of need	Proportion bereaved (Relf, Sobell House 1992-2002)	Proportion bereaved general sample (Aoun et al 2015)
<b>Universal</b>	1	Information about bereavement & relevant supports	Family & friends; verbal and written information from health and social care professionals	All bereaved Low level of need	54%	58%
<b>Selective or targeted</b>	2	Non-specialist support	Trained volunteers, mutual-help groups, community supports	Those at risk of developing complex needs Medium level of need	33%	35%
<b>Indicated</b>	3	Professional specialist interventions	Mental health services; bereavement specialists; psychotherapy	Those with complex needs High level of need	9%	6%

This framework offers a structure within which bereavement support should be considered, designed and operationalised (in palliative care and elsewhere).

There are important implications to this approach:

- It is not appropriate to offer specialist bereavement services to all bereaved people (Schut and Stroebe, 2005; Currier et al 2008; Wittouck et al, 2010; Aoun et al, 2015).
- Supportive families, social networks and communities are considered to be a necessary foundation for bereavement support/ ameliorating risk (Stroebe, Folkman et al, 2006; Aoun et al 2015).
- Widespread availability of accurate information about bereavement should be promoted (Component 1) and facilitated in line with the public health model (NICE, 2004; Aoun et al 2015; Salnow et al, 2015). This will help people recognise their own needs for help and to know what component 2 and 3 services are available should they need to support
- Bereavement care assessment is required and should recognise both need/risk and resilience/strengths. (Stroebe and Schut 2005; Bonanno, 2008)
- Identified need may be met within a palliative care service, but equally may be provided by appropriately qualified professionals in the wider network or by the voluntary sector. (NICE, 2004; Guldin et al, 2015)

## Assessment

There are contradictory research findings about bereaved people's own ability to find the support they require. Auon et al (2015) and Currow (2008) suggest that bereaved people reach out to a variety of sources for external support. However, others suggest that bereaved people, especially those who lack resources experience difficulty finding the *right help* for their needs (Guldin et al, 2012).

In general, research evidence suggests that services should be proactive in identifying those who may be at risk of poor bereavement outcome in order to ensure that the appropriate level of support is accessible to the bereaved (Relf, 2005; Schut and Stroebe, 2005).

However, while there is agreement on the importance of needs assessment in order to align needs and support, there is a lack of consensus on how risk assessment should be carried out, by whom and at what stage in the grief process (Agnew, 2011; Sealy et al, 2015 a & b). It could be argued that pre-death screening (for risk of poor outcome) and post death bereavement risk assessment (to match need with service) are terms that are often used interchangeably but which denote very different but equally necessary activities (Sealy et al 2015a).

Formal risk assessment using recognised instruments in palliative care settings is still low. The 2013/14 survey of palliative care bereavement services in Europe showed a minority used formal assessment tools and that decision-making was variable – often attributed to the full multi-disciplinary team (Guldin et al, 2015).

Of the 302 services that offered bereavement support, 197 (66%) stated that this support was not based on any formal policies or guidelines; 122 (40%) were not aware of any guidelines in their country; and 98 (33%) said formal guidelines did inform their bereavement services design. A quarter of the 302 services (n=75, 25%) described using a formal risk assessment tool (Guldin et al, 2015).

Pre-death assessments scales are based on aspects of risk and of resilience have been identified but are frequently based on staff observations rather than direct enquiry of caregivers own perceptions of need. Furthermore, these require considerable resources for staff training and implementation. (Sealy et al, 2015a)

There are a large number of bereavement measures available in the published literature (Sealy et al, 2015b)- many of which are used for research rather than clinical practice. Availability of psychometric instruments is only one factor in the use of assessment procedures – the timing of the assessment, the length of contact with patients and families and the range of referral options all play a role (Relf et al, 2010).

Sealy et al (2015a) have identified some of the other barriers to assessment including systems issues (e.g., whose responsibility is it to assess?); team issues 'gatekeeping' / a preference for 'informal chat' over formal assessment and they also note the different

dynamics for assessing pre-death as opposed to post death, with frequent conflating of care giver distress, burden and grief.

It is clear that assessment is not a simple matter and is one that will be debated for some time.

### Developing bereavement support within palliative care

Support for bereaved people is a core part of palliative care (WHO, 2002). Bereavement support in palliative care can be structured in different ways depending on identified need and the capacity of services to respond (Field et al, 2004, Field et al 2007; Demmer 2003). Care is provided in a changing social and cultural context (Sealy et al 2015b) and will also be framed by national health and social care policies. Bereavement assessment and bereavement care is planned and designed in complex situations. In some circumstances, pre-death assessment is more feasible than in the post –death phase (although length of contact with carers may be limited and make pre-death assessment more challenging). Knowledge of available supports should underpin assessment and Sealy (2015b) notes there needs to be referral pathways across a range of supports, not simply counselling or therapy.

While the vast majority of respondents to the EAPC Bereavement Task Force survey provide some bereavement support, almost 20% have no bereavement service. Almost half of all services wished to give priority in the future to the development of a more evidence-based and structured approach to bereavement care. (Guldin et al, 2015)

The literature review identified a range of service responses provided through palliative care (Field, 2004, Field 2007; Demmer 2003; O’ Connor 2009, Diamond, 2012; Brown, 2015). The EAPC survey of 2013/2014 describes similar types of service activity across Europe which can be described as universal, indicated and targeted supports (Guldin et al, 2015).

However, the survey also identified:

- The challenges of needs assessment with no dominant or reliable measure uncovered and most services having no national or local policy with respect to bereavement care.
- Amongst those who had bereavement services few bereavement-specific roles were noted (Guldin et al, 2015).
- In addition to service and structural issues, bereavement education varied across respondents and the extent to which training and education in bereavement is contemporary and relevant was not established (Guldin et al, 2015).
- Over half of the palliative care bereavement services were seen to reach out to their communities by providing advice and education/training to local health providers (n=151, 52%) and arguably there is scope for further interaction (Field et al, 2007).

## Conclusion

Current research and practice knowledge on grief and bereavement has been reviewed and how these understandings have been incorporated into models of support have been outlined. This document also identifies working frameworks for best practice in bereavement care in general and specifically within palliative care. Adoption of a three-tier model has implications for the development of bereavement care within palliative care which may be summarised across a number of dimensions:

- Structural/ System issues (e.g. clear policy frameworks on bereavement and funding)
- Clinical decision-making clarity (e.g. assessment & skill)
- Integrated care (e.g. access to a full range of proactive supports)

We propose that based on the literature, on findings of the EAPC bereavement taskforce survey and on taskforce and expert advisory discussions that we now devise a Delphi methodology to generate a consensus direction for the ongoing development of bereavement care in palliative care services in Europe.

## APPENDIX ONE

Figure two: Frequency of availability of range of bereavement supports in palliative care services in Europe (Guldin et al, 2015)

Level public health	NICE Level/ component	Type	Bereavement services with access N (%)*
Universal	1	Telephone support Literature – adult grief Literature – children’s grief Information/education sessions on bereavement Letters Memorial services Cards Attend funeral Anniversary Cards	254 (84) 245 (81) 225 (74) 196 (65) 179 (59) 170 (56) 149 (49) 123 (41) 68 (22)
Selective	2	One to one support by professionals employed by the palliative care organisation Home visits to provide bereavement support Referral to support groups run by other agency Provide support group Provide one to one volunteer support Referral to one to one volunteer support provided by external agency	237 (78.5) 177 (59) 176 (58) 169 (56) 135 (45) 106 (35)
Indicative	3	Provide bereavement counselling Referral to other counselling/psychotherapy Psychological support/psychotherapy following an agreed protocol Referral to psychiatrist	244 (81) 232 (77) 196 (65) 192 (64)

## References

Agnew, A., Manktelow, R., Haynes, T., Jones, L., (2011) Bereavement Assessment Practice, in Hospice Settings: Challenges for Palliative Care Social Workers. *British Journal of Social Work*, 41

American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. 5th ed. Washington, DC: American Psychiatric Association; 2013

Aoun, S. M., L. J. Breen, et al. (2012) A public health approach to bereavement support services in palliative care. *Australia and New Zealand Journal of Public Health* 36(1): 14-6.

Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, Hegney D. (2015) Who needs Bereavement support: A population based survey of bereavement risk and support need PLOS one 2015;26: 1-14.

Archer, N (2015) *Bereavement Help Points* Presentation at Help the Hospices, UK <https://www.hospiceuk.org/docs/default-source/What-We-Offer/Education-and-training/Conference-2015/1-1-an-innovative-and-collaborative-approach-to-providing-bereavement-support-nikki-archer.pdf?sfvrsn=0>

Azulay A. Dilemas bioéticos en la situación de enfermedad terminal y en el proceso de muerte. [Bioethical dilemmas in the end of life and in the dying process]. *Med Pal* 2000; 7: 145-56.

Benkel, I, Wijk H, Molander U. Family and friends provide most social support for bereaved. *Palliative Medicine* 2009; 13:1119-23.

Breen LJ, O'Connor M. Family and social networks after bereavement: Experiences of support, change and isolation. Edit Cowan University Publications 2011. Research online. 1-32. <https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.1010.6726&rep=rep1&type=pdf>

Brown, J., Gardner, J. (2015) Qualitative Evaluation of a hospital bereavement service: the perspective of grieving adults. *Bereavement Care*, 34:2

Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., et al. (2002) Resilience to loss and chronic grief: A prospective study from pre-loss to 18 months post-loss. *Journal of Personality and Social Psychology*; 83; 1150–1164.

Bonanno G, Neria Y, Mancini A, Coifman KG, Litz B, Insel B. Is there more to complicated grief than depression and post-traumatic stress disorder? A test of incremental validity. *J Abnormal Psychology* 2007; 116(2): 342-51.



- Bowlby, J. (1980) *Attachment and Loss: Vol 3 Sadness and Depression*. London: Penguin
- Boerner K, Mancini A, Bonanno G. (2013) On the nature and prevalence of uncomplicated and complicated patterns of grief. In: Stroebe M, Schut H, van den Bout J. (Eds) *Complicated grief. Scientific Foundations for health care professionals*. 1<sup>st</sup> Ed. New York: Routledge; 2013; 55-67
- Cadell, S and Sullivan, R. (2006) Posttraumatic growth in bereaved HIV caregivers: where does it start and when does it end? *Traumatology* 3(12) 45-59
- Currier, J. Neimeyer, R., Berman, J (2008) The Effectiveness of psychotherapeutic interventions for bereaved individuals: a comprehensive quantitative review. *Psychological Bulletin*, 132 (5)
- Currow, D., Allen, K., Plummer, J., Aoun, S., Hegarty, M and Abernethy, A (2008) Bereavement help-seeking following an 'expected' death: a cross-sectional randomised face-to-face population survey. *BMC Palliative Care* 7: 19 DOI: 10.1186/1472-684X-7-19
- Demner, C (2003) A national survey of hospice bereavement services *Omega: Journal of Death & Dying* , 47(4): 327-41
- 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 in *Death Studies*, 36, 6 p541-564
- Field, D., Reid, D., Payne, S., Relf, M (2004) Survey of UK hospice and specialist palliative care adult bereavement services *International Journal of Palliative Nursing*, Vol. 10, No 12 569-576
- Field, D., Payne, S, Relf, M. Reid, D (2007) Some issues in the provision of adult bereavement support by UK hospices. *Social Science & Medicine* 64 (2) 428-438
- Freud, S. (1917, 1953) *Mourning and Melancholia* in J.Strachey (Ed. and trans.)The standard edition of the complete psychological works of Sigmund Freud (Vol 14). London: Hogarth
- Gear R. Bereaved parents' perspective on informal social support: "What worked for you?" *Journal of loss and trauma*. 2014;19: 173-188.
- Guldin M-B, Vedsted P, Zachariae R, Olesen F, Bonde Jensen A. (2012) Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: a longitudinal cohort study. *Supportive Care Cancer* 2012; 20:1679-1685.
- Guldin, M., Murphy, I., Keegan, O., Monroe, B., Lacasta-Reverte, M and Benkel, I. (2015) Bereavement services in palliative care in Europe: A survey study by the European Association for Palliative Care bereavement taskforce. *European journal of Palliative Care* 22(4) 185-189

- Hall, C (2014) Bereavement theory: recent developments in our understanding of grief and bereavement. *Bereavement Care* 33(1):7-12
- Hall C, Hudson P, Boughey A. (2012) *Bereavement support standards for specialist palliative care services*. Department of Health, State of Victoria editor. Melbourne: Victorian Government. 2012:1-31.
- Jordan, AH, Litz, BT. (2014) Prolonged Grief Disorder: Diagnostic, assessment, and treatment considerations professional *Psychology: Research and practice* 4, (3), 180–187
- Lacasta MA, SanzB, SolerMC, et al. Atencion al duelo en Cuidados Paliativos: Guia clínica y Protocolo de actuación. [Bereavement care in Palliative Care: Clinical Guide and Action Protocol] Monografía N° 5 SECPAL, June, 2014
- Limonero JT. El fenómeno de la muerte en la investigación de las emociones. [The phenomenon of death in the research of emotions]. *Rev Psicol Gen Aplic* 1996; 49: 249-65.
- Love, A. Progress in understanding grief, complicated grief, and caring for the bereaved. *Contemporary Nurse*.2007;27:73-83.
- Maercker A, Brewin CR, Bryant RA, Cloitre M, Reed GM, van Ommeren M, et al. (2013) Proposals for mental disorders specifically associated with stress in the International Classification of Diseases-11. *Lancet*; doi:[http://dx.doi.org/10.1016/S0140-6736\(12\)62191-6](http://dx.doi.org/10.1016/S0140-6736(12)62191-6).
- McGrath P. (2010) Surviving spousal bereavement, Insight for GPs. *Australian Family Physicians*. 2010;39(10): 780-783.
- National Institute for Clinical Excellence (2004) *Supportive and palliative care for cancer with adults* [Online] Available from <http://www.nice.org.uk/guidance/csgsp/resources/supportive-and-palliative-care-the-manual-2>
- Neimeyer RA. (2000) Grief therapy and research as essential tensions: prescriptions for a progressive partnership. *Death Studies*. 24(7): 603-10
- Neimeyer, R., (2014) The changing face of grief: Contemporary directions in theory, research, and practice in *Progress in Palliative Care*, 22 (3) 125-130
- Neimeyer, R and Cacciatore, J. (2015) Toward a developmental theory of grief in Neimeyer, R.A. (2016) *Techniques of Grief Therapy: Assessment and Intervention New York, Routledge*
- O'Connor, M., Abbott, J., Payne, S., Demmer, C. (2009) A comparison of bereavement services provided in hospice and palliative care settings in Australia, the UK and the USA. *Progress in Palliative Care*, 17, (2) 69-74
- Parkes, C.M. and Weiss, R.S. (1983) *Recovery from Bereavement. New York: Basic Books*
- Prigerson, H. G., Maciejewski, P. K., Reynolds, C. F., Bierhals, A. J., Newsom, J. T., Fasiczka, A., et al. (1995) Inventory of Complicated Grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*; 29: 65–79.

Prigerson, H., Ahmed, I., Silverman, G. K., Saxena, A. K., Maciejewski, P. K., Jacobs, S. C., et al. (2002). Rates and risks of complicated grief among psychiatric clinic patients in Karachi, Pakistan. *Death Studies* 26: 781–792

Prigerson H, Horowitz MJ, Jacobs SC, Parkes CM, Aslan M, Goodkin K, et al. (2009) Prolonged grief disorder: psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med.* doi:10.1371/journal.pmed.1000121

Prigerson H, Jacobs S. (2001) Traumatic grief disorder: A rationale, consensus criteria, and a preliminary empirical test. In Stroebe M, Hansson W, Stroebe W & Schut H. *Handbook of bereavement research* 613 -637. Baltimore; United press.

Raphael B, Minkov C, Dobson M. (2001) Psychotherapeutic and pharmacological intervention for bereaved persons. In: M.S. Stroebe RO, Hansson W, Stroebe y Schut H, editors. *Handbook of bereavement research: Consequences, coping, and care*. Washington: American Psychological Association, 587-612.

Relf, M (2005) Bereavement Care in Monroe, B & Oliviere, D (eds) *Patient Participation in Palliative Care: A Voice for the Voiceless*, Oxford University Press, Oxford

Relf, M., Machin, L., Archer, N. (2010) 2<sup>nd</sup> Edition *Guidance for Bereavement Needs Assessment in Palliative Care*. London: Help the Hospices. Download from [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

Richardson, V E. (2006) 'A Dual Process Model of Grief Counseling', *L Gerontological Social Work* 2006; 48: 3, 311-329 DOI: 10.1300/J083v48n03\_03

Rumbold, B and Aoun, S (2014) Bereavement and palliative care: A public health perspective *Progress in Palliative Care* 22, 3 p131-135

Sallnow, L., Richardson, H., Murray, Scott, Kellehear, A (2016) The Impact of a New Public Health Approach to End-of-Life Care: A systematic Review *Palliative Medicine*, 30 (3), 200-211

Schut H, Stroebe M. (2005) Interventions to enhance adaption to bereavement. *Journal of Palliative Medicine*. 8: 140-147.

Sealy, M., O'Connor, M., Aoun, S. and Breen, L. (2015a) Exploring barriers to assessment of bereavement risk in palliative care: perspectives of key stakeholders *BMC Palliative Care* 14:49 DOI 10.1186/s12904-015-0046-7

Sealey, M., Breen, L., O'Connor, M., and Aoun, S. (2015b) A scoping review of Bereavement Risk assessment measures: implications for palliative care *Palliative Medicine* 29(7) 577-589

Shear K. (2015) Complicated Grief. *The New England Journal of Medicine*, 372; 2, 153-60

Stroebe W, Schut H, Stroebe M. (2005) Grief work, disclosure and counselling: Do they helped the bereaved? *Clinical Psychology Review*. 2005; 25: 395 -414.

Schut, H., & Stroebe, M. S. (2005). Interventions to enhance adaptation to bereavement. *Journal of palliative medicine, 8 Suppl 1*, S140–S147.  
<https://doi.org/10.1089/jpm.2005.8.s-140>

Stroebe, M.S. Folkman, S, Hansson, RO, Henk Schut, H. (2006) The prediction of bereavement outcome: Development of an integrative risk factor framework *Social Science of Medicine* 63: 2440–2451

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

Stroebe MS, Hansson RO, Stroebe W & Schut H. (2008) Introduction. Concepts and issues in contemporary research on bereavement. In: MS Stroebe, RO Hansson, W Stroebe & H Schut (red). *Handbook of Bereavement Research. Consequences, coping and care*. Washington, DC: American Psychological Association

Thomas, K., Hudson, P., Trauer, T. Remedios, C and Clarke, D (2014) Risk Factors for Developing Prolonged Grief During Bereavement in Family Carers of Cancer Patients in Palliative Care: A Longitudinal Study *J Pain Symptom Manage* 47:531e541.

World Health Organization's (2020) International Statistical Classification of Diseases and

Related Health Problems (11th ed.; ICD-11) Worden JW. (2009) *Grief Counseling and Grief Therapy*, Fourth Edition: A Handbook for the Mental Health Practitioner. New York: 2009.

Wittouck, C., S. Van Aultreuve, et al. (2010) The prevention and treatment of complicated grief: A meta-analysis. *Clinical Psychology Review* 31(1): 69-78.