Faculty of Health Sciences
School of Psychology

What is Normal Anyway? Exploring the Effect of Social Norms on Grief Expectations, Expressions, and Social Support

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Declaration

To the best of my knowledge and belief, this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Medical Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) — updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number RDHS-12-15 (Appendix A).

Emma Louise Logan

17 January 2018

Abstract

Introduction. Social support is widely regarded as one of the most significant predictors of psychosocial outcomes following bereavement. Once considered an intrapsychic and individual phenomenon, grief is increasingly being recognised as an intersubjective, social, and relational experience informed by historical, political, cultural, and spiritual contexts. A recently proposed three-tier approach to bereavement care suggests that, although a minority of bereaved persons require specialised grief therapy, the majority receive support through family, friends, neighbours, and work colleagues. However, positive social support is often assumed to be a given, with little regard for understanding or developing the community's capacity to provide compassionate support. The widespread acceptance of a dominant discourse of grief—informed by outdated grief theories and popularised by screen and print media—means that few bereaved people receive the quality or duration of social support necessary to enfranchise their grief and moderate their bereavement outcomes. To date, there has been scant attention in the literature on delineating the factors associated with community recognition of and willingness to support grief, or how grieving individuals negotiate absent or unhelpful social support whilst simultaneously integrating the loss into their lives.

Aims. Through distinct but interrelated study phases, the research sought to explain how 'normal' or 'typical' grief is conceptualised and experienced from the perspective of both bereaved persons and their network of natural supporters. The overarching aim of this research was to examine the nature and scope of grief-related norms and their influence on the experience of grief and provision and receipt of social support following bereavement.

Methods. Informed by pragmatist philosophy, the research adopted an explanatory sequential mixed methods design across three phases. Phase One was a systematic review of the literature investigating key determinants of supportive behaviours following bereavement. The review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) and conducted between January and March 2015 (with an update in January 2016). Included studies were analysed using narrative synthesis and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Phase Two was a quantitative community survey examining the influence of bereavement status, anticipation of death, and perceived social support on perceptions of, beliefs about, and intentions to provide support to, grieving persons. Participants were 476 Australian adults who self-identified according to whether they had been significantly impacted by bereavement. The

online survey included a fictional vignette and scales measuring expectations of grief symptomatology, intentions to provide support, beliefs about support-intended statements, and opinions towards a grief-related diagnostic classification. Data were analysed using Generalised Linear Mixed Models (GLMM) and content analysis.

Phase Three comprised in-depth qualitative interviews exploring experiences of grief-related norms and their impact on the expression of grief and mourning and receipt of social support. Respondents were 19 Australian adults who self-defined as having experienced a significant bereavement between 1 month and 29 years ago. The respondents were asked about their experiences of grief reactions, grief-related beliefs and expectations, social support, and change/growth. Data were analysed using the Constant Comparative Method (CCM) which encompassed memo-writing, reflexive journaling, and respondent validation.

Results. The systematic review included 42 studies from 1979 to 2015, uncovering 10 bereaved (e.g., gender), 5 decedent (e.g., cause of death), and 26 respondent (e.g., bereavement history) determinants of social support. Study quality ranged from adequate to good, with most studies limited by a lack of control over extraneous variables (including social desirability), no post-manipulation checks, low power to detect effects, and considerable heterogeneity across samples, manipulations, and measurement instruments.

The quantitative survey highlighted that factors relating to the potential supporter (i.e., gender, age, bereavement status) had a more significant influence on recognition of and responses to grief than factors relating to the bereaved (i.e., anticipation of death, perceived social support). Female respondents expected more intense grief symptomatology (as did those significantly impacted by bereavement), were more likely to offer support, endorsed more approach-oriented support statements, and, if significantly impacted by bereavement, rejected more avoidance-oriented support statements. The majority of the sample did not agree with (39.5%) or were undecided about (25.0%) a grief-related diagnostic classification, with endorsement higher in younger than older adults.

The qualitative interviews revealed 5 themes and 17 subthemes that encompassed experiences of loss, adaptation, and growth following bereavement. Respondents reported the establishment of an arbitrary standard against which their grief was measured, described actions by themselves and others that silenced their grief and minimised their loss, stressed the importance of developing holding spaces both within and outside the self that permit the natural expression of grief, emphasised efforts to integrate their losses through making sense of and finding meaning in experiences, and highlighted the potential to redefine perceptions of 'normal' grief through continuing bonds and self-acceptance.

Conclusion. Collectively, these research findings offer a substantial contribution to empirical literature and bereavement practice through describing the nature and scope of grief-related norms, the extent of their endorsement in an Australian community sample, and the ways in which they are negotiated by bereaved persons to help or hinder natural grieving processes. This research has built upon a growing evidence base that suggests enforcement of the dominant grief discourse results in higher levels of disenfranchised grief, which increases the likelihood of limited or absent social support, which in turn increases the risk for interpersonal isolation and complications of grief. Consequently, psychologists and other mental health professionals have a considerable role to play in fostering attachment security, re-enfranchising experiences of grief and loss, empowering bereaved individuals to communicate their needs, and improving grief therapy through advancing tertiary education and promoting ongoing professional development. Embedded in a compassionate community framework, there is a need to work collaboratively with the community to challenge the dominant grief discourse through public platforms, empower the bereaved as educators and advocates of grief and loss, and provide better support for social networks. For a three-tier public health approach to bereavement care to be effective, greater investment is needed at the community level to empower, resource, and support both the bereaved *and* their natural supporters.

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List of Included Publications

Chapter Four:

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Chapter Five:

Logan, E. L., Thornton, J. A., Kane, R. T., & Breen, L. J. (2017). Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies*. http://dx.doi.org/10.1080/07481187.2017.1382610

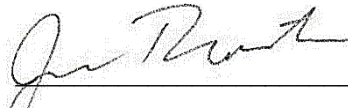### Copyright

Statements of Contributors

The purpose of this statement is to detail the nature and extent of the intellectual contribution by the PhD Candidate, Emma Logan, and all other co-authors of this study publication. Associate Professor Lauren Breen and Associate Professor Jennifer Thornton were involved in the overall supervision of the PhD, supporting the conception and design of the study, interpretation of results, and writing of the manuscript. Emma Logan contributed to the conception and design of the study, and led the data collection, analysis, and interpretation, and manuscript writing.

I affirm the details stated in the Statement of Contribution are true and correct.

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Logan, E. L., Thornton, J. A., Kane, R. T., & Breen, L. J. (2017). Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies*. http://dx.doi.org/10.1080/07481187.2017.1382610

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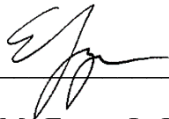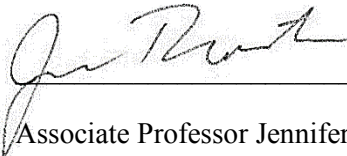I affirm the details stated in the Statement of Contribution are true and correct.

Ms Emma L. Logan

Associate Professor Jennifer A. Thornton

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Associate Professor Lauren J. Breen

List of Additional Publications and Conference Presentations

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Logan, E. L., Breen, L. J., & Thornton, J. A. (2016 May). *Determinants of grief support: A systematic review of community responses to bereavement*. Paper presented at the Australian Centre for Grief and Bereavement Conference, Melbourne, Australia.

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Penman, E. L., Thornton, J. A., & Breen, L. J. (2015). *A systematic review of the determinants of perceptions of and behavioural responses towards bereaved people*. Retrieved from http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42015016095

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List of Abbreviations

ABS	Australian Bureau of Statistics
ADEC	Association for Death Education and Counseling
APA	American Psychiatric Association
CCM	Constant Comparative Method
CG	Complicated Grief
DSM	Diagnostic and Statistical Manual of Mental Disorders
GLMM	Generalised Linear Mixed Model
HREC	Human Research Ethics Committee
ICD	International Classification of Diseases
PCBD	Persistent Complex Bereavement Disorder
PGD	Prolonged Grief Disorder
PICOS	Population, Intervention, Comparator, Outcome, Study Design
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTSD	Posttraumatic Stress Disorder
Q-LES-Q-18	Quality of Life Enjoyment and Satisfaction Questionnaire
SPSS	Statistical Package for the Social Sciences
TMT	Terror Management Theory
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Chapter 1   Introduction

"Well, everyone can master a grief but he that has it."

(Shakespeare, 1923, p. 42)

1.1   Chapter Overview

Chapter One provides an introduction to the thesis examining the conceptualisation of 'normal' grief and the relationship between social norms and grief expectations, expressions, and social support. This chapter frames the experience of loss and bereavement as both an individual and a social phenomenon and presents definitions of key terminology used throughout the thesis. The relationship between the profession of counselling psychology, the researcher, and the research is then outlined. The chapter concludes with the research aims and questions, followed by an outline of the structure of the thesis and the contents of each chapter.

1.2   Framing the Problem

Approximately 159,000 people die in Australia each year, with an estimated one death every 3 minutes and 19 seconds (Australian Bureau of Statistics [ABS], 2017). Just over half (54%) of these deaths occur in hospital, with the remaining 26% in residential care and 20% elsewhere, including private homes (Broad et al., 2013). Approximately 76% of deaths are described as expected (Department of Health, 2008), predominately attributed to ischaemic heart disease, dementia, cerebrovascular disease, respiratory cancers, and chronic lower respiratory diseases (ABS, 2017). However, these deaths do not occur in a vacuum. Every one of these deaths leaves behind an estimated half-dozen significant others faced with the task of accommodating the loss and readjusting to life without the deceased person (Shear, Frank, Houck, & Reynolds, 2005). Despite grief being recognised as both a normal and healthy reaction to loss, evidence suggests that few bereaved people are given the time, space, or support to express their grief openly and naturally (Harris, 2009-2010). In Australia, all employees are entitled to two days of compassionate leave (paid or unpaid) each time an immediate family or household member dies or is affected by a life-threatening illness/injury (Australian Government, 2017). An 'immediate family or household member' is defined as a spouse/partner (or former spouse/partner), child/step-child, parent/step-parent, grandparent, grandchild, sibling, or any of these relationships as they pertain to the employee's spouse/partner. By definition, this compassionate leave does not extend to more distant

relatives, neighbours, work colleagues, or even close friends. Although commonplace and rarely questioned, such workplace policies convey the messages that some lost relationships are most significant than others, the most intense period of grief occurs around the time of death or the funeral, and bereaved individuals can be considered competent and prepared to return to work after two days of dedicated mourning (D. Hall, Schucksmith, & Russell, 2013; N. Thompson & Lund, 2017). These contextual constraints raise questions about the conceptualisation of grief in Western culture and how socially-determined definitions of 'normal' or expected behaviour influence experiences of grieving and being supported in grief when bereavement occurs.

On April 17 2012, Australian television network SBS aired an episode of Insight titled 'Good Grief: What is Normal When it comes to Grief? And Can It Become a Mental Illness?' The panel discussion featured Professor Gordon Parker (psychiatrist), founder of the Black Dog Institute and a key figure guarding against the medicalisation of grief, and Professor Richard Bryant (psychologist), a committee member on boards of the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) who has previously been a strong advocate of diagnosing chronic grief that persists beyond 12 months. These experts in the field were also joined by six Australians who had experienced the death of a parent, sibling, or child in the previous 10 years and whose stories of loss and coping informed the debate of what constitutes 'normal' grief. This television feature was arguably the first of its kind in Australia to extend conversations about the impact of grief on mental health outside professional domains, unpack social conceptualisations of grief and mourning, and present a realistic snapshot of the lived experience of bereavement. Importantly, this feature also highlighted key support needs of grieving individuals and raised questions about where responsibility for bereavement support lies.

The most widely recognised public health model of bereavement support proposes that bereaved individuals may be classified into one of three tiers according to their level of risk for complications of grief and support need (Aoun, Breen, O'Connor, Rumbold, & Nordstrom, 2012). This model is based on empirical data that suggests the majority of bereaved people will eventually accommodate their loss and only a subset (approximately 7-10%) will remain consumed by their loss, experiencing persistent debilitating symptoms long after the death (Aoun et al., 2015; Kersting, Brähler, Glaesmer, & Wagner, 2011). According to this model, tier one (universal: low risk) comprises all bereaved individuals who have the right to compassion and high-quality information about grief and available services. Tier two (selective or targeted: moderate risk) comprises a smaller proportion who would benefit from non-specialist social and therapeutic support through peer or volunteer-led community

services. Tier three (indicated: high risk) comprises a minority who require specialist grief-specific interventions. In a study of 678 bereaved Australian adults, 58.4% met criteria for tier one, predominately accessing support from social networks, GPs, and funeral directors; 35.2% met criteria for tier two, utilising palliative care services and community support groups; and 6.4% met criteria for tier three, depending on the services of psychologists and psychiatrists trained in grief therapy (Aoun et al., 2015). This three-tiered approach assumes that bereavement support starts at the level of the community, with the majority of grieving persons expected to depend on their existing social networks, turning only to formal services if complications arise (Rumbold & Aoun, 2015).

Whether low, moderate, or high risk, the fact that few bereaved individuals navigate grief and mourning alone and many require the support of family, friends, neighbours, and work colleagues is uncontested in the literature (J. Y. Allen, Haley, Small, Schonwetter, & McMillan, 2013; L. A. Burke & Neimeyer, 2013; Lobb et al., 2010; Pål Kristensen, Weisæth, & Heir, 2010; M. S. Stroebe, Schut, & Stroebe, 2007). However, the capacity of members of the community to intuitively recognise grief, predict unique support needs, and respond with unconditional empathy and compassion appears to have received far less attention. Although a somewhat privatised experience, grief is set within a historical, political, cultural, and social climate which determines socially appropriate patterns of thought, feeling, and behaviour in response to loss (Neimeyer, Klass, & Dennis, 2014). Buckle, Dwyer, and Jackson (2010) propose that, in typically individualistic cultures, there lies a degree of uncertainty and discomfort in bearing witness to intense sadness, which is overcome through avoidance of topics likely to lead to emotional activation. In this way, loss and its associated grief become the so-called 'elephant in the room,' often seen, but rarely talked about. Bereaved individuals often report believing that others have 'moved on' and forgotten their loss (Breen & O'Connor, 2011; Ghesquiere, 2013), when memories of the loss may be very much alive, but consciously avoided to reduce distress both in the bereaved person and their potential supporter (Jalland, 2013). This paradox between the invisibility of grief and the universality of bereavement thus poses unique challenges for grieving persons in how to legitimise their grief and 'perform' as mourners, whilst at the same time just trying to accommodate the loss itself.

As the quote that opens this chapter suggests, grief following bereavement is one of the most inevitable and universal human experiences, yet can be subject to some of the greatest evaluations, judgements, and criticisms by those bearing witness to the experience. In this scene in Shakespeare's *Much Ado about Nothing*, Benedick reports a toothache to which all of the other characters are quick to share their personal opinions on what painful remedies he might try to alleviate his ailment. Through his reply, Benedick highlights the relative ease and

simplicity with which others have claimed complete understanding of his experience and are confidently offering support through well-intended (yet misattuned) advice. This quote was chosen to highlight the less often talked about dimensions of loss; that is, when an individual experience becomes a social spectacle. Recognising that social support is a key predictor of psychosocial outcomes following bereavement (L. A. Burke & Neimeyer, 2013), and the majority of bereaved persons turn to their community for support (Aoun et al., 2015), there is a clear need to understand how a typically individualistic culture constructs, approaches, and responds to grief as a social phenomenon. If community members are to be recognised for and supported within their caring role, greater awareness is needed about what helps or hinders their support attempts, and how these actions are perceived by those receiving them. This research sought to reaffirm the relationship between thanatology and counselling psychology, considering the role of professionals in facilitating timely and effective formal (i.e., grief counselling and therapy) *and* informal (i.e., social) support for bereaved people, and reconceptualise the experience of grief and loss as an intersubjective and relational, rather than intrapsychic and individual, phenomenon.

1.3   Terminology

This research is situated within the broad context of thanatological research; that is, the scientific study of death, dying, and bereavement (Fonseca & Testoni, 2012). Although the terms bereavement, grief, and mourning are often used interchangeably in this literature, it is important to note the different dimensions they represent. In the context of this research, bereavement refers to experiencing the death of a significant person (though not investigated in this study, the meaning of pet loss is not disregarded here), grief denotes the cognitive, emotional, behavioural, spiritual, and social responses to the death, and mourning depicts the specific routines, rituals, and practices through which grief is expressed (Hansson & Stroebe, 2003; Martin & Doka, 2000; M. S. Stroebe, Hansson, Stroebe, & Schut, 2001). Recognising that the placement and nomenclature of grief in diagnostic nosology is still in its infancy, this thesis will use the term 'grief complications' or 'complications of grief' to refer to clinical grief presentations. Similarly, the words 'symptom' and 'symptomatology' will be used to describe reactions or responses to bereavement (in alignment with the measures employed in this research), but do not refer specifically to a diagnosis or mental health condition. This thesis shifts away from the traditional language of deceased 'loved one' (recognising that grief may occur in the absence of love), referring instead to 'deceased persons' or 'decedent.' The terms 'natural supporter' and 'support network' represent anyone in the bereaved person's immediate or distal social system, whether family, friends, neighbours, or work colleagues, who are likely to converse about the loss and provide assistance. Finally, the term

'societal/social norms' refers to implicit and explicit criteria for 'normal' grief that may manifest through beliefs, expectations, assumptions, opinions, evaluations, and behaviours towards bereaved persons (Harris, 2009-2010). This choice of language acknowledges that community may represent multiple highly diverse cultures and culture may represent numerous ethnic groups, each with their own worldviews, values, and customs.

1.4   Grief and Loss from a Counselling Psychology Perspective

The present thesis represents the research component of a Doctor of Philosophy in Counselling Psychology. The following section is intended to contextualise the research topic from a counselling psychology perspective and offer the reader some insight into the background of the researcher. In Australia, counselling psychology denotes one of nine areas of practice endorsement alongside clinical psychology, clinical neuropsychology, community psychology, educational and developmental psychology, forensic psychology, health psychology, organisational psychology, and sport and exercise psychology (Psychology Board of Australia, 2011). Counselling psychologists in Australia work within clinical and community settings and are involved in the assessment, formulation, diagnosis, and treatment (counselling and psychotherapy) of a wide range of mental health issues (Australian Psychology Accreditation Council, 2017). Stemming from early identification as experts in vocation, education, and personal adjustment (Whiteley, 1984), counselling psychologists continue to offer specialty in problems that arise from adverse life events, such as death and bereavement (Di Mattia & Grant, 2016). The Psychology Board of Australia (2011) names grief and loss as a key competency area for counselling psychologists and in a recent profile of the profession in Australia, 95% of practitioners reported working regularly with this presentation (Di Mattia & Davis-McCabe, 2017).

Despite its prevalence in counselling psychology practice, a review of the *Journal of Counseling Psychology*, *The Counseling Psychologist*, and *Counselling Psychology Quarterly* over the last two decades revealed only 24 articles specifically relating to grief following bereavement. The dearth of thanatological research in counselling psychology journals has been recognised previously (Servaty-Seib & Taub, 2010), and may be due in part to "the illusory perception that bereavement therapy is a relatively simple affair that involves some form of active listening, straightforward normalisation of the client's responses, and the delivery of some generic psycho-education on bereavement stages" (MacKinnon et al., 2013, p. 217). Empirical evidence suggests that this view is little more than an illusion and recognition is overdue for the way in which the theoretical and practical orientations of counselling psychologists complement contemporary theories of grief (Servaty-Seib & Taub,

2010). The following provides a summary of the ways in which the core values of counselling psychology, in terms of how both people and their mental health issues are viewed, may contribute to, and be informed by, thanatological research.

Grief-related distress is not currently formally recognised in DSM-5 or ICD-11 nosology and evidence suggests that the majority of bereaved persons are not at risk of severe psychopathology (Aoun et al., 2015; Kersting et al., 2011). Strengths, therefore, exist in the potential of counselling psychologists to work outside disease models and support grieving individuals through natural processes of grief and mourning, through conceptualising grief as one of the "quintessential problems of living" (Servaty-Seib & Taub, 2010, p. 949). Working across individuals, couples, families, and groups, counselling psychologists also recognise that humans are essentially social and relational beings (Meteyard & O'Hara, 2016). Counselling psychology advocates a strengths-based approach to therapy that is underpinned by a strong emphasis on the therapeutic alliance (Psychology Board of Australia, 2011). The profession's focus on human connection and attachment as the primary agent of change is highly congruent with contemporary perspectives on grief, which recognise the complexity of human relationships with the living and deceased (Neimeyer & Hogan, 2001), and the substantial role of supportive alliances in coping following loss (L. A. Burke & Neimeyer, 2013). Similarly, counselling psychologists place considerable emphasis on person-environment interactions and sociocultural contexts, recognising systemic barriers that may affect individual experiences (Goodyear et al., 2016). From a counselling psychology perspective, grief and loss are, therefore, regarded as social phenomena largely embedded within interpersonal dynamics. Individuals are viewed as contributors to and products of their environment and the unique values, perspectives, and meanings people bring to their loss experiences (and that of those around them) are recognised as fundamental elements of mental health and wellbeing. Finally, counselling psychologists are strong advocates for individuals who typically hold less power in society (Romano & Hage, 2000) and, therefore, have a substantial role in working with grieving persons who have historically been marginalised, with their stories silenced (Harris, 2009-2010). Evidently, counselling psychologists not only have a role in promoting resilience and coping in individuals who have experienced loss, but also in harnessing the natural strengths of support networks to assist bereaved people when specialised grief intervention is not required or indicates gaps.

1.5   The Researcher

Whether quantitative, qualitative, or mixed methods, research is a social process subject to cultural and value biases that do not permit complete separation between the researcher and

the research (Williams, Woodby, Bailey, & Burgio, 2008). In the words of Yalom (2009), "the observer influences what is observed" (p. 284). This research adopted the stance of Buckle et al. (2010), who argue "there is no neutrality in any research endeavour, there is only variation in the extent to which researchers recognise and document their subjectivity and bias" (p. 120). The importance of elucidating the relationship between the researcher and the research is apparent in bereavement enquiry, where not even the most experienced researcher or practitioner can claim to be protected from, or impervious to, the experience of loss (Silverman, 2000). One of the most prominent international thanatological organisations, the Association for Death Education and Counseling (ADEC), hosts annual panel discussions titled 'Our Work, Ourselves,' enabling prominent researchers and practitioners in the field to reflect publically on the ways in which their own losses have influenced and shaped their professional work. These efforts by ADEC and others recognise that, akin to good psychotherapy, in research it is equally important that one "must know and understand the self first before entering into the lifeworld of another" (Ray, 1990, p. 175). The following section gives a rationale for how I positioned myself within the research, what efforts I engaged in to differentiate myself as a researcher from myself as a practitioner, and what personally motivated me to choose grief and loss as my overarching topic of investigation. It is important to note that much of this rationale pertains to the qualitative component of this research (Phase Three/Chapter Six) which inherently requires greater reflective practice and bracketing than the more objective first two phases of the research.

Theoretical orientation aside, arguably one of the biggest questions facing qualitative researchers is whether they will position themselves as insiders or outsiders of a field of research study (Adler & Adler, 1987). Typically, researchers are considered insiders if they hold some sense of belonging (through role, characteristics, or experience) to the group under study (Merton, 1972). Insider researchers benefit through increased insight into and empathy for the problem under investigation and more rapid acceptance by their participants, enhancing the richness of data collected (Dwyer & Buckle, 2009; Gair, 2012; Rabe, 2003). However, key challenges of this position include the potential for personal experiences, values, and reflections to impose on or conflate those belonging to the study participants, limitations in data due to assumptions of similarity (and therefore, understanding), and risks in role confusion if a researcher slips into the role of peer/co-participant (Dwyer & Buckle, 2009; Kanuha, 2000). In contrast, researchers are considered outsiders if they do not consider themselves as belonging to the group under study (Merton, 1972). Such a position guards against over-identification with study participants, offers opportunities to ask questions not permitted of insiders (due to shared societal norms), and may permit the viewing of processes and patterns from a vantage point and with a curiosity not afforded by those who are too

embedded in the experience (Dwyer & Buckle, 2009; Gair, 2012; Rabe, 2003). However, limitations of this position include failing to attend to the subtle nuances of a phenomenon and not achieving the same degree of participant trust and openness necessary for exploration of sensitive topics (Dwyer & Buckle, 2009; Rabe, 2003).

Although I do not consider this project to be insider research by its true definition, studying in this field has led me to believe that bereavement is too universal an occurrence for anyone to be truly labelled an 'outsider' of the experience. Irrespective of personal grief experience, bereavement research poses unique challenges associated with empathically and receptively enquiring about experiences of human suffering, whilst simultaneously impartially and objectively collecting data to answer pre-determined research questions (Williams et al., 2008). Such a balance does not appear honoured by traditional notions of insider or outsider research. For this reason, I have adopted the 'researcher in the middle' position proposed by Breen (2007), capitalising on the advantages of being able to personally appreciate and honour the idiosyncratic nature of the grief experience, while still maintaining sufficient distance to observe and confirm patterns in the data. This approach views inside/outside as a continuum, rather than a dichotomy, and does not equate membership with sameness or non-membership with difference (Dwyer & Buckle, 2009); a seemingly fitting match with the experience of bereavement, to which no two people respond the same.

This section also warrants brief mention of separation of the role of PhD Candidate (researcher) from the role of provisional psychologist (practitioner). Several authors have noted similarities between the research interview and the initial counselling interview (Birch & Miller, 2000; Coy, 2006). As outlined in Chapter Three, participation in bereavement research is associated with a range of therapeutic benefits and is regarded by many as a unique opportunity to share and reconstruct narratives around attachment and loss (Buckle et al., 2010). While honouring the potential of this research to have such an impact, it was equally important for me to establish boundaries around the researcher-participant relationship to clarify my position, not only as a potential fellow experiencer of grief, but also as a practitioner working with clients experiencing grief and loss. Firstly, this research rejected the notion of the researcher as the 'expert' and the respondent as the 'object' of study. Instead, I chose to convey a more level stance, positioning my respondents as 'knowers' and myself as the 'enquirer' of the phenomenon under enquiry; not unlike the standpoint taken by many contemporary psychologists (Buckle et al., 2010). Secondly, I spent considerable time explaining the research, ensuring respondents understood my role within the research and were aware of pathways to community support or counselling/therapy they could follow if they wished to continue processing their grief outside the research interview (Williams et al., 2008).

Finally, as described in detail in Chapter Three, I kept a reflexive journal before, during, and after interviews which allowed me to document all reactions to respondents—whether originating from myself as an individual, a researcher, or a practitioner—and monitor their impact on the way in which data were collected and interpreted.

I consider the manner in which I approached this field of research to be somewhat different from most. My professional journey in grief and loss began in 2011 nearing the end of an undergraduate degree in psychology. However, my personal journey started much earlier. Like the majority of young adults, I was not immune to bereavement, grief, and mourning. However, unlike many thanatological researchers, I had not experienced a loss so significant and all-consuming so as to steer the direction of this research. Instead, I sought inspiration from the context in which I was operating at the time. It was during that year and the next that mental health professionals from all over the world came together to discuss and debate revisions to one of the most significant pieces of text in global health care—the DSM-5 (American Psychiatric Association [APA], 2013). Alongside significant revisions to the formulation and diagnosis of many mental health issues, this new edition proposed the introduction of a new classification termed Persistent Complex Bereavement Disorder for grief reactions that are "out of proportion to or inconsistent with cultural, religious, or age-appropriate norms" (APA, 2013, p. 790). The concept of classifying and pathologising grief was very new to me so my first question of 'why?' was quickly followed by my second of 'but how?' Recognising that norms are primarily established, maintained, and questioned at the community level, I perceived a need to extend the disordered grief debate outside professional discourse. Through a year-long honours project I set out to explore, from a community perspective, the nature of some of these norms that might differentiate someone who was grieving 'well' from someone who was not (see Breen, Penman, Prigerson, & Hewitt, 2015; Penman, Breen, Hewitt, & Prigerson, 2014).

Although death had occurred and was continuing to occur all around me, the more immersed in this research I became, the more cognisant I became of the implicit social processes that shape and mould the grief experience. In the early days of my research, I encountered two typical responses. The first—people who enquired about my research topic and were quick to respond with diverted eye gazes, awkward silences, and rapid changes of topic—and the second—people who similarly enquired, yet instead responded by initiating courageous conversations about their own experiences of loss, disclosing stories of silencing and being silenced in their grief, and negotiating the interpersonal isolation that would follow. I observed that as much as society may wish to accept death as a natural part of life, and grief as a natural consequence of love, there appears to be monumental obstacles to doing so.

Consequently, where death represents a failure by the medical system to prolong or protect life (McConnell, Moules, McCaffrey, & Raffin Bouchal, 2012), grief represents the unfortunate and dreaded outcome that must be endured. If one cannot prevent it, one most accommodate it—but do so quickly and quietly. Recognising that a grief-related classification would likely reach full acceptance in the DSM-5 and ICD-11, I saw a need not only to uncover these grief-related norms, but also to explore their deeper influence beyond diagnostic classification. In turning to the literature, I observed that the research community was in agreement about the influential role of social support in the accommodation of loss and processing of grief; yet, scant attention had been given to what motivates the behaviours of potential supporters, nor what permits grieving persons to legitimise their own grief and actually accept and benefit from this support. So from this small project, a seed was sown to investigate what common beliefs, expectations, and assumptions are held of grievers and how these restraints influence the provision of social support and the experience of grief and mourning in contemporary Western culture.

1.6   Research Aims and Objectives

The overall purpose of this research was to explore the conceptualisation and experience of 'normal' or 'typical' grief from the perspective of bereaved persons and their network of natural supporters. Using a mixed methods research design, the aim was to examine the nature and scope of grief-related norms and their influence on the experience of grief and provision and receipt of social support following bereavement. The research objectives were to:

- Investigate societal norms for grief following bereavement by conducting a systematic review of existing literature covering beliefs, expectations, opinions, and intentions to act towards people who are bereaved;

- Address gaps in the existing literature through investigating expectations, beliefs, and intentions to support people who are bereaved, and whether these differ dependent on personal experience with grief and other key variables;

- Examine the level of community agreement with current proposals to include pathological forms of grief in diagnostic classification systems;

- Explore how people who are bereaved experience, make sense of, and negotiate these grief-related norms in the context of a significant bereavement; and

- Inform clinical practice with people who are bereaved, progress the research field, and make recommendations to contribute to best practice grief education for the general public.

1.7   Research Questions

The research was conducted across three core phases with each seeking to answer the following research questions:

Phase One: How do characteristics of the bereaved, the decedent, and the respondent impact on community responses to bereavement in terms of expectations of, beliefs about, evaluations of, and intentions to act towards bereaved people?

Phase Two: How do bereavement status, anticipation of the death, and level of social support affect expectations of grief symptomatology and intentions to provide social support to grieving persons? What effect does bereavement status have on beliefs about social support and endorsement of a grief-related diagnostic classification?

Phase Three: How do bereaved people experience societal norms, as expressed through beliefs, expectations, and assumptions, in the context of their own grief? What coping mechanisms or strategies are adopted by bereaved people to reconcile these norms with their actual experience of grief and mourning? How do bereaved people reflect on needs, both from the self and others, as integral to facilitating the grief experience?

1.8   Structure of the Thesis

This thesis is presented in the form of a hybrid, combining two published journal articles and one unpublished manuscript with four traditional typescript chapters to provide a comprehensive summary of the research undertaken. Each chapter will offer a brief introduction of its contents and an illustrative quote to personify the experiences and meanings embedded within that chapter. The thesis concludes with a master reference list and appendices relating to the preceding chapters. Where a chapter represents a published journal article, table, figure, and heading numbers have been modified to adhere to the overall formatting and flow of the thesis.

Chapter Two presents the background to the research through a literature review of published thanatological studies. The review considers the psychosocial impact of bereavement and key risk and protective factors for complications of grief. This chapter also provides a historical account of grief through a summary of theories and frameworks over the last 100 years, situates grief within current diagnostic nosology, and describes the efficacy of grief interventions in addition to barriers to help-seeking. Finally, the dominant discourse of grief is reviewed, describing the influence of social norms on expressions of grief and experiences of social support. The chapter concludes with a discussion of a community model of bereavement care and presents a rationale for the present research.

Chapter Three focuses on the overarching research methodology, providing reasoning and context for embedding a sequential explanatory mixed methods design within a pragmatist philosophy. A brief summary of each of the three phases of study is offered, with highlights of how each phase informs the next and contributes to the global research aim. This chapter concludes with a review of ethical considerations particular to research with bereaved and vulnerable populations.

Chapter Four is a published journal article that details the systematic review of literature undertaken to explore bereaved, decedent, and respondent-related determinants of social support following bereavement (Logan, Thornton, & Breen, 2017). This chapter offers a comprehensive summary of the significance of Phase One of the study, the methods employed to conduct the review, key findings, and directions for further research. The review highlights key strengths and limitations evident in this body of research and presents a call to the field for more rigorous study of social support determinants to inform work with bereaved persons and their natural support networks.

Chapter Five is a published journal article that outlines the quantitative study (Phase Two) designed to cross-sectionally examine how bereavement status, anticipation of death, level of social support, and other respondent characteristics are associated with grief-related beliefs, expectations, and support intentions in a sample of the general public (Logan, Thornton, Kane, & Breen, 2017). This chapter presents the rationale for this study (as informed by Phase One), describes the sample and method of data collection, summarises quantitative and qualitative findings from the survey, and reviews the practical and theoretical implications of the results. Recognising that the majority of grief support occurs at the community level, this study offers valuable insight into the preparedness, capacity, and willingness of the general public to provide timely and appropriate social support in the wake of bereavement.

Chapter Six is an unpublished manuscript that describes the qualitative study (Phase Three) designed to explore the influence of grief norms on experiences of loss, coping, and social support in a sample of adults significantly impacted by bereavement. This chapter is presented in the format of a manuscript to facilitate submission to a journal following submission of the thesis. This chapter outlines the rationale for this study (as informed by Phases One and Two), introduces the chosen sample and method of data collection, presents key themes and subthemes derived from the data, and makes recommendations for future research and clinical practice with bereaved populations. This study illustrates the unique challenges facing bereaved individuals and describes their efforts to reconcile their own normative beliefs and expectations of grief, and that of those around them, with their actual experience of grief.

Finally, Chapter Seven concludes the thesis with a comprehensive general discussion synthesising all elements of the research. This chapter summarises key findings of each study, integrates findings to review contributions to empirical research and bereavement practice, and offers recommendations to facilitate better formal and informal support of people who are bereaved. The chapter concludes with a discussion of key strengths and limitations and presents final conclusions.

Chapter 2   Literature Review

"There is no grief like the grief that does not speak."

Henry Wadsworth Longfellow: 1807-1882

2.1   Chapter Overview

The purpose of this chapter is to present the background to this research by providing a comprehensive overview of the literature on bereavement, grief, and mourning. This review of the literature covers four broad sections. The first offers a conceptual understanding of grief, highlighting the psychosocial impact of bereavement on individuals, families, and communities and summarising key risk and protective factors for complications of grief. The next section outlines dominant theories of grief from 1917 to the present, considers the placement of grief in diagnostic nosology, and describes formal support needs of bereaved individuals and their receptivity to receiving grief-related support. The third section introduces the notion of grief as an intersubjective and social experience, outlining the dominant discourse of grief, how it has originated, and its implications on the expression of grief and the provision and receipt of social support. Finally, the fourth section considers a model of community bereavement support, presenting key strengths and limitations in death and grief education and the potential of an innovative framework to enhance the informal support of people who are bereaved. The chapter concludes with the rationale for the present study, summarising limitations of past research and the significance of the proposed study.

2.2   A Conceptual Understanding of the Multiple Dimensions of Loss

Bereavement is widely regarded as one of life's greatest stressors, having wide-reaching effects across emotional, cognitive, behavioural, physical, spiritual/existential, financial, and social domains (Love, 2007). Grief and mourning are both healthy and adaptive reactions to the loss of a close attachment (Shear, Simon, et al., 2011); as portrayed by Parkes (2011), "grief, it seems, is the price we pay for love" (p. 36). Despite its universality, grief is recognised as one of the most highly individualised human phenomena, with no two people grieving or mourning the same (Allan & Harms, 2010). As such, grief may involve the expression of intense feelings of sadness, fear, anger, shame, jealously, or relief, disbelief that the death has occurred (sometimes labelled 'denial'), helplessness and hopelessness, intrusive

thoughts and/or feelings, avoidance of reminders of the death, hallucinatory-like experiences (including seeing or having conversations with the deceased), sleep and appetite disturbance, and other somatic experiences (Granek, 2016). Equally impactful secondary losses associated with bereavement may include housing rearrangements (Nihtilä & Martikainen, 2008), financial instability (Biro, 2013), changes to roles and responsibilities (Barlé, Wortman, & Latack, 2017; Dent & Stewart, 2004), familial conflict and relationship breakdown (Albuquerque, Pereira, & Narciso, 2016; Barlé et al., 2017), and social stigma and isolation (Breen & O'Connor, 2011; Dyregrov, 2005-2006). Although grief is often most intense in the first year, many bereaved individuals report the continual or intermittent experiencing of these symptoms for years or even decades following the loss (Carnelley, Wortman, Bolger, & Burke, 2006).

As highlighted in Chapter One, a minority of bereaved individuals will experience a prolonged and complicated grief reaction associated with considerable impairment to daily function, rarely diminishing without therapeutic intervention (Aoun et al., 2015; Kersting et al., 2011). Such complications of grief have been found to be associated with an increased risk of suicidality, substance use, self-neglect (nutrition and personal care), poorer quality of life, and comorbid depressive, anxiety, and adjustment disorders (Ajdacic-Gross et al., 2008; J. Y. Allen et al., 2013; Boelen & Prigerson, 2007; Latham & Prigerson, 2004; D. Lund, Caserta, Utz, & De Vries, 2010; Pilling, Konkolÿ Thege, Demetrovics, & Kopp, 2012; Prigerson, Vanderwerker, & Maciejewski, 2008). These individuals are also at higher risk of a range of adverse physical health outcomes including insomnia, overproduction of cortisol, high blood pressure, cardiovascular problems, and cancer (M. S. Stroebe et al., 2007).

2.2.1   Risk and protective factors

The question of how to protect bereaved individuals from developing grief complications has long been contested in bereavement research. Research has identified an extensive list of factors prior to (e.g., attachment style), associated with (e.g., anticipation of the death), and following the death (e.g., perceived social support) as key predictors of psychosocial outcomes following bereavement (L. A. Burke & Neimeyer, 2013; Lobb et al., 2010). It is important to note that the research summarised throughout this section is limited by its predominate focus on cancer/palliative care settings (where some type of formal support might be assumed), limited diversity in cultural contexts, low diversity samples (e.g., by gender and age), differences in outcome measures for complicated or prolonged grief, and failure to explore interactive effects of predictors. Though not exhaustive, this summary does highlight the idiosyncratic nature and complexity of individual grieving experiences.

2.2.1.1   Factors prior to or fixed at death

Personal factors prior to the death, including attachment, psychological comorbidity, gender, and caregiving role, have received the most attention in bereavement literature, yet are least amenable to change in therapy (L. A. Burke & Neimeyer, 2013). Attachment theorists posit that an individual's attachment style (including internal working models) and attachment relationship with the deceased person (prior to death) are highly predictive of psychosocial outcomes following bereavement, with grief representing a form of separation distress (Parkes, 2011). An individual's attachment system is activated by perceived psychological threat and serves to re-establish proximity to the attachment figure, always assuming a separation to be temporary and reversible (Field & Filanosky, 2010). According to Bowlby (1980), integration of loss, therefore, entails an individual accepting "both that a change has occurred in his external world and that he is required to make corresponding changes in his internal, representational world and to reorganize, and perhaps reorient, his attachment behaviour accordingly" (p. 18). As expected, secure attachment has been found to correlate with more positive adjustment to bereavement (Fraley & Bonanno, 2004; Shaver & Tancredy, 2001). Although initially distressed by repeated frustrated attempts at reunification, an individual with a secure attachment style will eventually revise their working model of the relationship to represent an internal, rather than external attachment (Bowlby, 1980). In contrast, insecure attachment styles (anxious, avoidant, or disorganised) are associated with complications of grief (Field & Filanosky, 2010; Mikulincer & Shaver, 2008; van der Houwen, Stroebe, Stroebe, et al., 2010; Vanderwerker, Jacobs, Parkes, & Prigerson, 2006; Wijngaards-de Meij et al., 2007). These individuals are more likely to demonstrate ongoing oscillation between avoidance of reminders of the loss and excessive rumination about the deceased, with the death representing a form of intolerable abandonment that cannot be reconciled with the individual's rigid internal working model of the relationship (Parkes, 2011).

Many studies have also explored the impact of caregiving at the end-of-life on bereavement outcomes (Breen, 2012). In a study of 127 bereaved former cancer caregivers, Abbott, Prigerson, and Maciejewski (2014) found that perceptions of lower quality of life in cancer patients (by their carers) at end-of-life was associated with higher rates of suicidal ideation in the initial months following the death. Additionally grief complications are predicted by greater dependency in the caregiving relationship, caring for a spouse, and a more intensive caregiving role (Thomas, Hudson, Trauer, Remedios, & Clarke, 2014). Caregiving factors associated with better bereavement outcomes include having a do-not-resuscitate order and perception of a better quality death (Garrido & Prigerson, 2014).

Research on gender has produced mixed findings, with some studies finding women to be more susceptible to grief complications (Chiu et al., 2010; Keesee, Currier, & Neimeyer, 2008; Kersting et al., 2011), whilst other studies have suggested that gender is not predictive (J. Y. Allen et al., 2013; L. A. Burke, Neimeyer, Bottomley, & Smigelsky, 2017). Empirically-supported theories suggest that gender in itself may not have a direct association with bereavement outcomes, but rather may mediate risk for complications of grief through preferred grieving styles and practices, which may be associated with, but not tied to gender (Doka & Martin, 2010). Supporting this argument, research has identified that women are more likely than men to confront and express their grief (M. S. Stroebe, 2001) and it is these symptoms that are more often the focus of measurement instruments (Doka & Martin, 2010).

Other important factors associated with complications of grief include experiences of early trauma or childhood adversity (Vanderwerker et al., 2006), psychological comorbidities such as depression and anxiety (J. Y. Allen et al., 2013; Bruinsma, Tiemeier, Verkroost-van Heemst, van der Heide, & Rietjens, 2015), neurotic personality structure (Boogar & Talepasand, 2015; van der Houwen, Stroebe, Stroebe, et al., 2010), avoidant coping style (Smith, Tarakeshwar, Hansen, Kochman, & Sikkema, 2009), and a lack of religion or spirituality (Brown, Nesse, House, & Utz, 2004; Chiu et al., 2010).

2.2.1.2 Factors associated with death

Circumstances of the death have received considerable attention in the literature, with factors such as anticipation of death and cause of death identified as influencing bereavement outcomes. The expression of grief may be intensified when a death is unexpected, often even more so when the death is also perceived as non-normative (untimely), for example, occurring in childhood or early adulthood (J. Y. Allen et al., 2013). Studies have found associations between unexpected deaths and major depressive disorder (Barry, 2002; Burton, Haley, & Small, 2006) and complications of grief (Barry, 2002; Fujisawa et al., 2010). However, as recognised by Zisook and Shuchter (1985), it is the meaning the individual attributes to the death, and not the timing of death per se, that has the potential to complicate the grieving process. Thus a sudden death may incite more distress related to the guilt of not being present at the time of death or having the opportunity to say goodbye, than distress relating to the premature ending of a life.

Violent or traumatic losses, for example through suicide, homicide, or accident, may also complicate the grieving process (Barlé et al., 2017). Studies have revealed an association between violent deaths and major depressive disorder (Barry, 2002) as well as complications of grief (L. A. Burke & Neimeyer, 2014; Field & Filanosky, 2010; Keesee et al., 2008). This

impact may be further intensified if the bereaved person discovers or witnesses the body after death (Feigelman, Gorman, & Jordan, 2009). However, Currier, Holland, and Neimeyer (2006) found the relationship between traumatic death and grief complications to be mediated by greater inability to make sense of the loss, indicating that similar to expectation of death, it is more about the meaning attributed to the death than the cause. Such losses challenge the bereaved person's assumptive world, calling into question fundamental beliefs about themselves, other people, and the justice and safety of the world in which they live (Neimeyer, 2006a). Deaths that are more incongruent with an individual's assumptive world often contribute to greater difficulty accepting or finding meaning in the death, inducing patterns of rumination relating to the fear of guilt and suffering (Barlé et al., 2017).

2.2.1.3 Factors following death

In the weeks, months, and years following a death, concurrent stressors, such as financial burden, relationships and parenting difficulties, and work strain, may increase the likelihood of grief complications (Ott, 2003; M. S. Stroebe et al., 2007; Worden, 2009). Other research has identified that meaning reconstruction—comprising sense making, benefit finding, and identity reconstruction—may mediate grief reactions through informing the bereaved person's subjective interpretation of the death which, in turn, enables or inhibits the assimilation of the loss into his or her life narrative (Currier et al., 2006; Holland, Currier, & Neimeyer, 2006; Keesee et al., 2008). Contributing to meaning reconstruction, engagement in funeral and mourning rituals (e.g., candle ceremonies and story circles) have also been recognised as protective against complications of grief, offering opportunities to internalise the relationship with the deceased and re-narrate the life and death stories (Cacciatore & Flint, 2011; Neimeyer, 2006b; Vale-Taylor, 2009). In individuals experiencing a more intense grief reaction, the timely introduction of psychotherapeutic interventions, delivered by trained psychologists, psychiatrists, or counsellors, may also buffer against ongoing grief complications (Currier, Neimeyer, & Berman, 2008).

Above all others, social support has received the most widespread attention for moderating or mediating the grief trajectory *after* the death has occurred (Bath, 2009). Following bereavement, an abundance of research has found an association between poor social support and posttraumatic stress disorder (PTSD; Bottomley, Burke, & Neimeyer, 2017), depressive and anxiety symptoms (Bottomley et al., 2017; Spino, Kameg, Cline, Terhorst, & Mitchell, 2016; van der Houwen, Stroebe, Stroebe, et al., 2010), and grief complications (J. Y. Allen et al., 2013; L. A. Burke et al., 2017; Chiu et al., 2010). This effect may be further pronounced if the deceased person formed an integral part of the bereaved person's primary support network (Barlé et al., 2017). However, a meta-analysis was unable

to identify the specific mechanism through which social support may serve as a risk or protective factor for complications of grief (Stroebe, Zech, Stroebe, & Abakoumkin, 2005). It is, therefore, likely that protective effects of social support are more complex than initially assumed and may even be mediated by previously uncontrolled for factors such as emotional loneliness (W. Stroebe, 2008), the bereavement experience of the supporter (Benkel, Wijk, & Molander, 2009a, 2009b), the level of congruence between support expected/required and support received (Ha & Ingersoll-Dayton, 2011), and perceptions of the actual helpfulness of the support received (Wågø, Byrkjedal, Sinnes, Hystad, & Dyregrov, 2017).

2.3 Dominant Theories of Grief

2.3.1 Stage, phase, and task-based models

Freud (1917/2005) was the first theorist to classify pathological grief, proposing that a minority of people will experience a prolonged, intense period of mourning clearly distinguishable from 'typical' grief or melancholia (clinical depression). From this psychoanalytic perspective, healthy grief was seen to require a detachment or 'decathexis' from a love object (the deceased person), with pathological symptoms arising out of resistance by the ego to complete the 'mourning work' and free itself from the lost object. However, Freud did not perceive a role in this process for health professionals, proposing that grief would always resolve within a reasonable timeframe, with intervention perceived as "pointless, or even damaging" (p. 204). In support of Freud's theory, Lindemann (1944) studied 101 bereaved individuals and concluded that the bereaved individual is responsible for 'working through' grief by successfully detaching from the deceased, readjusting to life without the person present, and engaging in new relationships. From these observations, Lindemann theorised that grief typically concludes in as little as four to six weeks, once again enforcing an arbitrary distinction between normal (acute, time-limited) and abnormal (delayed, exaggerated, or absent) grief.

The first stepped model of grief was proposed by Bowlby (1961) who theorised four overlapping phases of grief that required negotiation before resolution could occur: shock/numbness, yearning/searching for the deceased, despair/disorganisation, and reorganisation/recovery. Working closely with Bowlby, Parkes (1964, 1972a, 1972b) outlined seven phases, comprising initial denial and avoidance, subsequent alarm reactions, searching for the deceased, anger and guilt, feelings of internal loss, adopting traits/mannerisms of the deceased, and acceptance/resolution. Thought to originate from these models, Kübler-Ross (1969) developed one of the most highly cited models of grief comprising five sequential stages: denial, anger, bargaining, depression, and acceptance. Although initially devised based

on the experiences of over 200 terminally ill patients, Kübler-Ross and Kessler (2005) and others later assumed these stages of dying to be equally reflective of the experiences of the bereaved person, translating the model from 'on death and dying' to 'on grief and grieving,' without empirical evidence to support such generalisation. Worden (1982, 1991, 2002, 2009) introduced an explicitly active element to existing theories through shifting from the language of 'phases/stages' to 'tasks,' proposing that bereaved individuals must work through: accepting the reality of the loss, processing the pain of grief, adjusting to a world without the deceased, and withdrawing from the deceased to reinvest in other relationships (later changed to finding an enduring connection with the deceased whilst reengaging with life). Similarly, Rando (1993) proposed six tasks through which the bereaved must pass: recognition of the loss, emotional reaction to the separation, recollection of memories, relinquishing of past attachments to the deceased, readjustment of the loss into life, and reinvestment in relationships. Subsequent theorists built on these models to further conceptualise grief as a conscious working through of predicted stages, phases, or tasks resulting in successful resolution of loss (Horowitz, 1990; Horowitz, Bonanno, & Holen, 1993; Zisook, 1987; Zisook & Shuchter, 1985).

Although these early theories differ somewhat in formulation, they are all underpinned by the grief work/mourning work hypothesis which assumes psychopathology when an individual becomes stuck and does not 'break bonds' with the deceased or 'resolve' their grief (Freud, 1917/2005; Lindemann, 1944). However, there has been little consensus on whether bereaved individuals require weeks (Lindemann, 1944), months (Engel, 1961), or even years (Glick, Weiss, & Parkes, 1974) to complete grief work. The potential to 'work through' grief via successive stages has only been supported by one study, although there was considerable overlap between stages (Maciejewski, Zhang, Block, & Prigerson, 2007), with others refuting the applicability of the model (Holland & Neimeyer, 2010). Despite a lack of empirical evidence, these stages/phases/tasks have become more of a prescription than a conceptual guide for understanding grief (Wortman & Boerner, 2007). Although these theories offer the potential to simplify an otherwise complex phenomenon, they have been heavily criticised for their failure to capture the diversity of grief or take into account any of the aforementioned risk or protective factors for grief (C. Hall, 2014).

2.3.2   Continuing bonds, meaning-making, and dynamic process models

Shifting away from the assumption that relinquishing the affective bond with the deceased is necessary for accommodation of loss, Klass, Silverman, and Nickman (1996) proposed the concept of Continuing Bonds, arguing that many bereaved individuals sustain an internalised

attachment relationship with the deceased person which is not necessarily indicative of psychopathology or failure to complete 'grief work.' This concept adopts Bowlby's (1980) hypothesis of reorganisation and reorientation of attachment, rather than complete detachment. Bereaved individuals are assumed to be able to reconnect with life while still creating places of memorialisation, retaining personal possessions, and developing routines and rituals that honour the deceased person (Klass, 2006). Although there is some empirical support for the positive impact of continuing bonds on adjustment (Boelen, Stroebe, Schut, & Zijerveld, 2006; Malkinson, Rubin, & Witztum, 2006; Packman, Horsley, Davies, & Kramer, 2006), other research has found that certain types of continuing bonds (e.g., having visions of the deceased) may actually predict more intense grief symptomatology (Field, 2008; Field & Filanosky, 2010; Schut, Stroebe, Boelen, & Zijerveld, 2006). These conflicting findings are likely explained by Klass's (2006) assertion that the original concept never implied causality, but rather suggested that the impact of continuing or relinquishing bonds is dependent on the nature and integration of the bond, not its simple presence or absence.

Neimeyer (2000) added further depth to existing models with his theory of Meaning Reconstruction which seeks to explain the processes or drivers underpinning the outward emotions, cognitions, and behaviours typically recognised as grief. This theory posits that bereaved individuals integrate their losses through processes of sense making (explanations derived to comprehend the death), benefit finding (elements of the loss that can be identified as giving worth or adding value to life), and identity reconstruction (actions to reconceptualise one's sense of self following the death; Neimeyer, 2000). Meaning making may occur at practical ("*How* did my loved one die?"), relational ("*Who* am I, now that I am no longer a spouse?"), and/or spiritual/existential ("*Why* did God allow this to happen?") levels (Neimeyer & Sands, 2011, p. 11). Although there is some support for this theory and its attention to how individuals integrate losses into their self-narratives (MacKinnon et al., 2015; Neimeyer, Burke, Mackay, & van Dyke Stringer, 2010), the potential for sense making may be more pertinent than benefit finding following sudden, untimely, traumatic, or at-fault deaths (Neimeyer et al., 2010).

Recognising the idiosyncratic nature of grief, the Two-Track Model of Bereavement (Rubin, 1981) conceptualises grief as an approach-avoidance pattern of oscillating between contrasting aspects of the loss, each of which offer some relief from the other. The Two-Track Model proposes that bereaved persons shift between 10 domains reflecting biopsychosocial functioning (Track I: anxiety, depressive affect and cognitions, somatic concerns, symptoms of a psychiatric nature, familial relationships, general interpersonal relationships, self-esteem and self-worth, meaning structure, work, and investment in life tasks) and 10 domains

reflecting adaptation to the lost attachment relationship (Track II: imagery and memory, emotional distance, positive affect, negative affect, preoccupation with loss and the lost, idealisation, conflict, features of the loss process, impact upon self-perception, and memorialisation and transformation of the loss and the deceased). Strengths of this model include its recognition of individual challenges *and* strengths (Rubin, Malkinson, & Witztum, 2012) and its suitability for integration into already established cognitive behavioural and psychodynamic-existential treatment orientations (Malkinson et al., 2006). However, further empirical research is needed to determine the utility of its measurement in larger samples and across different cultural groups (Rubin et al., 2009).

Similar in approach to the Two-Track Model, but also informed by cognitive stress theory (Lazarus & Folkman, 1984), M. S. Stroebe and Schut's (1999) Dual Process Model of Coping with Bereavement proposes that bereaved individuals shift in a confrontation and avoidance pattern between loss-oriented processes (e.g., yearning for the deceased) and restoration-oriented processes (e.g., engaging in new roles). An assumption of this theory is that oscillation between both orientations is required for healthy grief to occur, thus grief complications may occur when there is a fixation on one of the two orientations (Caserta & Lund, 2007). Although the Dual Process Model has a more narrow empirical research base than other models such as Continuing Bonds and Meaning Reconstruction, it is currently the most accepted theory across both bereavement research and practice (Bennett, Gibbons, & MacKenzie-Smith, 2010; D. Lund et al., 2010; M. S. Stroebe & Schut, 2010).

Evidently, theories of grief have evolved to recognise the heterogeneity of loss experiences and the idiosyncratic nature of grief reactions (C. Hall, 2014). Rejecting universal assumptions and stage-based predictions, these contemporary theories are based on the notion that individuals may cycle back-and-forth through various cognitive, emotional, behavioural, and spiritual dimensions of grief, in no particular order and across no particular period of time. Such contemporary formulations of grief are descriptive rather than prescriptive, honour the considerable impact of anniversary reactions, and reject the notion that absent, delayed, and even anticipatory grief are synonymous with deviance or psychopathology.

2.4   Grief in Diagnostic Nosology

Underpinned by over 100 years of bereavement theory and research, the current argument in the grief literature is whether 'pathological' responses to bereavement can be differentiated from what is considered a 'normal' or 'typical' grief reaction (Granek, 2016). Since Freud's (1917/2005) initial depiction of 'pathological' grief, others have proposed a multitude of labels to describe deviations of grief including chronic, morbid, maladaptive, atypical, dysfunctional,

traumatic, absent, inhibited, delayed, distorted, abnormal, neurotic, intensified, unresolved, complicated, and prolonged (for a review, see M. S. Stroebe et al., 2000). However, for many years grief remained excluded from diagnostic nosology. The DSM-III-R (APA, 1987) was the first to include mention of 'uncomplicated bereavement,' yet every edition since has used the example of bereavement as the exclusion for diagnosis: "an expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder" (APA, 2013, p. 20). However, empirical research has recognised the need to differentiate individuals at higher risk for grief complications (Aoun et al., 2015; Bonanno, 2004; Bonanno et al., 2002), consistently showing the symptoms to be distinct from both depressive and anxiety disorders (Boelen, van de Schoot, ven den Hout, de Keijser, & Van den Bout, 2010; Bonanno et al., 2007; Prigerson et al., 2008; Shear, Simon, et al., 2011).

2.4.1 Complicated grief and prolonged grief disorder

Two prominent research teams have spent several years refining proposals to classify grief in diagnostic nosology as either Complicated Grief (CG; Shear, Simon, et al., 2011) or Prolonged Grief Disorder (PGD; Prigerson et al., 2009). Both conditions are associated with a similar range of cognitive, emotional, and behavioural responses to the loss, but differ in the combination of symptoms and the period of time required to meet a diagnostic threshold. Table 2.1 offers a summary of key similarities and differences between the two proposed criteria.

Table 2.1

Proposed Diagnostic Criteria for Complicated Grief (CG) and Prolonged Grief Disorder (PGD)

Criterion	CG (Shear, Simon, et al., 2011)	PGD (Prigerson et al., 2009)
Event	Death of a loved one	Death of a significant other
Time since death	At least 6 months	At least 6 months
Duration of symptoms	At least 1 month	Occurring daily or to a disabling degree
Cognitive, emotional, and behavioural symptoms	Yearning or longing Emptiness, or meaningless Suicidal ideation Preoccupying thoughts of the deceased	Separation distress (yearning) Role confusion Difficulty accepting the loss Avoidance of reminders Inability to trust others

	Rumination about the death	Bitterness or anger
	Disbelief	Difficulty moving on
	Shock or numbness	Numbness
	Anger or bitterness	Emptiness or meaningless
	Difficulty trusting others	Shock
	Somatisation or hallucinations	
	Emotional/physiological reactivity	
	Avoidance or proximity-seeking	
Impairment	Must cause clinically significant distress and impairment to social, occupational, or other functioning	Must cause clinically significant impairment to social, occupational, or other functioning

Note. PGD also specifies that the symptoms not be better accounted for by another depressive or anxiety disorder.

Research has found an ICD-11 specific variant of PGD to have greater predictive validity and diagnostic specificity for disordered grief than CG (Maciejewski, Maercker, Boelen, & Prigerson, 2016). However, key criticisms of both conditions is their disregard for the impact of anniversary reactions (which may intensify grief symptomatology around the 12 month mark), failure to take into account alternate forms of grief, including traumatic or delayed grief, and focus only on grief resulting from death (Rando et al., 2012). Further, it is recognised that any diagnosis must take into account the individual's personal, social, and cultural contexts (Allan & Harms, 2010), not readily appreciated by the models of classification thus far proposed.

2.4.2   DSM-5 and ICD-11 classifications

Upon release of the DSM-5, aspects of these two classifications were combined into one condition, termed Persistent Complex Bereavement Disorder, and included in the section of Conditions for Further Study (APA, 2013). This classification recommends diagnosis for children after 6 months and adults after 12 months when there is persistent yearning, intense emotional expression, and preoccupation with the deceased and the manner in which they died. The person must also exhibit at least six indicators of pathological grief causing significant distress and impairment to everyday functioning. The DSM-5 differentiates Persistent Complex Bereavement Disorder from depressive disorders, noting key differences in affect, pervasiveness of dysphoria, thought content, self-esteem, and suicidal ideation which, in grief, all centre on the loss itself (APA, 2013). PGD is also confirmed for inclusion as a stress-related

disorder in the forthcoming revision of the ICD-11 (Maercker et al., 2013), with specific classification criteria still under development (World Health Organization [WHO], 2017). The final criterion for Persistent Complex Bereavement Disorder specifies that the expression of grief must transcend "cultural, religious, or age-appropriate norms" (APA, 2013, p. 790); however, to date, there has been far greater focus on the legitimacy of a grief-related diagnosis, than on societal definitions of 'normal' versus 'abnormal' grief.

2.4.3   Why pathologise?

Despite mounting empirical evidence establishing the existence of complicated and prolonged grief, its inclusion in diagnostic nosology remains highly controversial. The most commonly cited concerns include risks associated with overdiagnosis and overtreatment (particularly through pharmacology), the invitation to pharmaceutical companies to expand their market, the potential for mental illness-related stigma, and the loss or invalidation of traditional mourning practices (Granek, 2014; Iglewicz, Seay, Vigeant, Jouhal, & Zisook, 2013; Thieleman & Cacciatore, 2013). However, many have argued that the risk to individuals and the community of not recognising complications of grief are much greater, and a diagnosis may even be associated with a range of benefits (Shear, Simon, et al., 2011). First, M. S. Stroebe et al. (2000) highlight that access to counselling and therapy may be limited without the existence of a diagnostic category for grief complications. This is certainly conceivable in Australia where individuals must be assessed for a mental health disorder by a general practitioner to obtain funding under the Medicare Better Access Scheme (Australian Government Department of Health, 2012). Without a widely accepted diagnostic classification, these individuals may not be eligible for financially-supported psychological treatment, or instead may be improperly diagnosed with a depressive, anxiety, or adjustment-related disorder for the purposes of treatment. Second, traditional interventions for grief have been based on pharmacology and psychology for depression or PTSD, resulting in ill-informed treatments that have the potential to cause greater harm than good (Shear, Simon, et al., 2011). With established classifications for grief in diagnostic nosology, there is much greater impetus to continue developing empirically-supported interventions that focus on the nuances of grief that are distinct from other mental disorders (Bandini, 2015). Finally, some have argued for the potential of a grief-related diagnosis to legitimise the experiences of individuals for whom grief does not progress in a typical or expected manner (Harris, 2009-2010). Studies of bereaved persons indicate some support for this argument, with the anticipation that a label could bring relief and evoke support from others, validating and normalising the bereaved person's experience (Ghesquiere, 2013; J. G. Johnson et al., 2009).

Support for a grief-related classification does appear to be growing with endorsement ranging from 43% in health professionals (Ogden & Simmonds, 2014) to between 51% (Rüsch, Evans-Lacko, & Thornicroft, 2012) and 75% (Breen et al., 2015) in the general public. As recognised by DSM and ICD working groups, the greatest challenge has been—and continues to be—determining a valid distinction between 'normal' and 'pathological' grief that takes into account symptomatology, intensity, and duration (Thieleman & Cacciatore, 2013). What is meant by the terms 'norm' or 'normal' has received scant attention but requires consideration of the cultural definitions that determine socially sanctioned customs, practices, routines, and rules (Stroebe et al., 2000). Further understanding of social perceptions of 'normal' and 'pathological' grief is, therefore, important given the likely contribution of these opinions towards help-seeking behaviours and receptivity towards receiving mental health support (Bambauer & Prigerson, 2006).

2.5   Interventions for Grief

2.5.1   Efficacy of targeted grief interventions

Recognising the breadth of interventions that might constitute bereavement care, Neimeyer (2009) has differentiated between grief support, grief counselling, and grief therapy. According to these definitions, grief support is most often provided by non-professionals and comprises compassionate behaviours and information, grief counselling is provided by professionals trained in empathic listening and responding (e.g., palliative care nurses or support groups), and grief therapy is provided by mental health professionals utilising evidence-based psychotherapies (e.g., psychologists, psychiatrists, counsellors, and social workers). Meta-analyses of psychotherapeutic interventions to date have yielded only weak to modest effect sizes (Currier, Holland, & Neimeyer, 2007; Currier et al., 2008; Neimeyer & Currier, 2009; Wittouck, Van Autreve, De Jaegere, Portzky, & van Heeringen, 2011), indicating that individuals who have received intervention are only moderately less distressed at follow-up than those who have not. However, these reviews identified that when treatment is solely focused on individuals exhibiting difficult adjustment to loss, effect sizes are comparable to general psychotherapy outcomes, indicating that therapeutic success depends considerably on the extent of bereavement-related distress and not the simple presence or absence of bereavement.

2.5.2   Who then, actually needs grief counselling or therapy?

As first acknowledged by Parkes (1998), there exists "no evidence that all bereaved people will benefit from counseling and research has shown no benefits to arise from the

routine referral to counseling for no other reason than that they have suffered a bereavement" (p. 18). Interventions designed to target grief may have no effect or a deleterious effect in people experiencing typical grief (Regehr & Sussman, 2004), but a much stronger positive effect in people who meet criteria for a grief-related diagnosis (Currier et al., 2008; Jordan & Neimeyer, 2003; Schut, Stroebe, van den Bout, & Terheggen, 2001). Providing blanket intervention to all bereaved individuals, particularly in the early stages of bereavement, may disrupt natural grieving processes, inhibit the development of coping strategies, and reduce the input of informal support networks to support and guide the grief (Aoun et al., 2012; Breen, Aoun, O'Connor, & Rumbold, 2014; Rumbold & Aoun, 2014). The greatest challenge thus lies in how to identify those at moderate or high risk for complications of grief from those at low risk. As outlined in Chapter One, Aoun et al.'s (2012) three-tiered approach to bereavement care has so far received the greatest empirical support (Aoun et al., 2015; Aoun, Breen, Rumbold, & Howting, 2014) and may provide the closest approximation of who is likely to require and benefit most from grief support, grief counselling, and grief therapy.

2.5.3   Help-seeking and receptivity to grief counselling and therapy

Even when a need exists, many bereaved persons do not access formal support services for their grief. Studies of bereaved persons have found that mental health service utilisation (e.g., psychologists, psychiatrists, counsellors) ranges from 2.2% (Currow et al., 2008) to 43% (Lichtenthal et al., 2011). However, service utilisation is considerably higher (51.6% to 88.5%) when a broader definition of 'grief service' (e.g., including physicians, nurses, or clergy members) is applied (Bergman & Haley, 2009; Bergman, Haley, & Small, 2010). Predictably, help-seeking is more prevalent in individuals who are female (Currow et al., 2008), care for the deceased prior to death (Cherlin et al., 2007; Currow et al., 2008), show higher levels of depressive symptomatology and grief (Bergman et al., 2010; Cherlin et al., 2007), and report more limited social networks (Bergman & Haley, 2009). In a study of bereaved former carers, 16% met criteria for PGD, yet over half of those were unaware that what they were experiencing met diagnostic threshold, so did not seek mental health support (Lichtenthal et al., 2011). Other reported barriers to accessing support include low awareness of grief-related support services, financial and time constraints, negative attitudes towards diagnosis, concerns about the effectiveness of available services, past experience of ineffective treatment, distress, shame or social stigma relating to asking for help, and not perceiving a need for support (Bergman & Haley, 2009; Cherlin et al., 2007; Lichtenthal et al., 2015; Lichtenthal et al., 2011). Notably, 19.6% of low-risk, 30.6% of moderate-risk, and 63.9% of high-risk grieving individuals still report not receiving enough grief-related support (Aoun et al., 2015); however, it is unclear whether this is due to inaccessibility or reluctance to engage with available

supports. The consequences of such low rates of engagement with specialised grief services is that the majority of bereavement care (even when grief is chronic) relies on the informal supportive capacity of friends, family, neighbours, and work colleagues (Benkel et al., 2009a; Li & Chen, 2016).

2.6   Grief as a Social Phenomenon

Although past and present theories, diagnostic classifications, and grief interventions typically conceptualise grief and mourning as individual phenomena, this one-dimensional perspective does little to honour the intersubjectivity of loss, meaning, and coping (Jakoby, 2012). Klass (2014) posed the question: "we might ask how often the individual diagnosis of pathological grief is really a complication in the social response that is part of the instinct. That is, the response of people and the larger culture is missing, inadequate, or twisted" (p. 6). Similarly, citing Stolorow's (2011) work on childhood trauma, Granek (2013) wrote "pain, or one might argue, grief, is not a pathology. It's our inability to respond to and acknowledge it that makes us sick" (p. 285). These quotes highlight the considerable impact of the sociocultural context and its norms on individuals' grieving experiences and illustrate the necessary shift in thanatology from the intrapsychic perspective of classic psychoanalytic theory to the interpersonal perspective of more contemporary attachment-focused frameworks (Allan & Harms, 2010).

As previously mentioned, the experience of grief may have far-reaching implications for family, friends, and community; however, the actions and reactions of these social networks may also have an equal or greater impact on the person grieving. In differentiating grief from depression, Pies (2009) proposed:

Generally, when we experience sorrow, we are capable of feeling intimately connected with others. In contrast, when we experience severe depression, we typically feel outcast and alone. Sorrow, to use Martin Buber's terms, is an *I-Thou* experience, whereas clinical depression is a morbid preoccupation with me. (p. 39)

Grief has been described as a social emotion, emerging from "relationships, attachments, expectations, and obligations" (Jakoby, 2012, p. 680). Consequently, patterns of emotional expression and coping style, sense- and meaning-making, and routine and ritual are conceived at the community level through the development of public discourses that are socially, culturally, and historically determined (Neimeyer et al., 2014). In this way, the practice of grief and mourning is socially constructed through implicit and explicit norms (Fowlkes, 1991). Some have even suggested that the expression of grief serves the primary function of

portraying the meaning of the lost attachment relationship to others and drawing support closer (Neimeyer, 2005). Although condolences are often perceived as something to be verbally given, the actual word stems from the Latin *dolere* (to feel hurt or suffer pain) and *con* (with), thus to be consoled in grief is to have others be and feel alongside, ameliorating the existential isolation inherent in loss (Klass, 2014). In this way, the social milieu of grief provides a type of 'holding environment,' similar to that proposed by Winnicott (1965) and Bowlby (1988), which has the potential to provide consolation and validation to the bereaved. However, it is recognised that this sociocultural context, through its norms and standards, has the power to cause as much harm as it does good.

2.6.1   Grief discourse

Discourses of grief play a pivotal role in societal understandings of what it means to experience a death, to take on the role of a bereaved person, and to grieve 'appropriately' (Harris, 2009-2010). Such patterns of thinking give structure to personal experiences and permit greater predictability in interpreting and making sense of everyday life; however, often at the risk of oversimplifying complex human experiences (Ord, 2009). The main discourse of grief is built on the assumption that grief should be time-limited and not transcend the range of expected or typical reactions (shock, followed by yearning, then recovery); the bereaved person is responsible for 'working through' their grief on their own (or, in some cases, with professional intervention); grief can and should reach resolution, as determined by breaking bonds with the deceased person and finding positive meaning in the death; and, where a death is expected, grief work should begin prior to the death (termed anticipatory grief) and thus reduce the intensity of feelings post-death (for a summary, see Breen & O'Connor, 2007). This discourse dictates private and public expressions of grief and mourning, policing thoughts, feelings, and emotion through rigid beliefs, expectations, assumptions, opinions, and evaluations of grief (Neimeyer et al., 2014). However, evidence suggests that the majority of bereaved persons do not 'close,' 'get over,' 'recover from,' or 'resolve' their grief, but rather learn to life with it through accommodation and integration (Begley & Quayle, 2007; Breen & O'Connor, 2010). For the majority, the intensity of feelings about the loss lessen over time, but often never completely dissipate (Carnelley et al., 2006). Grief and continued mourning may be triggered at any point following a loss including on anniversaries of the death, birthdays, holidays, or at age milestones (Barlow & Coleman, 2003; Benkel et al., 2009b). Despite empirical evidence to disprove the dominant grief discourse, Wortman and Silver (1989) propose that these myths are highly resistant to change due to society's reluctance to accept evidence that contradicts beliefs. The following section considers some potential

origins of the discourse, with particular attention given to the influence of outdated grief models, theories of death denial and death anxiety, and media portrayals of grief and mourning.

2.6.1.1   Subscription to outdated grief theories

Due to their simplicity and "seductive appeal" (p. 8), widely disseminated stage theories, such as that offered by Kübler-Ross (1969), have become the norm through being universally adopted and accepted as truth (C. Hall, 2014). Despite only a minority being based on empirical research, these theories are resistant to change because of their long-standing uncritical acceptance, their fit with the medical model of 'illness to wellness,' and the limited dissemination of more contemporary understandings of grief (Lindstrøm, 2002). Most problematic is the foundation upon which these theories were built, with the majority of empirical studies conducted on middle-class women in Western countries who have experienced the death of a spouse by natural causes (Breen & O'Connor, 2007). As highlighted by M. S. Stroebe, Gergen, Gergen, and Stroebe (1992), "psychological theories and practices frequently neglect the extent to which their subject matter is historically and culturally defined" (p. 1205). This dominant discourse thus might have less application and appeal when transferred cross-culturally or to less commonly occurring deaths. Specialised grief interventions are most often accessed by English-speaking women (Allan & Harms, 2010), which may serve to reinforce the foundation of these theories. Despite the movement away from stage, phase, or task models in the thanatological literature, the basic premise of these early models remain the dominant discourse of grief held by some health professionals, the media, and laypersons alike (Breen, 2010-2011; Breen, Fernandez, O'Connor, & Pember, 2012-2013; O'Connor & Breen, 2014; Wortman & Boerner, 2007).

2.6.1.2   Death denial

Society's willingness (or rather, unwillingness) to accept and confront death has also contributed to how grief and mourning are conceptualised. Death was once accepted as a familiar, inevitable part of living, and talking about and dressing according to one's grief was not uncommon one year or more after the death (Jalland, 2013). However, transformations in modern medicine at the turn of the 20th century led to the adoption of a 'death-denying' attitude (Kübler-Ross, 1969). With increases in life expectancy and declines in communicable diseases, death was reconstructed to represent a failed medical system and became the domain of health professionals, not priests (McConnell et al., 2012). Contributing to this, the mass mourning experienced throughout the World Wars forbade conventional grief responses, instead favouring a stoic response to bereavement through the resolution of grief, internalisation of emotion and privatisation of rituals, and endorsement of "a stiff upper lip"

(p. 17) mentality to boost public morale (Jalland, 2013). This denial has been further facilitated by death being less visible today than it once was (McConnell et al., 2012). Although the majority of people wish to die at home, few succeed in actually doing so, meaning that the majority of deaths occur in institutional settings, often out of sight of family and friends (ABS, 2017; Broad et al., 2013). In line with the privatisation and concealment of death, grief has evolved as an individual experience to be managed and worked through quickly and out of the public eye (McConnell et al., 2012). In an age of continued productivity, Allan and Harms (2010) propose that Western society affords little time to grief or grieving, seeing it as something to be managed solely by the bereaved person or, if required, a health professional. However, others have critiqued this notion, proposing that death is not as taboo a topic as once thought and there is evidence for greater acceptance than denial of death observed through the methods by which communities publically prepare for, organise, and respond to death with socially sanctioned rules and rituals (Lee, 2008; Sayer, 2010). Even if that is the case, and today's Western norms and practices evidence a more liberal, expressive style of grief, the traditional mourning practices embedded in our sociocultural history continue to influence social constructions of bereavement and what it means to grieve in an appropriate manner (Jalland, 2013).

2.6.1.3   Death anxiety

Existential theory posits that most forms of anxiety in life can be traced back to death anxiety, that is, the fear of inevitable deterioration and demise (Yalom, 2009). Although it has received scant attention in the literature (Bonanno et al., 2002), it seems intuitive that a reluctance to face one's own mortality might also correspond with unrealistic expectations of grief and averseness to acknowledging the entirety of grief in the self and others. In addition to popularising stage models of grief, Kübler-Ross (1969) was one of the first to empirically examine the extent of death anxiety in a Western sample, proposing that the fear of death is emotionally debilitating and universal. In her study of dying patients, Kübler-Ross observed discomfort leading up to imminent death, euphemisms used to talk about death and dying (e.g., passed away, went home, resting in peace), and routines and rituals that imitate life over death (e.g., embalming practices and placing make-up on corpses). This illustrates Yalom's (1980) assertion that "the fear of death plays a major role in our internal experience, it haunts as does nothing else; it rumbles continuously under the surface; it is a dark, unsettling presence at the rim of consciousness" (p. 27). However, it is not only one's own death that is feared and avoided, but also the deaths of others, for they represent an unwelcome reminder of the death of self (Spinelli, 2000). Yalom (1980) proposes that people erect defences (e.g., belief in one's own specialness) against the awareness of their own mortality which, although self-preserving,

may become dysfunctional. A key component of this anxiety is the fear of being powerless to predict the timing of, or prevent death (Cooper, 2015); therefore, the fear of death may be seen as parallel to the fear of grief and all of the distress, uncertainty, and unpredictability that accompanies it (Madison, 2005). Just as death is perceived as the thing that happens to everyone except the self (Yalom, 2009), so too is grief. Reluctance to acknowledge the inevitability and frequency of death may, therefore, reinforce grief as something to be quietly experienced, precluding supporters from responding to grief in a way that is most helpful to a bereaved person.

Terror Management Theory (TMT) may also clarify the link between death anxiety and grief discourse, proposing that almost all human action can be explained by the motivation to ignore or avoid the inevitability of death (Greenberg, Pyszczynski, & Solomon, 1986). Akin to death anxiety theory, TMT describes defences that may be adopted against the fear of death, including beliefs about the strength of one's physical health or life expectancy (Pyszczynski, Greenberg, & Solomon, 1999); assumptions that may be shattered by the untimely or unexpected death of a close attachment (or witnessing someone else bereaved by such a death). According to this theory, when faced with reminders of personal mortality, people bolster self-esteem through adherence to cultural norms, decreasing empathy for and ultimately rejecting those who do not share the same worldviews (Becker, 1973). B. L. Burke, Martens, and Faucher (2010) argue that "our most vile attitudes and actions toward other groups stem from a fear of death that we cannot fully cope with or comprehend" (p. 156). Such anxiety around death goes some way in explaining elements of the discourse, particularly that grief should be time-limited, worked through alone, and eventually resolved, returning to a state of pre-loss functioning.

2.6.1.4   Media portrayals of grief and mourning

Popular media may also play a considerable role in how dominant discourses are held, challenged, or affirmed. Death and grief are arguably given greater space for discussion in television, movies, games, and print media than anywhere else (Sofka, 2007). However, such depictions are rarely informed by contemporary perspectives on dying or grieving and may be best described as "illusively fantastical and frighteningly real" (Fulton & Owen, 1988, p. 383). Media outlets contribute substantially to societal definitions of which deaths are worth counting, how, and for how long (Fonseca & Testoni, 2012). From an analysis of grief in American news outlets, Baugher (2001) argued that, although thanatological literature has shifted away from the language of closure, acceptance, healing, and recovery, popular media has not. Instead, stories implying that grief is time-limited and finite, can be worked through by investing in a higher purpose, and that healing commences immediately following the

death, permeate news articles. Similarly, in a study of grief-related reporting post-2000 in the New York Times, Hilliker (2008) noted far greater attention given to mass mourning (e.g., 9/11) than private bereavement (if only for political gain; Pantti & Sumiala, 2009), an emphasis on stories of resilience and posttraumatic growth soon after the death, and the predominate focus on certain relationships (e.g., spouses, children) over others (e.g., grandparents, ex-spouses, friends). Hilliker argued that such a narrow focus isolates those whose grief is not typically represented in print media, compounds unhelpful attitudes, and contributes to societal definitions of how we understand grief. Evidently, media portrayals of grief, whether accurate or not, continue to be highly influential in educating the general public on issues of death, grief, and mourning.

2.7   Implications of Social Discourse for the Expression of Grief and Mourning

2.7.1   Disenfranchised grief

Doka (1989) defines disenfranchised grief as the experience of bereaved persons "when they incur a loss that is not or cannot be openly acknowledged, publicly mourned and/or socially supported" (p. 4). Central to this argument is the notion of 'grieving rules;' that is, a series of expectations around the who, when, where, how, for how long, and for whom grief can occur (Doka, 1989, 2002), which effectively define 'normal' grief (Harris, 2016). The enforcement of grieving rules results in a juxtaposition between losses that are socially sanctioned and legitimised, and losses that are disenfranchised and collectively disqualified. Where individuals are placed on this continuum depends on others' perceptions of the nature of the loss (e.g., perinatal death), the relationship to the deceased (e.g., extramarital affair), and the bereaved persons' capacity to grieve (e.g., a young child experiencing loss; Doka, 1989). Rando (1993) subsequently added a fourth condition relating to the social network's capacity to tolerate the loss (e.g., a mutilating death). According to C. W. Mills (1959/2000), enfranchisement of loss may also differ dependent on whether the death is seen as a 'private trouble' (e.g., death of a spouse in later life) or a 'public issue' (e.g., natural disaster or act of terrorism). Notably, rarely are any of these conditions within the control of the bereaved person (Chapple, Ziebland, & Hawton, 2015).

People whose grief is enfranchised are afforded what Harris (2009-2010) termed the 'sick role,' permitting them to outpour emotion, ruminate on their loss, and forgo usual routines and responsibilities in favour of taking time to grieve. Similarly, those who exhibit little distress may not be perceived as resilient, but rather assumed to be denying the loss or suppressing emotion, both societal indicators of poor coping (Boerner, Wortman, & Bonanno, 2005). For

some, this legitimisation might be helpful, creating safe and open spaces in which one can grieve. However, sickness is still viewed as an impermanent state, so the sick role becomes synonymous with 'grief work' and working to 'get well,' continuing to enforce timeframes around grief and mourning (Hilliker, 2008). Conversely, when death is disenfranchised, others will withhold validation of the loss and empathy, and rather than social support, these individuals are likely to experience social disapproval (Doka, 1989, 2002). However, it is important to note that the legitimisation and acceptance of grief is more complex than a binary enfranchised/disenfranchised, but may be better understood as a sliding continuum or hierarchy (Robson & Walter, 2012). Evidently, when popular discourse is not congruent with an individual's experience of grieving, these grieving rules become prescriptions, rather than descriptions, for how one must grieve and may have considerable impact on natural processes of grieving (Allan & Harms, 2010).

2.7.2   Internalisation of discourse and privatisation of grieving

For the majority of individuals, a short period of public mourning is permitted before grief is either privatised or suppressed (Chapple et al., 2015). According to self-labelling theory (Thoits, 1985), bereaved individuals perceive themselves as emotionally 'deviant' the moment they observe their reactions to be more intense or prolonged than what their cultural norms dictate. Awareness of a norm-state discrepancy usually arises from social comparison and results in overt attempts to achieve congruence between internal emotion states and societal views of what should be occurring. As identified by Harris (2009-2010), bereaved persons are highly cognisant of the importance of social support and acceptance, increasing the likelihood to which grieving rules are internalised and adhered, maintaining social order. Consequently, bereaved persons may not only be judged, but may also judge themselves against, unrealistic and inappropriate standards that do not account for the unique circumstances of their own bereavement (Breen & O'Connor, 2011).

Evidence of the dominant grief discourse has been observed in self-critical expectations about the length of grieving, potential for recovery, and necessity of anticipatory grief for expected deaths (Costa, Hall, & Stewart, 2007). The internalisation of social norms such as these have been found to predict higher levels of grief complications in woman who have experienced perinatal grief (Roberts & Lee, 2013). Some individuals may suppress their grief in order to appear stoic (Harris, 2016), stemming from self-critical judgements about experiencing too little or too much distress or failing to 'resolve' grief within an expected timeframe (Costa et al., 2007; Ghesquiere, 2013). Notably, these individuals often use the bereavements of close family and friends as points of reference, judging themselves to be more or less deserving of grief dependent on the cause and timing of death. Other individuals may

privatise or mask their grief, censoring conversations based on how much they believe others can tolerate (Begley & Quayle, 2007; McBride & Toller, 2011), or discounting their loss as unjustified and unworthy of public support (Cordaro, 2012). It is reasonable to assume that such self-disenfranchisement may also influence help-seeking and receptivity to receiving both formal and informal support, in addition to the strength and scope of beliefs and worldviews brought to therapy. This internalisation of grief and privatisation of mourning, thus, may be a considerable barrier to making sense of and finding meaning in loss (Chapple et al., 2015). As originally proposed by Fowlkes (1991) these tendencies may precipitate a shift from 'loss to self' to 'loss of self,' which may be further attenuated if social support is limited or absent following the death.

2.8 Implications of Social Discourse for Social Support

As previously highlighted, social support is one of the strongest predictors of psychosocial outcomes following bereavement and is a primary risk factor amenable to change after a death has occurred. Shumaker and Brownell (1984) defined social support as "an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (p. 13). However, to be effective, a need for support must be properly recognised, the supporter must have the willingness and capacity to provide support, and any supportive actions must be perceived as helpful by the receiver of the support (Kaunonen, Tarkka, Paunonen, & Laippala, 1999; Rando, 1993). More than previously, research is now beginning to explore informal support needs from the perspective of bereaved persons, as well as investigating the nature of disconnection and isolation when support needs are not met (e.g., Gear, 2014). However, in doing so, there is still far greater focus on the experience of receiving social support, and not on what predicts or motivates support providers (Bath, 2009), highlighting persistent gaps in this research area.

2.8.1 Informal support needs of bereaved persons

Bowlby (1980) was perhaps the first theorist to honour the interpersonal nature of loss, proposing that the impact of loss may be ameliorated by the formation of substitute attachments. The majority of bereaved persons report primary reliance on family and friends, only seeking out professional support if informal networks are unable to provide care (Benkel et al., 2009a) or there are concerns about burdening informal networks who may be simultaneously grieving (Benkel et al., 2009b). Cognitive stress theory (Lazarus & Folkman, 1984) posits that although bereavement is a stressor which places tension on an individual's coping resources, the availability of caring others to take some of the burden may moderate

the impact of the loss. Social support may be most beneficial to grieving individuals in Aoun et al's (2012) first tier (low risk) who predominately depend on informal support networks, but it is also integral to the adjustment of individuals in tiers two and three (moderate and high risk), complementing the support received through counselling or therapy. Bereaved individuals have argued that it is not a matter of *either* formal support *or* informal support, but rather how each might meet various needs at different points along the grief trajectory (Dyregrov, 2002).

Following Shumaker and Brownell's (1984) aforementioned definition of social support, an "exchange of resources" may include the communication of messages or enactment of behaviours towards bereaved persons (p. 13). Although often well-intended, not all 'supportive' messages are automatically perceived by bereaved persons as positive, or indeed helpful. Research using support-intended statements scales indicate that messages perceived as most helpful have centred on offering a felt presence, showing care and concern, and inviting the sharing of feelings (Lehman, Ellard, & Wortman, 1986; Marwit & Carusa, 1998). In contrast, messages perceived as least helpful in these studies included advice-giving, emphasising movement towards recovery, and minimising feelings. Seeking to answer why some support-intended statements are rated as more helpful than others, Servaty-Seib and Burleson (2007) identified that the most helpful messages were rated as higher in person-centredness (validating and legitimising feelings and experiences). Replicating this finding, Rack, Burleson, Bodie, Holmstrom, and Servaty-Seib (2008) found the effect of person-centredness to be further amplified for bereaved women and those who rated themselves as more disrupted by the death. Supportive behaviours or actions rated as most helpful by bereaved people tend to include any efforts to resist social pressure to suppress, internalise, or de-normalise grief (Chapple et al., 2015). According to the Social Support in Bereavement model (Li, Sha, & Chow, 2013), actions may take the form of emotional support (e.g., offering space to process emotions and memories), informational support (e.g., providing resources or linking in with other grievers), or practical support (e.g., funeral arrangements or financial assistance).

Whether through the communication of messages or enactment of behaviours, social support is perceived to be most helpful when it comes from naturally occurring networks, is perceived as authentic and in tune by the receiver, and emphasises and facilitates continuation of the bond with the deceased (Gear, 2014). Unconditional acceptance of grief has been rated as particularly important, with the most helpful social supports still available months and years after the death (Dyregrov & Dyregrov, 2008). Quality of bereavement-specific support has not been found to correlate with size, but rather the characteristics and functionality, of the

supportive relationships (Benkel et al., 2009a; L. A. Burke, Neimeyer, & McDevitt-Murphy, 2010). As such, empirical evidence suggests that many people do not receive the quality of support they desire, but rather report greater experiences of social stigma, disconnection, and isolation (Utz, Swenson, Caserta, Lund, & deVries, 2014).

2.8.2   Experiences of stigma, social disconnection, and isolation

For many bereaved persons, support is reasonable in the immediate aftermath of the death, but diminishes rapidly over the following 18 months (Utz et al., 2014). In this way, some have suggested that no loss is immune from eventually becoming disenfranchised over time (Walter, Hourizi, Moncur, & Pitsillides, 2011-2012). Grief that is not congruent with the dominant discourse of grief and does not meet the supporter's expectations is likely to be appraised as abnormal, deviant, or even pathological (Klass & Chow, 2011). Rather than inviting concern and support, such evaluations may result in social distancing and rejection by those best placed to support the bereaved (Dyregrov, 2003-2004). Equally harmful is when well-intended supports are interpreted as misguided, misattuned, and unhelpful, illustrating how social interaction does not necessarily equate with social support (L. A. Burke et al., 2010). The potential of social support to become a risk rather than protective factor for bereavement outcomes may, therefore, be a consequence of stigma around the death, social responses that discount the loss, and self-isolating behaviours.

Stigma has been identified as a key factor in determining whether or not support is offered to a bereaved person, and the degree and period of time for which it is offered (Cvinar, 2005). It is hypothesised that more stigmatised deaths incite greater shock and fear and are associated with fewer social rules governing appropriate support (Chapple et al., 2015). Bereavements particularly susceptible to stigma include those associated with higher levels of shame and blame, such as suicide and drug-related death (Feigelman, Jordan, & Gorman, 2011; Pitman, Osborn, Rantell, & King, 2016), resulting in uncomfortable social interaction, implicit and explicit judgement, and social rejection (Begley & Quayle, 2007; Chapple et al., 2015). Further complicating this, some people may engage in processes of 'self-stigmatisation,' where they misinterpret the helpful gestures of others, behaving in such a way as to unintentionally encourage avoidance from others (Barlow & Coleman, 2003; Botha, Guilfoyle, & Botha, 2009). This tendency initiates a feedback loop where people are less likely to offer support to a person bereaved by a stigmatised death, while that person is also less likely to seek out social support due to blame about the cause of death (Dyregrov, 2011). This finding is particularly concerning given that people bereaved by suicide deaths have a perceived need for professional support that is nine times higher than the general bereaved population (de Groot, de Keijser, & Neeleman, 2006), but do not consistently seek such support (Schneider, Grebner,

Schnabel, & Georgi, 2011), highlighting the risk of isolation from both formal and informal supports.

Social support may also be impacted by 'empathic failure' (Neimeyer & Jordan, 2002) and 'social ineptitude' (Dyregrov, 2003-2004); terms that have been derived to describe the inability of a bereaved person's social network to understand the meaning of and appropriately respond to the grief experience. In a study of 540 suicidally bereaved adults, Feigelman et al. (2009) identified six insensitive or unhelpful behaviour types commonly experienced: avoidance, unhelpful advice, a lack of consideration or compassion, spiritual rationalising, victim blaming, and blaming of the bereaved person. Similarly, a study of 90 adults bereaved by AIDS-related causes, explored the impact of two types of unsupportive social interactions: 'distancing' (behaviours that cause detachment from the bereaved person) and 'bumbling' (awkward behaviours that are perceived as intrusive or inappropriately solution-focused; Ingram, Jones, & Smith, 2001). This study found that both distancing and bumbling contributed significantly to levels of depression in the bereaved person, beyond that of grief alone. Several other studies have reported the enforcement of expectations that the bereaved should move on from the death or resolve their grief within a short period of time, with such beliefs observed to influence the willingness of social networks to offer continued support (Aho, Tarkka, Åstedt-Kurki, & Kaunonen, 2009; Ghesquiere, 2013; Jakoby, 2014). Other research has noted the prevalence of avoidance behaviours, with anticipated supports withdrawing physically (e.g., by crossing the road when approaching a bereaved person) or emotionally (e.g., through failing to mention the deceased in conversation) due to their own discomfort about the death (Dyregrov, 2003-2004).

Surprisingly, what predicts unhelpful or avoidant behaviours in potential supporters following bereavement has received scant attention in the literature. Calhoun and Allen (1991) published the only known review of research synthesising relevant research on what predicts social reactions to individuals bereaved by suicide death. This study highlighted four factors relating to the deceased (cause of death, age, gender, family composition) and three to the respondent (gender, age, bereavement experience) that have been identified as influencing support of people bereaved by suicide. Seeking to make sense of the behaviours of others, bereaved persons have reasoned that limited or absent social support from friends and family (who might otherwise be expected to support), may be attributed to limited resources or capacity to support (Costa et al., 2007; Dyregrov, 2003-2004), fear of the 'contagion' of untimely death (Chapple et al., 2015), or perception of the bereavement as an unwelcome reminder of personal mortality (Breen & O'Connor, 2011). Given that social support must start with a perception of need by the supporter (Rando, 1993), it is surprising that so little

attention has been given to what enables social networks to recognise and respond to the emotional suffering of another person.

Studies show that people who have been bereaved are quickly able to reflect on helpful and unhelpful actions by their social network after the fact; however, rather than confront, the default reaction is to be selective in choosing trusted confidantes, engage in filtering processes, or expect less of social networks and withdraw completely (Breen & O'Connor, 2010; Ghesquiere, 2013). Even where a well-functioning support system exists, bereaved individuals may retreat for fear of being unexpectedly reminded of their loss or becoming a burden on others (Barlé et al., 2017; Benkel et al., 2009a). Though not often investigated, self-isolation may also stem from a bereaved person's reluctance to ask for or accept support from others, even when it is appropriately offered (Ghesquiere, 2013; Jakoby, 2014). For example, repressing one's own grief to put the support needs of another first (Aho et al., 2009). It is important to note that accepting social support or being consoled requires a certain degree of vulnerability and trust in another person (Klass, 2014), highlighting that there may be mechanisms underlying the receipt of social support, as much as the provision of it. For many, this self-isolation may contribute to a deeper intrapersonal isolation rooted in the realisation of being completely alone in one's grief (Van Humbeeck, Dillen, Piers, Grypdonck, & Van Den Noortgate, 2016). Self-isolation further reinforces the dominant grief discourse and creates a culture in which people may wish to support the bereaved person, but are uncertain what support is needed or how to offer it (Dyregrov, 2005-2006).

2.9   A Model of Community Bereavement Support

Almost 30 years ago, Vachon and Stylianos (1988) put forth an initial social support framework that explained barriers to and impacts of social support, proposing the need for an ongoing research agenda that investigates key mechanisms for harnessing community based-support. Although highly cited in the literature, there has been limited ongoing investigation into what a model of community bereavement support might look like and how it might be implemented. Abel, Bowra, Walter, and Howarth (2011) highlighted "we do not know from research how formal services can support naturally occurring support networks, because we do not know how these naturally occurring networks operate or fail to operate" (p. 130). This statement represents one of the first areas in the literature to recognise that natural supporters might actually need support themselves and should not be assumed to hold the innate capacity or confidence to assume a primary supporting role. Although the Center for the Advancement of Health (2004) identified bridging the gap between health care systems and community resources as an area of research priority, surprisingly little attention has been granted over the

last 13 years. Although still in its infancy, there is growing research to suggest that (1) enhancing death and grief education (for health professionals and the lay public) and (2) translating a model of community support originally derived for the palliative care context, may be the next steps in continuing to challenge the dominant grief discourse and address the complex and multifaceted support needs of bereaved persons.

2.9.1 Death and grief education

2.9.1.1 Education for health professionals

Although a common presenting issue across health disciplines, evidence suggests that scant attention is given to grief and loss education in many university courses and professional development frameworks, leaving many health professionals misinformed and ill-equipped to work with bereaved clients (Balk, 2005; Breen et al., 2012-2013; Dickinson, 2007, 2012). Traditional stage, phase, and task models of grief have formed the basis of education and training in the fields of nursing, general practice, psychiatry, and psychology, and are consequently used to inform practice with bereaved clients (Breen, 2010-2011; Breen et al., 2012-2013; O'Connor & Breen, 2014). The uncritical acceptance of these theories has contributed to the development of poorly informed, inappropriate, and inadequate grief-related interventions (Breen & O'Connor, 2007; Lichtenthal et al., 2011). Other research has indicated that some health professionals partially depend on their own experiences of grief and loss to inform their work with clients (Chan & Tin, 2012; O'Connor & Breen, 2014), which may result in harm if stemming from an experience very different from the client's. Iglewicz et al. (2013) argue that the best way to guard against the over-medicalisation of grief is not necessarily to resist the inclusion of grief in diagnostic nosology, but rather to educate health professionals and the general public about the variability of grief responses and their relevance to mental health (termed grief or death 'literacy'). Preliminary evidence suggests that education interventions for health professionals are associated with notable increases in mindfulness and empathy (Cacciatore, Thieleman, Killian, & Tavasolli, 2015), offering weight to the argument that death and grief education must continue to expand beyond palliative care service provision (Breen et al., 2012-2013; Kellehear, 2016).

2.9.1.2 Education for the lay public

Death anxiety theories propose that the terror of death abates when people are supported to become aware of their defences, resulting in the approach, rather than avoidance, of painful emotions in the self and others (Greenberg et al., 1986; Yalom, 2009). This premise highlights the positive role of public grief education in challenging societal conceptualisations of grief

and behaviours towards grieving individuals. Supporters in Dyregrov's (2005-2006) study reported being paralysed by the fear that they would say or do something wrong, highlighting wishes and needs for grief-related education that is informed by the perspective of bereaved persons. Although research is sparse, early evidence suggests that psychoeducation on topics of grief and social support for primary supporters shows promising potential to reduce levels of grief complications in the bereaved (Nam, 2016). Abel et al. (2011) propose that death and grief education should be recognised as both a facilitator to and product of providing bereavement care. Support networks will provide better support through education that upskills them to do so (theoretical learning), but they will also gain crucial awareness and knowledge through simple exposure to people who are bereaved (experiential learning), augmenting supportive behaviours in the future (Noonan, Horsfall, Leonard, & Rosenberg, 2016).

2.9.2   Compassionate communities

The past decade has seen the introduction of a new term in public health: compassionate communities (Sallnow, Richardson, Murray, & Kellehear, 2016). Wegleitner, Heimerl, and Kellehear (2016) define this term as "communities that develop social networks, social spaces, social policies, and social conduct that support people through the many hours, days, weeks, months and sometimes years of living with a life-threatening illness, ageing, grief and bereavement, and long-term caregiving" (p. 1). The essential focus of this innovative model is on mobilising social networks to assume the role of primary supporters for people with physical, mental, or other social issues living in the community (Horsfall, Noonan, & Leonard, 2012). Within a compassionate communities framework, death and bereavement care is viewed as everyone's responsibility (Kellehear, 2013), and is characterised by mutual support, cooperation, trust, empathy, and a focus on strengths and wellbeing (Kellehear, 2016). Supports offered may be practical (e.g., assisting with shopping), emotional (e.g., being present or talking with), or informational (e.g., providing direction or linking in with relevant community services), with many people requiring some combination of all three (Abel et al., 2011; Horsfall et al., 2012). For compassionate communities to be effective, resources must be focused on the development of communication, problem solving, and decision-making capabilities, which are then assumed to remain present within the community (Horsfall et al., 2012).

The compassionate communities approach represents a substantial shift in public health and health promotion priorities around death and dying through harnessing and building community capacity for supportive action (S. Mills & Mills, 2016). However, the development and evaluation of compassionate communities in the literature so far has primarily focused on

palliation and end-of-life contexts, that is, community support of people who are dying (e.g., Abel et al., 2011; Adshead & Dechamps, 2016; Horsfall et al., 2012; Rosenberg, Horsfall, Leonard, & Noonan, 2015), with little regard for what happens to those left behind when a death occurs (particularly outside palliative care settings). Abel et al. (2011) propose that just as it takes a village to raise a child, so too does it take a village to care for someone who is dying. Not often recognised is that perhaps it also takes a village to support someone who is grieving an impactful loss. Recent proposals indicate that much of the literature on compassionate communities for end-of-life may translate or be adapted to support others for whom a death is less expected, specifically focused on the time following bereavement (Breen et al., 2017; Rumbold & Aoun, 2014). As highlighted in end-of-life contexts, such a model has the potential to minimise stress and burnout in health professionals (Breen, 2010-2011; Breen, O'Connor, Hewitt, & Lobb, 2014), reduce burden on under-resourced and costly specialised care services (Abel et al., 2011), address structural barriers to responding with compassion to death and grief (D. Hall et al., 2013), and build social capital (Horsfall et al., 2012). Communities themselves may also benefit from a model such as this through developing familiarity with and expertise in complex social issues that affect not only others but themselves too (i.e., death or grief literacy), contributing towards the re-attachment of communities and enhancement of sense of community, and shifting broader societal attitudes towards death and dying (Abel et al., 2011; Breen et al., 2017; Horsfall et al., 2012).

Despite its obvious benefits, Abel et al. (2011) highlighted that mobilising support networks is far more conceptually and practically challenging than it sounds. The first obstacle to this framework is that the traditional notion of family and community networks in Western cultures does not represent what it used to (Abel et al., 2011). In a time of industrialisation and privatisation, social connectedness and sense of community have been redefined; where families once comprised the primary support network following a death, people are now more geographically isolated than ever before with less availability of, and dependence, on family, friends, and neighbours (M. S. Stroebe, Stroebe, & Hansson, 1988). Second, Kellehear (2005) proposes that an increase in professional support services over the last 50 years has contributed to a resultant decrease in ownership by the community of issues of death and grief. Palliative and bereavement care are assumed to be the sole responsibility of health professionals, regardless of whether an individual's needs actually warrant formal intervention (Rumbold & Aoun, 2014). Rather than health professionals being viewed as a small part of the support network's team, support networks are viewed as being a small part of the health professional's team (Abel et al., 2011). Finally, community capacity for compassionate action depends on the acquisition of knowledge, skill, a sense of responsibility and empowerment in the general public, as well as overarching supportive systems (Kenny, 1994). These latter conditions have

received little attention in the literature, particularly as they pertain to contexts in which death is less expected and the window of opportunity for mobilising supports is small (i.e., outside palliative care).

2.10   Rationale for this Research Study

Past research has called for greater focus on initiatives to support the natural helpers of people who are bereaved, including their family, friends, neighbours, and work colleagues (Aoun et al., 2012; Breen & O'Connor, 2007). However, scant attention has been given to exploring how communities conceptualise 'normal' grief and, consequently, what barriers and enablers exist to the provision and acceptance of social support following bereavement. Reconciling community expectations of grief (what it 'should' be) with the reality of grief experiences (what it actually is) offers the potential to enfranchise and legitimise a greater range of grief responses, reconstructing a new 'normal' for grief. The proposed research provides a novel and innovative contribution to this research field through contributing to arguments about the legitimacy of grief in diagnostic nosology, expanding understanding of social norms for grief, unpacking associations between these norms and the expression of grief and experience of social support, and elucidating the support needs of bereaved individuals.

2.10.1   Contributing to the argument regarding the legitimacy of grief in diagnostic nosology

Acknowledging that the expression of grief must transcend societal norms to be considered disordered, the Center for the Advancement of Health (2004) placed a call for research to uncover perceptions of normal and complicated or prolonged grief. Since this publication, only a handful of studies using community samples have addressed this research question, tending to rely on binary yes/no response options and failing to differentiate the opinions of those who have experienced an impactful bereavement from those who have not (e.g., Breen et al., 2015; Holzinger, Matschinger, Schomerus, Carta, & Angermeyer, 2011; Rüsch et al., 2012). Regardless of if, when, or how, a grief-related disorder is formally included in diagnostic manuals, there remains a broader question about the degree to which the general public, and in particular, people who have been bereaved, endorse and would utilise such a diagnosis. Rates of help-seeking and receptivity to receiving grief-related support are dangerously low in people who meet criteria for a grief-related diagnosis (Lichtenthal et al., 2011). By unpacking societal perceptions about the potential positive and negative impacts of a grief-related diagnosis, this research offers evidence to dispel myths and ameliorate negative attitudes towards mental health diagnosis as a key barrier to help-seeking. Similarly, through determining whether rates of endorsement are higher in samples of bereaved or non-bereaved

individuals, the findings of this research may provide direction to focus community awareness-raising initiatives either towards people who are grieving (reducing fears associated with help-seeking) or their potential support networks (whose opinions may be equally influential in determining whether support is sought).

2.10.2 Expanding understanding of grief-related norms

Shifting towards an interpersonal framework for understanding grief, many have advocated for greater research focus on the social and cultural elements of the grief experience (Harris, 2009-2010; Neimeyer et al., 2014; Pressman & Bonanno, 2007); however, evaluation of the literature indicates persistent gaps. Social support is one factor that is strongly predictive of post-bereavement outcomes *and* amenable to change after the death has occurred (Bath, 2009); yet, what predicts its occurrence has received scant attention. Since the publication of Calhoun and Allen's (1991) literature review, research on the factors associated with social perceptions of, and responses to, grieving persons has been poorly informed and conducted, with few studies attempting to enhance or build on previous publications. A brief search of the literature indicates that research has predominately recruited university samples to represent broader community perceptions (e.g., Bath, 2009; Rack et al., 2008; Tedrick Parikh & Servaty-Seib, 2013), suggesting a need to further diversify research samples to capture more broadly the mechanisms underpinning why a particular loss may or may not be acknowledged and receive social support.

It is anticipated that conducting a comprehensive and systematic search of the literature will highlight what is known about social norms for grief and provide specific direction for future research to follow. As suggested by Doka (2002), a key focus of many grief therapies is on undoing the internalisation of grieving rules and re-enfranchising grief in order to release natural grieving processes. With greater insight into which bereavements may pose the greatest risk for disenfranchised grief, interventions may focus more on prevention than cure. Further, this research will explore associations between past bereavement experience and perceptions of and responses towards grieving individuals, offering weight to the argument of whether personal experience (i.e., in the form of peer supporters) can reduce the need for comprehensive grief education and form the foundation for the development of compassionate communities (Abel et al., 2011). Recognising that a lack of, or misguided, supportive action can be equally as impactful as helpful social support, much more is needed to expose and begin to challenge the specific myths and misconceptions that have contributed to the disenfranchisement of many forms of grief in Western society (Allan & Harms, 2010).

2.10.3 Unpacking the influence of social norms on grief expression and social support

It has been recognised that:

When we assess the ability of persons to cope with loss and to work through the grief that ensues, we take for granted a social setting that does not work against them, a social setting that recognizes and affirms the loss and extends permission to grieve (Fowlkes, 1991, p. 533).

However, research is beginning to demonstrate that such a social setting is more often the exception, than the rule. Although research consistently highlights that bereaved persons may either conform to or resist the dominant grief discourse (Neimeyer et al., 2014), there is still limited evidence for exactly what strategies are adopted to buffer the effects of prevailing myths and misconceptions about what is 'normal' or 'expected' when it comes to grief. Further, with social support recognised as a key predictor of bereavement outcomes, research to date has predominately focused on the quantitative assessment of support (in terms of how many, how much, and for how long), failing to appreciate the specific nature of dynamic interpersonal processes that occur between providers and recipients of support (Dyregrov, 2003-2004). Studies explicitly linking social norms to social support are scarce (e.g., Breen & O'Connor, 2010; Costa et al., 2007; Dyregrov, 2003-2004), and those targeting social support more generally have been limited by their predominate focus on middle-aged women, bereaved by a specific cause of death (often in close family members), who are already engaged in or connected to community or professional bereavement support (e.g., S. B. Scott et al., 2007; Toller, 2011; Wilsey & Shear, 2007), minimising the extent to which conclusions about supportive and unsupportive experiences can be translated to the general bereaved community.

With the specific buffering or recovery effects of social support still unclear (W. Stroebe et al., 2005), there is a need to explore how social support may be differentially experienced by grieving individuals dependent on factors such as the bereavement experience of the supporter or prior expectations of support. It is clear that for some, previous experiences of loss will enable and facilitate compassionate caring responses, while for others, grief will represent a too painful reminder of the previous loss, inciting avoidance (Rumbold & Aoun, 2015). Understanding the mechanisms behind why and how social networks respond to grief will further clarify current deficits that must be addressed for a compassionate communities approach to be effective. Additionally, there exists a considerable gap in the literature concerning the impact of rigid social norms, not only on the provision of social support, but

also the willingness of the recipient to accept support (often related to self-disenfranchisement). This research seeks to resolve these shortcomings by exploring the extent to which bereaved people are cognisant of common beliefs, expectations, and assumptions about grief and mourning, whether they apply these rules to their own grieving experiences, and how these norms may serve as facilitators or barriers to both providing and receiving social support. This research is innovative in its attempt to go beyond the simple description of unhelpful social supports, to evaluate how bereaved people negotiate the expectations and behaviours of others, whilst simultaneously adjusting to and integrating the loss itself.

2.10.4   Elucidating informal support needs of the bereaved

An extensive body of research has focused on developing interventions and supports for individuals at moderate or high risk for complications of grief; yet, there has been surprisingly little attention given to the support needs and availabilities of individuals at lower risk who are primarily supported by their community (Aoun et al., 2012). Evidently, there is some danger in assuming that tier one (low risk) grievers will rely entirely on informal social networks following a loss, when evidence suggests that these supports are not consistently available, sufficiently skilled, or unconditionally willing to provide support. A more comprehensive account of what constitutes helpful or unhelpful support, from the perspective of bereaved persons, will be integral in determining how community capacity to provide social support can be improved. The small number of studies that have explicitly described social support needs, from the perspective of bereaved persons, focus primarily on middle to older adults experiencing parental, spousal, or other close relative bereavement (Benkel et al., 2009a, 2009b; Gear, 2014; Li & Chen, 2016). It is reasonable to assume that the emotional, instrumental, and informational support needs of these individuals may differ substantially from those affected by deaths that typically receive less attention (e.g., friends, neighbours, colleagues) or are viewed as less impactful (e.g., death of a parent or grandparent in later life).

Across a range of bereavements, this research will seek to address key gaps through clarifying specific support needs in preparation for death, immediately following death, and—not often recognised—in the many months and years after a loss (Dyregrov, 2011), and will identify how social support may be facilitated or inhibited when two or more individuals are grieving the same loss (Toller, 2011). With this understanding, it will be possible to describe the unique (and often complementary) role of informal supports in adaptation to loss and offer direction for grief education, both for the lay public and health professionals. From a preventative health perspective, with knowledge of the influence of social support on psychosocial outcomes and the typical informal support needs of bereaved individuals, counselling psychologists may be able to assess and intervene prior to, or immediately

following, bereavement to promote the harnessing and upskilling of existing supports (L. A. Burke & Neimeyer, 2013). This thesis will contribute to a proposed new program of research exploring the development of community bereavement care (Breen et al., 2017), providing impetus for further focused study and encouraging collaboration between health professionals and community to translate the compassionate communities model outside the domain of palliative and end-of-life care.

2.11   Conclusion

This chapter has presented a comprehensive background to the research through highlighting the idiosyncratic nature of grief, particularly in terms of how key risk and protective factors may alter the course of 'typical' grief and predict grief complications. A historical account of dominant grief theories was outlined, situating grief in current diagnostic nosology, and considering barriers to and impacts of formal help-seeking. Recognising the limitations of viewing grief as an intrapsychic, intrapersonal phenomenon, attention was given to highlighting the intersubjective nature of grief and the influence of public discourse on the expression of grief and experience of social support. Finally, this chapter considered ways in which death and grief education and the development of compassionate communities might further resist the discourse and provide better informal support for people who are bereaved. Considering key limitations of existing research, the chapter concluded with a rationale for the present study. The following chapter (Chapter Three) outlines the underlying philosophy, methodology, and methods chosen to address the research aims and objectives listed in Chapter One.

Chapter 3   Research Methodology

"Study what interests you and is of value to you, study it in the different ways that you deem appropriate, and utilize the results in ways that can bring about positive consequences within your value system."

(Tashakkori & Teddlie, 1998, p. 30)

3.1   Chapter Overview

This chapter describes the research methodology for exploring the conceptualisation of grief, both from the experience of the bereaved and their network of natural supporters. The chapter begins with an explanation for the choice of pragmatism as the underlying philosophy guiding the development, execution, and presentation of this research. The application of a mixed methods design for addressing the research objectives is outlined, along with a review of the strengths and limitations of this research design for bereavement enquiry. This is followed by a brief summary of the three phases of study, highlighting how each phase informs the next. The chapter concludes with ethical considerations related to Phases Two and Three of the research, with particular attention given to the required sensitivities of conducting research with bereaved and vulnerable populations.

3.2   Research Design

3.2.1   Pragmatism as philosophy

As an underlying philosophy, the goal of pragmatism is to "gain knowledge in the pursuit of desired ends" (Morgan, 2007, p. 69). The tradition of pragmatism followed here originates from the works of John Dewey, Charles Sanders Pierce, and William James (R. B. Johnson & Onwuegbuzie, 2004). This form of pragmatic research is problem, rather than methods-driven, honouring multiple approaches to address a broad research aim with the goal of informing theory and practice (Lincoln, Lynham, & Guba, 2011). This approach is congruent with the aim of the present research; that is, to build knowledge on the nature, extent, and influence of grief-related norms in Australia in order to inform recommendations for clinical practice and grief education. The choice of this philosophy is particularly fitting given that counselling psychology in Australia has its philosophical roots in pragmatism, viewing people and their issues from multiple angles and adopting the notion of "if it works, do it, if it doesn't, don't" (Meteyard & O'Hara, 2016, p. 26). Pragmatism may be understood as a series of beliefs about

the nature of reality (ontology), how reality is known and emerges in the relationship between the researcher and the researched (epistemology), the role of values in research (axiology), and the fittingness of data collection and analysis approaches (methodology; Creswell, 2013), as outlined below.

From a pragmatist perspective, there is not considered to be a single or multiple realities, but rather reality is synonymous with what is deemed practical and workable (Lincoln et al., 2011). Rather than querying whether a piece of knowledge accurately mirrors or represents an underlying reality, pragmatism instead queries how a piece of knowledge serves a predetermined purpose; that is, how it can be used as a tool for action (Cornish & Gillespie, 2009). This approach fits well with the study of bereavement which recognises that grief is a socially embedded phenomenon which, although occurring universally, is experienced differently by bereaved individuals and members of their social networks according to what they hold to be meaningful and true (Breen & O'Connor, 2007). Pragmatist researchers purport that knowledge can be uncovered through a combination of deductive and inductive evidence, assuming an ongoing transaction between an organism and their environment (Lincoln et al., 2011). Therefore, depending on methods of data collection and analysis, pragmatist researchers may shift between standing on the objective edge of the research and engaging in a highly interactive relationship with their participants (Teddlie & Tashakkori, 2009). This epistemological position appears appropriate to bereavement enquiry where, as described in Chapter One, the researcher often takes an 'in the middle' position, traversing the divide between being an observant outsider of the researcher and an involved insider. Similarly, values have an important role in this form of research and are viewed as co-contributed by both the researcher and participant (Lincoln et al., 2011). This is evident through both the researcher and participant bringing their own personal, cultural, and historical experiences to the research, which ultimately shape conceptualisations, perspectives, and discourses of grief. Finally, pragmatism acknowledges the merits of both qualitative and quantitative approaches, with the selected methodology and methods contingent on the specific research questions asked (Muijs, 2011).

3.2.2   Mixed methods

Mixed method designs have been recognised as the natural partner of pragmatism, offering a sophisticated approach to collecting and synthesising multiple forms of data when one alone cannot holistically answer a research question (R. B. Johnson & Onwuegbuzie, 2004). Referred to as the 'third' methodological movement or research paradigm, mixed methods poses a neat solution to past paradigm wars through offering "an approach to knowledge (theory and practice) that attempts to consider multiple viewpoints, perspectives,

positions, and standpoints" (J. G. Johnson, Onwuegbuzie, & Turner, 2007, p. 113). Mixed methods operates on the premise that there are numerous ways of making sense of social phenomena and numerous valid perspectives on what is meaningful and valuable (Greene, 2008). As will be outlined in Chapter Four, grief-related norm research has evolved within a vacuum, such that researchers in this field typically show limited knowledge of or regard for other conceptually-related studies. Evidently, developing a holistic account of societal norms for grief—in terms of how they originate, what sustains them, and what influence they have—requires looking beyond current one-dimensional studies that only explain in isolation (1) what factors predict community perceptions of and responses towards grief and (2) how social support (or a lack thereof) is experienced by bereaved people.

The present research adopts the paradigm perspective outlined by Creswell and Tashakkori (2007), who argued that "mixed methods is less about methods or the process of research and more about the philosophical assumptions that researchers bring to their inquiries" (p. 305). In this way, mixed methods is viewed as a methodology (rather than a method), with a concrete pragmatist underpinning, which informs the choice of methods across the related studies contained within it (Creswell & Plano Clark, 2011). Respecting the tensions that can exist between multiple methods, this study sought to adhere to the quality criteria for combining quantitative and qualitative research proposed by Bryman, Becker, and Sempik (2008). This approach indicates that there should be a strong rationale for choosing mixed methods, procedures should be transparent, and findings across all phases should be integrated based on an overarching research aim. Similarly, the methods for assessing rigour and quality in each phase should parallel between the quantitative and qualitative components with a focus on truth value, applicability, consistency, and neutrality (Lincoln & Guba, 1985).

3.2.3   Strengths and limitations of the chosen design

The first key tension in mixed methods research is how to combine the seemingly contrasting positivist/post-positivist epistemologies of quantitative methods (where independent knowledge exists) with the constructionist/interpretive epistemologies of qualitative methods (where knowledge is subjective and culturally embedded; Creswell, Plano Clark, Gutmann, & Hanson, 2003). However, as mixed methods research has grown, so too has the argument for a less rigid, eclectic approach where a researcher may shift between worldviews across different phases of the research (Creswell & Tashakkori, 2007). A reasonable solution is to employ a single underlying philosophy (e.g., pragmatism) which acknowledges the traditionally distinct epistemological differences between qualitative and quantitative research (without viewing them as incompatible), and maximises their collective potential to answer complex research questions (Bishop, 2015). Through this lens, research is

assumed to be abductive (rather than inductive or deductive), intersubjective (rather than subjective or objective), and transferable (rather than context-specific or generalisable; Morgan, 2007).

Second, although pragmatism focuses on pursuing knowledge to offer feasible and meaningful solutions, R. B. Johnson and Onwuegbuzie (2004) argue that many pragmatist researchers fail to define *for whom* and *how* these solutions may be useful in real-world settings. This notion has been well recognised in the bereavement literature and aptly termed the 'so what?' test (D. A. Lund & Caserta, 1997). From early planning stages, this research was designed with three goals in mind: (1) to address limitations and provide a significant contribution to the thanatological literature, specifically that which focuses on social norms for grief and both the provision and receipt of social support following bereavement; (2) to devise practical recommendations to enhance community-wide grief education practices, considering the needs of both the general public and mental health professionals working with grief and loss; and (3) to inform clinical practice with bereaved populations, contextualising their grief within a broader social context and recognising the beliefs and worldviews they may bring to both formal and informal support systems. From this stance, the research had a clear 'desired end' and was focused on advancing knowledge and recognising both theoretical and practical implications for individuals and community.

Third, Creswell and Plano Clark (2011) argue that choosing amongst typologies of mixed method design require sound knowledge of the nature of the research questions and intended consequences of the research findings. In the context of this research, an explanatory sequential design was chosen for its congruence with the timing and emphasis planned for each study phase. As acknowledged by Feilzer (2010), such research also requires a certain skill in the researcher to comfortably shift between the roles of planner/designer, pollster, interviewer, statistician, analyst, writer, and advocator. Developing a supervisory committee that combined both qualitative and quantitative expertise was, therefore, recognised as particularly important for the successful and quality execution of this research project.

Despite some limitations, pragmatism and mixed methods were chosen as the logical framework for this research, recognising that no single worldview, methodology, or method could account for the complexity of this phenomenon, nor respond to the range of contexts—historical, political, social, cultural, and spiritual—in which grief is constructed. An obvious strength of this methodology is its already widespread use across the bereavement literature (e.g., Benkel et al., 2009a; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; S. B. Scott et al., 2007). These studies have recognised the potential of pluralistic methods to deepen understandings of phenomena through examining the complexity of grief from numerous

perspectives and different informants using multiple forms of knowledge. Another key advantage of this framework is that research informed by pragmatism does not assume a single, unchangeable truth (Lincoln et al., 2011). This assumption is particularly important given that this research theorises grief as a highly individual and unique phenomenon and does not seek to reduce the experience of bereaved individuals or their network of supporters into a prescribed single model.

3.3   Summary of Study Phases

The proposed research adopted an explanatory sequential mixed methods research design conducted across three phases (Figure 3.1). For each individual phase, the research question(s) were informed by previous phases but developed from within that phase's framework (i.e., quantitative within quantitative and qualitative within qualitative). The research commenced with a systematic review (incorporating both qualitative and quantitative evidence), which informed the development of a quantitative study, which shaped the design of a qualitative study. It was anticipated that Phases One and Two would set the groundwork for the research, while Phase Three would contextualise those findings and elaborate on their meaning in the form of lived experiences. No one phase or method was viewed as intrinsically more important than any other; rather, sequential components were weighted equally and in parallel to inform current understandings of societal norms for grief and how they are experienced by bereaved people. Following Moran-Ellis et al.'s (2006) 'interpretive integration' process, each phase of the research comprised independent methods and analyses (Chapters Four to Six), followed by a theoretical integration of findings to address the overarching research aim and propose recommendations (Chapter Seven).

Systematic Review

How do characteristics of the bereaved, the decedent, and the respondent impact on community responses to bereavement in terms of expectations of, beliefs about, evaluations of, and intentions to act towards bereaved people?

PHASE ONE

Informing the development of manipulations and sample selection

Community Survey

How do bereavement status, anticipation of the death, and level of social support affect expectations of grief symptomatology and intentions to provide social support to grieving persons? What effect does bereavement status have on beliefs about social support and endorsement of a grief-related diagnostic classification?

PHASE TWO

Informing theoretical sampling and interview guide

Bereaved Interviews

How do bereaved people experience societal norms, as expressed through beliefs, expectations, and assumptions, in the context of their own grief? What coping mechanisms or strategies are adopted to reconcile these norms with their actual experience of grief and mourning? How do bereaved people reflect on needs, both from the self and others, as integral to facilitating the grief experience?

PHASE THREE

Interpretive Integration

- Integration of phases
- Interpretations and implications
- Recommendations for research, practice, and community

SYNTHESIS

Figure 3.1. Research questions across the three study phases.

3.3.1   Phase one

The first phase comprised a systematic review of previous literature exploring community perceptions of, and responses towards, grief. The purpose of this phase was to examine community definitions of 'normal' grief, highlighting strengths and gaps in the current literature base. The necessity of conducting such a review was highlighted in the very early stages of this research, recognising that the last review (albeit not systematic) was published 26 years ago (Calhoun & Allen, 1991), and subsequent research has been highly scattered and often repetitive. A systematic review of the literature was recognised for its potential to establish a solid foundation for the research project and ensure subsequent study phases were theoretically informed.

The Phase One review was guided by the following research question: how do characteristics of the bereaved, the decedent, and the respondent impact on community responses to bereavement in terms of expectations of, beliefs about, evaluations of, and intentions to act towards bereaved people? The search strategy, screening criteria, and analysis plan for this review were specified *a priori* through a protocol registered with the International Prospective Register of Systematic Reviews (PROSPERO; Appendix D). The review was conducted between January and March 2015 (with an update in January 2016 prior to publication). PubMed, EMBASE, ProQuest Central, CINAHL Plus, PsychINFO, The Cochrane Database of Systematic Reviews, ProQuest Dissertations and Theses, NHS Evidence, and OpenGrey were searched using the following keywords: bereavement OR grief AND social norms OR judgment OR social support OR helping behaviour OR expectation OR belief OR evaluation. Additional articles were identified through a reference list and citation search, as well as hand-searching seven key journals.

Two independent raters assessed the eligibility of studies for inclusion based upon predetermined criteria. The data from chosen studies were extracted into a standardised spreadsheet and data were analysed using narrative synthesis (Popay et al., 2006). Included studies were assessed using the QualSyst quality appraisal tools (Kmet, Lee, & Cook, 2004) and the final review was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). A comprehensive account of Phase One is included in Chapter Four.

3.3.2   Phase two

Based on the findings of the systematic review, the second phase was designed as a quantitative investigation of some of the less well-researched areas in an online sample of the

general Australian public. The purpose of this phase was to highlight the influence of some key determinants on perceptions of, and intentions to provide social support towards, grieving persons. A quantitative approach was the most efficient approach to assessing societal norms through examining associations between a number of key manipulations and relevant outcome variables. Online data collection was chosen due to its suitability in previous related studies (e.g., Egnoto, Sirianni, Ortega, & Stefanone, 2014; Penman et al., 2014; Tedrick Parikh & Servaty-Seib, 2013) and its potential to gather a large sample that would be reflective of the broader Australian population (necessary when discussing social norms). This choice is supported by research by Tolstikova and Chartier (2010) whose results suggest that responses to outcome measures do not differ between online and offline bereaved samples, but online samples may achieve greater diversity in demographic characteristics (e.g., time since death and cause of death) and may attract a larger sample more quickly.

Phase Two asked whether (1) bereavement status, anticipation of the death, and level of social support affect expectations of grief symptomatology and intentions to provide social support to grieving persons, and (2) beliefs about the helpfulness of support-intended statements and endorsement of a grief-related diagnostic classification depend on past bereavement experience. Participants were 476 Australian adults (394 women, 82 men), aged between 18 and 93 years, recruited through convenience and purposive sampling. Participants self-identified according to whether they had been significantly impacted by bereavement (n = 54.8%) or not. Participants read an information statement and consent form (Appendix E) before participating in the study. Data were gathered through an online community survey hosted on Qualtrics® (Appendix F). Participants were exposed to one of four versions of a hypothetical experimental vignette which manipulated the anticipation of the death (sudden/unexpected, prolonged/expected) and level of social support (little, a lot) relating to a bereaved person. Two scales measured participants' reactions to this vignette in terms of expectations of grief symptomatology (12 items) and intentions to provide social support (5 items). Separate from the vignette, participants then completed a further two scales measuring their beliefs about the helpfulness of a range of support-intended statements (64 items) and the extent to which they agreed that certain manifestations of grief might warrant a grief-related diagnostic classification (2 items). The survey also measured participants' age, gender, country of birth, religion, education, occupational status, profession, professional exposure to/training in grief, and social desirability as potential covariates.

Quantitative data were analysed through a series of Generalised Linear Mixed Models (GLMMs) using the Statistical Package for the Social Sciences (SPSS® v20). Qualitative data

were analysed using Hsieh and Shannon's (2005) content analysis. A comprehensive account of Phase Two is included in Chapter Five.

3.3.3   Phase three

Stemming from the findings of Phases One and Two, the third phase followed up with qualitative in-depth interviews to explore bereaved individuals' experiences of grief-related norms and their impact on grief, mourning rituals, and the receipt of social support. The sampling strategy for this phase was informed by Phase Two and it was anticipated that its findings might help to generate explanations for some of the significant and non-significant results in Phase Two. A qualitative approach was viewed as most appropriate for this phase due to the underlying focus of the research questions on *exploring* processes, *uncovering* meanings, and *giving voice* to experiences that have traditionally been silenced (Creswell, 2013).

Phase Three asked the following questions: (1) how do bereaved people experience societal norms, as expressed through beliefs, expectations, and assumptions, in the context of their own grief; (2) what coping mechanisms or strategies are adopted by bereaved people to reconcile these norms with their actual experience of grief and mourning; and (3) how do bereaved people reflect on needs, both of the self and others, as integral to facilitating their grief experience? Respondents were 19 adults (13 women, 6 men), aged between 21 and 76 years, recruited through theoretical sampling. One or more significant bereavements were discussed by each respondent, with the time since death ranging from 1 month to 29 years. Respondents read an information sheet and consent form (Appendix G) prior to agreeing to the study. A semi-structured interview guide elicited information about the nature of the bereavement and grief reactions; expectations, experiences, and needs relating to support; personal reactions to how the grief was recognised and responded to; the nature and impact of personal beliefs and expectations about grief; and impacts of the grief experience and wisdom gained (Appendix H). Respondents also completed scales measuring their grief symptomatology, quality of life enjoyment and satisfaction, and demographic variables (Appendices I-K). Interviews were audio recorded and transcribed using Playscript transcription. Should distress arise, respondents were offered a list of local bereavement support services (Appendix L). NVivo® version 11 was used to manage the transcriptions and provide a platform for coding and categorising the data.

Data were analysed using the constant comparative method (CCM), a methodological technique that develops a conceptualisation of a social phenomenon that is grounded in the data (Glaser, 1965; Glaser & Strauss, 1967). To augment the rigour of the analysis, the

researcher engaged in memo-writing and reflexive journaling throughout Phase Three to document preliminary and emerging thoughts that had potential to influence data collection and analysis (Mays & Pope, 2000). Regular meetings were held with the supervisory team (experienced in qualitative research and counselling psychology practice) to discuss patterns in the data and respondent validation was used to invite comments and suggestions from the respondents on the final draft of findings. A comprehensive account of Phase Three is included in Chapter Six.

3.4   Ethical Considerations

Bereaved individuals are considered a vulnerable population to whom special ethical considerations apply when conducting research. Although ethics committees have traditionally steered away from or taken extreme precautions concerning research with vulnerable groups (Moore, Maple, Mitchell, & Cerel, 2013), evidence over the last decade suggests that limiting access might not only restrict the evidence base, but may also deprive bereaved individuals of a range of benefits (Alexander, 2010). Despite sometimes experiencing intense emotional reactions, the majority of bereaved people do not describe research engagement as adverse and report the impact of participation as overwhelmingly positive (Buckle et al., 2010). Following participation in grief-related research, bereaved individuals have reported benefiting from therapeutic or cathartic gains, social connection, insight, meaning-making, and the altruism of knowing that one's experiences might help others (Buckle et al., 2010; Dyregrov, Dieserud, Hjemeland, et al., 2011; Koffman et al., 2011). Likewise, in a study of bereaved individuals who had *not* previously participated in any bereavement research, Beck and Konnert (2007) found that the majority perceived bereavement research as worthwhile (98.1%), and beneficial to the self (84.4%) and others (94.0%). Risk of an adverse experience in bereavement research is considered lowest when bereaved individuals are competent to consent (e.g., showing rational thinking and ability to regulate emotion), are given adequate time and space to express their feelings, and have the sense that they are understood by the researcher (Beck & Konnert, 2007). Consequently, the researcher focused on demonstrating skill, experience, respect, and sensitivity in responding to and holding each grief story throughout the interviews (Dyregrov, Dieserud, Hjemeland, et al., 2011).

Prior to commencing the research, ethics approval was granted by the Curtin University Human Research Ethics Committee (HREC), approval number RDHS-12-15. The National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2007) and Australian Psychological Society Code of Ethics (Australian

Psychological Society, 2007) were adhered to in the design, collection, and reporting of data. Phases Two and Three required the collection of data from human participants and thus attention was given to ensuring informed consent was given, the research ensured greater good than harm to participants (beneficence), data were treated as private and confidential, and procedures were in place for the safe storage and handling of data.

3.4.1 Informed consent

In both phases, a minimum age of 18 years was set, recognising the sensitivity of the topic and importance of full informed consent. In Phase Two, participants read an information statement and consent form prior to entering the survey. This declaration informed participants of the purpose and requirements of the study, potential risks and benefits to participation, and provisions for use of the data. Participants were only permitted to move onto the survey once they had ticked a box of consent and entered their age as 18 years or above. It was made clear that participation was voluntary and participants could choose to withdraw from the study without consequence by closing their web browser at any point during the data collection process. Participants were advised that their online data was non-identifiable, therefore, captured data could not be deleted should they choose to withdraw from the study.

In Phase Three, respondents read an information statement and consent form prior to scheduling an interview. This declaration informed respondents of the purpose and requirements of the study, potential risks and benefits to participation, provisions for use of the data, and the necessity of audio recording. Respondents were invited to have a family member or friend sit with them during the interview (although no respondents actually chose to do so). When scheduling the interview (via telephone or email), respondents were informed about what to expect during the interview and were invited to ask any questions. At the beginning of the interview, respondents were given a paper copy of the information statement and consent form, with no interview commencing until the respondent showed a complete understanding of what participation entailed, had any questions answered, and signed the consent form. It was made clear that participation was voluntary and respondents could choose to pause, stop the interview, or withdraw completely without consequence. Respondents were advised that if they withdrew from the study at any point, all information they had provided would be confidentially destroyed.

3.4.2 Non-maleficence and beneficence

Across both phases of data collection, it was expected that the potential benefits of this research would outweigh any potential risks. In Phase Two, participants were asked to refrain

from participating in the study if they expected to experience significant distress as a result. Contacts for mental health supports were offered at the beginning of the survey so that they were available to all participants, regardless of completion status. As an acknowledgement of time and effort, participants were given the opportunity to enter a prize draw to win one of four $50 iTunes/Amazon gift cards following completion of the survey, or have the sum of the voucher donated to a charity of their choosing.

Recognising the greater degree of self-disclosure in Phase Three, several strategies were put in place to ensure that the benefits of participation outweighed any potential risks to the bereaved individuals. As recommended by Buckle et al. (2010), it was made clear that the welfare of respondents came before the welfare of the research. Although a semi-structured interview guide was flexibly followed, respondents were invited to direct the course of the interviews and build their grief narrative according to how they made sense of it (Williams et al., 2008). Buckle et al. (2010) pose the following question: "are we *causing* or *inducing* pain when we ask research participants about their experience of the death of their loved one or are we bearing witness to the pain that is already there?" (p. 117). It was anticipated that the opportunity to express one's grief and have it empathically listened to would result in greater good than harm and could ameliorate some of the isolation often reported in bereavement. Even so, throughout the interviews respondent distress was carefully monitored, queried, and responded to. There is little consensus amongst bereaved individuals about when and how is appropriate to contact a bereaved person to invite them to participate in a grief-related study (Beck & Konnert, 2007). Consequently, no constraints were passed on the time that had passed since the death, but rather it was decided on theoretical grounds that respondents should decide *if* and *when* they were prepared to discuss their bereavement (Williams et al., 2008). In line with recommendations by Dyregrov (2004), respondents were encouraged to choose a location for the interview which they identified as safe and private, given time to pause and reflect throughout the interviews, and invited to review and offer feedback on the findings. A list of bereavement-specific mental health supports was given to respondents upon completion of the interview and again when the respondent validation was sent out. In recognition of their time, respondents were offered a $15 Coles/Myer gift card, or have the sum of the voucher donated to a charity of their choosing.

3.4.3   Privacy and confidentiality

Through online data collection, participants in Phase Two were non-identifiable and offered complete anonymity in participation. The main survey and prize draw survey were conducted independent of each other, ensuring participants' email addresses could not be linked to their survey data. To facilitate the process of respondent validation in Phase Three,

respondents were re-identifiable through allocation of a unique identification number at the point of interview which permitted cross-reference between their consent form and data. Respondents were known only to the researcher and following interview transcription, all audio files were permanently deleted. Across both study phases, participants were not referred to by name in any resultant publications. In Phase Two, complete anonymity of participants was preserved and in Phase Three, pseudonyms were chosen to only reflect the gender of the respondent.

3.4.4 Data storage and handling

All audio recordings, digital transcripts, and data files were stored in a private file on a password-protected computer at Curtin University. For Phase Three, all consent forms, demographic questionnaires, self-report measures, and respondent validation letters were stored in a locked filing cabinet in an office at Curtin University. Only the researcher and supervisory team were granted access to the data and its contents will remain stored for a period of seven years before being securely disposed of as per ethical requirements.

3.5 Conclusion

This chapter comprised an overview of the methodology and methods used to collect and synthesise the data which addressed the overarching research aim. The rationale for adopting a pragmatist philosophy and mixed method design was outlined, alongside a summary of key strengths and limitations of this approach for bereavement enquiry. The research was briefly described, across its three phases, with detailed discussion of the participants, methods, procedures, and data analysis presented across Chapters Four, Five, and Six. The chapter concludes with a review of ethical considerations relating to bereavement research and this project specifically. The following chapter (Chapter Four) offers a detailed description of Phase One of the research, a systematic review of the literature exploring key determinants of social support following bereavement.

Chapter 4   What Determines Supportive Behaviours Following Bereavement? A Systematic Review and Call to Action

"I see people, as they approach me, trying to make up their minds whether they'll 'say something about it' or not. I hate if they do, and if they don't."

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(Lewis, 1961, p. 11)

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4.1   Chapter Overview

This chapter presents a summary of the first phase of this research, a systematic review of the literature exploring bereaved, decedent, and respondent-related determinants of the provision of social support following bereavement. This systematic review, titled "What determines supportive behaviours following bereavement? A systematic review and call to action" (Logan, Thornton, & Breen, 2017) is published in *Death Studies*, a premier international peer-reviewed journal disseminating empirical research on death and dying, bereavement and loss, and grief therapy to an interdisciplinary professional audience. The Accepted Manuscript below offers an in-depth analysis of the scope, quality, and contribution of published papers in this topic area between 1979 and 2015. The chapter concludes with broad conclusions about the potential implications of these findings and makes recommendations for future research. The findings of this systematic review were central to selecting the manipulations and sample for the experimental study in Phase Two (Chapter Five) and shaping the interview guide for the qualitative study in Phase Three (Chapter Six).

Logan, E. L., Thornton, J. A., & Breen, L. J. (2017). What determines supportive behaviours following bereavement? A systematic review and call to action. *Death Studies*. http://dx.doi.org/10.1080/07481187.2017.1329760

4.2 Abstract

Very few factors that impact the grieving process can be modified after the fact to the extent that social support can. However, social support has received limited research attention, resulting in little conceptual understanding of the mechanisms behind perceptions of, and intentions to support, grieving persons. This systematic review aimed to explore bereaved, decedent, and respondent-related determinants of the provision of social support. The review yielded 42 studies impacted by various methodological and sampling limitations. This review poses a call to the field for more rigorous study of social support determinants to better assist the bereaved and their natural supporters.

Keywords: systematic review; bereavement; grief; community norms; social support

4.3 Introduction

The provision of helpful, timely social support is one of the strongest determinants of positive psychosocial outcomes following bereavement (Hibberd, Elwood, & Galovski, 2010). Although a multitude of factors (e.g., attachment to the deceased or cause of death) may complicate the grieving process (Lobb et al., 2010), very few of these can be modified after the fact to the extent that social support can (Bath, 2009). However, bereaved people often do not receive the quantity or quality of social support that they would like (Aoun et al., 2015). For social support to be effective, a need must be recognised, the potential supporter must be capable and willing, and the gesture must be perceived as helpful by the receiver (Kaunonen et al., 1999; Rando, 1993). Doka (1989) was the first to theorise the provision of social support as a function of 'grieving rules,' that is, principles that govern who should grieve, when, where, how, for how long, and for whom. Bound by these rules, losses are appraised as either enfranchised and legitimate, or disenfranchised and illegitimate. While an enfranchised loss promotes offerings of instrumental and/or emotional support, when a loss is disenfranchised, the grief is not recognised or validated and support is generally not offered (Doka, 1989).

Although the role of informal supports in mediating the grief experience is increasingly well recognised, efforts to promote and enhance the community's capacity to provide bereavement support remain limited (Breen et al., 2017). Within the grief literature, there appears to be considerable emphasis on the experience of the bereaved, but far less so on the potential supporter and the mechanisms (i.e., determinants) that drive their perceptions of grief and intentions to provide social support (Bath, 2009). The authors know of only one other review that found four decedent-related determinants (cause of death, age, gender, family composition) and three respondent-related determinants (gender, age, experience with

bereavement) of social support following bereavement (Calhoun & Allen, 1991). However, their review comprised only studies previously known to those authors and focused solely on suicide bereavement.

Given the largest proportion of bereavement care occurs in communities, rather than professional settings (Aoun et al., 2015), a comprehensive understanding of the circumstances under which potential supporters respond to grieving persons is of critical importance. This study set out to search the thanatological literature to provide a systematic account of all determinants that may hinder or facilitate the provision of social support to grieving persons. Specifically, determinants of social support were conceptualised as those factors that influence community perceptions of, and behavioural intentions towards, bereaved people. A synthesis of this kind is important to inform and direct future research in this area, guide bereavement practitioners in their work with grieving persons, and develop a foundation from which to enhance and grow the community's capacity to provide bereavement support. In conducting this review, we were guided by the research question: How do characteristics of the bereaved, the decedent, and the respondent impact on community responses to bereavement in terms of expectations of, beliefs about, evaluations of, and intentions to act towards bereaved people?

4.4   Method

A systematic search of the literature was performed in January to March 2015 and updated in January 2016. Our search strategy, screening criteria, and analysis plan were specified *a priori* and registered with the International Prospective Register of Systematic Reviews (PROSPERO; www.crd.york.ac.uk/prospero), registration number CRD42015016095. The review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009).

4.4.1   Inclusion and exclusion criteria

Studies were considered if they described and/or manipulated one or more determinants which affect an individual's perception of and/or intended behaviours towards a bereaved person. Determinants could relate to the bereaved, the decedent, or the study respondent. Studies had to be published in English or available for English translation and all study designs and data types were eligible. Only studies that described original research, upon first publication, were included.

Given the focus on community capacity for support, studies were excluded if they specifically described responses to bereavement from the perspective of a bereaved person,

rather than their potential supporters. Similarly, studies examining specific respondent populations (e.g., health professionals or teachers) were excluded, in addition to those that did not clearly demarcate responses of specific populations from the general community. Studies were also deemed ineligible if full texts were not available once efforts to obtain a hard copy were exhausted.

4.4.2　Search strategy

An electronic search of databases was performed across PubMed, EMBASE, ProQuest Central, CINAHL Plus, PsychINFO, and the Cochrane Database of Systematic Reviews. Further studies were identified through grey literature searches of ProQuest Dissertations and Theses, NHS Evidence, and OpenGrey. The searches consisted of the keywords "bereavement" or "grief" AND "social norms" or "judgment" or "social support" or "helping behaviour" or "expectation or "belief" or "evaluation," with slight variations according to each database. No date or language restrictions were placed on the search. A reference list and citation search was also conducted to identify any further articles. Lastly, seven journals yielding the highest number of articles were hand-searched (Death Studies, Omega, Journal of Psychology, Journal of Consulting and Clinical Psychology, International Journal of Palliative Nursing, Bereavement Care, and Journal of Cultural Diversity).

4.4.3　Study selection and data extraction

Title and abstract screening was followed by an inspection of full text articles. A random 10% of full texts were reviewed by authors one and three with an inter-rater Cohen's Kappa reliability of .80 indicating substantial agreement (Landis & Koch, 1977). Disagreements were resolved by consensus and selection of the remaining 90% was determined by the first author.

Data were extracted from each study into a standardised, pre-piloted spreadsheet. Key variables included study characteristics, sample characteristics, determinant and outcome measurement, and direction and nature of reported effects. Data extraction of a random 10% of included studies were independently conducted by authors one and three to ensure consistency of reporting. Differences were discussed and data in the remaining 90% of studies were extracted by the first author.

4.4.4　Quality assessment

A quality assessment of the included studies was performed using the QualSyst quality appraisal tools (Kmet et al., 2004). Mixed-method studies were evaluated using both the

quantitative and qualitative checklists. Each study was scored out of 1 with quality appraised as: limited (less than .50), adequate (.50-.70), good (.70-.80), or strong (greater than .80). No studies were excluded on the basis of poor quality; however, limitations were considered in the reporting of findings.

4.4.5 Analysis

Heterogeneity in study designs, samples, and measurement of outcomes precluded the consideration of meta-analysis. To account for the breadth in study designs, a narrative synthesis was conducted following the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews (Popay et al., 2006).

4.5 Results

4.5.1 Study characteristics

Defining the research question and subsequent search words for this particular review using the traditional PICOS (population, intervention, comparator, outcome, study design) criteria proposed by The Cochrane Collaboration (Higgins & Green, 2008) proved challenging. This was due, in part, to the lack of a comparison/control group and a broad interest in all study designs, but could also be attributed to the generic nature of the keywords (e.g., belief, evaluation, judgment) relevant for describing the outcomes of interest. Consequently, although the authors developed a relatively narrow set of keywords, the initial database searches still yielded a total of 12967 studies.

After duplicates were removed, 9879 studies remained, of which 9769 were excluded on the basis of their title and/or abstract. Key reasons for exclusion included that the study did not describe or manipulate at least one variable that determines perceptions of/intended behaviours towards the bereaved, the sample was specific to one area of the population (e.g., teachers), and the study described responses to bereavement from the perspective of the bereaved rather than their potential supporters (e.g., narratives of how the bereaved recall being enfranchised/disenfranchised by others). Full texts of the remaining 110 studies were assessed for eligibility. At this point, 20 additional studies were identified through hand searches of relevant journals, reference list searches, and citation searches. Of the 130 studies, 88 were excluded leaving 42 studies accepted for inclusion in the review. Reasons for exclusion were very similar to those described above, with some decisions unable to be made at the title/abstract screening phase due to a lack of published detail. Studies were published

between 1979 and 2015, with 37 being journal articles and five unpublished theses/dissertations (see Figure 4.1).
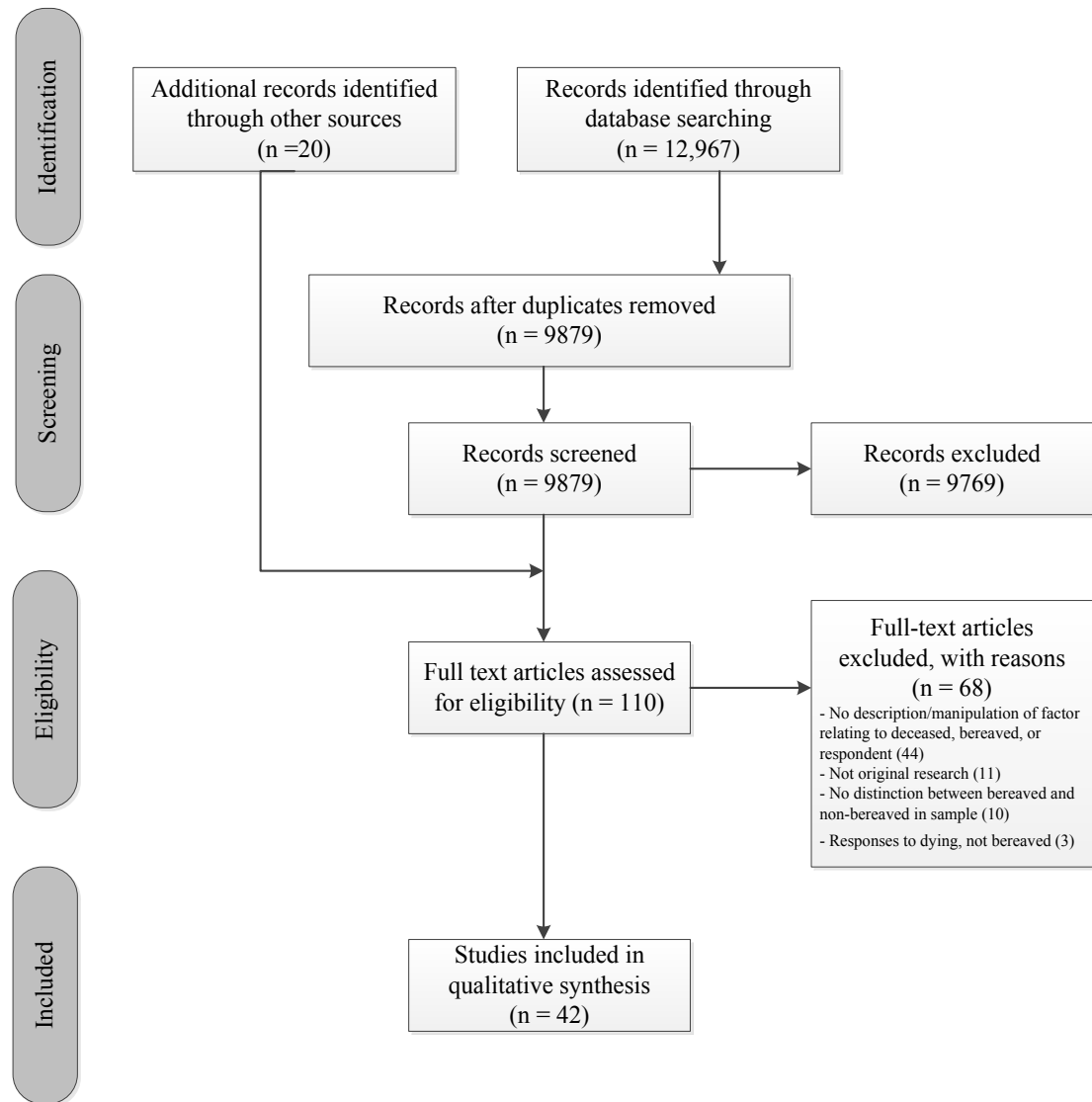
Figure 4.1. PRISMA flow chart of study selection and results.

The majority (*n* = 31) of included studies were quantitative, three were qualitative, and eight mixed-methods. There were 21 experimental (19 between-subjects and 2 within-subjects), 19 cross-sectional survey, and two exploratory qualitative designs. The experimental studies commonly presented participants with one version of a vignette, exploring how response outcomes differed dependent on levels of one or more manipulations in the vignette (as well as specific respondent characteristics). The cross-sectional and qualitative studies more generally explored participants' perceptions of grief or behavioural intentions towards grieving persons. The studies originated from: USA (*n* = 34), Australia (*n* = 2), Japan (*n* = 2), Ireland (*n* = 1), Norway (*n* = 1), UK (*n* = 1), and Spain (*n* = 1).

4.5.2   Quality appraisal and risk of bias

The included studies varied greatly in terms of study design, standards of reporting, and quality. The overall quality of the included studies was adequate for the quantitative studies (and mixed-methods quantitative) with an average score of .68 (*SD* = 0.13, range = .43-.95), and good for the qualitative studies (and mixed-methods qualitative) with an average score of .74 (*SD* = 0.13, range = .55-.90).

4.5.2.1   Participant selection

Despite attempting to represent general community experiences, there was a high likelihood of selection bias across the included studies due to unrepresentative sampling and mixed response rates. In the majority of cases, participants were recruited via convenience sampling (e.g., universities, shopping malls, churches, and schools). Of the 39 quantitative and mixed-method studies, only six reported response rates, ranging from 45% to 99%.

4.5.2.2   Confounding bias

Thirty-three of the studies conducted between-groups analyses, yet only six studies analysed group differences and of these, only two controlled for extraneous variables. None of the 21 studies employing experimental factorial designs reported post-manipulation checks. Post-manipulation checks are advocated as a method of identifying participants who overlook key information to minimise cognitive effort in completing the task (Krosniak, 1991). Despite the likely influence of confounding variables, only 10 studies investigated the effects of participants' own experiences of bereavement (bereavement history) and none included a measure of social desirability.

4.5.2.3   Power to detect effects

Sample sizes varied from 9 to 5154 participants. However, of the 39 quantitative and mixed methods studies, only three reported conducting *a priori* power analyses to determine adequate sample size to detect potential effects. It is probable that a large proportion of studies were underpowered, obscuring true findings.

4.5.2.4   Study heterogeneity

Heterogeneity in study samples, manipulations, and measurement instruments limits the comparability of findings across studies and likely contributed to the dissimilarity in the direction of reported effects. All studies selected participants from the general community;

however, there was a trend towards over-representation of women and Caucasian people. The mean reported age varied from 17.6 years to 56.1 years. Only 12 studies reported the bereavement history of its participants, with anywhere between 37% and 99% of samples having grieved one or more losses. Bereavement response outcomes predominately comprised behaviours or behavioural intentions towards bereaved people (both of the self and as expected of others), beliefs and expectations about the grief experience, ratings of appropriateness of specified grief reactions, and interpersonal reactions towards bereaved people. In general, key outcome variables were poorly defined and few studies employed the same or similar measures, obfuscating the direct comparison of study findings. There was also a distinct lack of psychometrically-sound instruments.

4.5.3 Synthesis of findings

A summary of the 42 studies is reported across Tables 4.1-4.3, with the 41 determinants summarised under the areas of bereaved, decedent, and respondent.

4.5.3.1 Bereaved determinants

Across the bereaved-related category 10 determinants were identified across 20 studies. Gender of the bereaved was the most highly studied bereaved-related determinant with 10 out of the 12 studies reporting an effect. Compared to women, men were offered fewer opportunities to talk (Calhoun, Abernathy, & Selby, 1986), and were perceived to have more difficulty confronting grief and expressing feelings, especially in later life (Costa et al., 2007). The remaining studies reported interaction effects between gender of the bereaved and cause of death, gender of the respondent, intensity of grief, anticipation of death, and time since death (Calhoun et al., 1986; Ginn, Range, & Hailey, 1988; Knight, Elfenbein, & Messina-Soares, 1998; Kubitz, Thornton, & Robertson, 1989; Miller, 2014; Penman et al., 2014; Range, Bright, & Ginn, 1985; Thornton, Whittemore, & Robertson, 1989; Villa, 2010). Two studies found no gender effect for any response outcome (Calhoun, Selby, & Walton, 1985; Versalle & McDowell, 2004).

Time since death received the next greatest attention with all six studies indicating the expected resolution of grief over time. As time since death increased, grief was perceived as more maladaptive (Costa et al., 2007), respondents expected fewer grief-related symptoms (Garson, 1994; Penman et al., 2014) and more recovery-related indicators (Garson, 1994; Vickio, Cavanaugh, & Attig, 1990), social engagements were rated as more appropriate (Miller, 2014), the bereaved was offered less social support (Dyregrov, 2005-2006), and respondents were less willing to talk with the bereaved about the death (Garson, 1994).

Interaction effects were also identified between time since death and gender of the respondent, bereavement history, gender of the bereaved, and relationship to the deceased (Garson, 1994; Miller, 2014).

Relationship to the deceased was explored in five studies. Greater enfranchisement was given to bereaved children, spouses, and parents compared with more distant relatives/friends and less well recognised relationships (e.g., abortion; Costa et al., 2007; Miller, 2014; Reynolds & Cimbolic, 1988; Robson & Walter, 2012; Thornton, Robertson, & Mlecko, 1991). In one study, an interaction was observed between relationship to the deceased and time since death, with seeking a romantic partner rated as more appropriate over time and feelings of sorrow for oneself rated as less appropriate for those who lost a spouse than a child (Miller, 2014).

Perception of coping emerged across two studies. One found that, compared with typical grief, brief and prolonged forms of grief were rated as less common and less healthy, with an expectation that the bereaved would rate lower in role functioning and be offered less support (Rosenberger, 1996). The other study showed an interaction between perception of coping, gender of the bereaved, and anticipation of death (Kubitz et al., 1989). Respondents generally expected less intense grief for women bereaved by anticipated than sudden deaths (responding more favourably to those conforming to the norm); no such effect was observed for men.

Perceived social support was identified in two studies. When perceived social support was high, the bereaved person was assumed to be coping better (Costa et al., 2007) and less support was offered (Villa, 2010). In addition to the determinants described above, age (Costa et al., 2007), religion (Costa et al., 2007), affective response (Garson, 1994), disability (McEvoy & Smith, 2005), and gender stereotypes of grief (Versalle & McDowell, 2004) were also examined; however, each were only identified in single studies.

Table 4.1

Summary of Studies Examining the Effect of Bereaved-Related Determinants on Community Responses towards Bereavement

Factor	Reference	Study designs	Sample	Quality appraisal
Gender	Calhoun et al., 1986; Calhoun et al., 1985; Costa et al., 2007; Ginn et al., 1988; Knight et al., 1998; Kubitz et al., 1989; Miller, 2014; Penman et al., 2014; Range et al., 1985; Thornton et al., 1989; Versalle & McDowell, 2004; Villa, 2010	Experimental between-subjects design (n=8), experimental within-subjects design (n=2), qualitative (n=2)	University students (n=7), general citizens (n=2), shopping mall attendees (n=2), online responders (n=1). Sample size range: 9 to 237	.43-.90
Time since death	Costa et al., 2007; Dyregrov, 2005; Garson, 1994; Miller, 2014; Penman et al., 2014; Vickio et al., 1990	Survey design (n=4), qualitative (n=1), experimental within-subjects design (n=1), experimental between-subjects design (n=1)	University students (n=4), supporters of someone bereaved by SIDS or young suicide (n=1), parents of school-aged children (n=1), online responders (n=1). Sample size range: 9 to 348	.68-.94

Relationship to deceased	Costa et al., 2007; Miller, 2014; Reynolds & Cimbolic, 1988; Robson & Walter, 2012; Thornton et al., 1991	Experimental between-subjects design (*n*=2), qualitative (*n*=1), experimental within-subjects design (*n*=1), survey design (*n*=1)	University students (*n*=4), general citizens (*n*=1)	.43-.94
			Sample size range: 9 to 161	
Perception of coping	Kubitz et al., 1989; Rosenberger, 1996	Experimental between-subjects design (*n*=2),	University students (*n*=2)	.61-.68
			Sample size range: 159 to 172	
Perceived social support	Costa et al., 2007; Villa, 2010	Qualitative (*n*=2)	University students (*n*=2)	.85-.90
			Sample size range: 9 to 25	

4.5.3.2   Decedent determinants

The decedent-related category was least represented with only five determinants across 22 studies. Cause of death was the single most researched decedent-related determinant with all 17 studies reporting some effect. The cause of death most often researched was suicide, which was often compared to deaths caused by illness, accident, or natural causes. Specifically, suicidal deaths were associated with ratings of greater psychological disturbance in the decedent and the bereaved (B. G. Allen, Calhoun, Cann, & Tedeschi, 1993; Calhoun, Selby, & Faulstich, 1980, 1982; Ginn et al., 1988; Range et al., 1985; Rudestam & Imbroll, 1983; Yamanaka, 2015); less likeability of the bereaved (Calhoun et al., 1980; Yamanaka, 2015); greater shame, blame, and guilt attributions (B. G. Allen et al., 1993; Calhoun et al., 1980, 1982; Calhoun et al., 1985; Rudestam & Imbroll, 1983; Sand, Gordon, & Bresin, 2013; Yamanaka, 2015); a more difficult grief experience (Calhoun, Selby, & Abernathy, 1984; Calhoun et al., 1985; Ginn et al., 1988; Villa, 2010); greater anticipated tension in expressing sympathy to, and interacting with, the bereaved (Calhoun et al., 1986; Calhoun et al., 1984; Calhoun et al., 1985; Ginn et al., 1988; Villa, 2010; Yamanaka, 2015); assumptions of less support by others (Range & Thompson, 1987; Villa, 2010); and stronger beliefs about maintaining secrecy around the cause of death (Calhoun et al., 1980, 1982; Calhoun et al., 1985; Ginn et al., 1988). One study reported death by murder to be equally difficult as death by suicide (Calhoun et al., 1984). Ten of the studies also reported no effects of cause of death on: psychological disturbance of bereaved, likeability, blame and guilt attributions, intensity of grief and difficulty of the experience, anticipated support by others, anticipated tension and difficulty expressing sympathy to and interacting with the bereaved, and appropriateness of various help sources and helping statements (B. G. Allen et al., 1993; Calhoun et al., 1984; Calhoun et al., 1980; Calhoun et al., 1985; Ginn et al., 1988; Knight et al., 1998; Penman et al., 2014; Range & Thompson, 1987; K. E. Thompson & Range, 1990; Thornton et al., 1989).

Two out of five studies reported a significant effect for anticipation of death. In one study, anticipated deaths were described as easier to accept and resolve than unanticipated deaths (Costa et al., 2007). Another study reported an interaction effect between anticipation of death, gender of the bereaved, and intensity of grief symptoms (Kubitz et al., 1989). The other three studies found no effect of anticipation of death on perceived helpfulness of support-intended statements, blame attribution, appropriateness of grief reaction, impact of event, prediction of post-bereavement outcome, and perceived social support (Range & Thompson, 1987; Range, Walston, & Pollard, 1992; K. E. Thompson & Range, 1990).

Gender of the decedent was manipulated in four studies. The only significant finding showed an interaction effect between deceased gender and gender of the respondent, with

participants expecting to be more relaxed around the bereaved family when the decedent was the same gender as them (Calhoun, Selby, & Gribble, 1979). There was, however, no effect of gender of the decedent on psychological disturbance of the deceased or bereaved, likeability of the bereaved, blame attributions, duration of sadness, and behavioural intentions (Calhoun et al., 1980; Lester, 1990; Sand et al., 2013).

Two studies examined the effect of decedent age on responses to suicide bereavement. One study observed that parents bereaved by older child deaths were rated as more psychologically disturbed (yet more likeable) than if the child was younger (Range et al., 1985). Another study also reported an interaction effect between decedent age and cause of death; with a child or adolescent death, blame was greater for suicide than illness; with an adult death, there was no association between cause of death and blame attribution (Thornton et al., 1989). However, these two studies found no effect of decedent age on psychological disturbance or role functioning of the parents, blame attribution, severity and duration of grief reaction, expectations of tension and difficulty when visiting, and usefulness of various help sources (Range et al., 1985; Thornton et al., 1989).

Two studies examined the effect of motive for suicidal death on responses to the bereaved (Calhoun et al., 1979; Lester, 1990). In Lester's (1990) study, participants believed it to be more difficult to express sympathy to a person bereaved by suicide where the decedent expressed self-blame, rather than anger or a desire to escape pain. Both studies found no effect of motive for death on reactions to the bereaved, expectations of tension, perceptions of responsibility, blame attribution, or psychological disturbance of the deceased.

Table 4.2

Summary of Studies Examining the Effect of Decedent-Related Determinants on Community Responses towards Bereavement

Factor	Reference	Study designs	Sample	Quality appraisal
Cause of death	Allen et al., 1993; Calhoun et al., 1986; Calhoun et al., 1984; Calhoun et al., 1980; Calhoun et al., 1982; Calhoun et al., 1985; Ginn et al., 1988; Knight et al., 1998; Penman et al., 2014, Range et al., 1985; Range & Thompson, 1987; Rudestam & Imbroll, 1983; Sand et al., 2013, Thompson & Range, 1990; Thornton et al., 1989, Villa, 2010, Yamanaka, 2015	Experimental between-subjects design (*n*=13), survey design (*n*=4), qualitative (*n*=1)	University students (*n*=11), shopping mall attendees (*n*=4), general citizens (*n*=2), online responders (*n*=1) \newline\newline Sample size range: 25 to 348	.43-.90

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Anticipation of death	Costa et al., 2007; Kubitz et al., 1989; Range & Thompson, 1987; Range et al., 1992; Thompson & Range, 1990	Experimental between-subjects design (n=3), qualitative (n=1), survey design (n=1)	University students (n=5) Sample size range: 9 to 172	.50-.85
Gender	Calhoun et al., 1979; Calhoun et al., 1980; Lester, 1990; Sand et al., 2013	Experimental between-subjects design (n=4), survey design (n=1)	University students (n=2), general citizens (n=2), church attendees (n=1) Sample size range: 50 to 253	.54-.94
Age	Range et al., 1985; Thornton et al., 1989	Experimental between-subjects design (n=2)	University students (n=1), shopping mall attendees (n=1) Sample size range: 89 to 90	.43-.61
Motive for suicidal death	Calhoun et al., 1979; Lester, 1990	Experimental between-subjects design (n=2)	University students (n=1), church attendees (n=1) Sample size range: 91 to 127	.54-.57

4.5.3.3   Respondent determinants

The respondent-related category was the most well represented of all the categories, with 26 determinants across 26 studies. Gender of the respondent was the most studied respondent-related determinant and revealed mixed findings across 20 studies. Compared with women, men expected less distress and shorter recovery time (Alford & Catlin, 1993; Calhoun et al., 1985; Range et al., 1985), were less likely to expect friends to help the bereaved (Range et al., 1985), endorsed more inappropriate and unhelpful behaviours towards the bereaved (Blair, 2003; Calhoun et al., 1986; Knight et al., 1998; Marwit & Carusa, 1998; Minamizono, Motohashi, Yamaji, & Kaneko, 2008), and offered less sympathy (Versalle & McDowell, 2004). However, in contrast with women, men were more likely to talk with the bereaved three months post-death (Garson, 1994) and were less likely to believe the bereaved could have prevented the death (Calhoun et al., 1985). Other studies reported an interaction between gender of the respondent and deceased gender, gender of the bereaved, time since death, and cause of death (Calhoun et al., 1979; Garson, 1994; Knight et al., 1998; Rudestam & Imbroll, 1983; Villa, 2010). The remaining studies found no effect of gender of the respondent on likeability of the bereaved, blame or shame attributed to the bereaved, psychological disturbance of the deceased or bereaved, expected sadness and recovery-related symptoms in the bereaved, acknowledgement of the death, and behavioural intentions towards the bereaved (B. G. Allen et al., 1993; Bath, 2009; Calhoun et al., 1980, 1982; Garson, 1994; Lester, 1990; Nathan, 1999; Rudestam & Imbroll, 1983; Sand et al., 2013).

The respondent's bereavement history was assessed in seven studies with five demonstrating a positive effect. Respondents with personal experience of bereavement were found to show greater empathy (Villa, 2010), acceptance and comfort with grieving (Egnoto et al., 2014), endorse more facilitative responses to the bereaved (Blair, 2003), and rate themselves as having more confidence in supporting grieving persons (Tedrick Parikh & Servaty-Seib, 2013; Villa, 2010) than those without. In contrast, the remaining studies found no effect of bereavement history on expectations of grief (Alford & Catlin, 1993), intentions to support a grieving person (Bath, 2009), or empathy (Nathan, 1999). Similarly, a further three studies examined the effects of current bereavement status on responses to bereavement. Non-bereaved respondents were less realistic in their assumptions about bereavement, underestimating grief-related thoughts/feelings (Lehman et al., 1986) and over-estimating acceptance of the loss (Lehman et al., 1986) and amount of contact between bereaved and others in the lead up to the death (K. E. Thompson & Range, 1990). There was, however, no effect of bereavement status on impact of event, prognosis and perceived recovery, and social support (K. E. Thompson & Range, 1990; Wagner & Calhoun, 1991).

Four studies examined the effect of normative beliefs about supporting a grieving peer. This variable was defined as the respondent's strength of belief that others in their life would endorse their engagement in a particular behaviour (e.g., talking with a bereaved parent about their loss; Garson, 1994). Garson (1994) found that intentions to support a grieving person were higher when others endorsed this behaviour, while Villa (2010) found the opposite. Other studies found that respondents were aware of normative beliefs (Tedrick Parikh & Servaty-Seib, 2013), but these beliefs did not affect intentions to support (Bath, 2009; Tedrick Parikh & Servaty-Seib, 2013).

Two studies investigated respondent age. The first study found an association between age and uncertainty in attitudes towards grieving; younger respondents were more likely to answer that they didn't know, rather than expressing a potentially appropriate or inappropriate response to the bereaved (Minamizono et al., 2008). In contrast, Blair (2003) found that younger respondents were no more likely to endorse facilitative responses to the bereaved than older respondents. This contrast is most likely the result of sampling variation; Blair's (2003) study comprised an American college student sample predominately aged between 17 and 29 years (with only 4.4% aged 30 years or over), while Minamizono and colleagues' (2008) study was a household survey of Japanese adults aged 30 to 69 years.

Familiarity with the cause of death (i.e., knowing someone who died by suicide) was examined across two studies. Two studies found some association, with higher familiarity with the cause of death associated with greater anger (Rudestam & Imbroll, 1983) and uncertainty in attitudes about grieving (Minamizono et al., 2008). Conversely, the latter study also found that respondents familiar with suicidal deaths were no more likely to hold appropriate or inappropriate attitudes about grieving than those not familiar.

In addition to these six determinants, a further 20 determinants were identified in isolation across 13 studies. These included country of residence (Alford & Catlin, 1993), behavioural beliefs (i.e., beliefs about the consequences of supporting a grieving person; Bath, 2009), control beliefs (i.e., belief that one possesses the necessary skills to support; Bath, 2009; Tedrick Parikh & Servaty-Seib, 2013), past experience supporting the bereaved (Bath, 2009), race (Blair, 2003), coping style (i.e., avoids or seeks to understand aversive events; Blair, 2003), locus of control (i.e., internal or external; Calhoun et al., 1979), religious affiliation (Egnoto et al., 2014), perceived consequences of supporting (Garson, 1994), affective response (Garson, 1994), education level (Minamizono et al., 2008), depressive symptomatology (Minamizono et al., 2008), country of birth (Nathan, 1999), income (Nathan, 1999), past history of counselling (Nathan, 1999), receipt of information about suicide (Reynolds & Cimbolic, 1988), parenting status (i.e., children versus no children; Rudestam & Imbroll,

1983), sex role (i.e., masculinity versus femininity; Versalle & McDowell, 2004), and relationship between the respondent and the bereaved (Villa, 2010).

Table 4.3

Summary of Studies Examining the Effect of Respondent-Related Determinants on Community Responses towards Bereavement

Factor	Reference	Study designs	Sample	Quality appraisal
Gender	Alford & Catlin, 1993; Allen et al., 1993; Bath, 2009; Blair, 2003; Calhoun et al., 1986; Calhoun et al., 1979; Calhoun et al., 1980; Calhoun et al., 1982; Calhoun et al., 1985; Garson, 1994; Knight et al., 1998; Lester, 1990; Marwit & Carusa, 1998; Minamizono et al., 2008; Nathan, 1999; Range et al., 1985; Rudestam & Imbroll, 1983; Sand et al., 2013; Versalle & McDowell, 2004; Villa, 2010	Experimental between-subjects design ($n=10$), survey design ($n=7$), experimental within-subjects design ($n=1$), qualitative ($n=1$)	University students ($n=10$), general citizens ($n=4$), shopping mall attendees ($n=3$), church attendees, ($n=1$), parents of school-aged children ($n=1$), high school students ($n=1$) Sample size range: 25 to 5154	.46-.95

Bereavement history	Alford & Catlin, 1993; Bath, 2009; Blair, 2003; Egnoto et al., 2014; Tedrick Nathan, 1999; Tedrick Parikh & Servaty-Seib, 2013; Villa, 2010	Survey design (*n*=6), qualitative (*n*=1)	University students (*n*=6), high school students (*n*=1) Sample size range: 23 to 349	.68-.95
Normative beliefs	Bath, 2009; Garson, 1994; Tedrick Parikh & Servaty-Seib, 2013; Villa, 2010	Survey design (*n*=3), qualitative (*n*=1)	University students (*n*=3), parents of school-aged children (*n*=1) Sample size range: 23 to 160	.68-.95
Current bereavement status	Lehman et al., 1986; Thompson & Range, 1990; Wagner & Calhoun, 1991	Survey design (*n*=2), experimental between-subjects design (*n*=1)	University students (*n*=1), suicide survivors and their social networks (*n*=1), bereaved individuals and matched controls (*n*=1) Sample size range: 22 to 194	.62-.85
Age	Blair, 2003; Minamizono et al., 2008	Survey design (*n*=2).	University students (*n*=1), general citizens (*n*=1) Sample size range: 349 to 5154	.68-.82

Familiarity with cause of death	Minamizono et al., 2008; Rudestam & Imbroll, 1983	Survey design (*n*=1), experimental between subjects design (*n*=1)	General citizens (*n*=1), shopping mall attendees (*n*=1) Sample size range: 80 to 5154	.46-.82

4.6   Discussion

This is the first systematic and comprehensive review of the literature on what determines supportive behaviours from the general public following bereavement. In addition to the seven determinants (four decedent, three respondent) identified by Calhoun and Allen (1991), the present study identified a further 35 determinants (2 decedent, 23 respondent, and 10 bereaved). These data indicate that the provision of social support is based on an interplay of variables relating to the bereaved, the deceased, and the potential supporter, and it is likely this complexity that accounts for why some bereaved persons do not consistently receive the support they require (Aoun et al., 2015). Understanding these factors has clinical significance in that inconsistent or unsupportive actions and the potential breakdown of social networks following a death may become a type of secondary loss, compacting and complicating the nature of the primary loss (Breen & O'Connor, 2011).

Despite a growing body of research, bereaved persons' perspectives on helpful and unhelpful support attempts are rarely converted into practical support strategies (Breen et al., 2017). Most bereaved people grieve within the context of their friend and family networks and do not seek (or need) formal services (Aoun et al., 2015), these findings indicate considerable potential for improving community-wide understanding about the individuality of grief responses and the impact of helpful, timely social support on the grieving process. As the first of its kind, this review provides a stronger theoretical base for continued exploration of the mechanisms behind support attempts, with a goal of translating these insights into targeted community education and therapeutic interventions that recognise the presence (or absence) of social support. Doing so would promote the offer and uptake of supportive behaviours by those surrounding the bereaved and, therefore, reduce the isolation and stigmatisation that is often reported by bereaved people (Dyregrov, 2011; Ghesquiere, 2013).

It is widely recognised that systematic reviews are only as sound as the evidence on which they are based. Whilst presenting the first international synthesis of the mechanisms behind the grieving rules originally proposed by Doka (1989), this review has simultaneously highlighted the significant methodological flaws and omissions that have plagued this field of research since its inception. This body of research has proven to be vastly diverse, such that there has been little recognition within studies of other related studies. The review revealed considerable variation in the quality of included studies, with a trend towards more recent studies achieving higher quality appraisal scores. Most studies were conducted on US samples and therefore little is known about social support elsewhere, student samples continue to be used to represent the general community, and there have been few attempts to control for the biases inherent in attitudinal social research (see Henrich, Heine, & Norenzayan, 2010). We

urge that the findings of this review be used to inform more rigorous, methodologically sound and representative studies, with a goal of overcoming the previous 35 years of highly fragmented evidence.

Building on the previous work of Calhoun and Allen (1991), this review has offered transparency of process and peer review of methods through the publication of a PROSPERO systematic review protocol. Quality appraisal, study eligibility, and data extraction were all conducted through collaboration between two authors, increasing the verifiability of the review. All identified studies were available for retrieval, thus none was excluded on the basis of accessibility. The review, however, was limited in that no studies required translation, indicating that some non-English language articles may have been missed, limiting cross-cultural generalisability. Further, reporting biases (particularly in the pre-2000 studies) limited the degree to which a full synthesis of the studies could be conducted. Although a more targeted review of conceptually or methodologically similar studies might have enabled a more complete synthesis, the purpose of this review was to conduct a broader examination of the full scope of determinants, irrespective of study quality or methods employed.

4.6.1   Conclusion

Very few factors that impact the grieving process can be modified after the fact to the extent that social support can, and the greatest responsibility for this role lies within the informal relationships surrounding the bereaved person. With a comprehensive understanding of the factors that affect community recognition of and intention to provide social support to grieving persons, and with greater insight into the conceptual shortcomings of this research field, this review presents a call to action. We propose that it is not possible to promote and enhance the community's capacity to provide bereavement support without an understanding of current grief norms and supportive practices, and it is unethical to speak of these without a robust research base employing valid and reliable instruments in representative samples. From the perspective of potential supporters, this review has highlighted the complexity of processes which influence what motivates everyday people to recognise and respond empathically to another's distress. These findings provide a strong base for future research on the experience of social support from the viewpoint of both the giver and the receiver, suggest avenues for focused community education through highlighting common misconceptions and assumptions, and offer bereavement practitioners a broader understanding of the secondary losses that may be encountered when a person's grief is not recognised as legitimate or warranted.

Chapter 5 Social Support Following Bereavement: The Role of Beliefs, Expectations, and Support Intentions

"Grief is one of life's passages we all experience. It is one of life's equalizers, a shared experience for everyone man and woman who lives. But though it is a shared experience, most of us go through it as little islands of pain. Most of the people around us don't know how to help….Our pain makes others uncomfortable. Our pain reminds them of their own, it reminds them of how precarious their lives are too. It is their own pain and fear that cause others to say such things as 'Get over it already,' or 'It's been six months, are you going to grieve forever?'"

(Kübler-Ross & Kessler, 2005, pp. 229-230)

5.1 Chapter Overview

This chapter presents findings from the second phase of this research, a quantitative study exploring how bereavement status, anticipation of death, level of social support, and other respondent characteristics are associated with grief-related beliefs, expectations, and support intentions. This cross-sectional study, titled "Social support following bereavement: The role of beliefs, expectations, and support intentions" (Logan, Thornton, Kane, et al., 2017) is published in *Death Studies*, a premier international peer-reviewed journal disseminating empirical research on death and dying, bereavement and loss, and grief therapy to an interdisciplinary professional audience. The Accepted Manuscript below provides a summary of data collection and analysis methods and presents key quantitative and qualitative findings, considering areas for improvement within a compassionate community model. The findings of this study helped to inform the structure and focus of the interview guide and theoretical sampling for Phase Three (Chapter Six).

Logan, E. L., Thornton, J. A., Kane, R. T., & Breen, L. J. (2017). Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies*. http://dx.doi.org/10.1080/07481187.2017.1382610

5.2   Abstract

Social support is one of the strongest determinants of bereavement outcomes, yet little is understood about the community's recognition of grief and intentions to provide social support to grieving persons. A total of 476 adults responded to an online vignette and questionnaire measuring grief norms and supportive intentions. Respondent gender, age, and bereavement status all had some association with expectations of grief, intentions to support, perceived helpfulness of support attempts, and opinions toward the diagnostic classification of grief. Given that most bereavement support is informal, this study informs the development of community capacity to provide constructive, timely bereavement support.

Keywords: grief; bereavement; public perceptions; community norms; social support

5.3   Introduction

Bereavement is a universal experience that will inevitably affect all people at some point during their lifetime. While the support of death, dying, and bereavement has increasingly been managed within formal medical settings, focus has shifted to building individual and group capacity to provide bereavement support through compassionate communities (Aoun et al., 2012; Kellehear, 2013; Paul & Sallnow, 2014; Rumbold & Aoun, 2014). New public health models recognise that the majority of bereaved persons do not require specialised bereavement services (Aoun et al., 2015), but do benefit from informal opportunities to express their feelings and have their grief responded to in a non-judgemental and empathic way (Breen et al., 2017). This bereavement care framework has the potential to reduce entrenched stigma around death and dying and empower individuals and their broader social networks to take collective responsibility for mental health and well-being (Paul & Sallnow, 2014).

Although social support is consistently reported to be one of the most significant predictors of psychological outcomes following bereavement (L. A. Burke & Neimeyer, 2013), studies have found that bereaved persons often do not receive sufficient or timely informal support to moderate their grief experience (e.g., Breen & O'Connor, 2011). To be of benefit, a need for support must be recognised accurately, the potential supporter must be capable of providing the support, and the supportive action must be perceived as helpful by its receiver (Kaunonen et al., 1999; Rando, 1993). Despite acknowledging the central role of informal supporters in bereavement care, thanatological research has placed far greater focus on how social support is received, than on predictors of supportive behaviours (Bath, 2009).

Recognising that a minority of individuals are at high risk for developing grief complications (Aoun et al., 2015; Kersting et al., 2011), a dominant argument in the grief

literature is whether 'pathological' responses to bereavement can be differentiated from what might be considered a 'normal' or 'typical' grief reaction (Doering & Maarten, 2016). The introduction of Persistent Complex Bereavement Disorder (PCBD) in the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013) did not escape criticism in professional or public domains. While one side of the argument promotes improved recognition of and treatment for at-risk individuals (Prigerson et al., 2009), the other takes the stance of the 'sceptical public,' focused on safeguarding a natural phenomenon against pathologisation and over-diagnosis (Iglewicz et al., 2013; Thieleman & Cacciatore, 2013). Although the final criterion for PCBD in the DSM-5 specifies that the expression of grief must be "out of proportion to or inconsistent with cultural, religious, or age-appropriate norms" (APA, 2013, p. 790), empirical evidence for, or public endorsement of, these norms is limited. In studies of health professionals, only 43.1% endorsed a grief-related classification in diagnostic nosology, despite 73.1% having witnessed client presentations that would meet diagnostic criteria (Ogden & Simmonds, 2014). In general community samples, endorsement has been greater, ranging from 51% (Rüsch et al., 2012) to 75% (Breen et al., 2015); however, some still remain less likely to recommend professional support for bereavement-related distress than other mental health issues (Holzinger et al., 2011). Whereas in in bereaved samples, 96.3% expect relief from a diagnosis and 98.5% would be receptive to receiving treatment for their grief (J. G. Johnson et al., 2009), others still propose that an understanding of the phenomenon is more important than any diagnostic label (Ghesquiere, 2013).

Discourses of grief play a pivotal role in societal conceptualisations of what it means to experience loss and grieve in a 'typical' or 'atypical' manner (Harris, 2009-2010). The most prominent discourse of grief is constructed on the assumption that grief is a finite, short-term experience that must be worked through in a predictable pattern across a series of quasi-linear stages, eventually culminating in detachment from the deceased (Breen & O'Connor, 2007). These ideas have been subject to robust theoretical and empirical challenges, suggesting that stage-based models perpetuate unrealistic expectations and a sense of inadequacy in those who fail to detach, move on, and 'resolve' their grief (C. Hall, 2014). However, within informal social networks and some health and social care settings, these myths and assumptions have become 'truths' that prescribe who should grieve, when they should grieve, how they should grieve, where the grief should occur, for how long they should continue grieving, and finally, for whom should they grieve (Doka, 1989, 2002). Through these implicit rules, a dichotomy is created where a loss is either appraised as enfranchised (legitimising displays of emotion and with the offer of social support) or disenfranchised (where others will not recognise or validate the loss, and support will not be offered; Doka, 2002). How these rules will apply to

any given person depend on a complex interplay of factors relating to the deceased (and their manner of death), the bereaved, and the potential supporter (Logan et al., 2017).

Two decades ago, Calhoun and Allen (1991) produced a literature review of 17 studies which identified three participant-related factors (age, gender, bereavement experience) and four decedent-related factors (age, gender, cause of death, family composition) that determined social reactions to suicide bereavement. Logan et al. (2017) conducted a systematic review of the entire bereavement literature and identified 42 studies yielding six participant-related factors (gender, bereavement experience, normative beliefs, current bereavement status, age, and familiarity with cause of death), five decedent-related factors (cause of death, anticipation of death, gender, age, and motive for suicidal death), and five bereaved-related factors (gender, time since death, relationship to the deceased, perception of coping, and perceived social support). This review highlighted significant methodological flaws and omissions in this research base, including inconsistent outcome measures with poor or no psychometric properties, little to no control of extraneous variables, non-representative samples, and low power to detect possible relationships.

Three key factors that emerged from Logan et al.'s (2017) review as warranting further investigation included the participants' own experience of bereavement (bereavement status), the anticipation of the death, and the level of social support the bereaved is perceived to already have. In terms of bereavement status, although some studies found greater empathy for and acceptance of bereaved individuals when the supporter had experienced a bereavement themselves (Blair, 2003; Egnoto et al., 2014; Villa, 2010), other studies noted no relationship between bereavement experience and expectations of the other's grief or intentions to provide support (Bath, 2009; Catlin, 1993; K. E. Thompson & Range, 1990; Wagner & Calhoun, 1991). However, these studies focused on the event of bereavement and overlooked the subjective impact of bereavement. In terms of anticipation of death, although some study participants have rated anticipated deaths as being easier to resolve than unanticipated (Costa et al., 2007; Kubitz et al., 1989), others have noted no difference in evaluations of the bereaved, prediction of bereavement outcomes, or supportive offerings (Range & Thompson, 1987; Range et al., 1992; K. E. Thompson & Range, 1990). Finally, perceptions of social support has only been investigated in two studies, demonstrating perceptions of better coping and less need for support when the bereaved person appeared to have a reasonable level of support (Costa et al., 2007; Villa, 2010). Further investigation is needed, controlling for extraneous variables, in order to verify the relative contribution of all three of these factors. Following a call to action for more rigorous, methodologically-sound exploration of these influences (Logan et al., 2017), this study was devised to examine some of these less well understood

factors that may affect community recognition of grief and intentions to support grieving persons.

Evidently, there are a broad range of factors that may either hinder or facilitate the provision of social support to grieving persons, but the evidence so far is poor in quality and limited in scope (Logan et al., 2017). Given the increasing emphasis on social support as a protective factor against complications of bereavement, an understanding of the mechanisms underlying when and how potential supporters respond to bereavement is of critical importance. The present study investigated whether bereavement status, anticipation of the death, and level of social support affect expectations of grief symptomatology and intentions to provide social support to grieving persons. Further, it explored relationships between bereavement status and beliefs about the helpfulness of support-intended statements and endorsement of a grief-related diagnostic classification. We predicted participants would rate grief more intensely and be more likely to provide support when they had a personal bereavement history and when the bereavement was characterised by both an unanticipated death and little available social support. We also hypothesised an association between bereavement status and helpfulness of support-intended statements and endorsement of a grief-related diagnostic classification; however, the literature did not provide sufficient evidence to support a directional prediction.

5.4   Methods

The role of bereavement status, anticipation of the death, and level of social support on expectations of grief symptomatology and intentions to provide social support to grieving persons was addressed using a between-groups 3 (bereavement experience: 'none', 'yes but not significantly impacted', 'yes and significantly impacted') x 2 (anticipation of the death: 'prolonged/expected', 'sudden/unexpected') x 2 (social support: 'little', 'a lot') factorial design with the latter two conditions fully randomised. Beliefs about the helpfulness of support-intended statements and opinions about a grief-related diagnostic classification were addressed using simple between-groups designs. Members of the general Australian public were recruited using convenience and purposive sampling through radio advertising, email lists, community noticeboards, and online noticeboards and discussion forums. An *a priori* power analysis (Faul, Erdfelder, Lang, & Buchner, 2007) determined that 318 participants were needed to detect a small ($f = .10$) to moderate ($f = .25$) effect at an alpha level of .05. As such, the final sample of 476 provided adequate power. Data were collected through an anonymous questionnaire hosted on Qualtrics®. Participants were randomly assigned to read one of four versions of a vignette before responding to the questionnaire.

5.4.1   Measures

5.4.1.1   Vignette

Vignettes are commonly used in social and attitudinal research to elicit a response that best approximates how that individual might respond in real life (Hughes & Huby, 2004). For this study, four versions of a vignette were developed to reflect a hypothetical bereavement scenario, varying only by the described anticipation of the death and level of social support. Vignettes were kept gender-neutral and only varied by the two manipulated factors, designed to provoke interest but minimise superfluous details that might distract participants. An example vignette read: "A.L's spouse died unexpectedly after a sudden illness. A.L lives alone and appears to have little support from family or friends." To increase the validity of responses to these vignettes, participants were exposed to a post-manipulation check in the form of two questions that tested recognition of specific details in the vignette.

5.4.1.2   Expectations of grief and intentions to support

The first two scales assessed participants' expectations of grief and intentions to provide support to the person in the vignette. Participants' expectations of the severity and intensity of the target figure's grief was measured using the 12-item expectations of grief symptomatology scale previously published by Penman et al. (2014) as a modified version of Prigerson and Maciejewski's (2009) prolonged grief disorder scale. This revised scale asks participants to rate a series of grief symptoms (e.g., How often do you think this person would be avoiding reminders that the person lost is gone?) on a 5-point Likert scale from 1 (*never*) to 5 (*always*), with higher scores indicating an expectation of more intense grief. This scale demonstrated unidimensionality and acceptable internal consistency in the present sample ($\alpha = .87$) as in past studies ($\alpha = .87$; Penman et al., 2014). Intentions to provide social support was measured using the 4-item Intentions subscale of the theory of planned behaviour for social support of grieving persons scale (Bath, 2009). This scale explores general intentions to support grieving persons, so the wording was modified to make judgements specific to the person in the vignette. Responses to items were measured on a 7-point Likert scale from 1 (*strongly disagree*) to 7 (*strongly agree*), with higher overall scores reflecting a greater intention to provide social support. This scale demonstrated unidimensionality and acceptable internal consistency reliability in the present study ($\alpha = .90$) as in past studies ($\alpha = .71$; Bath, 2009). A single item from the same scale was used to examine past behaviours of providing social support to grieving persons from 1 (*none of the possible times*) to 7 (*all of the possible times*).

5.4.1.3 Perceived helpfulness of support attempts

Helpfulness of support attempts was assessed using the 64-item support-intended statements scale (Rack et al., 2008). Responses to items were measured on a 5-point Likert scale from 1 (*very harmful*) to 5 (*very helpful*) with a midpoint of 3 (*neither*); higher scores indicated a greater perceived helpfulness rating. This scale was theoretically devised and comprises 16 conceptually independent subscales with Cronbach's alphas ranging from $\alpha = $ .60-.92 (Rack et al., 2008). However, no published studies known to these authors have examined the higher-order factor structure of these 16 subscales. In the present study, principal components analysis with a follow-up parallel analysis indicated a two component model with eight subscales loading on each component. This two-component solution accounted for 51.5% of the total variance. The first factor comprised: offer presence/being there, express willingness to listen/provide opportunities to express feelings, express care and concern, include in social activities, compliment the deceased, offer contact with similar others, discuss memories of the deceased, and provide tangible support. This factor appeared to represent efforts by the participants to support through closely connecting with the bereaved and tuning into the unique emotional experience (thus named *Support through Approach*). The second factor comprised: compliment the living, discuss being reunited, highlight the positive, provide a religious perspective, identify with the other's feelings, provide a philosophical perspective, give advice, and minimise feelings/force cheerfulness. This factor appeared to represent efforts by the participants to support through offering distal suggestions and seeking sameness without emotionally connecting to the individual's unique experience (thus named *Support through Avoidance*). The internal consistencies of *Support through Approach* ($\alpha = .83$) and *Support through Avoidance* ($\alpha = .85$) were both adequate.

5.4.1.4 Endorsement of a grief-related classification in diagnostic nosology

These opinions were measured using a 2-item scale modified from Breen et al. (2015). The first item asked participants to rate the extent to which they agreed with a grief-related classification for individuals showing a complex set of symptoms indicating difficult adjustment to a death. Responses to items were measured on a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*), with a mid-point of 3 (*unsure*); with higher scores reflecting greater agreement. A follow-up open-ended question then asked participants to explain how they believed a diagnosis might affect an individual's experience of grief.

5.4.1.5 Demographics

Bereavement status was assessed using a single item which asked participants whether they had experienced bereavement and, if so, whether it had or continues to have a significant impact on their life. Recognising grief as a lifelong experience for some, focus was placed on the subjective impact of the loss, rather than how recently it occurred. To ensure group equivalence for this bereavement status condition, a range of other demographic variables were measured and analysed. The questionnaire included demographic questions relating to age, gender, country of birth, religion, highest level of completed education, occupational status, profession, professional exposure to/training in grief, and social desirability. Social desirability was measured using a 10-item version of the Crowne-Marlowe Social Desirability Scale (Strahan & Gerbasi, 1972). This scale is commonly used alongside other self-report measures to control for tendencies to respond in what is perceived to be a socially desirable way (i.e., to prevent faking 'bad' or 'good'; Crowne & Marlowe, 1960). Responses to items are measured on a forced-choice *yes/no* scale (with five items keyed true and five false). Higher summed scores indicate more socially desirable responding. Although this scale demonstrated adequate internal consistency in past research ($\alpha = .84$; Fischer & Fick, 1993), in the present sample, internal consistency was moderate ($\alpha = .63$).

5.4.2 Analysis

Possible group non-equivalence was assessed by exploring whether the conditions differed in their demographic characteristics. Variables which correlated significantly with the dependent variable were treated as bona-fide covariates and included as control variables in subsequent analyses. The only exception is gender, which correlated with some dependent variables so was included as an additional independent variable in order to analyse, rather than simply control for, its impact. Generalised linear mixed models (GLMMs) were run using the Statistical Package for the Social Sciences (SPSS v20). To optimise the likelihood of convergence, separate GLMM analyses were run for each of the four dependent variables: expectations of grief symptomatology, intentions to provide social support, beliefs about social support, and endorsement of a grief-related diagnostic classification. As these variables are conceptually independent, statistical significance was evaluated at the conventional per-test alpha level of .05 and effect sizes were interpreted using Cohen's (1988) conventions.

The single open-ended question was analysed using content analysis (Hsieh & Shannon, 2005). Analysis focused on identifying the range of effects (both positive and negative) that the participants believed a bereavement-related classification might have on the experience of grieving. Two researchers conducted an independent, blind open coding of 10% ($n = 43$) of

the responses according to general effect with any disagreement resolved before the remaining responses were coded by the first author. All responses were open coded before concepts were refined, collapsed, renamed, and categorised to represent the final 6 positive and 10 negative effects.

5.5   Results

5.5.1   Demographics

The sample comprised 476 Australian adults (394 women, 82 men) aged between 18 and 93 years ($M = 39.76$, $SD = 15.64$). The majority of the sample (69.1%) was born in Australia. Approximately half (53.4%) of the participants had no religious affiliation, with the remainder identifying as Christian (37.0%), Buddhist (3.2%), Hindu (1.5%), Islamic (0.4%), and other (4.6%). The sample was predominately well educated with 70.4% having completed a tertiary qualification, 13.7% high school, 10.3% vocational education/training, and 5.7% not completed high school. Just under half (46.2%) reported working full-time, 31.9% part-time, 13.4% away from work, and 8.4% were unemployed.

In terms of bereavement status, 261 (54.8%) participants identified as having experienced a death that *did have* a significant impact on their life. The greatest proportion of bereavements were parents ($n = 80$), followed by extended family members ($n = 74$), friends ($n = 35$), spouses/partners ($n = 25$), children ($n = 15$), siblings ($n = 13$), and other ($n = 19$), which comprised in-law relatives, step-parents, perinatal deaths, ex-spouses/partners, children of friends, friends of parents/partners, and work clients. Time since death ranged from less than one month to 62.75 years ($M = 7.62$, $SD = 9.14$). In contrast, 149 participants (31.3%) reported having experienced bereavement(s) that *did not have* a significant impact on their life, and 66 (13.9%) had not experienced the death of someone close to them. These two categories were collapsed for analysis. One-hundred and seventy-five participants (36.8%) identified as having a professional role with some exposure to, or training in, grief following bereavement.

5.5.2   Expectations of grief and intentions to support

There were no significant three- or two-way interactions involving bereavement experience, anticipation of death, and level of social support on either the expectations of grief symptomatology or intentions to support scales, permitting evaluation of each main effect independently of the others. In total, 136 participants (28.6%) incorrectly answered one or more of the questions in the post-manipulation check. Further analysis revealed that the binary post-manipulation check variable only moderated one effect within the Expectations of Grief

Symptomatology scale and is described in detail below. Before analysis, all potential covariates were examined for their effects on the Expectations of Grief Symptomatology and Intentions to Support scales. Only participant age was correlated and so was included as a control variable in both analyses.

For expectations of grief symptomatology, neither support level (F [1, 460] = 1.54, p = .216) nor anticipation of the death (F [1, 460] = 2.34, p = .127) directly affected participants' ratings of the anticipated intensity of the grief reaction. There was a significant small two-way post-manipulation check x anticipation of death interaction on expectations of grief symptomatology (F [1,444] = 9.41, p = .002, η^2 = .020), indicating that the relationship between anticipation of death and the expectations of grief symptomatology scale varied as a function of whether the participant passed or failed the manipulation check. For participants who failed, there was no significant difference in the expected severity of grief between the 'anticipated' (M = 3.70, SE = .068) and 'unanticipated' (M = 3.45, SE = .128) groups, F (1, 444) = 2.99, p = .082). In contrast, participants who passed the manipulation check rated the 'anticipated' death (M = 3.41, SE = .086) as lower in grief intensity than the 'unanticipated' death (M = 3.70, SE = .050), representing a small effect, F [1, 444] = 8.44, p = .004, η^2 = .019. Both participant gender and bereavement status had small, significant effects on expectations of grief symptomatology. Female participants (M = 3.75, SE = 0.028) expected a more intense grief reaction than males (M = 3.43, SE = 0.077), F (1, 460) = 15.31, p < .001, η^2 = .032. Participants impacted by bereavement (M = 3.72, SE = .066) also expected a more intense grief reaction than those not impacted (M = 3.47, SE = .049), F (1, 460) = 9.62, p = .002, η^2 = .020.

For intentions to support, support level (F [1, 460] = 0.33, p = .568), anticipation of death (F [1, 460] = 0.19, p = .662), and bereavement status (F [1, 460] = 0.02, p = .886) did not significantly affect participants' ratings of how likely they would be to offer the target figure support following the death. However, again participant gender had a small, significant effect. Female participants (M = 6.25, SE = 0.050) indicated greater intentions to support than males (M = 5.72, SE = 0.146), F (1, 460) = 11.99, p = .001, η^2 = .025. Past behaviours providing social support was significantly correlated with future intentions to support, r_s [N = 476] = .368, p < .001; however, the relationship was not particularly strong with the two variables only sharing 13.5% of variance.

5.5.3   Perceived helpfulness of support attempts

For *Support through Approach* statements, participant gender had a small, significant effect, F (1, 472) = 6.90, p = .009, η^2 = .014. Female participants (M = 0.07, SE = 0.047) rated

Support through Approach statements as significantly more helpful than male participants (M = -0.30, SE = 0.131). For *Support through Avoidance* statements, there was a significant bereavement status x participant gender interaction, F (1, 455) = 4.97, p = .026. For male participants, there was no significant difference in ratings of helpfulness between those impacted by bereavement (M = 0.99, SE = .203) and those not impacted (M = 0.68, SE = .170), F (1,455) = 1.68, p = .195. For female participants, compared with those not impacted by bereavement (M = 0.71, SE = 0.118), those impacted (M = 0.46, SE = 0.117) rated *Support through Avoidance* statements as significantly less helpful, representing a small effect, F (1,455) = 7.78, p = .005, η^2 = .017.

5.5.4 Endorsement of a grief-related classification in diagnostic nosology

In total, 188 participants (39.5%) disagreed/strongly disagreed with the concept of a grief-related diagnostic classification, 169 (35.5%) agreed/strongly agreed, and 119 (25.0%) were undecided. There was no significant main effect for bereavement status on endorsement of a grief-related classification, F (1, 471) = 1.71, p = .192. Participant age had a small, significant effect with younger participants more likely to endorse the classification than older participants, F (1, 471) = 8.57, p = .004, η^2 = .018. A total of 425 participants further qualified their response to this item by explaining how they believed a diagnosis might affect the experience of grieving. Of these 425, only six (1%) participants proposed that a diagnosis would have no effect whatsoever. Responses of all others are summarised in Tables 5.1-5.2 with effects quantified to illustrate the extent to which participants shared views about the potential impacts of a diagnosis. The majority of participants mentioned more than one effect and many mentioned both positive and negative consequences.

The written responses of participants indicated six positive effects of a diagnostic classification. Participants acknowledged that a formal diagnosis might improve access to and quality of professional support, with a shift from traditional depression-focused therapies to more specialised interventions that target the grief itself. Similarly, it was proposed that formal recognition would increase validation, legitimisation, and normalisation of each individual's unique grieving patterns. Some participants noted that a diagnosis might promote coping by providing some context and meaning to the experience of grief which could facilitate the active expression of feeling. Others suggested that a diagnosis might facilitate the provision of special entitlements (e.g., extended bereavement leave) and social support which may reduce isolation and create space for mourning. Finally, participants highlighted the power of a diagnosis to accurately demarcate low-risk individuals experiencing 'typical' grief from higher risk

individuals exhibiting 'atypical' symptoms over an extended period of time, facilitating decisions about who will benefit most from specialised bereavement support.

Table 5.1

Positive Effects of a Bereavement-Related Diagnosis on the Grief Experience

Effect	*n*	Exemplar Response
Improves access to and quality of professional support	94	"Not having grief recognised in the DSM will not change its existence, only its possible treatment and understanding" – 60 "Having a classification of grief in the DSM may result in easier access to and more tailored support for people suffering from grief" – 162
Validates, legitimises, and normalises	94	"If the grief issue were unusually prolonged, it might be comforting to know that it was a mental health issue, which they could get help for, rather than feeling like they're losing their mind" – 167 "It may allow the person going through grief some sort of social legitimacy that their feelings are reasonable, especially if they are feeling pressured to 'get over it' or 'move on'" – 250
Promotes coping	33	"A grief-related classification would help an individual dealing with loss make sense of their emotions and give reason to them. By better understanding their emotional response, I believe that they would be in a better position to move through the grieving process and begin to feel better" – 215 "Sometimes giving someone a medical name for symptoms and letting them know it is something that people get diagnosed with can help them accept their feelings and try to find a positive resolution" – 298
Reduces isolation and increases support	22	"It might make people more aware that grief is a real issue for people and that, by bringing awareness to it, they can offer support to the person" – 18

		"It may open the doors to more support and recognition which, given society's inherent inability to confront and recognise grief, is useful" – 194
Facilitates entitlements	14	"If an individual was having difficulty in receiving adequate support from their workplace, having a classified mental disorder would allow them to justify taking as much time off as they needed to deal with their grief" – 3 "I think other people, in particular the workplace, may be more sympathetic" – 81
Delineates 'atypical' from 'typical' grief	9	"It may help to recognise negative signs of grief, for example when it lasts an extended period of time or the person is having thoughts of harming themselves or others" – 243 "There is a need to develop more effective ways of reaching and assisting individuals experiencing prolonged complex grief that is clearly outside of the normal range….In this way, complex bereavement could be distinguished from 'typical' bereavement in the same way that low mood is currently distinguished from depressive disorders, or stress from anxiety disorders" – 280

Note. Some participants noted more than one effect.

Paradoxically, many of the aforementioned positive effects were also interpreted as potential negative effects by participants. Participants argued that a diagnosis invalidates a natural phenomenon and suggests abnormality without reason, potentially risking the invitation of label-induced stigma associated with other mental health diagnoses. Some proposed that diagnosis encourages a reductionist approach which simplifies understanding of an individual's grief while ignoring the nuances that make it unique. Although some suggested that a diagnosis might promote coping, others stated that a diagnosis might escalate distress, encourage a self-fulfilling prophecy, or even suppress the grief due to connotations associated with the diagnostic label. Participants reported that a diagnosis represents the pathologisation and medicalisation of grief, rather than the acceptance and integration of a natural consequence of loss. It was argued that diagnosing symptoms may impose unrealistic expectations and regulations on mourning, introduce intervention where it is not necessary, or reduce the likelihood that an individual will seek help for their experience.

Table 5.2

Negative Effects of a Bereavement-Related Diagnosis on the Grief Experience

Effect	*n*	Exemplar Response
Invalidates and suggests abnormality	145	"I think it may send the message that the grieving process is not a normal or acceptable part of life and could even be considered a weakness. Individuals may begin to question their grief and think that it may not be okay to feel the way they do which, in turn, could perpetuate the negative feelings" – 15 "Labelling the grief as a 'problem' could ingrain a problem or make the person think they are a problem" – 112
Invites label-induced stigma	87	"Because mental illness continues to carry an amount of stigma, grieving people might feel even more unusual from what they used to feel (prior to the death) and even more distant from others around them and broader society" – 148 "It could box them in so that their future decisions and life experiences are framed by this classification that they were given 10 or 20 years ago when they were having trouble coping with the loss of a loved one" – 96
Promotes a one-size-fits-all approach	68	"We are so keen on classifying everything instead of allowing people to be who they are. Grief is personal, individual, and takes time. Classification does not assist in any of this" – 43 "You can't quantify an individual experience. By trying to contextualise or classify an individual experience, I think you demean it in some way by assuming it's the same" – 105
Escalates distress	59	"It could be detrimental to the person and only intensify the bereavement process by adding another step" – 227 "I think if someone is classified as having a mental health disorder in times of grieving, this may make them feel worse and less able to cope and might drive them to further, darker places" – 302

Pathologises and medicalises	58	"I think pathologising grief and the experience of grief is unhelpful because it is yet another way in which we are trying to sanitise death out of our lives" – 26 "I worry something like this may lead to over-diagnosis/over-classification of something which isn't necessarily pathological or chronic. I worry also that diagnostic criteria for how a person deals with grief may emphasise what is 'normal' and what is 'abnormal' in a way that is not helpful or accurate" – 364
Encourages a self-fulfilling prophecy	53	"Some people can become very involved with their mental health issue and almost wear it as a badge of honour, causing them to remain stuck in their ways" – 233 "It would allow them to accept the way that they are feeling as something that is not able to be controlled or changed" – 434
Imposes expectations and regulations	27	"We live in a culture of grief aversiveness, whereby deep sorrow is too confronting for most people and therefore we are hasty in encouraging people to move on from these feelings before they are ready to or have had a forum in which to experience and understand their feelings" – 235 "I think that imposing boundaries on a very personal issue like grief/death is detrimental to the person and the wider community. It suggests that a person's pain is understood and measurable. I contend that the death of a person you love is a process that you go through, and it is not up to mental health professionals to place artificial constructs on grief." – 258
May result in suppression or internalisation of grief	22	"Grief would become something that no-one would want to display or share for fear of being labelled mentally ill/abnormal/incompetent" – 32 "I believe it might make people believe that it was not normal to experience grieving. They may feel that they should not talk about it too much to other people" – 134

Risks unnecessary intervention	13	"Pharmaceutical companies could get in on the act and prescribe drugs which exacerbate the 'problem' and delay true healing" – 112
		"To medicalise it creates the risk of labelling a normal reaction as 'disordered' and suggesting interventions where none are required" – 300
Reduces help-seeking	7	"To classify it as a mental disorder would mean that people with complex grief might feel that only a mental health professional can help them and discourage the natural support network, who might then consider it 'best left to the professionals'" – 137
		"For some people, they may be confronted by the fact that they have been classified as suffering from a mental disorder and may pull back from support - in denial that they need it" – 162

Note. Some participants noted more than one effect.

5.6   Discussion

The aim of this study was to explore some of the key mechanisms motivating participants' expectations of grief, intentions to provide social support, beliefs about the helpfulness of support-intended statements, and opinions on a diagnostic classification for grief. For the majority of bereaved individuals who do not require specialised complicated grief interventions, the study's findings highlight that characteristics of the responder (gender, age, bereavement status) may have a more profound impact on community recognition of grief than characteristics of the bereaved or decedent (support level, anticipation of death). Social support is strongly correlated with bereavement outcomes (L. A. Burke & Neimeyer, 2013); yet, as these findings suggest, the assumption that the general public is universally prepared, capable, and willing to provide such support is not well evidenced. Recognising that few protective factors in bereavement can be modified to the extent that social support can (Bath, 2009), these findings support a growing initiative to realign public expectations of grief and improve community capacity to provide timely and appropriate bereavement care (Aoun et al., 2015).

For the small proportion of bereaved individuals who are at high risk for developing complications of bereavement (Aoun et al., 2015; Kersting et al., 2011), a slight majority of participants in this study would not support a diagnostic classification. This finding is similar

to figures in a health professional sample (Ogden & Simmonds, 2014), but is considerably lower than in general community samples (Breen et al., 2015; Rüsch et al., 2012) and bereaved populations (J. G. Johnson et al., 2009). The one-quarter of participants who were undecided may indicate a perception of not being able to hold an informed opinion or indeed conceptualise the consequences of such a decision. This hypothesis is supported by findings that many people fail to access bereavement support services due to low awareness that what they are experiencing might be pathological (Lichtenthal et al., 2011). In line with Breen et al. (2015), responses in this study highlighted mixed perceptions about the potential effects of a grief-related diagnosis on the experience of grievers. Those favouring a diagnosis tended to focus on recognising the small proportion of individuals whose grief is intense and persistent, validating the complexity of their experience, and providing them with informal supports and specialised formal interventions to hold their grief. In contrast, those more cautious about applying a diagnosis warned against reducing a natural phenomenon to a single label and viewing it through a medical lens, suggesting that formal and informal supports are still possible without classifying the experience. Further research is needed to identify the relative impact of these beliefs on bereaved people and how this may influence their receptivity to receiving support, both formal and informal.

Contrary to predictions, participants' bereavement status held no relationship with intentions to support the bereaved or endorsement of a grief-related diagnostic classification, but did impact expectations of grief symptomatology. This finding suggests that experiencing a significant bereavement may not be as clearly associated with particular responses to another person's grief as once thought. Identifying spaces where one can develop a sense of common understanding and similarity to others is often reported by bereaved persons to be a significant therapeutic process following bereavement, and indeed forms the basis for the effectiveness of many bereavement support groups (Umphrey & Cacciatore, 2011). It is plausible that personal bereavement experience may facilitate more realistic expectations of another person's grieving, but may inhibit closer empathic attunement, possibly due to fears of becoming engulfed by the other person's grief. This hypothesis is supported by Logan et al.'s (2017) finding that, although potential supporters with a bereavement experience may indicate greater empathy for and acceptance of bereaved persons, they may be no more prepared to offer support than someone not personally impacted by bereavement. Similarly, they may be no more informed in their opinion of whether or not a grief-related diagnostic classification would have merit, particularly when they are encouraged to think outside their own bereavement to how it would affect bereaved persons more generally. This finding has significance, given the only two existing studies using bereaved samples both asked respondents whether a diagnosis would have been helpful to them specifically (Ghesquiere, 2013; J. G. Johnson et al., 2009).

Against predictions, neither the described level of social support nor anticipation of the death affected expectations of grief symptomatology or intentions to provide support. These findings refute previous conclusions that anticipated deaths are perceived to be quicker to resolve than unanticipated deaths (Costa et al., 2007; Kubitz et al., 1989) and may require less support (Villa, 2010), but confirms other research where participants have perceived that anticipated deaths might be equally challenging, dependent on the strength of the attachment bond (Range & Thompson, 1987; Range et al., 1992; K. E. Thompson & Range, 1990). These findings are supported by empirical evidence that circumstances of the death have less impact on the manifestation of grief as time progresses (Feigelman, Jordan, & Gorman, 2008-2009), and quantity of support does not always correspond to quality of support when it comes to informal bereavement care (Breen & O'Connor, 2011).

In line with past studies (for a full review, see Logan et al., 2017), participant gender was significant, with women expecting more intense levels of grief of the target figure and being more willing to offer support than men. Women were also more likely than men to endorse *Support through Approac*h statements as helpful and, if affected by bereavement, were more likely to rate *Support through Avoidanc*e statements as less helpful (where no difference existed in men). This finding contributes to contemporary theory that although a person's gender does not *predict* their grief reaction, it may influence their bereavement experience depending on their grieving style (intuitive versus instrumental; Doka & Martin, 2010). In line with this, these findings suggest that men may recognise and respond differently than women to the grief of others based on their own natural grieving style and whether they have been socialised in early years to experience grief and loss in a certain way. Similarly, participant age impacted opinions towards a grief-related diagnostic classification, with older participants being less likely to endorse the proposed diagnosis than younger participants. Higher levels of mental health-related stigma have been found to correlate with age (Jorm & Oh, 2009); thus, the older adults in this study may have been more cautious in classifying grief that persists beyond 'the norm,' with a broader understanding of the potential impacts such a label might have.

The emergence of age, gender (and bereavement status in interaction) as significant variables in this study indicates that the general public predominately recognise and respond to grief according to personal frame of reference. This finding is noteworthy, given such factors are amenable to change through community education and support. Empirical evidence dictates that it is not financially viable or effective to invest in a one-size-fits-all approach to the delivery of bereavement care (Aoun et al., 2015), but rather the majority of grieving individuals can benefit from the knowledge, insight, and resources that exist within their own

communities (Rumbold & Aoun, 2014). However, as this study and others have found, the general public may not be as prepared, capable, or willing to assume responsibility for supporting grieving family, friends, colleagues, and neighbours as health and social care professionals might hope or expect. As identified by Kaunonen et al. (1999) and Rando (1993), the existence of social networks alone is not sufficient, but rather these networks must be able to recognise a need, and offer an intervention which is perceived as helpful by its receiver, in order to affect the trajectory of grief. Recognising such deficits, there is growing advocacy for stronger partnerships between formal bereavement services and communities in order to upskill the general public and develop more appropriate, targeted grief support from the ground up (Paul & Sallnow, 2014). Research findings such as these provide valuable insight into how grief is currently conceptualised and responded to in contemporary society, and how compassionate communities might be realised, particularly beyond palliative and end-of-life domains.

Empirical evidence suggests that behavioural intentions are usually fairly predictive of real-world behaviours (Jorm & Oh, 2009). The vignettes in this study were hypothetical and contained very little information; however, it is possible that participants may have responded differently if they had better identified with or known the person in the vignette. Vignettes are limited in their capacity to capture full individual realities and elicit valid responses (dependent on the validity of the vignettes themselves); however, this method is still recognised as the best approximation of real-life responding (Hughes & Huby, 2004). This study is the first to include a measure of social desirability which, contrary to expectation, did not significantly influence any of the results. Despite social desirability having low impact in online surveys (Duffy, Smith, Terhanian, & Bremer, 2005), future research should seek to rule out such influence using the full version of this scale, particularly given the less than adequate internal consistency of the short form used in the present study. Due to the study's focus on community norms, the representativeness of the sample is also worth mention. In line with previous studies (Logan et al., 2017), the present sample predominately comprised well educated women which may have skewed the findings somewhat. However, data in this study relating to mean age, country of birth, and religious affiliation/denomination closely approximated recent census data (Australian Bureau of Statistics, 2016), permitting some generalisation. Just over one-third of participants identified as having a professional role with some exposure to, or training in, grief following bereavement. Although this figure is noteworthy and we might expect different grieving norms in this third of our sample, professional exposure/training did not emerge as a significant covariate for any of the outcome measures. This result may be due to the limited quality and outdated nature of grief education to which many professionals are exposed (Breen et al., 2012-2013; O'Connor & Breen, 2014). Future studies could investigate

how quality of education might affect recognition of grief and intentions to support grieving persons.

This study is the first to examine some of the less well understood factors that may affect community recognition of grief, intentions to support grieving persons, and endorsement of a grief-related classification using robust research methods with strict control of extraneous variables. A particular strength of this study was its exploration of bereavement status as a non-binary concept, permitting participants to self-define according to their bereavement experience and whether they believed it had significantly impacted on their life. Recognising that the experience of bereavement may not, in itself, correlate with distress or an altered perception of grief, it is anticipated that this study may have more accurately captured the true relationship between bereavement status and grieving norms than past research.

5.6.1   Conclusion

Community expectations of grief, intentions to provide social support, and beliefs about the support and classification needs of grieving persons are dependent on a range of respondent characteristics including age, gender, and bereavement status. This study highlights the need to expand research beyond the experiences of the bereaved, to understand the motivations of the providers of social support. In order for communities to be compassionate in the wake of bereavement, there is a need for awareness-raising initiatives, distribution of resources to inform the public of current theories of grief, and clear and open communication between specialised bereavement services and communities so that each is informed of the unique role of the other. The findings offer insight into the direction of such strategies, for example, focusing on potential responders who hold less realistic expectations of bereaved persons or who may be less willing to offer support when it is needed. Although a minority of bereaved persons will have many of their support needs met through formal bereavement services, for both these individuals and others, there is a need to deepen investment in the natural supporters of grief through improving perceptions of and attitudes towards death, dying, and bereavement and harnessing the informal resources inherent in communities. If community members are to assume the greatest bereavement support role and should 'pathological' grief shift into mainstream diagnostic nosology, further research will be needed to inform efforts to enhance treatment receptivity for those at greatest risk for complications of bereavement, and facilitate constructive, timely social support for those who are not.

Chapter 6   Grief Myths and Misconceptions: Influences on Loss, Coping, and Social Support

"We were even promised sufferings. They were part of the programme. We were even told, 'Blessed are they that mourn' and I accept it. I've got nothing that I hadn't bargained for. Of course it is different when the thing happens to oneself, not to others, and in reality, not imagination."

(Lewis, 1961, p. 32)

6.1   Chapter Overview

This chapter presents an account of the third phase of this research, a qualitative exploration of grieving norms in a sample of bereaved adults. This study sought to expand the normative beliefs, expectations, and assumptions highlighted in Phases One (Chapter Four) and Two (Chapter Five) and explore their influence on experiences of loss, coping, and social support in a sample of adults significantly impacted by bereavement. This unpublished manuscript offers a background to the research, provides a summary of data collection and analysis methods, presents themes and subthemes through a comprehensive narrative of the nineteen stories, and highlights implications for clinical practice, grief education, and future research. The findings of this study contextualise the results of Phases One and Two and contribute towards the implications and recommendations outlined in Chapter Seven.

6.2   Abstract

Social support is touted as one of the most significant predictors of post-bereavement outcomes; however, grieving persons do not consistently receive the quantity or quality of support they require. Grounded in death-denying attitudes and outdated grief theories, societal beliefs, expectations, and assumptions about grief rarely match or honour the variability of individual grief responses. Little is known about how grief-related norms directly influence support of people who are bereaved, and how this support or lack thereof, in turn, shapes the experience of grief. This study aimed to explore how people who are bereaved reconcile their own normative beliefs and expectations, and that of those around them, with their actual experience of grief. Nineteen bereaved informants were interviewed about their experience of grief-related norms in the context of loss, coping, and social support following a significant

bereavement. Data were analysed using the constant comparative method, seeking to provide a systematic account of this complex social phenomenon. Five key themes depicted how the respondents' grief was measured and judged against an arbitrary standard (*setting the bar*); suppressed due to mutual discomforts, empathic failures, and self-sacrificing behaviours (*dual silencing of grief*); honoured through the creation of secure intra- and interpersonal spaces (*holding space*); integrated through efforts to contextualise and make sense of the experience (*processes of meaning making*); and accepted as their version of reality (*redefining normal*). These findings strongly support the important role of compassionate communities in bereavement care, but highlight the persistence of outdated myths and misconceptions which underlie challenges in navigating both the individual and social/relational elements of grief.

Keywords: grief; bereavement; community norms; coping; social support

6.3   Introduction

Once perceived as the specialty of formal health and social services, bereavement care is increasingly being recognised as a collective community responsibility (Kellehear, 2013). Acknowledging that the majority of bereaved persons do not benefit from specialised bereavement services, and those who do benefit often do not seek out such services (Aoun et al., 2015), focus has shifted to how intrinsic knowledge, skill, and experience can be harnessed to make communities more compassionate in the wake of bereavement (Aoun et al., 2012). Evidence suggests that although social support is a strong predictor of bereavement outcomes and many bereaved people are drawn to connect following a loss (L. A. Burke & Neimeyer, 2013), social support is not consistently offered and when it is, may not meet the unique needs of bereaved individuals (Breen & O'Connor, 2011). Intentions to provide support may be more complex than once thought and influenced by resistance to thinking or talking about death and loss, in combination with rigid societal expectations of the circumstances under, and manner in which, grief is permitted (Logan, Thornton, Kane, et al., 2017).

Underscored by the 'grief work' hypothesis, early theories positioned the grief experience as a linear, predictable, time-limited, stage/phase/task-oriented course, eventually culminating in detachment from the deceased and resolution of the loss (for a summary, see Breen & O'Connor, 2007). However, empirical research suggests that most bereaved individuals assimilate, rather than recover from, significant loss, and the grief trajectory depends on a complex interplay of factors relating to the strength of the attachment relationship, beliefs about the nature of the death, and internal and external coping mechanisms (L. A. Burke & Neimeyer, 2013). Thus although bereavement is rightfully recognised as a universally experienced phenomenon, its natural consequence, grief, is not. More recent theories have

succeeded in recognising the broader cultural, social, cognitive, emotional, behavioural, and spiritual dimensions of grief, promoting continued bonds with the deceased and redefined meaning both within and beyond the death (C. Hall, 2014).

Despite robust challenges in the literature, research highlights permeation of this dominant grief discourse through contemporary social and community circles due to the perceived ease at which these ideas and assumptions bring order and sense to an otherwise complex and misunderstood process (C. Hall, 2014). Grieving 'rules' prescribe who, when, where, how, how long, and for whom grief can occur (Doka, 1989). How these norms will apply is arbitrarily determined based on circumstances relating to the deceased (e.g., cause of death), the bereaved (e.g., relationship to the deceased), and the potential supporter (e.g., personal bereavement history) and may be communicated implicitly or explicitly (Logan, Thornton, & Breen, 2017). According to Doka (2002), individuals may experience disenfranchised grief when the nature of their loss is highly stigmatised or not socially sanctioned, disallowing public acknowledgement or mourning. These grieving rules have been observed to extend beyond the social domain, with professional helpers expressing mixed confidence in working with issues of grief and loss and continuing to refer to obsolete grief theories and treatment models based on outdated bereavement training (Breen et al., 2012-2013; O'Connor & Breen, 2014; Ober, Granello, & Wheaton, 2012). Although it is expected that such rigid enforcement of standards would be detrimental to grief processes, there is limited research to suggest how cognisant bereaved people are of these rules and, in turn, how any discrepancies between external expectations and internal experiences are negotiated by grieving individuals.

The impact of such strongly held myths and misconceptions about grief are twofold. First, they may shape the extent and duration of social support offered to a bereaved person. Social support is a buffer against stressful life events and offers the sense that one is loved and valued by others through acts of instrument (practical goods), information (direction or advice), emotion (empathy and connection), or appraisal (affirmation; Heaney & Israel, 2008). The provision of timely, targeted social support is recognised as both a significant predictor of bereavement outcomes and one of the only grief moderators (unlike cause of death or attachment to the deceased) that is amenable to change *after* the death (Bath, 2009). Key benefits of social support include lower levels of rumination, depressive symptoms, and grief symptomatology, and increased formal help-seeking behaviours (Ghesquiere, 2013; van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2010). However, for social support to be effective, a specific need must be recognised, the supporter must be competent, and the action must be perceived as helpful not only by the supporter, but also by the receiver (Kaunonen et

al., 1999; Rando, 1993). Given that the general public expect grief to de-intensify over time (Penman et al., 2014), are reluctant to offer support if they do not believe they are sufficiently skilled or their supportive actions will have impact (Bath, 2009), and typically endorse many harmful support-intended statements as being 'helpful' (Lehman et al., 1986), it is not surprising that many bereaved persons do not receive the support that they require, and at a time when it is needed most.

Second, these norms may shape the nature of public mourning dependent on whether the grief is legitimised or disqualified. There has been a small amount of research into the detrimental impact of grief-related beliefs and expectations on the lived experience of bereaved people. Wortman and Silver (1989) suggest appraisals of one's own grief response are determined by both one's own and significant others' conceptualisations and expectations of grief. To illustrate, in a sample of 21 bereaved individuals, Breen and O'Connor (2011) observed enforcement of a dominant grief discourse by friends and family of the bereaved who assumed that the grief would follow a short-term pattern across a series of stages, involving conscious work, detachment from the deceased, and meaning taken from the death. Consequently, respondents in this study reported the deterioration and collapse of many close relationships following their loss. Similarly, Costa et al. (2007) highlighted respondents' challenges with naïve prior expectations and assumptions of grief, negative self-evaluations, and insensitive reactions by others when grief did not follow a predetermined, time-limited course, resulting in heightened levels of distress and compounded loss. Experiences such as this may result in self-disenfranchisement (discounting one's own grief as unjustified and not warranting support; Cordaro, 2012) or the internalisation of grieving (selectively controlling where grief is shared or inhibiting responses altogether; Begley & Quayle, 2007). Interestingly, far less is known about how bereaved persons conceptualise their needs following a loss and, if not met, what mechanisms or strategies they adopt to reconcile the differences and effectively grieve anyway.

The quality of social support provided following a death can have a profound impact on bereavement outcomes; yet, the extent to which grieving norms influence supportive behaviours and the experience of grief, remains unclear. Although there is growing empirical evidence for the nature and scope of grief-related beliefs, expectations, and assumptions in the general public (for a review, see Logan, Thornton, & Breen, 2017), few studies have explored both perceptions of and experiences within this phenomenon in bereaved persons. Similarly, the concepts of grief norms and social support appear to have received scant attention in the development of targeted grief interventions, despite their obvious role in contextualising individual grief experiences. This study aimed to explore the influence of grieving norms on

the experience of grief in a community sample of people significantly impacted by bereavement. The research questions were: (1) how do bereaved people experience societal norms, as expressed through beliefs, expectations, and assumptions, in the context of their own grief; (2) what coping mechanisms or strategies are adopted by bereaved people to reconcile these norms with their actual experience of grief and mourning; and (3) how do bereaved people reflect on needs, both from the self and others, as integral to facilitating their grief experience? It was anticipated that the findings of this study may provide insight into the nature, extent, and influence of grieving norms in contemporary Australian culture, and demarcate the extent to which social networks can be relied upon to provide a supportive function complementary to, or in place of, formal grief counselling or therapy.

6.4   Method

6.4.1   Participants

Theoretical sampling was used to recruit Australian adults who had been bereaved by the death of a person that had, or continues to have, a significant impact on their life. The study was advertised through local radio advertising, online discussion forums, and community noticeboards. Recruitment and data collection occurred alongside transcription and analysis, to inform the diversity of the sample and saturation of developing categories (Boeije, 2002). No constraints were placed on the cause of death or time that had passed since the death; rather, respondents were empowered to decide whether they felt prepared to discuss their bereavement (Williams et al., 2008). One interview was terminated early due to the presence of considerable emotional distress, with the data excluded from analysis.

The final sample comprised 19 adults (13 women, 6 men) aged between 21 and 76 years (M = 52.16, SD = 17.50). A slight majority of the sample was born in Australia (68.4%) and educated to a tertiary level (57.9%). Most respondents (63.2%) had no religious affiliation, 21.1% identified as Christian, and the remainder identified as 'other.' As illustrated in Table 6.1, the majority of the sample (89.5%) referred to one significant bereavement, which was most often a parent, followed by a spouse/partner, sibling, child, friend, aunt, or grandmother. The time that had passed since the death ranged from 1 month to 29 years (M = 8.47 years, SD = 7.66). Ages of the deceased ranged from 22 to 84 years (M = 55.29, SD = 22.94) and causes of death included cancer (n = 9), suicide (n = 3), cardiac arrest (n = 2), overdose (n = 2), respiratory illness (n = 2), epileptic seizure (n = 1), dementia (n = 1), and accident/missing presumed deceased (n = 1). Names used throughout this section are pseudonyms, protecting the identities of respondents and their family/friends.

Table 6.1

Demographic Data

Respondent	Age (years)	Relationship to the respondent (age in years)	Time since death (years)
Rose	61	Daughter (22)	13
Joe	62	Wife (63)	1
Alex	76	Wife (66)	7
James	63	Mother (78)	20
Penny	59	Son (23)	4
George	45	Brother (29); best friend (25)	17; 17
Julia	31	Mother (48)	12
Alice	61	Mother (79)	3
Olivia	21	Brother (27)	1
Maggie	65	Partner (75)	1 month
Lily	21	Father (67)	4
Jane	38	Mother (31)	29
Ruth	54	Mother (88)	2
Mary	72	Husband (77)	4
Jacob	65	Wife (39)	10
Sally	71	Sister (67)	2
Claire	59	Partner (58)	6
Henry	39	Father (77)	1
Helen	28	Aunt (38); Grandmother (84)	9; 14

6.4.2   Measures

Grief symptoms were measured using the PG-13, which is a 13-item self-report assessment of an individual's maladaptive grief symptoms over the past month (Prigerson & Maciejewski, 2009). Diagnosis of PGD is contingent on meeting five criteria: (1) event of death, (2) separation distress, (3) duration $\geq$ 6 months following death, (4) cognitive, emotional, and behavioural symptoms, and (5) significant impairment to functioning. Responses to this measure are on a 5-point Likert scale from 1 (*not at all*) to 5 (*several times a day* or *overwhelmingly*), with two questions structured as forced choice *yes*/*no*. The PG-13 has previously demonstrated unidimensionality with good internal consistency reliability (α = .82) and incremental validity (Lichtenthal et al., 2011; Prigerson et al., 2009).

Quality of life was measured using the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q-18) which is an 18-item self-report assessment of physical health, leisure time activities, social relationships, subjective feelings, and satisfaction with medication (Ritsner, Kurs, Gibel, Ratner, & Endicott, 2005). Responses to this measure are on a 5-point Likert scale from 1 (*not at all* or *never*) to 5 (*frequently* or *all the time*). Domain scores and a general quality of life index are measured by averaging items, with higher scores representing higher quality of life. The Q-LES-Q-18 has previously demonstrated high internal consistency reliability (α = .82 to .96), and test-retest reliability (ICC = .71 to .83; Ritsner et al., 2005).

A demographics form was used to collect data on age, gender, birthplace, religious affiliation, education, and postcode. Respondents were also asked to describe their bereavement(s) in terms of the time that had passed since the death, their relationship to the deceased, and the gender and age of the person who had died.

6.4.3 Interview guide

A semi-structured interview guide was developed to explore the influence of grieving norms on the experience of grief for bereaved persons. The focus of the questions was informed by previous related studies (e.g., Breen & O'Connor, 2011; Costa et al., 2007), but more specifically addressed the nature, influence, and reconciliation of grief-related beliefs, expectations, and assumptions. The guide covered (1) grief reactions, (2) expectations, experiences, and needs relating to support (formal and informal), (3) personal beliefs and expectations about grief, (4) reflections on growth and change following loss, and (5) recommendations for bereaved individuals and their potential supporters. Example questions included: What forms of support did you receive immediately following the death? What do you wish others had done or said at the time? What beliefs or expectations did you hold of your own grief? The interviews ranged from 14 to 87 minutes (*M* = 53.89, *SD* = 17.74).

6.4.4 Procedure

Ethics approval was granted by the Curtin University HREC. Through advertising materials, interested respondents were invited to contact the researcher for more information and to schedule an interview either at the respondents' home (*n* = 12) or at the university (*n* = 7). Following reading and completion of a participant information sheet and consent form, respondents were invited to ask questions. During this time, many enquired about the motivations behind the research study and intended outcomes of the findings, which assisted in developing a relationship with each respondent and setting the scene for the interview

questions that would follow. Respondents were given paper copies of the PG-13, Q-LES-Q-18, and demographics form; all chose to complete the scales prior to the interview. The interview guide was used flexibly to gather all relevant information while still taking time to build rapport and allow the grief narrative to unfold naturally. The emotional responses and body language of respondents was monitored closely throughout the interviews and the pace and phrasing of questions were adjusted accordingly. At any time during the interview, respondents were given the option to take a break, terminate the interview and continue at another time, or withdraw from the study without consequence. Interviews were audio recorded and transcribed verbatim. Following the interview, all respondents were provided with community mental health contacts should they require follow-up support.

6.4.5   Analysis

Data were analysed using CCM to develop a conceptualisation of the phenomenon that was grounded in the data (Glaser, 1965; Glaser & Strauss, 1967). CCM assumes a creative interplay between researcher and data focused on exploring complex social phenomena and comparing the unique meaning and value each individual attaches to his or her experience. Although originating in grounded theory methodology, CCM is increasingly being used as a methodological technique in its own right (Fram, 2013). In this way, CCM is not used to inductively generate a theory, but rather is a method of systematically processing discrete incidents of data and producing a complete account of a social phenomenon or process (Lincoln & Guba, 1985). Variations of the CCM method have been used previously in bereavement research where no theory exists, but where there are clear links between sociocultural processes and individual experiences (e.g., Hebert, Schulz, Copeland, & Arnold, 2009; S. B. Scott et al., 2007). At the core of CCM is a continual process of comparing and contrasting through: (1) forming categories from incidents within interviews, (2) integrating conceptually-related categories across interviews, (3) identifying boundaries around categories, and (4) developing core themes that are embedded in and consistent with the data (Glaser, 1965).

Interview transcription and analysis commenced immediately following each interview to enhance accuracy and evaluate progress towards data saturation (Glaser, 1965). NVivo® version 11 was used to manage the transcripts and provide a platform for coding and categorising the data. Each interview was thoroughly read with the aim of coding as many pieces of text as relevant and possible, comparing source to source, incident to incident, incident to category, and category to category (Glaser, 2001). Within each category, both positive (in support of the category) and negative (in contradiction to the category) cases were examined and integrated to inform the development of the emerging themes. The author

engaged in memo-writing and reflexive journalling throughout the process of analysis to write propositional statements (rules for inclusion in the category), define category boundaries, document emerging interpretations, and ensure traceability of the analysis process. Sampling saturation was determined through evaluation within categories (when sources contributed no new information) and across categories (when no new categories emerged; Fram, 2013). The supervisory team (with experience in qualitative methods, grief research, and counselling psychology practice) reviewed and provided feedback on a preliminary summary of categories which were subsequently refined and collapsed to inform the final thematic map. Respondent validation occurred 11 months following data collection through inviting respondents to review a summary of emergent themes and provide feedback on whether their individual view was represented in its entirety (Torrance, 2012). Although no specific changes were requested, respondent comments were reviewed to inform the writing of themes.

6.5   Results

6.5.1   Quality of life and grief symptomatology

Of the 19 respondents, none met all five criteria for PGD according to the PG-13. Tables 6.2 and 6.3 provide a summary of criterion and domain scores.

Table 6.2

Prolonged Grief Disorder Symptomatology

	n	*%*
Number of criterion met		
Five	0	0.0
Four	1	5.3
Three	5	26.3
Two	4	21.1
One	9	47.4
Prevalence of specific criteria		
Event criterion	19	100.0
Separation criterion	8	42.1
Duration criterion	7	36.8
Cognitive, emotional, behavioural symptoms	0	0.0
Impairment	2	10.5

Table 6.3

Quality of Life Enjoyment and Satisfaction

	M	*SD*	Min-Max
General quality of life	3.76	0.48	2.89-4.67
Physical health	3.36	0.95	1.50-5.00
Subjective feelings	3.95	0.76	2.20-5.00
Leisure time activity	3.60	0.83	2.00-5.00
Social relationships	3.91	0.70	2.00-4.80
Medication	2.32	2.36	0.00-5.00

6.5.2   Themes

Five core themes were identified in the data which encompassed respondents' experiences of loss, adaptation, and growth following bereavement: *setting the bar*, *dual silencing of grief*, *holding space*, *processes of meaning making*, and *redefining normal*. The 5 themes and 17 subthemes are displayed in Table 6.4 alongside the number of respondents who contributed to each subtheme. Considering the representative of the findings to the sample (Hill, Thompson, & Williams, 1997), 1 subtheme was general (applying to every respondent),

15 were typical (applying to more than half of the sample), and 1 was variant (applying to fewer than half of the sample).

Table 6.4

Summary of Themes and Subthemes

Theme	Subtheme	*n* (%)
Setting the bar	Emotional conformity	13 (68.4)
	The preparation myth	18 (94.7)
	Social recognition of the loss	16 (84.2)
Dual silencing of grief	The shared taboo	17 (89.5)
	Empathic failures	17 (89.5)
	To burden and be burdened	14 (73.7)
	Self and other isolation	18 (94.7)
Holding space	Acknowledge, validate, and normalise	18 (94.7)
	Checking in and practically supporting	19 (100.0)
	Sharing the grief	18 (94.7)
	Looking outwards and turning inwards	18 (94.7)
Processes of meaning making	Facing the inevitability of death	10 (52.6)
	Making sense through metaphor	4 (21.1)
	Weaving common threads	17 (89.5)
	Finding purpose and inviting growth	14 (73.7)
Redefining normal	Enduring connection	15 (78.9)
	The cyclic model of living with grief	17 (89.5)

6.5.2.1   Setting the bar

Through this theme, respondents talked about the construction of an arbitrary standard against which their grief was measured. Respondents reported holding themselves, and being aware of being held, to this standard that, when not conformed to, resulted in confusion, social distancing, or critical judgement. The bar itself determined who could grieve (and for whom), as well as where, in what manner, and for how long following the death. The bar was established through expectations of emotional conformity, myths around preparing for the loss (i.e., an expectation of anticipatory grief), and broader social recognition of different loss types. It was reported to be rare that the bar was set at the appropriate height by both the bereaved person and their support network; rather, many respondents commented on experiencing unrealistic expectations that their grief would be more or less intense than it actually was.

6.5.2.1.1   Emotional conformity

Respondents described being prescribed and conforming to certain standards of emotion. Some experienced expectations that they would feel more angry or guilty than they did, solely because of the manner in which the person died which, at times, appeared more important to the potential supporter, than the bereaved person themselves. Others described being surprised, and experiencing others' surprise, that they were not more distressed than they were:

> I think people were relatively shocked that I wasn't as upset as I, well, visibly upset. That's the difference. So, you know, around Mother's and Father's Day and birthday, my brother's birthday, and things like that. (Olivia)

As a result of these expectations, some questioned whether they were uncaring or whether the relationship was not as significant as they remembered it to be. One respondent described this incongruence as distressing, turning to her deceased mother for reassurance that what she was feeling was right:

> I actually felt guilty because I think I should feel worse sometimes, when actually I don't. I had to think, I've got to allow myself to be happy. Then I feel guilty, then I go back, "What would your mum do?" (Alice)

However, more commonly respondents experienced the containment of emotion, whether it be sadness, anger, guilt, or otherwise. Often this process involved attempts to repress feeling, showing an outward appearance of stoicism, as if one was coping well. This containment was exemplified through statements such as "bottle it all up," "be in control," "kept myself up to par," and "blocked it all off." Respondents noted that men may be even more pressured to conform to this norm than women, due to societal conceptualisations of gender roles. Two respondents noted their inability to subscribe to this notion and regulate themselves, despite self or other wishes to do so. While one expressed acceptance of this state, the other reported some degree of shame and regret:

> I think people are taught to not let their emotions go. You've got to be in control of your emotions. Well, when you're grieving, I'm sorry, you don't. (Rose)

> My expectations for myself wouldn't have been to lose it at the funeral, but I daresay that was as a result of trying to contain it for the week and the lead-up. It just got to the point where I could no longer contain that level of distress. I guess the expectation for myself was just to manage and not let it disrupt my life, and I was able to do that, to a certain point. (Julia)

6.5.2.1.2 The preparation myth

The majority of respondents reported experiencing themselves as completely unprepared for the death and/or their grief that would follow, with 12 out of the 19 rejecting the notion that their grief should be less intense because the death was foreseen. Many described the experience of grief to be vastly different from what they had expected, while others again expressed no prior expectations, due to a belief that it would never happen to them. For instance, one respondent stated:

> I didn't know what to expect and when Allie went, my whole world just came crashing down….That thing that happened with Allie was just completely out of left field, you wouldn't have known what to expect. No idea whatsoever. (Joe)

For some, even prior bereavements could not prepare them for what came next. Several respondents described their resistance to prepare for the death and associated grief, due to "glimmers of hope" or enduring optimism that the ending might be different:

> I didn't ask. Part of me didn't want to know what the future held, so I didn't find out. (James)

6.5.2.1.3 Social recognition of the loss

Many losses were described as disenfranchised to some degree, where unique circumstances resulted in the grief not being socially sanctioned or understood as much as it could have been. Respondents were expected to experience less severe grief in response to deaths of older adults or more distant (or estranged) family members. Many did not experience the direct invalidation of their bereavement, but rather picked up on subtle social cues by others. Responses were either to assert one's right to grieve the loss, or conform and adjust the expression of grief accordingly:

> Just this stigma because she's an aunt, it's not like your grandmother, it's not your mum, it's not immediate family and such, which was hard to deal with, so I didn't talk about it quite as much as maybe I should have. (Helen)

Representing a form of ambiguous loss, one respondent shared her belief that the process of her grief and its recognition by others would have been different had her son's body been found. Less common deaths like this appeared to present unique challenges, with few templates for the experience or rules governing the process of grief that would follow:

By this time it starts getting longer and longer and longer, and we still class him as a missing person, but I supposed in the end you kind of accept that that's where he is. We've never had a memorial service, nothing. Because nobody wanted to make that decision. Everybody said he's missing. (Penny)

For several other respondents, the loss was experienced as legitimate but the grief was not due to the age of the bereaved and their perceived capacity to experience grief. These individuals were driven to suppress or postpone their grief in order to realign their experiences with others' expectations:

Even though I was kind of a good student, it didn't mean that I wasn't troubled, it's just that no one really took the time to try to find out….You're a child, you're very intuitive about these things and I probably just picked up, like I'm actually not supposed to talk about it, I'm actually not supposed to get upset. I'm just supposed to be a good girl, get on with being a good girl and not make too much trouble for dad because he's not doing that great. (Jane)

Maybe there was an underlying expectation that being children, or being teenagers, that we were fairly resilient, and that we would just eventually cope and deal with it and bounce back. I guess, in a way, we met those expectations, whether it be consciously or unconsciously, but actively trying to keep it together, and avoiding it, and going across the other side of the world and being like, "Look at me, I'm okay!" (Julia)

Challenging the notion that any bereavement could be 'worse' than another, respondents strongly asserted the belief that their grief was proportionate to the relationship they held with the person who had died. In the words of two respondents, the nature and course of their grief appeared testament to the strength and quality of the attachment bond:

She was a friend, we travelled together sometimes, as well as my sister. I think the journey in that 18 months was, for me, like a journey to my own death in a sense. (Sally)

I've decided it doesn't matter how old the person is, and how long you've had them around, it still hurts….There is no good way for someone to die when you've got family or people close to you. The person who's gone might be okay, but everyone else left behind are still picking up the pieces of their lives. (Rose)

6.5.2.2   Dual silencing of grief

Through various social processes, this theme describes ways in which respondents both silenced and were silenced in their grief. Although well-intended, the spread of many commonly held beliefs, assumptions, and routines minimised the impact of the respondents' losses and drew lines around with whom their grief could be expressed. This silencing was bound by perceptions of grief as a taboo topic, incidents of empathic failure, and conflicts associated with honouring one's own feelings at the same time as another's, resulting in experiences of isolation from self and others.

6.5.2.2.1   The shared taboo

Whether immediately following the death or after some time had passed, the topic of grief became a shared taboo between some respondents and their social networks. Grief was described as having a specific time and place and, outside of this, emotion was avoided and 'normal' functioning was assumed. One respondent expressed concerns that the longevity of her grief was often underestimated by others:

> By six months down the track, most people don't want to talk about it because they've moved on with their lives and you're still trying to pick up the pieces of your own. (Rose)

As a consequence, another respondent described the way in which her grief was quietened by others and she, in turn, embraced this silencing. This example illustrates how significant others may provide a model or template of 'typical' grief that is implicitly followed:

> It's a bit harder to rely on those informal supports after it's been awhile, because there's an element of forgetting, if that makes sense. Like, "Oh, now it's been a year and a half," so it's not something that is brought up often. If I like, I can bring it up whenever I want to, I know that, but I'm not really the type to do that, so it can get a little bit lost in that way. (Olivia)

Respondents talked in depth about observing society's common culture for grief and mourning, invariably dictating the extent to which grief could be brought up in conversation. Some targeted the media for its inaccurate and sensationalised portrayals of grief, and society more broadly for perpetuating this culture. Others described grief norms as being transmitted through generations of their family, centred on being self-reliant, avoiding difficult emotion, and holding a "stiff upper lip" mentality. One respondent reflected on her experience of grieving within a family where grief was not acknowledged:

My dad was pretty messed from it, maybe he just didn't have the capacity, and my family certainly didn't. Not that I mean [pause], they're a loving group of people, like my aunts and grandparents and things, I just don't think, as a family, we deal with grief very well and I know that's not uncommon. (Jane)

6.5.2.2.2   Empathic failures

Respondents described numerous efforts by others to connect with the loss, make sense of it, and assist the bereaved person to develop some acceptance. These attempts were almost always viewed as well-intended and meaningful, but experienced as misattunements, disconnections, and failures. Examples of empathic failures included platitudes in acknowledging the loss ("it's going to be alright"), forced positives ("at least she's in heaven now"), advice-giving ("you've just got to get on with it"), idealising or devaluing the deceased ("they're amazing beautiful people and they did no wrong"), and rationalising about the meaning of the death ("you had it coming"). As described by these two respondents, social networks were described to add to the respondent's pain, rather than alleviate it, due to their own fears and insecurities being activated:

Her method was sometimes to tell me that, you know, dad wouldn't want me to be sad. If I was in a particular state, I'd be like, "Well, I don't want him to be dead. We don't get what we want." (Lily)

I was told that, "You just have to go back to school, she'd want you to go back to school." I was like, "Okay," so I did. My family probably don't deal with emotional grief and stuff very well. (Helen)

Similarly, another respondent described efforts by others to express sympathy for the loss, which he interpreted as little more than a superficial acknowledgement of a much deeper impact:

They would all go, "Oh I'm so sorry, dah, dah dah." As I said before, I find that ridiculous for me personally. Other people might like it, but for me definitely I just find it, "What are you sorry for?" To go, "I feel really bad for you" is better than saying "I'm sorry." (George)

These empathic failures often left respondents feeling very alone in their grief, as if no one could possibly understand what they were going through:

My boss at work said to me one day, "Penny, I know this is going to sound a bit horrible. I'm just glad it's not me." "No," I said, "Because the thing is that I am so glad it's not you either, because I wouldn't wish this upon anybody, I just wouldn't." I don't expect anybody else to understand who has not lost a child. I just don't. They can't. It's just not how it's meant to be. (Penny)

6.5.2.2.3 To burden and to be burdened

Through grief, respondents described a role switch between the one burdening and the one being burdened. There was a strong view amongst respondents that certain expressions of grief must be held to avoid upsetting or burdening others. In this way, respondents wore masks to only show elements of the grief that they believed others should or would be able to tolerate:

It's almost like, I found it hard to share it with other people. I've been there for lots of people when things have gone wrong or somebody's died and that's got something, probably, to do with me too. That I don't want to take up your space or somebody else's space and that's why, in the end, I decided to pay and go to counselling. (Sally)

Simultaneously, there was a belief that social networks avoided exploring the grief for fear that they would upset or burden the bereaved by bringing the loss to mind. It appeared that social networks viewed themselves as responsible for the bereaved person's feelings and so acted in ways to protect and minimise the impact of potential triggers. Although understood as well-intended, not mentioning the loss was always rated as more distressing, than mentioning it:

Often people don't want to say something—they remember the death date, or they remember Chelsea at a certain time—because they think they're going to upset you. It's like, it would be so nice to know that somebody else was thinking. (Rose)

I've said to a few of my friends, "I'll either talk about it if you ask me about it, or I won't. You'll know which one I want to do when you ask, so don't feel scared to ask." Because a lot of them have said that they are scared to bring it up as well, because they don't want to ruin the mood, or ruin my mood. (Lily)

In line with this, respondents discussed an evolving paradigm between the supporter and the supported when negotiating relationships with other people who were simultaneously grieving. Some respondents compared and contrasted others' grief with their own, reporting interaction effects where the nature and trajectory of a significant other's grief could either magnify or minimise the impact of their own:

My father, I think he's quite a broken person. How he coped was he, I don't know, he had many, many women in his life and so my sister and I were exposed to many different kinds of women….He was not cognisant to what effect that would have on us. He actually hasn't really dealt with his grief very well at all. (Jane)

Many saw sides to their loved ones that they had not seen before, which was frightening for some. Others were disappointed, saddened, or confused by others' attempts at coping, for example, observing parents hide photos of the deceased or sell the family home to avoid painful reminders. Conflict was experienced between giving time and space to one's own grief and silencing this to attend to another person's grief when that took higher priority. Those describing themselves as natural nurturers (predominately women) appeared to experience the greatest difficulty in giving time to their own grief:

I guess not talk about what I'm feeling as much because I don't want to be the person that's like, holding onto them. Especially around my family….because my parents are grieving over the loss of their son, my brother is grieving over the loss of his brother and best friend, and my sister is, you know, obviously grieving for her brother….[I am] the person that, yeah, tries not to be as sad as everyone else. (Olivia)

6.5.2.2.4 Self and other isolation

All of these experiences contributed to a deep sense of isolation from the self and from others. Respondents described grief to be an incredibly lonely place to sit and reported experiences of repeated conflict and family/friend estrangement as a consequence of the death. For some, conflict centred on disagreements about the deceased's estate, funeral arrangements, or feelings of abandonment following the death, while for others it exacerbated long-standing family dynamic issues. These relationship breakdowns represented a form of secondary loss which compounded the impact of the death itself. Although some pre-empted these losses, having been pre-warned that some relationships would grow closer while others would be lost, the pain was no less. In many cases, social networks appeared unable to tolerate the grief, distancing themselves to avoid doing or saying the wrong thing:

There's a lot of people, like one of my closest friends just opted out. "I don't know what to say or do with you." "You don't have to do anything. I don't expect anything from you." I think that's their problem. (Penny)

Others described themselves as being in rooms full of people, yet still feeling completely alone, often like a part of themselves was missing:

Then we had a marvellous wake, a really wonderful wake, but I felt very isolated at the wake. As an individual, I was flying around like a bumble bee looking and making sure it was working, but I felt very lonely. I probably needed someone to take me and sit down, but no one did that. (Alex)

In other cases, respondents reported protectively distancing themselves from others due to past experiences of empathic failure, discomfort accepting help or support from others, or a wish to avoid the reality of the loss in any way possible. By withdrawing from others, respondents often also split off from the self, retreating from everything that previously offered them connection, purpose, and meaning:

I might have been my biggest problem. I might have been too brusque and too confident, "I'm all right Jack, I'm okay, let's get on with it." In the family, there's no one I could point my finger at, and so they gave me good support, and I might have been the problem, not them. Okay? (Alex)

Although still recognised as avoidance, some described their withdrawal from others as not only self-protective, but also beneficial or even necessary for their longer term process of healing. In order to redefine the emotional attachment to the deceased, some physical detachment was needed from the people, places, and things that served as reminders of the loss. One respondent viewed her mother's death as a catalyst for exploring elements of life that she was unable to when her mother was ill, knowing that her grief would still be waiting for her when she returned:

It got to the point where I actually dropped out of [university] and went travelling. Just up and left and moved across the world for two years just to avoid having to even talk about it, being the person who lost their mum, and not be around people who knew that that is what happened, and checking in with you, and that sort of stuff. I got to go somewhere and lived what I perceived to be a normal life, or the life that I hadn't up until that point. (Julia)

6.5.2.3   Holding space

Describing their grief as an unpredictable, untamed, and tumultuous journey, respondents promoted the need for a secure base to return to recharge themselves and gather strength. This holding space was seemingly co-created, occurring both within the bereaved (when alone) as well as in the physical and emotional space between the bereaved and their supporters. The space was characterised by acknowledging, validating, and normalising the grief, checking in and practically supporting, identifying ways in which to share the grief, and finding optimum

balance between looking to outward supports and turning to inward resources. Through these practices, the space was described as a conscious process of nurturing and containing, developing meaningful connection, allowing a sense of being heard and understood, offering freedom to express and release, and facilitating healing and growth without any intention to change or fix. A key message from respondents was that they found comfort when both they and others stopped trying to solve what was perceived to be unsolvable. Although some described having and benefiting from elements of this space, all were able to report ways in which it could have been improved if they or others had better recognised what was needed at the time.

6.5.2.3.1   Acknowledge, validate, and normalise

The respondents placed a great deal of importance on others recognising and responding to the death itself and the grief that followed. First and foremost, they needed the magnitude of their loss and difficulty of their grief to be acknowledged, no matter how much time had passed since the death. Respondents looked for verbal affirmations that others still remembered the deceased and appreciated what it meant to live with, rather than recover from, grief:

> The way that people could help is just to acknowledge it. Just acknowledge. You don't have to do anything about my feelings, but just acknowledge that they exist and they're there, and that would be beneficial to anybody that's grieving. (Ruth)

Unfortunately as this respondent notes, the deceased is often brought up in conversation less as time passes:

> "I'm so sorry that you lost your mum, or let's bring out some photos and talk about your mum, or let's just kind of acknowledge it and keep it alive." Not just the few weeks after she died, but on a regular basis for the last 29 years, because she's still as important to me now as she was then. I think it would have been really helpful had that been just part of the family discussion, yeah, "Let's sort of check in and let's acknowledge what these girls have lost." (Jane)

For many respondents, anniversaries of the death, birthdays, and other holidays were significant and challenging times of year when affirmations were needed most. By acknowledging the loss at these times, support networks gave the message that they remembered that the deceased once lived and that the relationship was a significant one. For another respondent, small physical gestures by close friends were really significant for her to know that she was not alone in her grief, particularly at those difficult times of year:

That girlfriend I told you made that lovely memory book, she gave me a gerbera plant because our daughter was going to have gerberas at her wedding. That's a memory thing for her. My gerbera which I had had for quite a few years died, so it's the replacement gerbera now. Out of the blue she said, "I just saw this the other day, I thought of Chelsea. It's around this time, I know." (Rose)

Equally important, was for social networks to validate and accept the grief, however it presented itself. Respondents needed to embrace (and have embraced) their unique experience with curiosity, time, and space, rather than reacting with fear or judgement. A powerful experience was for respondents to be given permission to sit with difficult feelings and unexpected responses and simply let them be, without wishing for anything to be different, respecting the respondent's readiness, pace, and process:

We sort of accepted that there was going to be that grief. There was going to be heartache and the tears, and they're still there. (Henry)

Finally, respondents needed to know that their response to what had happened was normal. Many shared fears and concerns about being "abnormal," "failing," and "going crazy" or "around the twist." With no previous experience to compare to, respondents desperately wished for confirmation that whatever they were feeling or doing was normal and right for them. Several mentioned Kübler-Ross's (1969) five stages of grieving, arguing that not everyone experiences every stage, and not necessarily in the prescribed order. In addition to feelings, respondents also sought normalisation about seeking the support of a health professional, talking aloud to the person who had died, or experiencing paranormal phenomena. For many, it was reassuring to know that they were not the first person to experience grief in this way:

If that's grief, then so be it. If it hurts, then so be it. I don't think I'm unhealthy for feeling sad. I don't. I think that's perhaps a good thing to try and communicate to other people. It's okay to be sad, and it's okay to be happy equally. You shouldn't feel guilty because life goes on and you had a great holiday. (Ruth)

Through acknowledging, validating, and normalising, respondents came to understand that although bereavement is a universal phenomenon, grief is not. Respondents respected and honoured the different ways in which people grieve which gave them a greater appreciation for what both they and others were experiencing:

If they perceive grief should be done this way, and that's their way, they're going to grieve that way. I'm going to grieve my way. I didn't felt like I needed to conform to their idea of grief or anything like that. I was quite content doing grief my way, you know? (George)

6.5.2.3.2   Checking in and practically supporting

The respondents placed significant emphasis on taking time to check in with the bereaved about how they are managing and what needs are going unmet. This included offering a stable presence and being with, as well as enquiring about practical needs and doing for. Many respondents described this form of support as coming from some of the most unexpected places, and proposed that this should be embraced:

I've got this one friend who basically sent a message to me, like a quote or whatever, every day for at least the last three and a half years. Every morning she sends me a message. It just says, "Sending you lots of love. Lots of love is on its way, big hugs with lots of love," and a message for the day. It will be absolutely spot on every time. It will either be something that's happening or just anything….I said, "It's alright, you can stop whenever you like"….She said, "I just send it to you, because I just feel like I just need to be doing that for you." (Penny)

Acknowledging that many people do not know how to help a person who is grieving; respondents suggested that people should always ask, rather than presuming to know and acting on assumption. Respondents commended courageous acts by others to honestly admit when they did not know what to say or do:

I had a girlfriend who asked me to explain things, and she was willing to listen. That was good, because then she was trying to know what to say, do, whatever, because she hadn't lost anybody close, but at least she was asking. Whereas, the others didn't ask. They just bolted in and did their thing. That, unfortunately, does not help. (Rose)

Respondents also described their own need to recognise supports as fallible and human, knowing that others would not get it right every time, even if intentions were good. Through acknowledging and accepting the limitations of others, some onus was placed on the bereaved to check in with themselves and when turning to supporters, be specific in asking for what they need. Respondents came to appreciate who they could safely share their grief with, and who it was best left unmentioned around. For many, there was an assumption that grief could only be truly known by those who had experienced it themselves:

With that particular person I mentioned, saying, "The person's in heaven," I realised it came from an understanding that she hadn't experienced what I was going through. That's why I didn't say anything. There's no point. Somewhere along the line, she will lose somebody close from her family, somewhere along the line, and she will understand. (Rose)

I found that a lot of people just would say, "I honestly don't know what to say," and my response to that was, "I don't know either. I have no idea what to say." It wasn't anything. Just being there was enough, in that way. (Olivia)

6.5.2.3.3 Sharing the grief

More than anything else, respondents expressed a need to share their grief. Sharing the grief was about being invited to a space where problem-solving, advice-giving, and judgement were left at the door, and the bereaved person could simply be given the gift of presence by another caring person. This space held no agenda and was unconditional, meeting the bereaved person wherever they were at. Grief was shared through expressing thoughts and emotions, retelling stories of life and death, sharing photos and other memorabilia, and introducing the person who had died to new friends. For many, laughter and jokes were equally as important as tears, and this space offered an honouring of the deceased through keeping their memory alive in people's minds. Several respondents reported benefits derived from engaging in this research project, recognising the interview as another opportunity to share their grief and talk about their loss.

This is what really came out for me, probably more than anything else, how important it is to give people the opportunity to talk about it. Without any expectations, without any goals, without anything. Just be with that person, just like you've done today. (Sally)

For some respondents, this process of sharing started immediately following the death, with families meeting around the body and making funeral arrangements. This time was described to be highly therapeutic, offering a sense of meaning and purpose in an otherwise confusing time:

I liked sitting around that table with everyone who loved mum, talking about how we were going to respect her memory and how we were going to celebrate her life and where we were going to go. We had none of those things planned, even though we knew mum was dying, we had none of those ideas before she passed away. It gave us a common purpose….It was kind of like, almost like she was there and we were having a party for her. (Ruth)

Although struggling to find it initially, one respondent discussed the cathartic benefits of eventually finding people with whom she could discuss both the death and the person's life, breaking a cycle of rumination:

I think your supporters need to talk about the person, which enables you to talk about the person, which enables you to get it out, instead of hanging onto it. Because when you hang onto it, you just go back over it. (Claire)

Another respondent described how sharing strengthened relationship ties, combated the loneliness and isolation of grief, and provided comfort and emotional regulation that extended beyond the self:

I just needed to be near my sister. I needed to be near my dad. Almost like going back to a time before it all happened. That's where I wanted to be, like coming home. (Penny)

6.5.2.3.4 Looking outwards and turning inwards

Respondents reported treading a fine line between relying on the self as a stable and consistent source of support, and knowing when to turn to more formal, specialised supports to assist them in their grief. Respondents placed different importance on self- versus other-support and usually leant towards one when the other was not sufficient or available. Some respondents expressed surprise at the safety and comfort they could create within themselves through taking time for reflection, writing, reading, and other forms of self-education. One respondent described finding places where she could ground herself and let her emotions be:

I just went out in the garden. I felt at peace when I was out there. So I started to dig, I started to plant, I started to do things being with the earth. I didn't have to think, I could just be there and cry. That's all I felt like doing. (Sally)

Another respondent detailed her journey of learning self-care, which meant putting herself and her needs ahead of others, a concept that had been relatively foreign to her before her loss:

Note to self, you're not selfish, you're being self-caring. Take time for you….I'll always say if you didn't care, you wouldn't grieve. It's okay to care. But care for yourself. And that's what I did. (Alice)

In terms of formal supports, 11 out of the 19 respondents reported accessing some form of individual or group counselling, while others instead benefited from services provided by churches, general practitioners, or palliative care staff. All except one respondent described

the experience of connecting with formal supports as cathartic and emotionally regulating; however, some reported that these supports were not available immediately after the death or did not last for as long as they were required. There were also many challenges reported in coming to terms with the fact that external support was necessary, or battling the stigma associated with accessing help:

> For people who are going through it, seeking professional help doesn't mean that you're weak, and that you can't handle anything. It just means that you're getting the help of someone outside of the situation. Then that means that when you explain how you're going through things, and you're dealing with the people who are telling you that you should be 'better' by now, for them to say that you're where you should be is actually quite helpful. (Lily)

6.5.2.4 Processes of meaning making

This theme characterises respondents' endeavours to make meaning both within and beyond the death. Captured here are efforts to make sense of the loss, put the grief into context, and achieve growth through recapturing some of the purpose lost when the death occurred. While some of the processes described appeared as intentional behaviours, others seemingly occurred on a subconscious level but were recognised by respondents as integral to facilitating their grief and continued connection with life.

6.5.2.4.1 Facing the inevitability of death

Some respondents stated a need to come to terms with and accept the inevitability of death, regarding loss as a natural part of life. Although all wished for more time with their family member or friend, some were able to reflect positively on the opportunities they had to say goodbye, which helped with acceptance:

> Every time I see somebody going through what is inevitable, I wish for them the death my mum had. That's made my grief easier, because I think we really did it well. We really did it well. (Alice)

> I miss my mother a lot. If there's anything, she couldn't live forever. You kind of justify it. You sort of think that's how things are supposed to go. (Ruth)

Although some reached this realisation relatively quickly, others needed time to sit with the injustice of death before they could face that it was unavoidable. These respondents described becoming stuck in an oscillating pattern of "what if?" versus "now what?" Although

numerous hours were spent reflecting on what might have saved the person who died, and envisaging all of the things this person would miss in future, many were eventually able to just be present with the feelings of sadness. One respondent described her release once she accepted that neither she nor others were responsible for her partner's untimely (suicide) death:

> What if I'd rang him at half past eight? What if his mum didn't take him to buy grog and she had told me he was buying grog? There's so many things that I tried going over and over and over and over, and try to change it, and you can't....Anyway, it's gone. It's done. He's gone. He needed to go....So maybe sometimes, we have to be strong enough to be aware that we can't do anything and we have to be strong enough to realise that nothing's going to change, no matter how many times we go back over it. (Claire)

6.5.2.4.2 Making sense through metaphor

For several respondents, making sense of their loss and its impact was made easier by likening it to some other known experience. Through sharing these metaphors, respondents described ways in which the body adapts and adjusts to a significant change and grows around it to continue living. Examples included amputated limbs, physical injury, or illness:

> I've never lost a body part, but if you lose your arm, apparently you still have memories of having your arm and going to use it. You learn to do things without your arm. That's what it was like for me losing a daughter....You go on in your life because you have to, but it's not the same. There'll be times when you go to, say, use your arm that's not there, or think, "That would be nice to tell Chelsea. That's right, she's not here." That's when you realise it never goes away, you learn to live with it. (Rose)

6.5.2.4.3 Weaving common threads

The importance of identifying common threads was revealed throughout the interviews as respondents described seeking out others who had experienced a significant bereavement. Empathy and attunement were often described as greatest when coming from supporters who had encountered a loss themselves. Through both supporting and being supported, a common narrative of loss, grief, and survival was woven, leaving respondents more resourced, empathic, and willing to connect with others in their grief. Some offered useful books or articles, others took time to check in and acknowledge the loss at different times of year, and others again made a point of just being present. Several expressed a wish that through contributing their stories to this research study, their experiences might be of help to others. As these respondents note, shared experiences create a level of connection, reducing feelings of isolation:

People have to be ready to listen to you. Sometimes you're aware they're not ready to listen, whereas if they've lost somebody close to them already, [they] are open to listen because you've lost someone. You instantly have a connection. It's a good thing. Hindsight, it's amazing how grief can connect you to other people. (Rose)

You can definitely recognise it in people after you've been through it, and then you kind of say, "I'm here to talk," and you know that everyone's saying that, but it's like, you're trying to convey like, "I *actually* mean it, because I know what you've gone through." (Lily)

Several respondents described themselves as "softer" and "more vulnerable" following their loss. Two respondents reported taking time to repair relationships, realising that they had not responded to others' grief in the best way they could have:

I even spoke to a friend probably 18 months after Tim died and I said, "I am so sorry. I couldn't say anything when your mum died." I was 25 or 30, or something and I didn't deal with it very well at all. Since Tim has died, now I know just to let people know you're thinking of them. (Claire)

However, equally important, others noted the importance of not imposing your experience on others, or assuming what worked for you will also work for them:

I'm very aware of, whenever I'm working with grief, whether it's with kids or adults, about keeping my own stuff, and that this is their journey, and absolutely there are common things and common threads and things that I can relate to, but that my experience is my experience, and it will be different from that person's experience. (Jane)

6.5.2.4.4 Finding purpose and inviting growth

Both immediately after and in the months and years that followed the death, respondents described investing themselves in family and friends, work pursuits, spiritual endeavours, and other activities that offered them purpose to continue living and develop within themselves. Some gained an appreciation of the value of life and relationships that they had not previously experienced, while others found their passion in prevention, advocacy, and supportive work around death and grief. As these respondents noted, while giving time to grieve, it was important to also give time to rediscovering joy in life:

Maybe you can't focus on anything else at the moment, but eventually you'll find there are things in your life that you enjoy. Any chance, find something that you do enjoy and make the most of it, if you can. Give yourself a chance to recover bit by bit. (James)

As you move on, when you do actually think about those people, it's like, "Oh yeah, I do still remember them. They're not forgotten. They're still loved and cared for." So look forward to those days in the future. (George)

Spirituality and religion were often mentioned, with some respondents finding a new or strengthened belief in a higher power. For these respondents, religion was an important healing factor, coupled with the expectation of eventually reuniting with the person who had died. One reported finding meaning in small moments:

At that precise moment, I didn't know where I was going. Then comes this hymn 'Be not afraid, I'll go before you,' and I just burst into tears. Every time it's played, I still burst into tears, but it gave me faith back. (Alex)

In contrast, others renounced their beliefs in search of something that fit better following the loss. For one respondent, her partner's death confirmed her belief in the finiteness of death:

I knew then that Paul would not have let me go through all that without contacting me in some way, or helping me in some way. There was nothing, and there's been nothing for four years. Anybody says there's an afterlife? Sorry, I don't believe it. You're gone, you're gone. (Mary)

6.5.2.5 Redefining normal

Not content with societal conceptualisations of grief, this theme represents respondents' efforts to resist, oppose, and push back against the dominant grief discourse and instead redefine a new sense of 'normal' for theirs and others' grief. Through connecting with others, self-education, and self-compassion, respondents first defined what this new normal would look like, then took time to accept this new normal as their form of truth and reality. Often contrasting with what they previously thought to be true, 'normal' was considered to be maintaining an enduring connection with the person who had died, and experiencing grief as a perpetual cycle, rather than a linear process.

6.5.2.5.1 Enduring connection

Many respondents described routines and practices aimed at maintaining some connection with the deceased person, long after the death had occurred. Death was viewed as

the end of a life, but not the end of a relationship, and respondents worked to redefine this important attachment bond post-death. This bond was described by all as a significant source of comfort and meaning, and any ties that maintained the relationship were honoured. Some respondents described maintaining a felt presence with the person who had died, actively engaging in conversations and continuing to involve the person in their everyday activities:

> I heard this said at somebody's funeral, "To be able to talk about the person as if they're just in the next room. That, "I hate the way you do that," or whatever, as if they are still there. I do find myself doing that. Like when I'd find a beer can in the garden, "Bloody typical!" (Claire)

For others, it was about finding places or tokens of memorial which helped them to remember and feel close to the person who had died. These chosen places and things served a temporary purpose for some and a more permanent function for others:

> We used to go and sit out on the mole and we'd just sit there. He used to love that because he spent his whole life on the river….As far as we're concerned, that's where we see him. We go down there and see him. We talk to him. (Maggie)

One respondent explained how her chosen place of memorial became something she could share with younger family members in order to open up conversations about her late partner and death more generally:

> I took her out there. We cleaned Tim's grave and we talked about, "That's his bed. Don't walk on it. That's his bed. And these are all the people's beds now they're dead." She loved it, but she said, "Next time, can we bring some food?"….I think that sort of thing, that really helped me and maybe helped her with her understanding of grief, and we never had that. (Claire)

Seven respondents reported intense gratitude at having received signs and messages from the person who had died through various extraordinary experiences. Some sought out connection through psychics and mediums, but most had experiences when they least expected it. This respondent described receiving a message on one of his darkest days, renewing his energy to continue on:

> I woke up in bed and Allie was next to me, laying, playing, kicking me in the foot, playing footsies. That's when I said to her, "You're here! You're here!" I don't know whether this was a dream or what. I said, "I love you." She said, "I love you too but I'm only here to let you know, do not worry, everything will be alright." "Are you going to stay? Are

you going to stay Allie?" She said, "No, I have to go." She got up, walked to the door, and kind of went into different colours….The following Monday I got a call from [the cemetery], "Don't worry Joe, we're sorry for causing you so much grief and distress, we're allowing Allie to have her colours on her plaque." (Joe)

As this respondent described, these experiences often questioned previously held beliefs and provided a great deal of comfort and reassurance:

I don't know what to make of that, like if people said to me, "Do you believe in ghosts?" I'd say, "I don't know"….It was great. I had no problem at all. It was a nice sensation. It was like being rooted to the ground almost. (Jacob)

One respondent described the importance of keeping an open mind and open eyes to seeing these signs:

Everywhere I go, I see yellow Getz [model of car] everywhere, everywhere….Just believe that they're still there. They're still there. Look for signs. There's always signs there if you look for them. It makes you feel good, because you know they're close. (Maggie)

6.5.2.5.2   The cyclic model of living with grief

Although respondents came to recognise some of their personal triggers over time, grief was still described to be highly unpredictable. As illustrated by these two respondents, self-compassion and acceptance were important in preparing themselves for when their grief might be activated:

All of a sudden, I feel like someone's whacked me in the chest with this big sledgehammer. It just floors me to think that that's where he is, or that that happened, or that my son's not here. (Penny)

I've had to pull over to the side of the road a couple of times. Sometimes I'm driving and something will come on or something will remind me and I think, "You're rotten Paul. Why did you leave me? You're a rotten bugger." Then I feel guilt. He couldn't help anything. It was time. (Mary)

The question of whether it is possible to move on or recover from grief was raised by many respondents. In most cases, social networks expected the respondent to move on or resolve their grief, often underestimating the impact of the death or expecting greater resilience than existed. The strength of recovery-related expectations were dependent on the cause and expectation of death and age of the bereaved person. In only one case, did a respondent

describe himself as having "moved on" from his bereavement, which interestingly was met with equally critical judgement from those around him. In most cases where grief was permitted, strict timeframes were placed around grieving with an anticipated end-point or resolution to the grief. As this respondent noted:

> I don't think grief is something you recover from. I don't think the death of someone you love, I don't think you recover from it, and I don't think you should. (Ruth)

Respondents refuted the notion of grief having a linear, predictable course, and instead described it as a process of cyclic revisiting, more akin to a complex and intricate web, than a neat circle. This process recognises the significance of anniversaries, birthdays, and other holidays as grief triggers. Further, it appreciates that due to emotional readiness or other commitments, the processing of some elements of grief may be delayed or may be re-experienced in different ways at distinct points in the lifespan:

> It works on a continuum where the longer time passes, the more it decreases and has an impact, but there is always going to be bumps along the way where it will flare up, like having some sort of chronic underlying illness that, most of the time, can be contained, but every now and then, if it's triggered by stress or whatever, it will flare up and impact you for a short period of time. (Julia)

> You can get these grief periods that hit you much later after the event. I guess I had probably a perception that grief would hit. You'd grieve. There'd be an underlying sorrow that they're gone, but you wouldn't get these peaks and troughs coming through, and I guess it's like any emotion. A bit the same like depression, it's not constant, it comes and it goes. (Henry)

Ultimately, it appeared more realistic for respondents to think about "learning to live" with grief through gradual integration and assimilation, rather than expecting to resolve it or completely recover:

> It just doesn't go away. Like I said, the intensity of it is different at different times, it is just part of who I am, it's just part of my life now and it'll be with me forever. When I'm an old woman, I'll still be loving my mum and missing my mum. Yeah, that's fine, that's fine with me. (Jane)

6.6   Discussion

This study highlights that bereaved persons are highly cognisant of societal expectations, beliefs, and assumptions about grieving. The risk of such pervasive and rigid grieving rules is that people who are bereaved are open to being judged, and judging themselves against a dominant prescription that is not necessarily congruent with their unique manifestation of their own grief (Breen & O'Connor, 2007). However, the findings also indicate that the respondents' conceptualisations of grief were irrevocably changed by their experience of significant loss. Respondents were quick to reject traditional notions of grief as short-term, predictable, and finite and adopted a range of coping mechanisms to accept their experience of grief as reality, negotiate relationships with significant others, and ensure their unique needs were met (whether resources were found within the self or sought from others). This study offers insight into how people who are bereaved accommodate their own beliefs, as well as those imposed by others, all the while trying to cope with the magnitude of the loss itself. Consequently, these findings have significant practical and theoretical implications for therapy with bereaved individuals, grief education, and future research.

Akin to previous studies (Breen & O'Connor, 2011; Dyregrov, 2003-2004), respondents described an arbitrary standard against which their grief was measured and evaluated. Respondents were observed to self-disenfranchise their grief, questioning the intensity or duration of their emotional reaction and its appropriateness relative to their age, the expectation of death, or the amount of time that had passed. Incongruence between how an individual's grief was appraised and their actual lived experience often resulted in a two-way silencing where neither the bereaved nor their social networks sufficiently acknowledged the impact of the loss and its associated grief. This finding underscores the importance of normalisation and validation as a crucial component of grief support, recognising a lack of self-acceptance and self-compassion as one of the many reasons why individuals may become 'stuck' in their grief (D. P. Scott, 2016). Exemplifying the terms 'empathic failure' (Neimeyer & Jordan, 2002) and 'social ineptitude' (Dyregrov, 2003-2004), respondents experienced a range of unhelpful statements and gestures by people in their support networks that were intended to alleviate distress, but instead only operated to reduce discomfort in the support provider. Similar to Feigelman et al. (2009), experiences of avoidance, unhelpful/unwanted advice, low levels of compassion, spiritual and philosophical rationalisations, and blaming of the deceased and the bereaved were all reported as detrimental to the grieving process. In line with previous research (Breen & O'Connor, 2011; Dyregrov, Nordanger, & Dyregrov, 2003), respondents found it more helpful to acknowledge their supporter's limitations and selectively choose who to share their grief with, rather than confronting the behaviours as failures.

Although self-protective, there is a risk that this avoidance will only serve to reinforce, and not correct, misconceptions and myths held by the general public about helpful grief support and further isolate the bereaved person. This issue highlights the need for mental health professionals working with bereaved people to build assertive communication skills which will not only strengthen networks around the bereaved, but also challenge wider notions of what it means to support.

Through promoting the normalisation of all grief reactions, respondents provided further challenge to the dominant argument in the grief literature concerning whether 'pathological' responses to bereavement can be differentiated from what might be considered a 'normal' or 'typical' reaction, without increasing stigma and marginalisation of bereaved persons (Doering & Maarten, 2016). More than in past research (e.g., Cherlin et al., 2007), the majority of respondents in this study had received or were receptive to receiving specialised support for their grief, indicating a shift in attitudes towards formal bereavement support. Whether through formal or informal support, supporting earlier research (Dyregrov, 2003-2004; Rynearson, Correa, Favell, Saindon, & Prigerson, 2006), respondents were found to benefit most from opportunities to retell the story of the relationship and the death and keep the deceased person alive in everyday conversation. Respondents sought out ways in which their grief could be acknowledged, validated, and normalised both within themselves and in their interactions with other people. Respondents rated efforts to be present with and accept the grief as significantly more helpful than attempts to devise solutions or act to alleviate the grief. These findings highlight the simplicity of providing basic grief support and may be used in community interventions to reduce some of the fear identified in supporters associated with saying or doing the 'wrong' thing (Dyregrov, 2005-2006).

Respondents engaged in a range of processes to create meaning both within and beyond their loss. These efforts seem to fit with theories of meaning-making which describe an adaptive process of making sense of the death, reconstructing personal identity, and finding benefit in the loss (Neimeyer et al., 2014). Respondents found meaning in their loss through accepting death as a natural part of life, making some sense of their experience through metaphorical analogies, connecting with others who had experienced bereavement, and allowing themselves to find purpose and growth following the loss. Similar to Costa et al. (2007), a significant degree of meaning came from connecting with and receiving social support from like-minded others, creating a form of shared identity. Although meaning-making was not reported as necessary for grief to occur, it was described as an integral component that facilitated the expression of grief, reduced isolation and disorientation, and

allowed respondents to remain grounded both in their attachment with the deceased person and their connection to life and relationships going forward.

Rejecting traditional stage/phase/task models of grief, respondents' experience of grief was not predictable or linear and did not culminate in detachment from the deceased or resolution of the grief. Respondents oscillated between engaging in career, family, and friend pursuits and being shook months and years later by reminders that the person they loved was no longer alive, re-experiencing feelings of distress often as intense as when the death itself occurred. The notion of looking back while still looking forward was embraced by respondents and appears most reflective of Stroebe and Schut's (1999) dual process model of coping with bereavement where time is given to both loss-focused (e.g., rumination about life as it was) and restoration-focused (e.g., investing in new relationships) orientations. Supporting previous research (e.g., Breen & O'Connor, 2011; Costa et al., 2007), grief was not seen as an experience to be 'recovered' from, but rather something to be assimilated and integrated into life going forward. Many respondents reported the benefits that came from retaining a connection, akin to a redefined attachment bond, with the person who had died through ongoing conversations and extraordinary experiences. This notion of continuing bonds is relatively new in the literature but well evidenced as a potentially healthy form of adaptation (Klass, 2006). Although some respondents internalised and conformed to widely held expectations about their grief, others resisted, opposed, and pushed back against the dominant discourse, accepting that they could choose to grieve their own way. In this way, grief was viewed as a social construction where meaning and process are ultimately determined by the individual experiencing the phenomenon (Neimeyer et al., 2014).

The findings of this study have important implications for improving clinical interventions with bereaved populations and enhancing community-wide awareness and understanding of grief. With regard to clinical practice, the data presented here highlight some of the challenges in effectively screening for bereavement risk both prior to bereavement and in the early days following the death (for a review, see Sealey, Breen, O'Connor, & Aoun, 2015). Respondents in this study were quick to reject Lindemann's (1944) notion of 'anticipatory grief,' proposing that even when death was imminent, nothing could prepare them for the impact of the loss or the grief that would follow. This notion is supported by recent research that has challenged the label of 'anticipatory grief' (for its assumption that grief will be alleviated prior to the death), proposing instead 'pre-loss' grief (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). Notably, some of the respondents in this study described their grief as most intense months or even years after the death when social support had diminished and others were perceived to have 'moved on' and forgotten the death. These

findings highlight the importance of extending bereavement support far beyond the death itself, acknowledging that both the intensity of grief and experiences of isolation may heighten as time passes.

Recognising that much bereavement care occurs at the community level (Aoun et al., 2015), it is imperative that mental health professionals have a sound understanding of how individual experiences of grief are shaped by the context in which the bereaved person operates. For some bereaved individuals, it may be important to reconcile prior expectations of grief with what actually eventuated, while others may benefit from creating routines or rituals that give new meaning to the loss (Jaffe & Diamond, 2011). In building the therapeutic alliance, time should be given to adequately acknowledging and validating the loss, recognising that the bereaved person may come to anticipate the same unsupportive interactions with their therapist as they have previously experienced with social networks (Worden, 2009). Data in this study suggest that most bereaved persons will present with some beliefs about how their grief should be manifesting that, if not addressed, may be detrimental to progress in therapy. Notably, bereaved clients may immobilise in therapy if they perceive therapeutic progress to be synonymous with losing the attachment bond or failing to honour the deceased (Jaffe & Diamond, 2011). Through asking such questions as "is it okay for you to be okay?" (Rando, 2012, p. 149), some of the more common forms of resistance may be addressed and therapist-client expectations realigned before therapy progresses. Although social support should continue to be recognised for its protective impact, it is remiss to assume that social networks are consistently prepared, capable, or willing to provide bereavement care (Logan, Thornton, Kane, et al., 2017). As suggested by these study findings, mental health professionals should balance the building of internal resilience and self-regulation, with the development of assertive communication skills to educate bereaved individuals' natural supporters. In addition to working with bereaved individuals, mental health professionals may also have some role in providing psychoeducation to partners or families who wish to help but lack the resources to do so. Community-wide grief education provides another opportunity to address some of the more resistant myths and misconceptions about grief. Given that some respondents referred to popular media to inform their understandings of grief, there is a clear need to disseminate a more realistic conceptualisation of grief through popular media, awareness-raising initiatives, and mental health resources that does not blindly follow the dominant grief discourse.

This study had a number of strengths and weaknesses. The broad range of bereavement types (cause of death, age, time since death) and extent of social support was a particular strength of this study. Enabling respondents to self-select based on whether they had

experienced a bereavement that had or continues to have a significant impact on their life resulted in a diverse range of grief and loss experiences. However, it is important to note that the selected sample was biased towards middle-aged, well-educated women residing only in the metropolitan area who did not meet criteria for PGD. Bereavement research has been recognised as having a predominately female sampling bias (Center for the Advancement of Health, 2004), providing an impetus for future research to over-sample for men. However, as previously acknowledged, it may be more important that research seeks to represent a range of grieving styles (e.g., intuitive versus instrumental) than diversity in gender per se (Doka & Martin, 2010). Compared with previous studies (e.g., Aoun et al., 2015; Aoun et al., 2014), levels of grief symptomatology were comparatively lower, with a larger proportion of respondents in the low risk (meeting one or two PGD criteria) than moderate risk (meeting three or four criteria) or high risk (meeting five criteria) categories. Not unlike previous research (e.g., Benkel et al., 2009a; S. B. Scott et al., 2007), the sample also appeared largely reflective of individuals bereaved by an illness-related death whose experiences may differ from those bereaved by untimely or accident-related deaths. Despite these apparent limitations, it is important to recognise that CCM analysis focuses on transferability (comparing context to context) rather than generalisability of findings more broadly (Boeije, 2002), thus its intention is not to describe all experiences of grief, but to account for this very complex and multifaceted social phenomenon. This study relied on respondents' retrospective recall of their bereavement which, given the time that had passed since some of the deaths, could arguably be subject to memory biases. However, the focus of the research was on the interpretations and meanings drawn from the experience of grief experience now, rather than back then, so less attention is given to how respondents would have described phenomena at the time of bereavement (Williams et al., 2008).

Although these research findings continue to highlight some of the key benefits of social support from the perspective of bereaved individuals, it was beyond the scope of this study to unpack the specific mechanisms through which this support may have served as a risk or protective factor for grief reactions in this sample. Future research may seek to explicate the relationship between social support and grief outcomes through the quantitative analysis of mediating and moderating variables. There is also a need to narrow research focus to populations who report higher levels of disenfranchisement (e.g., end-of-life 'expected' deaths) to provide a more specific account of their experience of grief norms. Similarly, exploring experiences in bereaved individuals who do meet criteria for PGD or who have lower quality of life may provide more insight into how a perceived lack of social support serves as a risk factor for complications of grief. Interestingly, of the 19 respondents, 13 engaged in the study within a three month timeframe of the anniversary of the death and

several others commented on the proximity of the interview date to the birthday of the person who had died. Current literature indicates much clearer understanding of *why* bereaved individuals are motivated to engage in grief-related research (e.g., Buckle et al., 2010; Dyregrov, Dieserud, Straiton, et al., 2011; Koffman et al., 2011) than *when* they are motivated to engage. Key insights are that bereaved persons may seek out therapeutic or cathartic gains, self-insight, social connection, and altruism; however, at which point in the grieving process this is most important, remains unclear. Future research should explore possible links between research engagement and anniversary/birthday reactions, particularly given that some respondents reported they often wished for, but did not receive, recognition of their grief around these times.

6.6.1 Conclusion

Although much is known about the impact of social support (both helpful and harmful) on bereavement outcomes, the extent to which grieving norms influence supportive behaviours and, in turn, are reconciled with the experience of grief, has remained unclear. This study provides an innovative contribution to the literature highlighting the rigidity and pervasiveness of societal beliefs, expectations, and assumptions of grief. Although these norms have some utility in providing a simplistic template for understanding a complex social phenomenon, they do little justice to honouring the diversity of individual experiences. Although many experience grief as a lifetime phenomenon, few bereaved individuals are given the flexibility, freedom, or support to live with their grief in this way. Assuming grief to be both an individual and a social phenomenon, mental health professionals must acknowledge the influence of societal norms on the internalisation of emotion states and the controlled (and time-limited) provision of social support. Specialised grief interventions should recognise social support (or lack thereof) as a potential impediment to adjustment following a significant death and focus on building bereaved individuals' capacity for self-regulation and assertive communication in the wake of loss. It is heartening to observe that many bereaved individuals report a significant change in their perceptions of grief following a significant loss and, despite some negative reactions by others, persist in finding acceptance of and compassion for their experience. Whether informally or formally, the opportunity to share one's grief and reflect on the significance of the relationship months and years after the death is a fundamental component of learning to live with loss. Given how cognisant bereaved people are of their own needs following bereavement, more attention should be given to integrating these unique wisdoms into targeted grief interventions and community awareness-raising initiatives.

Chapter 7   General Discussion

"The reality is that you will grieve forever. You will not 'get over' the loss of a loved one, you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same nor would you want to."

(Kübler-Ross & Kessler, 2005, p. 230)

7.1   Chapter Overview

Chapter Seven concludes this thesis with a summary of major findings across the three phases of study. The findings are synthesised to discuss overall contributions to empirical literature, consider directions for future research, and present practical recommendations to advance grief therapy and develop community capacity to provide support. Finally, strengths and limitations of the research are presented before overall conclusions.

7.2   Summary of Major Findings

The overarching aim of this research was to examine the nature and scope of grief-related norms and their influence on the experience of grief and provision and receipt of social support following bereavement. Using an explanatory sequential mixed methods design informed by pragmatist philosophy, the research comprised: (1) a systematic review investigating key determinants of supportive behaviours following bereavement in the literature to date; (2) a quantitative community survey examining the influence of bereavement status, anticipation of death, and perceived social support on perceptions of, beliefs about, and intentions to provide social support to, grieving persons; and (3) in-depth qualitative interviews exploring experiences of grief-related norms and their influence on the expression of grief and mourning and receipt of social support. Each phase of the research was weighted with equal importance, informing the next phase of study and contributing to the overall research aim and objectives.

7.2.1   Canvassing the literature

Phase One represented the first systematic and comprehensive review of the literature to be conducted on what factors influence community perceptions of, and willingness to support, grieving persons. Specifically, this phase sought to unpack social norms through synthesising the factors that determine expectations, perceptions, evaluations, beliefs, and judgements held

of grieving persons. The review comprised 42 studies (predominately quantitative) from 1979 to 2015, uncovering 10 bereaved, 5 decedent, and 26 respondent-related determinants. In the bereaved category, gender, time since death, relationship to the deceased, perception of coping, and perceived social support received the most attention, alongside five others. In the decedent category, cause of death, anticipation of death, gender, age, and motive for suicidal death were the only determinants studied. Recognising that many perceptions and behaviours are personally motivated, the respondent category was the most highly studied with six main determinants: gender, bereavement history and current bereavement status, normative beliefs, age, and familiarity with cause of death, alongside 20 others. For the majority of these studies, as much support was found for the influence of each determinant, as was found against them; highlighting how effects may largely depend on the relevance of the outcome variable under investigation (e.g., for anticipation of death, ease of acceptance [significant] versus attributions of blame [non-significant]). The quality of included studies was judged to be adequate to good, with findings limited by the lack of control over extraneous variables (e.g., bereavement experience of rater), failure to measure the salience of manipulations through post-manipulation checks, disregard for the risk of social desirability associated with attitudinal research, low power to detect effects, and considerable heterogeneity across samples, manipulations, and measurement instruments.

The findings of this study supported previous assertions that the protective or buffering effects of social support largely transcend the simple presence or absence of support networks (Ha & Ingersoll-Dayton, 2011; Wågø et al., 2017), with the likelihood of compassionate responding dependent on a complex interplay of factors relating to the bereaved, the decedent, and the respondent. Although almost all of these factors are completely beyond the control of the bereaved person (Chapple et al., 2015), many are amenable to change through therapeutic and psychoeducational interventions. In order to harness the potential of death and grief education to address some of the fear and ignorance around death, dying, and bereavement, more must be known about the current state of grief and bereavement literacy (Kellehear, 2016). Although this review succeeded in summarising key grief-related norms studied thus far, it simultaneously highlighted a number of methodological gaps in the literature base, offering a sound theoretical base for further study in this area.

7.2.2   A view from the outside

Phase Two built on the findings of Phase One through investigating the nature and scope of specific grief-related norms from the perspective of potential providers of support. This online community survey measured the grief-related expectations, beliefs, and behavioural intentions of 476 Australian adults (54.8% having experienced a significant bereavement). The

first major finding was that participants who were women or identified as impacted by bereavement expected a more intense grief reaction than men or those not impacted; potentially indicating higher levels of empathy and a more attuned understanding of the experience as was also identified in Phase One. Contrary to hypotheses and findings from Phase One, neither anticipation of death nor perceived social support affected expectations of grief intensity, suggesting some recognition that anticipated deaths may still incite shock and pain, and although social support is beneficial in sharing the grief, emotions may be no less intense with others present. Second, women responders were found to be more willing to support a grieving person than men, reinforcing the previous finding that women may perceive themselves as more empathic or resourced to offer support following a loss. Participants indicated they would be no less willing to offer support if the death was anticipated in advance and social support was plentiful, suggesting cognisance of the universal need for social support. Third, women rated *Support through Approach* statements (e.g., 'I really care about how you are doing') as significantly more helpful than men. Compared to women not impacted by bereavement, those impacted also rated *Support through Avoidance* statements (e.g., 'everything that happens is for a purpose, you just don't see it') as significantly less helpful, with no difference observed in men. This finding demonstrated that women's beliefs about the helpfulness of certain supportive actions may be more realistic than men's, and may be further in line with beliefs reported by bereaved persons (Lehman et al., 1986). Finally, 39.5% disagreed with the notion of a grief-related diagnostic classification, 35.5% agreed/strongly agreed, and 25.0% were undecided, with all except six participants citing a range of potential positive and negative effects on the experience of grieving. These consequences predominately centred on access to and quality of support, validation and normalisation, distress and coping, connection and isolation, and conceptualisation of the phenomenon. Although younger participants were more likely to support a classification than older, there was no effect of bereavement status, suggesting that hesitancy to accept a diagnosis (and potentially seek formal support) may be similar in bereaved persons and their non-bereaved support networks, but may be higher in older adults who tend to exhibit greater mental illness-related stigma (Jorm & Oh, 2009).

Informed by the systematic review in Phase One, this study was the first robust investigation of the general public's expectations of and beliefs about grief (measuring social norms) and their subsequent willingness to offer social support, controlling for the salience of manipulations, social desirability bias, and the background culture of the respondent. In line with past research (e.g., Breen & O'Connor, 2010; Costa et al., 2007), these findings provided some evidence of challenging ingrained societal beliefs, such that anticipated deaths and well-supported bereavements were rightfully not assumed to be easier to resolve or deserving of

less social support than unanticipated. However, it also emphasised the strength of characteristics of the potential supporter (e.g., gender, and age, and bereavement status) that influenced responses towards grief and grieving persons. The findings of this study challenged the assumption that social networks are universally prepared, willing, and capable of adopting the primary supporting role following bereavement. Evidently, community capacity to provide bereavement care still depends on the disputation of some key myths and misconceptions, in addition to the dissemination of resources to increase skill and confidence in the general public to provide support. It is anticipated that this study may set the foundation for more rigorous investigation of social support, particularly from the perspective of potential support providers, in order to inform community education and grief interventions.

7.2.3   A view from the inside

Phase Three evolved from the findings of Phases One and Two and shifted perspective to explore bereaved individuals' experiences of grief-related norms in the context of loss, coping, and social support. Through five distinct but complementary themes, respondents described challenges associated with expressing grief, integrating one or more losses, and remaining connected with others in a milieu where their grief was not consistently acknowledged or socially sanctioned. Respondents reported the establishment of an arbitrary standard against which their grief was measured, describing expectations around emotion expression, preparation for death, and the legitimacy of different loss types. In many cases, respondents experienced actions by others that silenced their grief and minimised the impact of their loss, which in turn contributed to behaviours in the bereaved to protect others and further hide the grief. Notably, as illustrated by the quotes in Chapter Six, messages rated as most helpful by respondents in Phase Three closely aligned with the *Support through Approach* statements endorsed by female participants in Phase Two, while messages rated as least helpful in Phase Three tended to align with the *Support through Avoidance* statements rejected by women impacted by bereavement in Phase Two. Encouragingly, respondents also sought out and were offered holding spaces in which they could safely express their grief and experience normalisation, validation, and support. These three processes were also a key finding from Phase Two, where some participants proposed that a grief-related diagnostic classification could normalise and validate suffering and invite formal support, while others argued that there is too great a risk of abnormalising and invalidating experiences and undermining informal support systems. Ultimately rejecting notions of 'normality' or 'abnormality,' many respondents in Phase Three abandoned expectations of relinquished bonds, resolution, or recovery, and accepted their unique experiences as reality.

The findings of this study indicated that social norms pervade the experience of grief and are sometimes held to be true as much by grievers as they are by potential supporters. These results supported assumptions that bereaved individuals exhibit a range of behaviours and defenses that indicate the dominant grief discourse either being internalised and adhered to (Harris, 2009-2010) or opposed and resisted against (Neimeyer et al., 2014). As found in previous studies, respondents in this study were very clearly able to articulate their support needs within the research, yet, rarely reported confronting the unhelpful actions of others or asserting their needs in actuality (Breen & O'Connor, 2010; Ghesquiere, 2013). Although intervention for high risk grievers has grown exponentially over the last 20 years, availability of, and receptivity to receiving, community-based support in low risk grievers has received scant attention (Breen et al., 2017; Rumbold & Aoun, 2014). This study highlighted how bereaved persons perceive and negotiate the inevitable gap between expectation and reality while grieving, providing a clear outline of the social support needs of grieving individuals in the context of social rules and constraints.

7.3   Contributions to Empirical Literature

Taken together, the findings across all three phases of this research contribute to understandings of the nature and scope of grief-related norms, the extent of their endorsement in an Australian community sample, and how they are experienced and negotiated by bereaved persons in the context of loss, coping, and social support. The last decade has seen an increase in the independent study of grief-related beliefs and expectations (Miller, 2014; Penman et al., 2014; Sand et al., 2013), endorsement of grief in diagnostic nosology (Breen et al., 2015; Rüsch et al., 2012), experiences of and needs relating to social support (Benkel et al., 2009a, 2009b; Gear, 2014), and initiatives to increase community capacity to provide support (Abel et al., 2011; Aoun et al., 2012). However, this research is the first to combine all elements into one program of study, with each study phase theoretically and methodically informed by and informing another. In doing so, this research recognises the unique and complex interrelationships between social norms, grief literacy, provision and receipt of social support, and mental health outcomes. Seeking to address the gaps and deficits identified in the systematic review (Phase One), Phases Two and Three employed robust research methods to test and substantiate findings of past research and advance the research field for more rigorous examination of grief-related norms and their application to helping or hindering natural processes of grief.

Across all phases of study, there was some evidence for the persistence, rigidity, and impracticality of the dominant grief discourse previously described in the literature (Breen &

O'Connor, 2007; Harris, 2009-2010; Neimeyer et al., 2014). Specifically, grief was framed as a time-bound, predictable process which could be worked through (often beginning prior to the death), culminating in resolution or recovery indicated by relinquishing bonds with the deceased and drawing meaning from the death. Although often held as much by grievers as by their social networks, these inflexible expectations and assumptions of grief were rarely reported to be helpful markers of coping nor congruent with most people's actual experiences of grieving (Breen & O'Connor, 2010; Costa et al., 2007). This research expands on existing literature to explicitly describe the coping mechanisms and strategies adopted by bereaved persons to reconcile grief-related norms, whilst simultaneously adjusting to and accommodating the loss itself. Encouragingly, the research provides evidence that elements of the discourse and grieving rules are beginning to be challenged, with some grieving individuals responded to similarly regardless of circumstances of the death or the bereaved.

Notably, although palliative and end-of-life care domains have invested considerable resources in developing the compassionate communities model outlined in Chapter Two (Sallnow et al., 2016), empirical evidence to support how this model might be operationalised, developed, and effectively put into practice is lacking. On the one hand, the present research highlights that in some cases, both bereaved persons and their support networks are consciously working to redefine 'normal' grief and become advocates for compassionate responding in their communities, moving towards greater enfranchisement than disenfranchisement of loss. However, equally important to note is that many factors relating to the bereaved, decedent, and/or respondent continue to preclude potential supporters from actively engaging within the model. The evidence presented in this thesis points to the need to attend to research both within and outside of palliative and end-of-life to not simply assume the community as the primary bereavement supporter, but to also explore the feasibility of this model and how it might be achieved from the perspective of informal support networks.

7.3.1   Directions for future research

Chapters Four, Five, and Six presented recommendations for future research specifically stemming from the results of each respective study. This section offers several broader directions for research, underpinned by the integration of all three phases of study. First, it is recommended that research extend beyond studies conducted *on* bereaved participants, to studies conducted *with* bereaved participants as co-researchers. Findings from Phase Three of this research illustrated the extent to which respondents were interested to engage with the research project, drew benefit from sharing their stories of loss and coping, and wished for dissemination of their experiences to help others facing similar struggles. It is anticipated that many of the questions asked and answers derived from this research project would have been

different had the research problem been framed by recently bereaved persons. Participatory action research (PAR), also known as community-based participatory research, is recognised for its potential to develop enquiry that harnesses the knowledge and insights of research subjects through active participation, resulting in conclusions and recommendations that are firmly grounded in the data and have practical application (Kemmis, McTaggart, & Nixon, 2014). Although PAR has received a small amount of attention in the research areas of physical illness (e.g., Jones, Auton, Burton, & Watkins, 2008) and end-of-life care (e.g., Marsh, Gartrell, Egg, Nolan, & Cross, 2017); there are few known applications of this methodology in grief or bereavement research. However, the basic principles of PAR are already evident across some qualitative bereavement research where this is recognition of the importance of 'insiders' within such a sensitive topic of research (Davies, Reimer, Brown, & Martens, 1995), the benefit to bereaved individuals of participating in grief-related research (Rosenblatt, 1995), and the greater depth of meaning and understanding that can be derived from narrative story-telling, compared with statistical, approaches (Gilbert, 2002). It is anticipated that participatory action research methods may offer a substantial contribution to this research field, particularly given the push for health professionals to form a small part of the support network's team, rather than the converse (Abel et al., 2011). Such an active and engaged approach to research offers the potential to further operationalise the compassionate communities approach (Sallnow & Paul, 2014), extending its application into research as well as practice.

Second, recognising grief discourse to be socially, historically, and culturally determined (Neimeyer et al., 2014), there is a need to explore the nature, extent, and impact of grief-related norms outside individualistic Western cultures. Although country of birth and religious affiliation did not emerge as significant covariates in Phase Two, both Phases One and Three indicated that elements of cultural background may have some bearing on supportive communication/behaviours and experiences of grief through implicit and explicit norms. To date, the voices of many bereaved individuals are missing from the literature, limiting the extent to which grief is universally understood and can be appropriately responded to (Dyregrov, 2011). The systematic review in Phase One revealed only two studies conducted in collectivist cultures (both Japan), highlighting the bias towards American, Australian, and British samples that, although potentially multicultural, are unlikely to reflect the unique nuances of grief and mourning across different races, ethnicities, and cultures. Similarly across Phases Two and Three, the majority of each sample was born in Australia and all resided in Australia, limiting the extent to which culture was measured in this research. Although rarely investigated, it is reasonable to assume that beliefs about grief, expectations of grievers, and

support intentions and needs would differ dependent on cultural customs, rules, and rituals (Klass & Chow, 2011).

Third, it is recommended that researchers explore adherence to or endorsement of the dominant grief discourse in psychologists and other mental health professionals, recognising the extent and impact of their involvement with grieving individuals. Phase Three highlighted some of the misattuned and unhelpful interactions respondents had experienced within health services and, when the respondent was a health professional, how their treatment of patients or clients had evolved as a direct consequence of their own loss experiences. To date, research has investigated beliefs, expectations, and assumptions about grief primarily in general practitioners, nurses, and counsellors (Breen, 2010-2011; Breen & O'Connor, 2013; O'Connor & Breen, 2014; Wiles, Jarrett, Payne, & Field, 2002). Two specific studies of bereavement counsellors revealed that theoretical, practice, and personal wisdom tend to be favoured over empirical knowledge (Coyne & Martin, 2007), and the most widely recognised theory in practice is Kübler-Ross's (1969) stage theory (Ober et al., 2012). Given the inconsistent and limited focus on grief and loss in formal education (Balk, 2005; Breen et al., 2012-2013; Dickinson, 2007, 2012), there is a need to explore grief perceptions and competencies in a larger sample of psychologists, particularly those whose education was directly informed by stage/phase-based models. It will be important to understand whether these mental health professionals are cognisant of and recognise the unique nuances of treating grief presentations, or whether there is evidence of standard supportive therapy being offered, which has been found to lack empirical support (MacKinnon et al., 2013).

7.4 Contributions to and Recommendations for Bereavement Practice

Arguably, the greatest test of pragmatist research is whether and how its findings can be applied in practice (Cornish & Gillespie, 2009). A key strength of the pragmatist approach is its focus on designing research according to the problems people encounter in everyday life; however, equal emphasis is placed on ensuring that the findings of such research contribute to or inform change for the people facing that problem. To date, there has typically been limited translation of bereavement research findings into practical support strategies (Balk, 2013; Jordan, 2013). For this reason, this research sought to not only improve the quality of research concerning grief norms and the provision and receipt of social support, but also to enhance the potential of this research agenda to shape education planning and the development of specialised grief-specific interventions that take into account the presence (or absence) of social support. This section highlights overall contributions of this research to bereavement

practice, first proposing suggestions for how the roles and responsibilities of counselling psychologists might be redefined to improve formal support of bereaved individuals, and second offering recommendations for how a compassionate community model may be translated outside palliative and end-of-life care to harness and strengthen informal support for these same individuals and others who are at lower risk for complications of grief.

7.4.1   Redefining the roles and responsibilities of counselling psychologists in grief

Grief and loss is regarded a key competency of counselling psychologists in Australia and many report regularly working with this presentation (Di Mattia & Davis-McCabe, 2017); yet, there are still considerable gaps between the fields of counselling psychology and thanatology (Servaty-Seib & Taub, 2010). This research provides a valuable contribution to bereavement practice through exploring grief as an intersubjective and social experience through the lens and philosophy of counselling psychology. Collectively, the three studies contribute towards current understandings of bereavement risk and support need, and comprehensively explore some of the key social processes that may help or hinder natural processes of grief and mourning. Negative or absent social support must be recognised by psychologists as a considerable impediment to adjustment and integration following loss, but also notably a factor that is amenable to change in the context of grief therapy (L. A. Burke & Neimeyer, 2013). Going beyond the simple recognition of social support as a protective factor against complications of grief, this research supports the imminent need to adapt empirically-supported psychotherapies to recognise situations in which social support is absent, or is present but does not meet the needs of the bereaved. Recommendations are made here for the role of counselling psychologists in creating internal and external supportive spaces, responding to experiences of stigma and disenfranchisement, and addressing support deficits with their clients. Attention is also given to considering limitations in grief education, and counselling psychologists' responsibilities regarding bracketing and self-care.

This research emphasises the importance of safe bases (Bowlby, 1988) or holding spaces (Winnicott, 1965) for the recognition, normalisation, and validation of grief, but indicates that few support networks may inherently have the time, skill, or confidence to consistently provide such spaces. However, as highlighted by Field, Gao, and Paderna (2005), and consistently observed in this research, accommodation to and integration of grief may be as much about creating these spaces within the bereaved person (e.g., through internalising the attachment relationship, and developing capacity for distress tolerance and affect regulation), as outside (i.e., through social networks, community groups, and grief counselling or therapy). With such a focus on the therapeutic alliance (Meteyard & O'Hara, 2016), counselling psychologists are

well placed to offer clients the gift of presence and recognition, offering clients a temporary substitute attachment figure. Unlike support networks who may, at times, offer well-intended *yet* uninformed or misinformed interactions, trained professionals have the potential to offer well-intended *and* informed interactions that support, rather than disown grief. Over time, clients will internalise these supportive functions and foster attachment security through developing the capacity to recognise, tolerate, and regulate emotion (Kosminsky & Jordan, 2016). Recognising the prevalence of unsupportive social interactions, it appears that many clients would benefit from psychoeducation on which information and advice to regard and which to discard, and how to develop realistic expectations of potential supporters, knowing that others will not consistently get it right. Mindfulness-based approaches (e.g., B. E. Thompson, 2012) may be useful in developing some tolerance for the misattuned behaviours of others which, in Phase Three of this research, was described by respondents to reduce the distress associated with unhelpful supportive interactions.

It is important that psychologists respond to experiences of stigmatisation or disenfranchisement in a timely and empathic manner. This re-enfranchisement of loss has been recognised by Doka (2002) as an often necessary and integral part of grief therapy. The findings of this research offer some insight into how and why clients may internalise their grief reactions and how these patterns may become reinforced over time by others in the social network. Importantly, the therapeutic alliance should be viewed as a social microcosm in which the psychologist may either be experienced as similar to others who have previously invalidated and minimised the loss (questioning the legitimacy of grief) or as a conduit for a corrective emotional experience that increases the likelihood of continued connection to social networks. If not occurring anywhere else, clients should experience therapy as a place where their grief is given time, space, and flexibility for complete empathic understanding, resulting in a sense of being understood and validated, rather than judged (Klasen, Bhar, Ugalde, & Hall, 2017). This validation of grief is particularly important, given the proportion of clients who drop out of therapy due to a belief that their pain is not understood (Lichtenthal et al., 2015). As highlighted in this research, elements of grief that appear most often associated with greater concealment (e.g., talking to or having visions of the deceased) may benefit most from attempts to acknowledge and normalise, recognising that informal supports may be less likely to meet this need.

Counselling psychologists have a considerable role to play in empowering clients to articulate their needs and 'teach' friends, family, neighbours, and work colleagues, who may be willing to provide support, but lack the confidence or capacity to know where to begin (Dyregrov, 2005-2006). Research suggests that bereaved individuals who operate very

autonomously or who have an avoidant attachment style may be especially likely to require assistance in fostering healthy relationships through mobilising existing and new supports (Somhlaba & Wait, 2008). Therapeutic interventions to increase empowerment and ownership of this process may include elements of assertiveness training, to improve confident communication of emotional and physical needs (Arnal & Juliá, 2012), and self-compassion training, to reduce self-disenfranchisement and increase the likelihood that support is sought and accepted (D. P. Scott, 2016). Other interventions may include activities to differentiate the bereaved person's support network into doers, listeners, respite figures, and negative/destructive figures, recognising that family, friends, neighbours, and colleagues may serve different functions that collectively support (or limit) the griever (Doka & Neimeyer, 2012). This approach is supported by findings from Phase Three where respondents came to predict who they could rely on for different supportive functions, reducing the distress initially experienced when one supporter did not serve the function initially expected of them. Cherlin et al.'s (2007) reported that 16% of bereaved individuals stop using bereavement services within the first year post-loss because, by that time, they have developed adequate support networks. Counselling psychologists who can focus therapy on developing regulatory capacity both within the client *and* the network of supporters around them are likely to see more rapid and greater improvements in the mental health of the individual and reduced dependence on formal services over time.

Across the literature, there have been recommendations to improve grief education of mental health professionals through implementing existing empirically-supported guidelines (e.g., Balk, 2005) and extending death and grief education beyond palliative care service professionals (Breen et al., 2012-2013; Kellehear, 2016); yet, to date there has been little research to evidence any change. There is a clear need for greater quantity and quality of education around grief and loss in tertiary psychology courses, particularly given the shift towards grief in mainstream diagnostic nosology (APA, 2013; WHO, 2017). There is also a need to realign contemporary grief theories with traditional counselling theories (e.g., Servaty-Seib, 2004), recognising that although counselling psychologists are well placed to work with grieving individuals, families, and groups, many may wrongly assume that the demonstration of basic counselling skills is synonymous with delivering effective grief therapy (MacKinnon et al., 2013). Acknowledging the rapid shift in empirical and theoretical understandings of grief over the last 35 years (C. Hall, 2014), counselling psychologists have a responsibility following completion of formal education to upskill and remain abreast of emerging theories that should inform their formulation and treatment of bereaved persons. Recognising that just like their clients, counselling psychologists have their own assumptive worlds and expectations about grief, awareness of personal limitations and triggers is important to ensure

the psychologist's own worldview is not doubled onto those they are serving. Indeed, within this profession, many have emphasised the particular importance of self-care practices to reduce compassion fatigue (Krawchuk, 2012) and attendance to countertransference reactions to minimise client harm (Katz & Johnson, 2016).

7.4.2   Setting the foundation for a compassionate community

Despite playing an important role, research strongly indicates that professional supports are not sufficient to solely manage the complexity of grief and loss in the community or, as indicated by some respondents in this research, may even be unnecessary for people experiencing low-risk grief (Rumbold & Aoun, 2014). Representing a new wave of public health, the compassionate community model introduced in Chapter Two recognises that there are unique resources inherent in social networks that cannot be replaced by formal bereavement services (Kellehear, 2005, 2013, 2016). As highlighted by Rosenberg, Mills, and Rumbold (2016):

> Professional caregivers do not share the intimate knowledge that underpins the support of family and friends, nor do they have the time to be companions. They may be welcome visitors along the road, but they cannot share the journey in the way that our family and our friends share it (p. 1).

However, all three phases of this research have highlighted a number of gaps and deficits at the community level that require attention. Recent proposals suggest that compassionate communities may have applicability outside palliative and end-of-life care domains (Aoun et al., 2015; Rumbold & Aoun, 2014), but the present research is the first to consider potential obstacles and make recommendations for implementing a sustainable community support structure, informed by empirical research on social norms and their influence on social support.

Abel et al. (2011) proposed two approaches to the development of a compassionate community: first, through investing in resources to engage and educate the general public (changing attitudes to change behaviour), and second, through supporting bereaved individuals to draw on existing support networks to cultivate more compassionate communities (changing behaviour to change attitudes). For the first approach, recommendations that can be drawn from the palliative care literature include providing education across community groups informed by current theories and empirical research, normalising and de-medicalising conversations around bereavement, grief, and mourning, and raising awareness in settings (e.g., schools, workplaces, sport and recreation clubs, churches)

about the support needs of grieving persons (Abel et al., 2011; Adshead & Dechamps, 2016). Recommendations for the second approach include providing bereaved individuals with resources or advisors (peer-based or volunteer) who can assist them in identifying the nature and strengths of their existing support networks (Abel et al., 2011). A good example of this is Palliative Care Australia's (2017) new mobile application, 'AllowMe!', which assists end-of-life carers to mobilise their support networks through task delegation, creation of events and visiting times, news board postings, and useful resources. Although specifically designed for the palliative care context, from the stories in this research, it is anticipated that such a tool has equal potential to mobilise supports following a death and improve the specification and targeting of grief-related needs. Given that over three-quarters of deaths in Australia are expected (Department of Health, 2008), this research highlighted that for some, this mobilisation of supports can even begin prior to the death occurring.

One assumed challenge of the compassionate community model is that it requires a degree of communication and collaboration between health professionals (particularly psychologists, counsellors, and social workers) and the community that is not typical of, or financially supported by, traditional service delivery models (Horsfall, Leonard, Noonan, & Rosenberg, 2013). Further, it necessitates a role shift for health professionals "from helping patients to enabling citizens, from being powerful to being empowering, from service provider to community developer, from expert to mentor" (Abel et al., 2011, p. 132). However, a key strength is its already successful implementation in palliative and end-of-life care settings (e.g., Adshead & Dechamps, 2016; Horsfall et al., 2012; Wegleitner et al., 2016) and its capacity to theoretically frame and set in motion ideas that have been proposed in the grief and bereavement literature for more than 25 years (e.g., Vachon & Stylianos, 1988).

With their emphasis on supportive alliances for intrapsychic change (Meteyard & O'Hara, 2016), it is anticipated that counselling psychologists may play a notable role in the development of both approaches to a compassionate community through (1) resourcing individuals to mobilise their networks in times of stress (as previously identified), and (2) contributing to the awareness and education of communities to be more accessible to grieving persons. Based on the findings of the present research, key areas to target include challenging the dominant grief discourse through public platforms, empowering the bereaved as educators and advocates, and enhancing support for the natural supporters of grief. These recommendations consider the foundations necessary for implementation of a compassionate community model, with the next step conceivably being translation of these principles into specific community contexts such as workplaces (e.g., D. Hall et al., 2013), local businesses (e.g., The 100-Member Committee, 2012), schools (e.g., Kennedy, Keeffe, Gardner, &

Farrelly, 2017), or café conversations (e.g., Death Café or Death Over Dinner) based on the growing international World Café movement (e.g., McLoughlin et al., 2016).

7.4.2.1   Challenging the discourse

Although poorly evidenced and openly rejected by theorists, researchers, and practitioners in thanatology (Wortman & Boerner, 2007; Wortman & Silver, 1989), this research indicates that elements of the dominant grief discourse are still often endorsed by members of the bereaved and non-bereaved public. It is anticipated that disseminating ideas that challenge the dominant grief discourse may offer the potential to break down stigma around dying and loss, increase the likelihood of social supports engaging with the bereaved, and promote grieving persons' receptivity to receiving mental health supports when indicated (Blackburn, McGrath, & Bulsara, 2016). Evidently both the bereaved and non-bereaved public are still cautious of diagnosing grief-related presentations and have mixed expectations of the potential impacts of a diagnosis on an individual. Through various platforms, grief needs to be framed as a normal reaction to an abnormal situation, which can predominately be supported by the individual's social network, but with clear demarcation around who is eligible for *and* may benefit from grief counselling or therapy.

Respondents in this research attributed a considerable proportion of their grief and loss literacy to media depictions of mourning and intergenerational transmission of rules. Recognising that the portrayal of grief in film and television is still largely inaccurate and misinformed (Fonseca & Testoni, 2012), harnessing this outlet to correct myths and misconceptions and present a more realistic picture of the phenomenon is, therefore, central in normalising conversations around dying and grieving and enfranchising a greater range of loss experiences. The Internet and social media have also been recognised as platforms that offer the potential for dissemination of accurate information quickly and to a broad audience (S. Mills & Mills, 2016). Encouragingly, studies have documented the benefits of social media for challenging dominant notions of grief recovery and resolution through offering resources, compassionate discussion forums, and spaces of ongoing memorialisation which support continuing bonds (Aho, Paavilainen, & Kaunonen, 2012; Chapple & Ziebland, 2011). This research and others (e.g., Breen & O'Connor, 2011; Costa et al., 2007) indicates that the general public have demonstrated their capability to adopt and apply once-popular stage theories of grief; suggesting that, if delivered via the right platforms, they may be equally capable of embracing more contemporary theories to align with the way in which research and clinical practice is moving. Although specific interventions to disseminate information and target stigma are limited in the bereavement literature, it is reasonable to assume that many

lessons may be learnt from the broader mental health literature (for a review, see Mehta et al., 2015).

7.4.2.2 Empowering the bereaved as educators and advocates

As indicated in Phase Three, bereaved individuals are best positioned to illustrate and explain the extent to which loss is subjective and grief is idiosyncratic. Horsfall et al. (2012) refer to this process as 'rippling out,' arguing that bereaved persons are the experts on their own experiences and many are driven to share their wisdom with others experiencing similarly, thus offering the potential to build social capital. Following this assumption, there is the potential to harness these individuals as both informed educators who can shape societal understandings of grief and experienced advocates who can take an active role in facilitating timely and positive social support. Both approaches are well evidenced, with information or guidance provided by peer supporters perceived to be more credible and meaningful and incite greater hope for the future (Dyregrov, 2011).

From an educator perspective, bereaved individuals hold a wealth of knowledge about their needs for support as well as enablers and barriers to help-seeking (formal and informal); yet, these perceptions are more often described in the literature, than actually translated into meaningful action (Breen et al., 2017). It is important that specific support needs, for example, the need for professional support one year or more after the death (when most social support has dissipated and the reality of the loss has been realised) as reported by respondents in this research, are addressed when considering how and when to make bereaved individuals aware of support services. Similarly, understanding what inhibits bereaved individuals from engaging with supports, for example, stigma around help-seeking or burdening others, may be used to improve the way in which supports (formal and informal) approach the bereaved. As previously suggested, participatory action research is another method through which the views of bereaved individuals can be harnessed and simultaneously applied, ensuring that community decision-making is collaborative and informed by the experiences of insiders.

From an advocator perspective, bereaved individuals should be valued for their insight, experience, and expertise which may be translated through peer support to other people grieving a similar loss. This potential was realised by many respondents in Phase Three who engaged with other bereaved peers and who expressed a wish for their research contributions to assist other bereaved individuals in similar situations. According to this approach, support is provided to the bereaved, by the bereaved (McNess, Stebbins, & Stebbins, 2013). As these research findings suggest, individuals with some bereavement experience may be somewhat better equipped to provide positive social support, holding more realistic expectations of grief

and support needs. Bereaved persons might reinvest their insights and experiences through engaging in or leading mutual-help support groups (e.g., The Compassionate Friends), training as volunteer counsellors (e.g., Stillbirth and Neonatal Death Society [SANDS]), or engaging in online support communities (social media and chat forums). Empirical evidence for both mutual-help support groups (Aho, Åstedt-Kurki, & Kaunonen, 2013-2014; Barlow, Schiff, Chugh, Rawlinson, & Leith, 2010) and Internet-based forums (Aho et al., 2012; Chapple & Ziebland, 2011) is strong. Promoting a psychological sense of community, grieving persons are more likely to encounter others like them and report experiences of enfranchisement, validation, and normalisation, no matter the circumstances of death (Walter et al., 2011-2012). Although these resources are often heralded for their direct social and emotional support following a death, they may also have an integral role in assisting bereaved individuals to identify and mobilise their existing offline support networks (Aho et al., 2012). Importantly, harnessing people as 'assets' and reinvesting expertise is an integral part of the compassionate community model, allowing for resources to be redistributed, rather than new costs generated for mental health care (Aoun et al., 2012; Rumbold & Aoun, 2015).

7.4.2.3   Support for the natural supporters

Empirical research suggests that many bereavement supporters find it challenging to remain supportive following certain deaths and may experience personal strain resulting from perceptions of being inept or insufficient in the support they offer (Dyregrov, 2005-2006). The findings of all three phases of this research build on past research to highlight the complex interaction of processes that determine when, where, why, and how social support is given and in turn, whether it is received as helpful or unhelpful by its receiver. Notably, Phases Two and Three illustrate some marked differences in what is perceived as helpful by bereaved people and their potential supporters, supporting previous assertions that the general public cannot be assumed to hold the knowledge, skill, or capacity to support, and may require some degree of education and support themselves (Abel et al., 2011). Just as grieving individuals are required to adapt their assumptive world to the reality of their loss (Neimeyer, Baldwin, & Gillies, 2006), so to might bereavement supporters be required to adapt their assumptive world (of what they expect of others and the world more broadly) with the reality of what they see in the grieving person in front of them. Given the increasing trend towards death in institutional settings and grief in therapeutic settings (McConnell et al., 2012), it is important that communities be continually encouraged to take greater ownership of supporting of grieving individuals, realising their own potential to assume a primary supporting role, and referring on to formal services only when indicated.

The findings of this research highlight that support for supporters needs to cover several domains. Phase Three offered numerous examples of supporters responding, in messages and actions, according to what they 'knew' to be true about grief and loss. It is pertinent that supporters appreciate that loss is subjective and can only truly be appraised by the person who has experienced the death (Wortman & Boerner, 2007). Supporters must come to view grief through a lens of diversity, allowing for the range of expressions and experiences that may manifest following a death, and continuing to support long after the death has occurred. The present research and others (e.g., Murray, 2002) support the notion of utilising analogies for grief (e.g., missing limb or chronic illness metaphors) that accurately recognise the experience as potentially life-long, emotionally debilitating, and unique to the individual. Informed by the Phase Two findings, such models of understanding may be particularly beneficial for developing empathic understanding in male supporters or those who have not experienced considerable loss themselves. A clear finding that emerged from this research was that broaching the topic of the loss never makes it worse, but ignoring it does. Rather than diminishing or dismissing intense responses to unrecognised losses, it is important that bereaved people are encouraged to talk about and express their grief in a way that is best suited to them, rather than to those around them. Many bereaved people in Phase Three required more than a simple verbal platitude (e.g., "I'm sorry"), but rather needed others to be alongside them in their grief, remaining present without expectation, advice, or judgement. As evidenced by this research, it is also important to note that social support is framed differently by different people. Through the lens of the dual process model, some bereaved persons may require their supporter for the expression of emotion and sharing of memories (loss-orientation), while others may seek support for engaging in new activities and interests (restoration-orientation; Li & Chen, 2016). Recognising that individuals at different levels of bereavement risk are likely to require different forms of social support (Aoun et al., 2015), supporters will likely need to be educated about different styles and scopes of support, depending on whether the social support is serving to complement or replace formal grief counselling or therapy.

There are several pathways through which supporters might be supported. The last two decades in Australia has seen an increase in community awareness-raising initiatives and campaign centred on the promotion of general mental wellness (e.g., Mental Health Week, National Psychology Week), specific mental health disorders or presentations (e.g., Perinatal Depression and Anxiety Awareness Week, R U OK? Day, Borderline Personality Disorder Awareness Week), and death (e.g., Dying to Know Day). Despite bereavement being both a universal and inevitable consequence of death, it has received far less attention of its own in mainstream campaigns and associated media. An initiative such as this may offer the potential to normalise conversations about grief and loss, increase public knowledge of and empathy

for people experiencing certain types of loss, and upskill the general public on both recognising and responding to needs that they observe in family, friends, neighbours, and work colleagues. Given the opportunity to work with the client's immediate social system, it is also recommended that counselling psychologists assume an active role in educating potential supporters through inviting them into sessions and offering the assistance necessary to perceive the self as confident, capable, and prepared to take ownership of this supporting role (Shear, Boelen, & Neimeyer, 2011). As a potential framework, Vaughans (2016) propose the concept of 'grief etiquette coaching' which has utility across therapeutic, educational, employment, religious, and social settings. Offered by health professionals or trained volunteers, this coaching involves gathering information about the unique circumstances of the death and associated loss and educating support networks of the bereaved about what specific gestures they can offer to convey compassionate, meaningful support. However, as previously identified in the literature (Bath, 2009; Dyregrov, 2005-2006), for some supporters the greatest barrier to engagement may be a lack of confidence or self-assurance, rather than limited knowledge per se. Focus may, therefore, be on breaking down potential fears of engulfment or dependency, potentially underpinned by death denial or anxiety, and addressing stigma around certain types of death (e.g., suicide) which may otherwise preclude supporters from being willing to support. Additionally, it may be important to assist potential supporters to become aware of their own limitations and personal triggers. Respondents in Phase Three reported benefiting more from social networks who admitted a lack of knowledge and asked what was needed, than those who assumed to know and acted harmfully, or failed to connect at all. Evidently, building community capacity to provide bereavement support is complex and requires substantial change across multiple levels, but its potential to reduce burden on existing health care systems and improve psychosocial outcomes for individuals in the community is immeasurable.

7.5   Strengths and Limitations of the Research

Chapters Four, Five, and Six presented strengths and limitations of each research study. This section offers several strengths and limitations of the broader research project and its design. Given the cross-sectional nature of Phases One and Two and the qualitative style of Phase Three, it is not possible to draw conclusions about the predictive power of grief-related norms on the provision and acceptance of social support, nor the definitive impact of such support on levels of coping and risk of grief complications. Another limitation of the research is its focus on social support more broadly, precluding a more in-depth analysis of the nuances of supportive behaviour compared with supportive communication and even verbal (i.e., spoken) compared with non-verbal (i.e., body language, gestures) communication. The extent

to which the findings of this research can be generalised or transferred to other bereaved populations and their support networks is somewhat limited by the representativeness of the self-selected samples. Grief-related research has the potential to attract a large, but rather homogenous demographic of people who may have considerable experience with or exposure to loss, be more open to discussing or learning about issues of death and grief, or report higher levels of social connection than isolation. Similarly, the findings of this research should be interpreted in light of the country and culture in which the studies were conducted. Conducted in a Western country, this research is well situated within the existing bereavement literature, enabling some reasonable comparison of the findings of Phases Two and Three with previously published studies in other Western cultures. However, extrapolation of the findings should be made with caution, respecting that Australia has a unique history of grief and loss through colonisation, the enforcement of Government policies for Indigenous persons, and war-related trauma which have undoubtedly shaped normative practices of grief and mourning (Damousi, 2001, 2002). As previously mentioned, culture may have a considerable influence on expectations of human emotion and behaviour, definitions of 'normal' grief, and supportive tendencies.

Despite these limitations, a key strength of the research was its use of a sequential explanatory mixed methods design, which offered greater insight into this multifaceted construct than could have been afforded by qualitative or quantitative methodologies alone (Bishop, 2015). Each study served not only to contextualise and extend the results of the previous study, but also offered some explanatory power for making sense of key findings. No one phase was viewed as more or less important than the rest, but rather each was recognised as addressing a different element of the overall research aim, strengthening the conceptualisation and evaluation of this phenomenon (Cornish & Gillespie, 2009). Employing valid and reliable measures across Phases Two and Three increases confidence in the conclusions drawn from the data and provides opportunity for study replication, a particularly important consideration given that much of the research in this area has occurred largely within a vacuum with little practical application.

7.6   Conclusion

Social support is consistently implicated as both a risk and protective factor for psychosocial outcomes following bereavement. Previous literature has identified a lack of evidence to guide the development of bereavement programs, with even less focused on developing community capacity to deliver compassionate support. The present research sought to examine the nature and scope of grief-related norms and their influence on the experience

of grief and provision and receipt of social support. This research answers a frequent call in the literature to shift perspective from grief as an intrapsychic and individual issue, to grief as an intersubjective, social, and relational experience. Across three interrelated studies, this research has built upon a growing evidence base which suggests that enforcement of the dominant grief discourse and associated norms results in higher levels of disenfranchised grief, which increases the likelihood of limited or absent social support, which in turn increases the risk for interpersonal isolation and complications of grief. This thesis has made a substantial contribution to empirical literature through challenging and strengthening the current research base from the perspective of bereaved persons *and* their natural supporters, and has application for informing and implementing practical and meaningful change to improve holistic support of people experiencing bereavement. Although considerable progress has been made since Freud's first attempt to conceptualise and demarcate different forms of grief 100 years ago, there is still substantial ground to be covered. More must be done so that counselling psychologists and the wider community are appropriately empowered, resourced, and supported to provide timely and appropriate bereavement support.

"There are no happy endings.
Endings are the saddest part,
So just give me a happy middle
And a very happy start."

(Silverstein, 2011, p. 22)

References

Abbott, C. H., Prigerson, H. G., & Maciejewski, P. (2014). The influence of patients' quality of life at the end of life on bereaved caregivers' suicidal ideation. *Journal of Pain and Symptom Management, 48*, 459-464. http://dx.doi.org/10.1016/j.jpainsymman.2013.09.011

Abel, J., Bowra, J., Walter, T., & Howarth, G. (2011). Compassionate community networks: Supporting home dying. *BMJ Supportive & Palliative Care, 1*, 129-133. http://dx.doi.org/10.1136/bmjspcare-2011-000068

Adler, P. A., & Adler, P. (1987). *Membership roles in field research*. Thousand Oaks, CA: SAGE.

Adshead, L., & Dechamps, A. (2016). End of life care: Everybody's business. *Journal of Social Work Practice, 30*, 169-185. http://dx.doi.org/10.1080/02650533.2016.1168379

Aho, A. L., Åstedt-Kurki, P., & Kaunonen, M. (2013-2014). Peer supporters' experiences of a bereavement follow-up intervention for grieving parents. *Omega: Journal of Death and Dying, 68*, 347-366. http://dx.doi.org/10.2190/OM.68.4.d

Aho, A. L., Paavilainen, E., & Kaunonen, M. (2012). Mothers' experiences of peer support via an Internet discussion forum after the death of a child. *Scandinavian Journal of Caring Studies, 26*, 417-426. http://dx.doi.org/10.1111/j.1471-6712.2011.00929.x

Aho, A. L., Tarkka, M.-T., Åstedt-Kurki, P., & Kaunonen, M. (2009). Fathers' experiences of social support after the death of a child. *American Journal of Men's Health, 3*, 93-103. http://dx.doi.org/10.1177/1557988307302094

Ajdacic-Gross, V., Ring, M., Gadola, E., Lauber, C., Bopp, M., Gutzwiller, F., & Rössler, W. (2008). Suicide after bereavement: An overlooked problem. *Psychological Medicine, 38*, 673-676. http://dx.doi.org/10.1017/S0033291708002754

Albuquerque, S., Pereira, M., & Narciso, I. (2016). Couple's relationship after the death of a child: A systematic review. *Journal of Child and Family Studies, 25*, 30-53. http://dx.doi.org/10.1007/s10826-015-0219-2

Alexander, S. J. (2010). "As long as it helps somebody": Why vulnerable people participate in research. *International Journal of Palliative Nursing, 16*, 173–178. http://dx.doi.org/10.12968/ijpn.2010.16.4.47783

Alford, J. W., & Catlin, G. (1993). The role of culture in grief. *Journal of Social Psychology, 133*, 173-184. http://dx.doi.org/10.1080/00224545.1993.9712135

Allan, J., & Harms, L. (2010). "Power and prejudice": Thinking differently about grief. *Grief Matters: The Australian Journal of Grief and Bereavement, 13*, 72-75. Retrieved from https://search.informit.com.au/fullText;dn=587610363212616;res=IELFSC

Allen, B. G., Calhoun, L. G., Cann, A., & Tedeschi, R. G. (1993). The effect of cause of death on responses to the bereaved: Suicide compared to accident and natural causes. *Omega: Journal of Death and Dying, 28*, 39-48. http://dx.doi.org/10.2190/t44k-l7uk-tb19-t9uv

Allen, J. Y., Haley, W. E., Small, B. J., Schonwetter, R. S., & McMillan, S. C. (2013). Bereavement among hospice caregivers of cancer patients one year following loss: Predictors of grief, complicated grief, and symptoms of depression. *Journal of Palliative Medicine, 16*, 745–751. http://dx.doi.org/10.1089/jpm.2012.0450

American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders (3rd, Text Revision ed.)* Washington, DC: Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.

Aoun, S. M., Breen, L. J., Howting, D., Rumbold, B., McNamara, B., & Hegney, D. (2015). Who needs bereavement support? A population based survey of bereavement risk and support need. *PLoS One, 10*(3), 1-14. http://dx.doi.org/10.1371/journal.pone

Aoun, S. M., Breen, L. J., O'Connor, M., Rumbold, B., & Nordstrom, C. (2012). A public health approach to bereavement support services in palliative care. *Australian and New Zealand Journal of Public Health, 36*, 14-16. http://dx.doi.org/10.1111/j.1753-6405.2012.00825.x

Aoun, S. M., Breen, L. J., Rumbold, B., & Howting, D. (2014). Reported experiences of bereavement support in Western Australia: A pilot study. *Australian and New Zealand Journal of Public Health, 38*, 473-479. http://dx.doi.org/10.1111/1753-6405.12177

Arnal, R. B., & Juliá, B. G. (2012). Assertiveness training. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Creative practices for counseling the bereaved* (pp. 117-119). New York, NY: Routledge.

Australian Bureau of Statistics. (2016). *Census data summary: Snapshot of Australia*. Retrieved from http://www.ausstats.abs.gov.au/

Australian Bureau of Statistics. (2017). *Causes of death, Australia 2016 (3303.0)*. Retrieved from http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3303.02016?OpenDocument

Australian Government. (2017). *Fair Work Act 2009 (No. 28)*. Retrieved from https://www.legislation.gov.au/Details/C2017C00288/Download

Australian Government Department of Health. (2012). *Better access to mental health care: Fact sheet for patients*. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/betteraccess_factsheet_for_patients

Australian Psychological Society. (2007). *APS code of ethics*. Retrieved from https://www.psychology.org.au/about/ethics/

Australian Psychology Accreditation Council. (2017). *Accreditation standards for psychology programs*. Retrieved from https://www.psychologycouncil.org.au/Assets/Files/APAC_Accreditation%20Standards_20170908_Final.pdf

Balk, D. E. (2005). Scholarship, students, and practitioners: Bringing scholarship into the expectations of practitioners. *Death Studies, 29*, 123-144. http://dx.doi.org/10.1080/07481180590906147

Balk, D. E. (2013). Building a bridge to span the research-practice gap *Grief Matters: The Australian Journal of Grief and Bereavement, 16*, 4-7. Retrieved from https://search.informit.com.au/documentSummary;dn=413896746573272;res=IELFSC

Bambauer, K. Z., & Prigerson, H. G. (2006). The stigma receptivity scale and its association with mental health service use among bereaved older adults. *Journal of Nervous and*

Mental Disease, 194, 139-141.
http://dx.doi.org/10.1097/01.nmd.0000198200.20936.03

Bandini, J. (2015). The medicalization of bereavement: (Ab)normal grief in the DSM-5.
Death Studies, 39, 347-352. http://dx.doi.org/10.1080/07481187.2014.951498

Barlé, N., Wortman, C. B., & Latack, J. A. (2017). Traumatic bereavement: Basic research
and clinical implications. *Journal of Psychotherapy Integration, 27*, 127-139.
http://dx.doi.org/10.1037/int0000013

Barlow, C. A., & Coleman, H. (2003). The healing alliance: How families use social support
after a suicide. *Omega: Journal of Death and Dying, 47*, 187-201.
http://dx.doi.org/10.2190/8n00-477q-kun1-5acn

Barlow, C. A., Schiff, J. W., Chugh, U., Rawlinson, D. H., E., & Leith, J. (2010). An
evaluation of a suicide bereavement peer support program. *Death Studies, 34*, 915-
930. http://dx.doi.org/10.1080/07481181003761435

Barry, L. C. (2002). Psychiatric disorders among bereaved persons: The role of perceived
circumstances of death and preparedness for death. *The American Journal of
Geriatric Psychiatry, 10*, 447–457. http://dx.doi.org/10.1176/appi.ajgp.10.4.447

Bath, D. M. (2009). Predicting social support for grieving persons: A theory of planned
behavior perspective. *Death Studies, 33*, 869-889.
http://dx.doi.org/10.1080/07481180903251547

Baugher, R. (2001). How long (according to the media) should grief last? *Columbia
Journalism Review, 39*, 58-59. Retrieved from https://search-proquest-
com.dbgw.lis.curtin.edu.au/docview/230364299/fulltextPDF/CCCEE68F4B094A96
PQ/1?accountid=10382

Beck, A. M., & Konnert, C. A. (2007). Ethical issues in the study of bereavement: The
opinions of bereaved adults. *Death Studies, 31*, 783-799.
http://dx.doi.org/10.1080/07481180701537220

Becker, E. (1973). *The denial of death*. New York: Free Press.

Begley, M., & Quayle, E. (2007). The lived experience of adults bereaved by suicide. A
phenomenological study. *Crisis, 28*, 26-34. http://dx.doi.org/10.1027/0227-
5910.28.1.26

Benkel, I., Wijk, H., & Molander, U. (2009a). Family and friends provide most social support for the bereaved. *Palliative Medicine, 23*, 141-149. http://dx.doi.org/10.1177/0269216308098798

Benkel, I., Wijk, H., & Molander, U. (2009b). Managing grief and relationship roles influence which forms of social support the bereaved needs. *American Journal of Hospice and Palliative Care, 26*, 241-245. http://dx.doi.org/10.1177/1049909108330034

Bennett, K. M., Gibbons, K., & MacKenzie-Smith, S. (2010). Loss and restoration in later life: An examination of dual process model of coping with bereavement. *Omega: Journal of Death and Dying, 61*, 315-332. http://dx.doi.org/10.2190/OM.61.4.d

Bergman, E. J., & Haley, W. E. (2009). Depressive symptoms, social network, and bereavement service utilization and preferences among spouses of former hospice patients. *Journal of Palliative Medicine, 12*, 170-176. http://dx.doi.org/10.1089/jpm.2008.0237

Bergman, E. J., Haley, W. E., & Small, B. J. (2010). The role of grief, anxiety, and depressive symptoms in the use of bereavement services. *Death Studies, 34*, 441-458. http://dx.doi.org/10.1080/07481181003697746

Birch, M., & Miller, T. (2000). Inviting intimacy: The interview as therapeutic opportunity. *International Journal of Social Research Methodology, 3*, 189–202. http://dx.doi.org/10.1080/13645570050083689

Biro, A. (2013). Adverse effects of widowhood in Europe. *Advances in Life Course Research, 18*, 68-82. http://dx.doi.org/10.1016/j.alcr.2012.10.005

Bishop, F. L. (2015). Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective. *British Journal of Health Psychology, 20*, 5-20. http://dx.doi.org/10.1111/bjhp.12122

Blackburn, P., McGrath, P., & Bulsara, C. (2016). Looking through the lens of receptivity and its role in bereavement support: A review of the literature. *American Journal of Hospice and Palliative Care, 33*, 989-995. http://dx.doi.org/10.1177/1049909115595608

Blair, C. W. (2003). *College students' response preferences for responding to the bereaved* (Doctoral dissertation, University of Florida, USA). Retrieved from https://archive.org/stream/collegestudentsr00warr/collegestudentsr00warr_djvu.txt

Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity, 36*, 391-409. Retrieved from http://search.proquest.com.dbgw.lis.curtin.edu.au/docview/60455854?accountid=10382

Boelen, P. A., & Prigerson, H. G. (2007). The influence of symptoms of prolonged grief disorder, depression, and anxiety on quality of life among bereaved adults: A prospective study. *European Archives of Psychiatry and Clinical Neuroscience, 257*, 444-452. http://dx.doi.org/10.1007/s00406-007-0744-0

Boelen, P. A., Stroebe, M. S., Schut, H., & Zijerveld, A. M. (2006). Continuing bonds and grief: A prospective analysis. *Death Studies, 30*, 767-776. http://dx.doi.org/10.1080/07481180600852936

Boelen, P. A., van de Schoot, R., ven den Hout, M. A., de Keijser, J., & Van den Bout, J. (2010). Prolonged grief disorder, depression, and posttraumatic stress disorder are distinguishable syndromes. *Journal of Affective Disorders, 125*, 374-378. http://dx.doi.org/10.1016/j.jad.2010.01.076

Boerner, K., Wortman, C. B., & Bonanno, G. (2005). Resilient or at risk? A 4-year study of older adults who initially showed high or low distress following conjugal loss. *Journal of Gerentology: Psychological Sciences, 60*, 67-73. http://dx.doi.org/10.1093/geronb/60.2.p67

Bonanno, G. A. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist, 59*, 20–28. http://dx.doi.org/10.1037/0003-066x.59.1.20

Bonanno, G. A., Neria, Y., Mancini, A. D., Coifman, K. G., Litz, B. T., & Insel, B. (2007). Is there more to complicated grief than depression and posttraumatic stress disorder? A test of incremental validity. *Journal of Abnormal Psychology, 116*, 342-351. http://dx.doi.org/10.1037/0021-843X.116.2.342

Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., . . . Nesse, R. M. (2002). Resilience to loss and chronic grief: A prospective study from

preloss to 18-months postloss. *Journal of Personality and Social Psychology Reports, 83*, 1150–1164. http://dx.doi.org/10.1037/0022-3514.83.5.1150

Boogar, I. R., & Talepasand, S. (2015). The role of defense mechanisms, personality and demographical factors on complicated grief following death of a loved one by cancer. *Iranian Journal of Psychiatry, 10*, 79-85. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4752529/

Botha, K.-J., Guilfoyle, A., & Botha, D. (2009). Beyond normal grief: A critical reflection on immediate post-death experiences of survivors of suicide. *Australian e-Journal for the Advancement of Mental Health, 8*, 1-11. http://dx.doi.org/10.5172/jamh.8.1.37

Bottomley, J. S., Burke, L. A., & Neimeyer, R. A. (2017). Domains of social support that predict bereavement distress following homicide loss: Assessing need and satisfaction. *Omega: Journal of Death and Dying, 75*, 3-25. http://dx.doi.org/10.1177/0030222815612282

Bowlby, J. (1961). Processes of mourning. *International Journal of Psychoanalysis, 42*, 317-340.

Bowlby, J. (1980). *Attachment and loss (Vol. 3): Loss: Sadness and depression*. New York: Basic Books.

Bowlby, J. (1988). *A secure base: Clinical applications of attachment theory*. London, UK: Routledge.

Breen, L. J. (2007). The researcher 'in the middle': Negotiating the insider/outsider dichotomy. *The Australian Community Psychologist, 19*(1), 163-174. Retrieved from https://groups.psychology.org.au/Assets/Files/Breen_19(1).pdf

Breen, L. J. (2010-2011). Professionals' experiences of grief counseling: Implications for bridging the gap between research and practice. *Omega: Journal of Death and Dying, 62*, 285-303. http://dx.doi.org/10.2190/om.62.3.e

Breen, L. J. (2012). The effect of caring on post-bereavement outcome: Research gaps and practice priorities. *Progress in Palliative Care, 20*, 27–30. http://dx.doi.org/10.1179/1743291x12y.0000000003

Breen, L. J., Aoun, S. M., O'Connor, M., & Rumbold, B. (2014). Bridging the gaps in palliative care bereavement support: An international perspective. *Death Studies, 38*, 54-61. http://dx.doi.org/10.1080/07481187.2012.725451

Breen, L. J., Aoun, S. M., Rumbold, V., McNamara, B., Howting, D., & Mancini, V. (2017). Building community capacity in bereavement support: Lessons learnt from bereaved former caregivers. *American Journal of Hospice and Palliative Care, 34*, 275-281. http://dx.doi.org/10.1177/1049909115615568

Breen, L. J., Fernandez, M., O'Connor, M., & Pember, A.-J. (2012-2013). The preparation of graduate health professionals for working with bereaved clients: An Australian perspective. *Omega: Journal of Death and Dying, 66*, 313-332. http://dx.doi.org/10.2190/om.66.4.c

Breen, L. J., & O'Connor, M. (2013). Rural health professionals' perspectives on providing grief and loss support in cancer care. *European Journal of Cancer Care, 22*, 765-772. http://dx.doi.org/10.1111/ecc.12091

Breen, L. J., O'Connor, M., Hewitt, L. Y., & Lobb, E. (2014). The "specter" of cancer: Exploring secondary trauma for health professionals providing cancer support and counseling. *Psychological Services, 11*, 60-67. http://dx.doi.org/10.1037/a0034451

Breen, L. J., & O'Connor, M. (2007). The fundamental paradox in the grief literature: A critical reflection. *Omega: Journal of Death and Dying, 55*, 199-218. http://dx.doi.org/10.2190/OM.55.3.c

Breen, L. J., & O'Connor, M. (2010). Acts of resistance: Breaking the silence of grief following traffic crash fatalities. *Death Studies, 34*, 30-53. http://dx.doi.org/10.1080/07481180903372384

Breen, L. J., & O'Connor, M. (2011). Family and social networks after bereavement: Experiences of support, change and isolation. *Journal of Family Therapy, 33*, 98-120. http://dx.doi.org/10.1111/j.1467-6427.2010.00495.x

Breen, L. J., Penman, E. L., Prigerson, H. G., & Hewitt, L. Y. (2015). Can grief be a mental disorder? An exploration of public opinion. *Journal of Nervous and Mental Disease, 203*, 569-573. http://dx.doi.org/10.1097/nmd.0000000000000331

Broad, J. B., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. J. (2013). Where do people die? An international comparison of the percentage of deaths occurring in

hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health, 58*, 257-267. http://dx.doi.org/10.1007/s00038-012-0394-5

Brown, S. L., Nesse, R. M., House, J. S., & Utz, R. L. (2004). Religion and emotional compensation: Results from a prospective study of widowhood. *Personality and Social Psychology Bulletin, 30*, 1165–1174. http://dx.doi.org/10.1177/0146167204263752

Bruinsma, S. M., Tiemeier, H., Verkroost-van Heemst, J., van der Heide, A., & Rietjens, J. A. C. (2015). Risk factors for complicated grief in older adults. *Journal of Palliative Medicine, 18*, 438-446. http://dx.doi.org/10.1089/jpm.2014.0366

Bryman, A., Becker, S., & Sempik, J. (2008). Quality criteria for quantitative, qualitative and mixed methods research: A view from social policy. *International Journal of Social Research Methodology, 11*, 261-276. http://dx.doi.org/10.1080/13645570701401644

Buckle, J. L., Dwyer, S. C., & Jackson, M. (2010). Qualitative bereavement research: Incongruity between the perspectives of participants and research ethics boards. *International Journal of Social Research Methodology, 13*, 111-125. http://dx.doi.org/10.1080/13645570902767918

Burke, B. L., Martens, A., & Faucher, E. H. (2010). Two decades of terror management theory: A meta-analysis of mortality salience research. *Personality and Social Psychology Review, 14*, 155-195. http://dx.doi.org/10.1177/1088868309352321

Burke, L. A., & Neimeyer, R. A. (2013). Prospective risk factors for complicated grief: A review of the empirical literature. In M. S. Stroebe, H. Schut, & J. van den Bout (Eds.), *Complicated grief: Scientific foundations for healthcare professionals* (pp. 145-161). London, UK: Routledge.

Burke, L. A., & Neimeyer, R. A. (2014). Complicated spiritual grief I: Relation to complicated grief symptomatology following violent death bereavement. *Death Studies, 38*, 259-267. http://dx.doi.org/10.1080/07481187.2013.829372

Burke, L. A., Neimeyer, R. A., Bottomley, J. S., & Smigelsky, M. A. (2017). Prospective risk factors for intense grief in family members of veterans who died of terminal illnesses. *Illness, Crisis & Loss*. http://dx.doi.org/10.1177/1054137317699580

Burke, L. A., Neimeyer, R. A., & McDevitt-Murphy, M. (2010). African American homicide bereavement: Aspects of social support that predict complicated grief, PTSD, and depression. *Omega: Journal of Death and Dying, 61*, 1-24. http://dx.doi.org/10.2190/OM.61.1.a

Burton, A. M., Haley, W. E., & Small, B. J. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. *Aging & Mental Health, 10*, 319-326. http://dx.doi.org/10.1080/13607860500410045

Cacciatore, J., & Flint, M. (2011). Mediating grief: Postmortem ritualization after child death. *Journal of Loss and Trauma, 17*, 158-172. http://dx.doi.org/10.1080/15325024.2011.595299

Cacciatore, J., Thieleman, K., Killian, M., & Tavasolli, K. (2015). Braving human suffering: Death education and its relationship to empathy and mindfulness. *Social Work Education, 34*, 91-109. http://dx.doi.org/10.1080/02615479.2014.940890

Calhoun, L. G., Abernathy, C. B., & Selby, J. W. (1986). The rules of bereavement: Are suicidal deaths different? *Journal of Community Psychology, 14*, 213-218. http://dx.doi.org/10.1002/1520-6629

Calhoun, L. G., & Allen, B. G. (1991). Social reactions to the survivor of a suicide in the family: A review of the literature. *Omega: Journal of Death and Dying, 23*, 95-107. http://dx.doi.org/10.2190/5bmq-awhg-79kn-t619

Calhoun, L. G., Selby, J. W., & Abernathy, C. B. (1984). Suicidal death: Social reactions to bereaved survivors. *Journal of Psychology, 116*, 255-261. http://dx.doi.org/10.1080/00223980.1984.9923645

Calhoun, L. G., Selby, J. W., & Faulstich, M. E. (1980). Reactions to the parents of the child suicide: A study of social impressions. *Journal of Consulting and Clinical Psychology, 48*, 535-536. http://dx.doi.org/10.1037/0022-006x.48.4.535

Calhoun, L. G., Selby, J. W., & Faulstich, M. E. (1982). The aftermath of childhood suicide: Influences on the perception of the parent. *Journal of Community Psychology, 10*, 250-254. http://dx.doi.org/10.1002/1520-6629(198207)

Calhoun, L. G., Selby, J. W., & Gribble, C. M. (1979). Reactions to the family of the suicide. *American Journal of Community Psychology, 7*, 571-575.

Calhoun, L. G., Selby, J. W., & Walton, P. B. (1985). Suicidal death of a spouse: The social perception of the survivor. *Omega: Journal of Death and Dying, 16*, 283-288. http://dx.doi.org/10.2190/v4fwpf4k-mrpk-15fw

Carnelley, K. B., Wortman, C. B., Bolger, N., & Burke, C. T. (2006). The time course of grief reactions to spousal loss: Evidence from a national probability sample. *Journal of Personality and Social Psychology, 91*, 476-492. http://dx.doi.org/10.1037/0022-3514.91.3.476

Caserta, M. S., & Lund, D. A. (2007). Toward the development of an inventory of daily widowed life (IDWL): Guided by the dual process model of coping with bereavement. *Death Studies, 31*, 505-535. http://dx.doi.org/10.1080/07481180701356761

Catlin, G. (1993). The role of culture in grief. *Journal of Social Psychology, 133*, 173-184. http://dx.doi.org/10.1080/00224545.1993.9712135

Center for the Advancement of Health. (2004). Report on bereavement and grief research. *Death Studies, 28*, 491-575. http://dx.doi.org/10.1080/07481180490461188

Chan, W. C. H., & Tin, A. F. (2012). Beyond knowledge and skills: Self-competence in working with death, dying, and bereavement. *Death Studies, 36*, 899-913. http://dx.doi.org/10.1080/07481187.2011.604465

Chapple, A., & Ziebland, S. (2011). How the Internet is changing the experience of bereavement by suicide: A qualitative study in the UK. *Health, 15*, 173-187. http://dx.doi.org/10.1177/1363459309360792

Chapple, A., Ziebland, S., & Hawton, K. (2015). Taboo and the different death? Perceptions of those bereaved by suicide or other traumatic death. *Sociology of Health & Illness, 37*, 610-625. http://dx.doi.org/10.1111/1467-9566.12224

Cherlin, E. J., Barry, C. L., Prigerson, H. G., Schulman-Green, D., Johnson-Hurzeler, R., Kasl, S. V., & Bradley, E. H. (2007). Bereavement services for family caregivers: How often used, why, and why not. *Journal of Palliative Medicine, 10*, 148–158. http://dx.doi.org/10.1089/jpm.2006.0108

Chiu, Y.-W., Huang, C.-T., Yin, S.-M., Huang, Y.-C., Chien, C.-H., & Chuang, H.-Y. (2010). Determinants of complicated grief in caregivers who cared for terminal

cancer patients. *Supportive Care in Cancer, 18*, 1321-1327.
http://dx.doi.org/10.1007/s00520-009-0756-6

Cohen, J. (1988). *Statistical power for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.

Cooper, M. (2015). *Existential psychotherapy and counselling*. Thousand Oaks, CA: SAGE.

Cordaro, M. (2012). Pet loss and disenfranchised grief: Implications for mental health counseling practice. *Journal of Mental Health Counseling, 34*, 283-294.
http://dx.doi.org/10.1080/07481180902805715

Cornish, F., & Gillespie, A. (2009). A pragmatist approach to the problem of knowledge in health psychology. *Journal of Health Psychology, 14*, 800–809.
http://dx.doi.org/10.1177/1359105309338974

Costa, B. M., Hall, L., & Stewart, J. (2007). Qualitative exploration of the nature of grief-related beliefs and expectations. *Omega: Journal of Death and Dying, 55*, 27-56.
http://dx.doi.org/10.2190/cl20-02g6-607r-8561

Coy, M. (2006). This morning I'm a researcher, this afternoon I'm an outreach worker: Ethical dilemmas in practitioner research. *International Journal of Social Research Methodology, 9*, 419–431. http://dx.doi.org/10.1080/13645570601076785

Coyne, E., & Martin, R. (2007). Mapping the knowledge bereavement counsellors use in practice. *Grief Matters: The Australian Journal of Grief and Bereavement, 10*, 64-68. Retrieved from
https://search.informit.com.au/documentSummary;dn=057433485221927;res=IELFSC

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: SAGE.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: SAGE.

Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 209-240). Thousand Oaks, CA: SAGE.

Creswell, J. W., & Tashakkori, A. (2007). Differing perspectives on mixed methods research. *Journal of Mixed Methods Research, 1*, 303-308. http://dx.doi.org/10.1177/1558689807306132

Crowne, D. P., & Marlowe, D. (1960). A new scale of social desirability independent of psychopathology. *Journal of Consulting Psychology, 24*, 349-354. Retrieved from http://psycnet.apa.org/record/1961-02183-001

Currier, J. M., Holland, J. M., & Neimeyer, R. A. (2006). Sense-making, grief, and the experience of violent loss: Toward a mediational model. *Death Studies, 30*, 403-428. http://dx.doi.org/10.1080/07481180600614351

Currier, J. M., Holland, J. M., & Neimeyer, R. A. (2007). The effectiveness of bereavement interventions with children: A meta-analytic review of controlled outcome research. *Journal of Clinical Child & Adolescent Psychology, 36*, 253-259. http://dx.doi.org/10.1080/15374410701279669

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*, 648-661. http://dx.doi.org/10.1037/0033-2909.134.5.648

Currow, D. C., Allen, K., Plummer, J., Aoun, S., Hegarty, M., & Abernethy, A. P. (2008). Bereavement help-seeking following an 'expected' death: A cross-sectional randomised face-to-face population survey. *BMC Palliative Care, 7*, 1-7. http://dx.doi.org/10.1186/1472-684X-7-19

Cvinar, J. G. (2005). Do suicide survivors suffer social stigma: A review of the literature. *Perspectives in Psychiatric Care, 41*, 14-21. http://dx.doi.org/10.1111/j.0031-5990.2005.00004.x

Damousi, J. (2001). *Living with the aftermath: Trauma, nostalgia and grief in post-war Australia*. Cambridge, UK: Cambridge University Press.

Damousi, J. (2002). History matters: The politics of grief and injury in Australian history. *Australian Historical Studies, 33*, 100-112. http://dx.doi.org/10.1080/10314610208596183

Davies, B., Reimer, J., Brown, P., & Martens, N. (1995). *Fading away: The experience of transition in families with terminal illness*. Amityville, NY: Baywood.

de Groot, M. H., de Keijser, J., & Neeleman, J. (2006). Grief shortly after suicide and natural death: A comparative study among spouses and first degree relatives. *Suicide and Life-Threatening Behavior, 36*, 419–433. http://dx.doi.org/10.1521/suli.2006.36.4.418

Dent, A., & Stewart, A. (2004). *Sudden death in childhood: Support for the bereaved family*. New York: Butterworth-Heinemann.

Department of Health. (2008). *A healthier future for all Australians: Interim report*. Canberra: Commonwealth of Australia.

Di Mattia, M., & Davis-McCabe, C. (2017). A profile of Australian counselling psychologists. *InPsych: The Bulletin of the Australian Psychological Society, 39*(2), 38-39. Retrieved from http://search.informit.com.au/fullText;dn=922293255098319;res=IELAPA

Di Mattia, M., & Grant, J. (2016). Counselling psychology in Australia: History, status and challenges. *Counselling Psychology Quarterly, 29*, 139-149. http://dx.doi.org/10.1080/09515070.2015.1127208

Dickinson, G. E. (2007). End-of-life and palliative care issues in medical and nursing schools in the United States. *Death Studies, 31*, 713-726. http://dx.doi.org/10.1080/07481180701490602

Dickinson, G. E. (2012). Twenty-first century end-of-life issues in selected U.S. professional schools. *Illness, Crisis & Loss, 20*, 19-32. http://dx.doi.org/10.2190/il.20.1.c

Doering, B. K., & Maarten, C. E. (2016). Treatment for complicated grief: State of the science and ways forward. *Current Opinion in Psychiatry, 29*, 286-291. http://dx.doi.org/10.1097/YCO.0000000000000263

Doka, K. J. (1989). Disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief: Recognising hidden sorrow* (pp. 3-12). Massachusetts, USA: Lexington Books.

Doka, K. J. (2002). How we die: Stigmatized death and disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 323-336). Champain, IL: Research Press.

Doka, K. J., & Martin, T. L. (2010). *Grieving beyond gender: Understanding the ways men and women mourn*. New York: Routledge.

Doka, K. J., & Neimeyer, R. A. (2012). Orchestrating social support. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Creative practices for counseling the bereaved* (pp. 315-317). New York, NY: Routledge.

Duffy, B., Smith, K., Terhanian, G., & Bremer, J. (2005). Comparing data from online and face-to-face surveys. *International Journal of Market Research, 47*, 615-639. Retrieved from http://web.b.ebscohost.com.dbgw.lis.curtin.edu.au/ehost/pdfviewer/pdfviewer?sid=c 21d1b38-bfd7-4015-957a-3b1d42849ed5%40sessionmgr107&vid=1&hid=101

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Research, 8*, 54-63. http://dx.doi.org/10.1177/160940690900800105

Dyregrov, K. (2002). Assistance from local authorities versus survivors' needs for support after suicide. *Death Studies, 26*, 647–669. http://dx.doi.org/10.1080/07481180290088356

Dyregrov, K. (2003-2004). Micro-sociological analysis of social support following traumatic bereavement: Unhelpful and avoidant responses from the community. *Omega: Journal of Death and Dying, 48*, 23-44. http://dx.doi.org/10.2190/T3NM-VFBK-68R0-UJ60

Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science & Medicine, 58*, 391–400. http://dx.doi.org/10.1016/s0277-9536(03)00205-3

Dyregrov, K. (2005-2006). Experiences of social networks supporting traumatically bereaved. *Omega: Journal of Death and Dying, 52*, 339-358. http://dx.doi.org/10.2190/CLAA-X2LW-JHQJ-T2DM

Dyregrov, K. (2011). What do we know about needs for help after suicide in different parts of the world? A phenomenological perspective. *Crisis, 32*, 310-318. http://dx.doi.org/10.1027/0227-5910/a000098

Dyregrov, K., Dieserud, G., Hjemeland, H. M. H., Straiton, M., Rasmussen, M. L., Knizek, B. L., & Leenaars, A. A. (2011). Meaning-making through psychological autopsy interviews: The value of participating in qualitative research for those bereaved by suicide. *Death Studies, 35*, 685-710. http://dx.doi.org/10.1080/07481187.2011.553310

Dyregrov, K., Dieserud, G., Straiton, M., Rasmussen, M. L., Hjelmeland, H., Knizek, B. L., & Leenaars, A. A. (2011). Motivation for research participation among people bereaved by suicide. *Omega: The Journal of Death and Dying, 62*, 149-168. http://dx.doi.org/10.2190/OM.62.2.d

Dyregrov, K., & Dyregrov, A. (2008). *Effective grief and bereavement support: The role of family, friends, colleagues, schools and support professionals*. London, UK: Jessica Kingsley.

Dyregrov, K., Nordanger, D., & Dyregrov, A. (2003). Predictors of psychosocial distress after suicide, SIDS and accidents. *Death Studies, 27*, 143-165. http://dx.doi.org/10.1080/07481180390136973

Egnoto, M. J., Sirianni, J. M., Ortega, C. R., & Stefanone, M. (2014). Death on the digital landscape: A preliminary investigation into the grief process and motivations behind participation in the online memoriam. *Omega: Journal of Death and Dying, 69*, 283-304. http://dx.doi.org/10.2190/OM.69.3.d

Engel, G. L. (1961). Is grief a disease? *Psychosomatic Medicine, 23*, 18-22.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191. http://dx.doi.org/10.3758/bf03193146

Feigelman, W., Gorman, B. S., & Jordan, J. R. (2009). Stigmatization and suicide bereavement. *Death Studies, 33*, 591-608. http://dx.doi.org/10.1080/07481180902979973

Feigelman, W., Jordan, J. R., & Gorman, B. S. (2008-2009). How they died, time since loss, and bereavement outcomes. *Omega: Journal of Death and Dying, 58*, 251-273. http://dx.doi.org/10.2190/OM.58.4.a

Feigelman, W., Jordan, J. R., & Gorman, B. S. (2011). Parental grief after a child's drug death compared to other death causes: Investigating a greatly neglected bereavement population. *Omega: Journal of Death and Dying, 63*, 291-316. http://dx.doi.org/10.2190/OM.63.4.a

Feilzer, M. Y. (2010). Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm. *Journal of Mixed Methods Research, 4*, 6-16. http://dx.doi.org/10.1177/1558689809349691

Field, N. P. (2008). Whether to maintain or relinquish a bond with the deceased in adapting to bereavement. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and practice* (pp. 113–132). Washington, DC: American Psychological Association.

Field, N. P., & Filanosky, C. (2010). Continuing bonds, risk factors for complicated grief, and adjustment to bereavement. *Death Studies, 34*, 1-29. http://dx.doi.org/10.1080/07481180903372269

Field, N. P., Gao, B., & Paderna, L. (2005). Continuing bonds in bereavement: An attachment theory based perspective. *Death Studies, 29*, 1–23. http://dx.doi.org/10.1080/07481180590923689

Fischer, D. G., & Fick, C. (1993). Measuring social desirability: Short forms of the Marlowe-Crowne social desirability scale. *Educational and Psychological Measurement, 53*, 417-424. http://dx.doi.org/10.2466/pr0.71.8.1155-1160

Fonseca, L. M., & Testoni, I. (2012). The emergence of thanatology and current practice in death education. *Omega: Journal of Death and Dying, 64*, 157-169. http://dx.doi.org/10.2190/OM.64.2.d

Fowlkes, M. R. (1991). The morality of loss: The social construction of mourning and melancholia. *Contemporary Psychoanalysis, 27*, 529–551. http://dx.doi.org/10.1080/00107530.1991.10746711

Fraley, R. C., & Bonanno, G. A. (2004). Attachment and loss: A test of three competing models on the association between attachment-related avoidance and adaptation to bereavement. *Personality and Social Psychology Bulletin, 30*, 878-890. http://dx.doi.org/10.1177/0146167204264289

Fram, S. M. (2013). The constant comparative analysis method outside of grounded theory. *The Qualitative Report, 18*, 1-25. Retrieved from http://search.proquest.com.dbgw.lis.curtin.edu.au/docview/1373426716?accountid=1 0382

Freud, S. (1917/2005). *On murder, mourning and melancholia*. London, England: Penguin Books.

Fujisawa, D., Miyashita, M., Nakajima, S., Ito, M., Kato, M., & Kim, Y. (2010). Prevalence and determinants of complicated grief in general population. *Journal of Affective Disorders, 127*, 352-358. http://dx.doi.org/10.1016/j.jad.2010.06.008

Fulton, R., & Owen, G. (1988). Death and society in twentieth century America. *Omega: Journal of Death and Dying, 18*, 379-395. http://dx.doi.org/10.2190/6kym-f9eb-vy1j-fqwe

Gair, S. (2012). Feeling their stories: Contemplating empathy, insider/outsider positionings, and enriching qualitative research. *Qualitative Health Research, 22*, 134-143. http://dx.doi.org/ 10.1177/104973231142

Garrido, M., & Prigerson, H. G. (2014). The end-of-life experience: Modifiable predictors of caregivers' bereavement adjustment. *Cancer, 120*, 918-925. http://dx.doi.org/10.1002/cncr.28495

Garson, C. L. (1994). *Variables related to the behavioral intention of talking with bereaved parents about their loss experience* (Doctoral dissertation, University of Pennsylvania, USA). Retrieved from http://repository.upenn.edu/dissertations/AAI9427540/

Gear, R. (2014). Bereaved parents' perspectives on informal social support: "What worked for you?". *Journal of Loss and Trauma, 19*, 173-188. http://dx.doi.org/10.1080/15325024.2013.763548

Ghesquiere, A. (2013). "I was just trying to stick it out until I realized that I couldn't": A phenomenological investigation of support seeking among older adults with complicated grief. *Omega: Journal of Death and Dying, 68*, 1-22. http://dx.doi.org/10.2190/OM.68.1.a

Gilbert, K. R. (2002). Taking a narrative approach to grief research: Finding meaning in stories. *Death Studies, 26*, 223-239. http://dx.doi.org/10.1080/07481180211274

Ginn, P. D., Range, L. M., & Hailey, B. J. (1988). Community attitudes toward childhood suicide and attempted suicide. *Journal of Community Psychology, 16*, 144-151. http://dx.doi.org/10.1002/1520-6629

Glaser, B. G. (1965). The constant comparative method of qualitative analysis. *Social Problems, 12*, 436-445. http://dx.doi.org/10.2307/798843

Glaser, B. G. (2001). *The grounded theory perspective: Conceptualization contrasted with description*. California: Sociology Press.

Glaser, B. G., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Glick, I. O., Weiss, R. S., & Parkes, C. M. (1974). *The first year of bereavement*. New York: Wiley.

Goodyear, R., Lichtenberg, J., Hutman, H., Overland, E., Bedi, R., Christiani, K., . . . Young, C. (2016). A global portrait of counselling psychologists' characteristics, perspectives, and professional behaviors. *Counselling Psychology Quarterly, 29*, 115-138. http://dx.doi.org/10.1080/09515070.2015.1128396

Granek, L. (2013). Disciplinary wounds: Has grief become the identified patient for a field gone awry? *Journal of Loss and Trauma, 18*, 275-288. http://dx.doi.org/10.1080/15325024.2012.688708

Granek, L. (2014). The complications of grief: The battle to define modern mourning. In E. D. Miller (Ed.), *Stories of complicated grief: A critical anthology* (pp. 30–53). Washington, DC: NASW Press.

Granek, L. (2016). Medicalizing grief. In D. L. Harris & T. C. Bordere (Eds.), *Handbook of social justice in loss and grief: Exploring diversity, equity, and inclusion* (pp. 111-124). New York: Routledge.

Greenberg, J., Pyszczynski, T., & Solomon, S. (1986). The causes and consequences of a need for self-esteem: A terror management theory. In R. F. Baumeister (Ed.), *Public self and private self* (pp. 189-212). New York: Springer-Verlag.

Greene, J. (2008). Is mixed methods social inquiry a distinctive methodology? *Journal of Mixed Methods Research, 2*, 7-22. http://dx.doi.org/10.1177/1558689807309969

Ha, J.-H., & Ingersoll-Dayton, B. (2011). Moderators in the relationship between social contact and psychological distress among widowed adults. *Aging & Mental Health, 15*, 354-363. http://dx.doi.org/10.1080/13607863.2010.519325

Hall, C. (2014). Bereavement theory: Recent developments in our understanding of grief and bereavement. *Bereavement Care, 33*, 7-12. http://dx.doi.org/10.1080/02682621.2014.902610

Hall, D., Schucksmith, J., & Russell, S. (2013). Building a compassionate community: Developing an informed and caring workplace in response to employee bereavement care. *Bereavement Care, 32*, 4-10. http://dx.doi.org/10.1080/02682621.2013.779819

Hansson, R. O., & Stroebe, M. S. (2003). Grief, older adulthood. In M. Bloom & T. P. Gullotta (Eds.), *Encyclopedia of primary prevention and health promotion* (pp. 515-521). New York: Kluwer Academic.

Harris, D. L. (2009-2010). Oppression of the bereaved: A critical analysis of grief in western society. *Omega: Journal of Death and Dying, 60*, 241-253. http://dx.doi.org/10.2190/OM.60.3.c

Harris, D. L. (2016). Social expectations of the bereaved. In D. L. Harris & T. C. Bordere (Eds.), *Handbook of social justice in loss and grief: Exploring diversity, equity, and inclusion* (pp. 165-175). New York: Routledge.

Heaney, C. A., & Israel, B. A. (2008). Social networks and social support. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (4th ed., pp. 189-210). San Francisco, CA: Jossey-Bass.

Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management, 37*, 3–12. http://dx.doi.org/10.1016/j.jpainsymman.2007.12.010

Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world? *Behavioral and Brain Sciences, 33*, 61-83. http://dx.doi.org/10.1017/S0140525X0999152X

Hibberd, R., Elwood, L. S., & Galovski, T. E. (2010). Risk and protective factors for posttraumatic stress disorder, prolonged grief, and depression in survivors of the violent death of a loved one. *Journal of Loss and Trauma, 15*, 426-447. http://dx.doi.org/10.1080/15325024.2010.507660

Higgins, J. P. T., & Green, S. (2008). *Cochrane handbook for systematic reviews of interventions*. England: John Wiley & Sons.

Hill, C. E., Thompson, B. J., & Williams, E. N. (1997). A guide to conducting consensual qualitative research. *The Counseling Psychologist, 25*, 517–572. http://dx.doi.org/10.1177/0011000097254001

Hilliker, L. (2008). The reporting of grief by one newspaper of record for the U.S.: The New York Times. *Omega: Journal of Death and Dying, 57*, 261-278. http://dx.doi.org/10.2190/OM.57.3.c

Holland, J. M., Currier, J. M., & Neimeyer, R. A. (2006). Meaning reconstruction in the first two years of bereavement: The role of sense-making and benefit-finding. *Omega: Journal of Death and Dying, 53*, 175-191. http://dx.doi.org/10.2190/fkm2-yjty-f9vv-9xwy

Holland, J. M., & Neimeyer, R. A. (2010). An examination of the stage theory of grief among individuals bereaved by natural and violent causes: A meaning-oriented contribution. *Omega: Journal of Death and Dying, 61*, 103-120. http://dx.doi.org/10.2190/OM.61.2.b

Holzinger, A., Matschinger, H., Schomerus, G., Carta, M. G., & Angermeyer, M. C. (2011). The loss of sadness: The public's view. *Acta Psychiatrica Scandinavica, 123*, 307-313. http://dx.doi.org/10.1111/j.1600-0447.2010.01669.x

Horowitz, M. J. (1990). A model of mourning: Changes in schema of self and other. *Journal of the American Psychoanalytic Association, 38*, 297-324. http://dx.doi.org/10.1177/000306519003800202

Horowitz, M. J., Bonanno, G., & Holen, A. (1993). Pathological grief: Diagnosis and explanation. *Psychosomatic Medicine, 55*, 260-273. http://dx.doi.org/10.1097/00006842-199305000-00004

Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J. P. (2013). Working together-apart: Exploring the relationships between formal and informal care networks for people dying at home. *Progress in Palliative Care, 21*, 331-336. http://dx.doi.org/10.1179/1743291x12y.0000000047

Horsfall, D., Noonan, K., & Leonard, R. (2012). Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities. *Health Sociology Review, 21*, 373-382. http://dx.doi.org/10.5172/hesr.2012.21.4.373

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277-1288. http://dx.doi.org/10.1177/1049732305276687

Hughes, R., & Huby, M. (2004). The construction and interpretation of vignettes in social research. *Social Work and Social Sciences Review, 11*, 36-51. http://dx.doi.org/10.1921/17466105.11.1.36

Iglewicz, A., Seay, K., Vigeant, S., Jouhal, S. K., & Zisook, S. (2013). The bereavement exclusion: The truth behind pathology and politics. *Psychiatric Annals, 43*, 261-266. http://dx.doi.org/10.3928/00485713-20130605-05

Ingram, K. M., Jones, D. A., & Smith, N. G. (2001). Adjustment among people who have experienced AIDS-related multiple loss: The role of unsupportive social interactions, social support, and coping. *Omega: Journal of Death and Dying, 43*, 278-309. http://dx.doi.org/10.2190/tv1j-543l-m020-b93v

Jaffe, J., & Diamond, M. O. (2011). *Reproductive trauma: Psychotherapy with infertility and pregnancy loss clients*. Washington, D.C.: American Psychological Association.

Jakoby, N. R. (2012). Grief as a social emotion: Theoretical perspectives. *Death Studies, 36*, 679–711. http://dx.doi.org/10.1080/07481187.2011.584013

Jakoby, N. R. (2014). Talking about grief: Conversational partners sought by bereaved people. *Bereavement Care, 33*, 13-18. http://dx.doi.org/10.1080/02682621.2014.902611

Jalland, P. (2013). A culture of silent grief? The transformation of bereavement care in 20th century England. *Bereavement Care, 32*, 16-22. http://dx.doi.org/10.1080/02682621.2013.779821

Johnson, J. G., First, M. B., Block, S., Vanderwerker, L. C., Zivin, K., Zhang, B., & G., P. H. (2009). Stigmatization and receptivity to mental health services among recently bereaved adults. *Death Studies, 33*, 691-711. http://dx.doi.org/10.1080/07481180903070392

Johnson, J. G., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*, 112-133. http://dx.doi.org/10.1177/1558689806298224

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*, 14-26. http://dx.doi.org/10.3102/0013189X03300701

Jones, S. P., Auton, M. F., Burton, C. R., & Watkins, C. L. (2008). Engaging service users in the development of stroke services: An action research study. *Journal of Clinical Nursing, 17*, 1270–1279. http://dx.doi.org/10.1111/j.1365-2702.2007.02259.x

Jordan, J. R. (2013). A personal reflection on bridging research and practice in thanatology. *Grief Matters: The Australian Journal of Grief and Bereavement, 16*, 14-18. Retrieved from http://search.informit.com.au/documentSummary;dn=413934012515789;res=IELFSC

Jordan, J. R., & Neimeyer, R. A. (2003). Does grief counseling work? *Death Studies, 27*, 765-786. http://dx.doi.org/10.1080/713842360

Jorm, A. F., & Oh, E. (2009). Desire for social distance from people with mental disorders. *Australian & New Zealand Journal of Psychiatry, 43*, 183-200. http://dx.doi.org/10.1080=00048670802653349

Kanuha, V. K. (2000). "Being" native versus "going native": Conducting social work research as an insider. *Social Work, 45*, 439-447. http://dx.doi.org/10.1093/sw/45.5.439

Katz, R., & Johnson, T. A. (Eds.). (2016). *When professionals weep: Emotional and countertransference responses in palliative and end-of-life care* (2nd ed.). New York, NY: Routledge.

Kaunonen, M., Tarkka, M.-T., Paunonen, M., & Laippala, P. (1999). Grief and social support after the death of a spouse. *Journal of Advanced Nursing, 30*, 1304-1311. http://dx.doi.org/10.1046/j.1365-2648.1999.01220.x

Keesee, N. J., Currier, J. M., & Neimeyer, R. A. (2008). Predictors of grief following the death of one's child: The contribution of finding meaning. *Journal of Clinical Psychology, 64*, 1-19. http://dx.doi.org/10.1002/jclp.20502

Kellehear, A. (2005). *Compassionate cities: Public health and end of life care*. London, UK: Routledge.

Kellehear, A. (2013). Compassionate communities: End-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine, 106*, 1071-1075. http://dx.doi.org/10.1093/qjmed/hct200

Kellehear, A. (2016). Commentary: Public health approaches to palliative care – The progress so far. *Progress in Palliative Care, 24*, 36-38. http://dx.doi.org/10.1080/09699260.2015.1103499

Kemmis, S., McTaggart, R., & Nixon, R. (2014). *The action research planner: Doing critical participatory action research*. London, UK: Springer.

Kennedy, C. J., Keeffe, M., Gardner, F., & Farrelly, C. (2017). Making death, compassion and partnership 'part of life' in school communities. *Pastoral Care in Education, 35*, 111-123. http://dx.doi.org/10.1080/02643944.2017.1306873

Kenny, S. (1994). *Developing communities for the future*. South Melbourne, VIC: Thomas Nelson.

Kersting, A., Brähler, E., Glaesmer, H., & Wagner, B. (2011). Prevalence of complicated grief in a representative population-based sample. *Journal of Affective Disorders, 131*, 339-343. http://dx.doi.org/10.1016/j.jad.2010.11.032

Klasen, M., Bhar, S. S., Ugalde, A., & Hall, C. (2017). Clients' perspectives on outcomes and mechanisms of bereavement counselling: A qualitative study. *Australian Psychologist, 52*, 363-371. http://dx.doi.org/10.1111/ap.12280

Klass, D. (2006). Continuing conversation about continuing bonds. *Death Studies, 30*, 843-858. http://dx.doi.org/10.1080/07481180600886959

Klass, D. (2014). Grief, consolation, and religions: A conceptual framework. *Omega: Journal of Death and Dying, 69*, 1–18. http://dx.doi.org/10.2190/om.69.1.a

Klass, D., & Chow, A. Y. M. (2011). Culture and ethnicity in experiencing, policing, and handling grief. In R. A. Neimeyer, D. Harris, H. R. Winokuer, & G. Thornton (Eds.), *Grief and bereavement in contemporary society: Bridging research and practice* (pp. 341-353). New York, NY: Routledge.

Klass, D., Silverman, P. R., & Nickman, S. L. (1996). *Continuing bonds: New understandings of grief*. Washington, DC: Taylor & Francis.

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*. Alberta, Canada: Alberta Heritage Foundation for Medical Research.

Knight, K. H., Elfenbein, M. H., & Messina-Soares, J. A. (1998). College students'
    perceptions of helpful responses to bereaved persons: Effects of sex of bereaved
    persons and cause of death. *Psychology Reports, 83*, 627-636.
    http://dx.doi.org/10.2466/pr0.1998.83.2.627

Koffman, J., Higginson, I. J., Hall, S., Riley, J., McCrone, P., & Gomes, B. (2011). Bereaved
    relatives' views about participating in cancer research. *Palliative Medicine, 26*, 379-
    383. http://dx.doi.org/10.1177/0269216311405091

Kosminsky, P. S., & Jordan, J. R. (2016). *Attachment-informed grief therapy*. New York,
    NY: Routledge.

Krawchuk, L. (2012). Wisdom circles for when helping hurts. In R. A. Neimeyer (Ed.),
    Techniques of grief therapy: Creative practices for counseling the bereaved (pp.
    359-361). New York, NY: Routledge.

Krosniak, J. A. (1991). Response strategies for coping with the cognitive demands of attitude
    measures in surveys. *Applied Cognitive Psychology, 5*, 213-236.
    http://dx.doi.org/10.1002/acp.2350050305

Kubitz, N., Thornton, G., & Robertson, D. U. (1989). Expectations about grief and
    evaluation of the griever. *Death Studies, 13*, 39-47.
    http://dx.doi.org/10.1080/07481188908252278

Kübler-Ross, E. (1969). *On death and dying. What the dying have to teach doctors, nurses,
    clergy, and their own families*. New York, NY: Scribner.

Kübler-Ross, E., & Kessler, D. (2005). *On grief and grieving: Finding the meaning through
    the five stages*. New York, NY: Scribner.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical
    data. *Biometrics, 33*, 159-174.

Latham, A., E., & Prigerson, H. G. (2004). Suicidality and bereavement: Complicated grief
    as a psychiatric disorder presenting greatest risk for suicidality. *Suicide and Life-
    Threatening Behavior, 34*, 350-361. http://dx.doi.org/10.1521/suli.34.4.350.53737

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY:
    Springer Publishing Company.

Lee, R. L. M. (2008). Modernity, mortality and re-enchantment: The death taboo revisited. *Sociology, 42*, 745–759. http://dx.doi.org/10.1177/0038038508091626

Lehman, D. R., Ellard, J. H., & Wortman, C. B. (1986). Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal of Consulting and Clinical Psychology, 54*, 438-446. http://dx.doi.org/10.1037/0022-006X.54.4.438

Lester, D. (1990). Attitudes towards the survivors of suicide as a function of the motive for suicide. *Omega: Journal of Death and Dying, 22*, 215-218. http://dx.doi.org/10.2190/vpp1-ka8r-7muk-0jr0

Lewis, C. S. (1961). *A grief observed*. London, UK: Faber and Faber.

Li, J., & Chen, S. (2016). A new model of social support in bereavement (SSB): An empirical investigation with a Chinese sample. *Death Studies, 40*, 223-228. http://dx.doi.org/10.1080/07481187.2015.1127296

Li, J., Sha, W., & Chow, A. Y. M. (2013). Social support for bereaved people: A reflection in Chinese society. In S. Chen (Ed.), *Social support and health: Theory, research, and practice with diverse populations* (pp. 209–222). New York: Nova Science Publishers.

Lichtenthal, W. G., Corner, G. W., Sweeney, C. R., Wiener, L., Roberts, K. E., Baser, R. E., . . . Prigerson, H. G. (2015). Mental health services for parents who lost a child to cancer: If we build them, will they come? *Journal of Clinical Oncology, 20*, 2246-2253. http://dx.doi.org/10.1200/JCO.2014.59.0406

Lichtenthal, W. G., Currier, J. M., Neimeyer, R. A., & Keesee, N. J. (2010). Sense and significance: A mixed methods examination of meaning making after the loss of one's child. *Journal of Clinical Psychology, 66*, 791-812. http://dx.doi.org/10.1002/jclp.20700

Lichtenthal, W. G., Nilsson, M., Kissane, D. W., Breitbart, W., Kacel, E., Jones, E. C., & Prigerson, H. G. (2011). Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatric Services, 62*, 1225-1229. http://dx.doi.org/10.1176/appi.ps.62.10.1225

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: SAGE.

Lincoln, Y., Lynham, S. A., & Guba, E. (2011). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (4th ed., pp. 97-128). Thousand Oaks, CA: SAGE.

Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry, 707*, 141-148. Retrieved from http://www.nyu.edu/classes/gmoran/LINDEMANN.pdf

Lindstrøm, T. C. (2002). "It ain't necessarily so"…Challenging mainstream thinking about bereavement. *Family & Community Health, 25*, 11–21. http://dx.doi.org/10.1097/00003727-200204000-00005

Lobb, E. A., Kristjanson, L. J., Aoun, S. M., Monterosso, L., Halkett, G. K. B., & Davies, A. (2010). Predictors of complicated grief: A systematic review of empirical studies. *Death Studies, 34*, 673-698. http://dx.doi.org/10.1080/07481187.2010.496686

Logan, E. L., Thornton, J. A., & Breen, L. J. (2017). What determines supportive behaviours following bereavement? A systematic review and call to action. *Death Studies*. http://dx.doi.org/10.1080/07481187.2017.1329760

Logan, E. L., Thornton, J. A., Kane, R. T., & Breen, L. J. (2017). Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies*. http://dx.doi.org/10.1080/07481187.2017.1382610

Love, A. W. (2007). Progress in understanding grief, complicated grief, and caring for the bereaved. *Contemporary Nurse, 27*, 73-83. http://dx.doi.org/10.5172/conu.2007.27.1.73

Lund, D., Caserta, M., Utz, R., & De Vries, B. (2010). Experiences and early coping of bereaved spouses/partners in an intervention based on the dual process model (DPM). *Omega: Journal of Death and Dying, 61*, 291-313. http://dx.doi.org/10.2190/OM.61.4.c

Lund, D. A., & Caserta, M. S. (1997). Future directions in adult bereavement research. *Omega: Journal of Death and Dying, 36*, 287–303. http://dx.doi.org/10.2190/efgk-lral-3fmb-897j

Maciejewski, P. K., Maercker, A., Boelen, P. A., & Prigerson, H. G. (2016). "Prolonged grief disorder" and "persistent complex bereavement disorder", but not "complicated grief", are one and the same diagnostic entity: An analysis of data from the Yale

Bereavement Study. *World Psychiatry, 15*, 266–275.
http://dx.doi.org/10.1002/wps.20348

Maciejewski, P. K., Zhang, B., Block, S. D., & Prigerson, H. G. (2007). An empirical
examination of the stage theory of grief. *Journal of the American Medical
Association, 297*, 716-723. http://dx.doi.org/10.1001/jama.297.7.716

MacKinnon, C. J., Milman, E., Smith, N. G., Henry, M., Berish, M., Copeland, L. S., . . .
Cohen, S. R. (2013). Means to meaning in cancer-related bereavement: Identifying
clinical implications for counseling psychologists. *The Counseling Psychologist, 41*,
216-239. http://dx.doi.org/10.1177/0011000012459969

MacKinnon, C. J., Smith, N. G., Henry, M., Milman, E., Chochinov, H. M., Körner, A., . . .
Cohen, S. R. (2015). Reconstructing meaning with others in loss: A feasibility pilot
randomized controlled trial of a bereavement group. *Death Studies, 39*, 411-421.
http://dx.doi.org/10.1080/07481187.2014.958628

Madison, G. (2005). Bereavement and loss. In E. van Deurzen & C. Arnold-Baker (Eds.),
Existential perspectives on human issues (pp. 197-206). Hampshire, UK: Palgrave
MacMillan.

Maercker, A., Brewin, C. R., Bryant, R. A., Cloitre, M., Reed, G. M., van Ommeren, M., . . .
Saxena, S. (2013). Proposals for mental disorders specifically associated with stress
in the ICD-11. *Lancet, 381*, 1683-1685. http://dx.doi.org/10.1016/S0140-
6736(12)62191-6

Malkinson, R., Rubin, S. S., & Witztum, E. (2006). Therapeutic issues and the relationship
to the deceased: Working clinically with the two-track model of bereavement. *Death
Studies, 30*, 797-815. http://dx.doi.org/10.1080/07481180600884723

Marsh, P., Gartrell, G., Egg, G., Nolan, A., & Cross, M. (2017). End-of-life care in a
community garden: Findings from a participatory action research project in regional
Australia. *Health & Place, 45*, 110-116.
http://dx.doi.org/10.1016/j.healthplace.2017.03.006

Martin, T. L., & Doka, K. J. (2000). *Men don't cry… women do: Transcending gender
stereotypes of grief.* Philadelphia: Brunner/Mazel.

Marwit, S. J., & Carusa, S. S. (1998). Communicated support following loss: Examining the experiences of parental death and parental divorce in adolescence. *Death Studies, 22*, 237-255. http://dx.doi.org/10.1080/074811898201579

Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal, 320*, 50-52. http://dx.doi.org/10.1136/bmj.320.7226.50

McBride, M. C., & Toller, P. (2011). Negotiation of face between bereaved parents and their social networks. *Southern Communication Journal, 76*, 210–229. http://dx.doi.org/10.1080/10417940903477647

McConnell, S., Moules, N. J., McCaffrey, G., & Raffin Bouchal, S. (2012). The hidden nature of death and grief. *Journal of Applied Hermeneutics, 11*, 1-7. Retrieved from http://jah.journalhosting.ucalgary.ca/jah/index.php/jah/article/viewFile/28/pdf

McEvoy, J., & Smith, E. (2005). Families' perceptions of the grieving process and concept of death in individuals with intellectual disabilities. *British Journal of Developmental Disabilities, 51*, 17-25. http://dx.doi.org/10.1179/096979505799103803

McLoughlin, K., McGilloway, S., Lloyd, R., O'Connor, M., Rhatigan, J., Shanahan, M., . . . Keevey, A. (2016). Walls, wisdom, worries, and wishes: Engaging communities in discussion about death, dying, loss, and care using café conversation. *Progress in Palliative Care, 24*, 9-14. http://dx.doi.org/10.1179/1743291X15Y.0000000011

McNess, A., Stebbins, J., & Stebbins, S. (2013). Ongoing support for the supporters: An outreach program for bereavement group leaders. *Grief Matters: The Australian Journal of Grief and Bereavement, 16*, 42-45. Retrieved from https://search.informit.com.au/documentSummary;dn=566426249292898;res=IELFSC

Mehta, N., Clement, E., Marcus, E., Stona, A.-C., Bezborodovs, N., Evans-Lacko, S., . . . Thornicroft, G. (2015). Evidence for effective interventions to reduce mental health-related stigma and discrimination in the medium and long-term: Systematic review. *The British Journal of Psychiatry, 207*, 377-384. http://dx.doi.org/10.1192/bjp.bp.114.151944

Merton, R. (1972). Insiders and outsiders: A chapter in the sociology of knowledge. *American Journal of Sociology, 78*, 9-47. http://dx.doi.org/10.1007/978-1-349-24984-8_19

Meteyard, J., & O'Hara, D. (2016). Counselling psychology: A view from Australia. *Counselling Psychology Review, 30*, 20-31. Retrieved from https://www.researchgate.net/profile/Denis_OHara/publication/275583574_Counselling_psychology_A_view_from_Australia/links/5574e69e08aeacff1ffcc0f7/Counselling-psychology-A-view-from-Australia.pdf

Mikulincer, M., & Shaver, P. (2008). An attachment theory perspective on bereavement. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 87−112). Washington, DC: American Psychological Association.

Miller, E. D. (2014). Evaluations of hypothetical bereavement and grief: The influence of loss recency, loss type and gender. *International Journal of Psychology, 50*, 60-63. http://dx.doi.org/10.1002/ijop.12080

Mills, C. W. (1959/2000). *The sociological imagination*. Oxford, UK: Oxford University Press.

Mills, S., & Mills, J. (2016). Future directions for community engagement as a public health approach to palliative care in Australia. *Progress in Palliative Care, 24*, 15-18. http://dx.doi.org/10.1179/1743291X15Y.0000000012

Minamizono, S., Motohashi, Y., Yamaji, M., & Kaneko, Y. (2008). Attitudes towards those bereaved by a suicide: A population-based, cross-sectional study in rural Japan. *BMC Public Health, 8*, 334. http://dx.doi.org/10.1186/1471-2458-8-334

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PloS Medicine, 6*(7), 1-6. http://dx.doi.org/10.1371/journal.pmed1000097

Moore, M., Maple, M., Mitchell, A. M., & Cerel, J. (2013). Challenges and opportunities for suicide bereavement research: The experience of ethical board review. *Crisis, 34*, 297-304. http://dx.doi.org/10.1027/0227-5910/a000191

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: Processes, claims and

implications. *Qualitative Research, 6*, 45–59.
http://dx.doi.org/10.1177/1468794106058870

Morgan, D. L. (2007). Paradigms lost and pragmatism regained. *Journal of Mixed Methods Research, 1*, 48-76. http://dx.doi.org/10.1177/2345678906292462

Muijs, D. (2011). Introduction to quantitative research. In D. Muijs (Ed.), *Doing quantitative research in education with SPSS* (2nd ed.). London, UK: SAGE.

Murray, J. A. (2002). Communicating with the community about grieving: A description and review of the foundations of a broken leg analogy of grieving. *Journal of Loss and Trauma, 7*, 47–69. http://dx.doi.org/10.1080/108114402753344481

Nam, I. S. (2016). Effects of psychoeducation on helpful support for complicated grief: A preliminary randomized controlled single-blind study. *Psychological Medicine, 46*, 189-195. http://dx.doi.org/10.1017/S0033291715001658

Nathan, A. J. (1999). *Development of the empathy for loss in adolescent bereavement scale* (Doctoral dissertation, California School of Professional Psychology, USA). Retrieved from https://elibrary.ru/item.asp?id=5481439

National Health and Medical Research Council. (2007). *Australian code for the responsible conduct of research*. Retrieved from http://www.arc.gov.au

Neimeyer, R. A. (2000). Searching for the meaning of meaning: Grief therapy and the process of reconstruction. *Death Studies, 24*, 541-558.
http://dx.doi.org/10.1080/07481180050121480

Neimeyer, R. A. (2005). Defining the new abnormal: Scientific and social construction of complicated grief. *Omega: Journal of Death and Dying, 52*, 95-97.
http://dx.doi.org/10.2190/31rv-dbpg-q1m3-peda

Neimeyer, R. A. (2006a). Complicated grief and the quest for meaning: A constructivist contribution. *Omega: Journal of Death and Dying, 52*, 37–52.
http://dx.doi.org/10.2190/eql1-ln3v-knyr-18tf

Neimeyer, R. A. (2006b). Widowhood, grief, and the quest for meaning: A narrative perspective on resilience. In D. Carr, R. M. Nesse, & C. B. Wortman (Eds.), *Late life widowhood in the United States* (pp. 227-252). New York, NY: Springer.

Neimeyer, R. A. (2009). Grief and bereavement counseling. In C. D. Bryant & D. L. Peck (Eds.), *Encyclopedia of death and the human experience* (pp. 543-546). Thousand Oaks, CA: SAGE.

Neimeyer, R. A., Baldwin, S. A., & Gillies, J. (2006). Continuing bonds and reconstructing meaning: Mitigating complications in bereavement. *Death Studies, 30*, 715–738. http://dx.doi.org/10.1080/07481180600848322

Neimeyer, R. A., Burke, L. A., Mackay, M. M., & van Dyke Stringer, J. G. (2010). Grief therapy and the reconstruction of meaning: From principles to practice. *Journal of Contemporary Psychotherapy, 40*, 73-83. http://dx.doi.org/10.1007/s10879-009-9135-3

Neimeyer, R. A., & Currier, J. M. (2009). Grief therapy: Evidence of efficacy and emerging directions. *Current Directions in Psychological Science, 18*, 352-356. http://dx.doi.org/10.1111/j.1467-8721.2009.01666.x

Neimeyer, R. A., & Hogan, N. S. (2001). Quantitative or qualitative? Measurement issues in the study of grief. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 89–118). Washington, DC: American Psychological Association.

Neimeyer, R. A., & Jordan, J. R. (2002). Disenfranchisement as empathic failure: Grief therapy and the co-construction of meaning. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 95-126). Chicago, IL: Research Press.

Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death Studies, 38*, 485-498. http://dx.doi.org/10.1080/07481187.2014.913454

Neimeyer, R. A., & Sands, D. C. (2011). Meaning reconstruction in bereavement: From principles to practice. In R. A. Neimeyer, D. Harris, H. R. Winokuer, & G. F. Thornton (Eds.), *Grief and bereavement in contemporary society: Bridging research and practice* (pp. 9–22). New York, NY: Routledge.

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M.-B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review, 44*, 75-93. http://dx.doi.org/10.1016/j.cpr.2016.01.002

Nihtilä, E., & Martikainen, P. (2008). Institutionalization of older adults after the death of a spouse. *American Journal of Public Health, 98*, 1228–1234. http://dx.doi.org/10.2105/ajph.2007.119271

Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. P. (2016). Developing death literacy. *Progress in Palliative Care, 24*, 31-35. http://dx.doi.org/10.1080/09699260.2015.1103498

O'Connor, M., & Breen, L. J. (2014). General practitioners' experiences of bereavement care and their educational support needs: A qualitative study. *BMC Medical Education, 14*, 1-10. http://dx.doi.org/10.1186/1472-6920-14-59

Ober, A. M., Granello, D. H., & Wheaton, J. E. (2012). Grief counseling: An investigation of counselors' training, experience, and competencies. *Journal of Counseling and Development, 90*, 150-159. http://dx.doi.org/10.1111/j.1556-6676.2012.00020.x

Ogden, S. P., & Simmonds, J. G. (2014). Psychologists' and counsellors' perspectives on prolonged grief disorder and its inclusion in diagnostic manuals. *Counselling and Psychotherapy Research, 14*, 212-219. http://dx.doi.org/10.1080/14733145.2013.790456

Ord, R. L. (2009). "It's like a tattoo": Rethinking dominant discourses on grief. *Canadian Social Work Review, 26*, 195-211. Retrieved from http://www.jstor.org/stable/41669912

Ott, C. H. (2003). The impact of complicated grief on mental and physical health at various points in the bereavement process. *Death Studies, 27*, 249-272. http://dx.doi.org/10.1080/074811803901370

Packman, W., Horsley, H., Davies, B., & Kramer, R. (2006). Sibling bereavement and continuing bonds. *Death Studies, 30*, 817–841. http://dx.doi.org/10.1080/07481180600886603

Pål Kristensen, P., Weisæth, L., & Heir, T. (2010). Predictors of complicated grief after a natural disaster: A population study two years after the 2004 South-East Asian tsunami. *Death Studies, 34,* 137-150. http://dx.doi.org/10.1080/07481180903492455

Palliative Care Australia. (2017). AllowMe. Retrieved from http://palliativecare.org.au/allowme/

Pantti, M., & Sumiala, J. (2009). Till death do us join: Media, mourning rituals and the sacred centre of the society. *Media, Culture & Society, 31*, 119-135. http://dx.doi.org/ 10.1177/016344370809

Parkes, C. M. (1964). Recent bereavement as a cause of mental illness. *The British Journal of Psychiatry, 110*, 198–204. http://dx.doi.org/10.1192/bjp.110.465.198

Parkes, C. M. (1972a). *Bereavement*. New York: International University Press.

Parkes, C. M. (1972b). Components of the reaction to loss of a limb, spouse or home. *Journal of Psychosomatic Research, 16*, 343-349. http://dx.doi.org/10.1016/0022-3999(72)90087-6

Parkes, C. M. (1998). Editorial comments. *Bereavement Care, 17*, 18-18. http://dx.doi.org/10.1080/02682629808657431

Parkes, C. M. (2011). Recent developments in loss theory and practice: Individual, family, national, and international implications. *Grief Matters: The Australian Journal of Grief and Bereavement, 14*, 36-40. Retrieved from http://search.informit.com.au/documentSummary;dn=339879324144712;res=IELFSC

Paul, S., & Sallnow, L. (2014). Understanding community engagement in end-of-life care: Developing conceptual clarity. *Critical Public Health, 25*, 231-238. http://dx.doi.org/10.1080/09581596.2014.909582

Penman, E. L., Breen, L. J., Hewitt, L. Y., & Prigerson, H. G. (2014). Public attitudes about normal and pathological grief. *Death Studies, 38*, 510-516. http://dx.doi.org/10.1080/07481187.2013.873839

Pies, R. (2009). Depression or "proper sorrows"—Have physicians medicalized sadness? *Primary Care Companion Journal of Clinical Psychiatry, 11*, 38-39. http://dx.doi.org/10.4088/pcc.08l00618

Pilling, J., Konkolÿ Thege, B., Demetrovics, Z., & Kopp, M. S. (2012). Alcohol use in the first three years of bereavement: A national representative survey. *Substance Abuse Treatment, Prevention, and Policy, 7*, 1-5. http://dx.doi.org/10.1186/1747-597x-7-3

Pitman, A. L., Osborn, D. P. J., Rantell, K., & King, M. B. (2016). The stigma perceived by people bereaved by suicide and other sudden deaths: A cross-sectional UK study of

3432 bereaved adults. *Journal of Psychosomatic Research, 87*, 22-29.
http://dx.doi.org/10.1016/j.jpsychores.2016.05.009

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., . . . Duffy, S.
(2006). *Guidance on the conduct of narrative synthesis in systematic reviews*.
Southampton, UK: Economic and Social Research Council.

Pressman, D. L., & Bonanno, G. A. (2007). With whom do we grieve? Social and cultural
determinants of grief processing in the United States and China. *Journal of Social
and Personal Relationships, 24*, 729–746.
http://dx.doi.org/10.1177/0265407507081458

Prigerson, H. G., Horowitz, M. J., Jacobs, S. C., Parkes, C. M., Aslan, M., Goodkin, K., . . .
Maciejewski, P. K. (2009). Prolonged grief disorder: Psychometric validation of
criteria proposed for DSM-IV and ICD-11. *PloS Medicine, 10*(12), 1-2.
http://dx.doi.org/10.1371/journal.pmed.1000121

Prigerson, H. G., & Maciejewski, P. K. (2009). *Prolonged grief disorder: PG-13*. Boston,
MA: Center for Psychooncology and Palliative Care Research.

Prigerson, H. G., Vanderwerker, L. C., & Maciejewski, P. K. (2008). A case for inclusion of
prolonged grief disorder in DSM-V. In M. S. Stroebe, R. O. Hansson, W. Stroebe, &
H. Schut (Eds.), *Handbook of bereavement research and practice: Advances in
theory and intervention* (pp. 165-186). Washington, DC: American Psychological
Association.

Psychology Board of Australia. (2011). *Guidelines on area of practice endorsements*.
Retrieved from http://www.psychologyboard.gov.au

Pyszczynski, T., Greenberg, J., & Solomon, S. (1999). A dual-process model of defense
against conscious and unconscious death-related thoughts: An extension of terror
management theory. *Psychological Review, 106*, 835–845.
http://dx.doi.org/10.1037/0033-295x.106.4.835

Rabe, M. (2003). Revisiting 'insiders' and 'outsiders' as social researchers. *African
Sociological Review, 7*(2), 149-161. http://dx.doi.org/10.4314/asr.v7i2.23150

Rack, J. J., Burleson, B. R., Bodie, G. D., Holmstrom, A. J., & Servaty-Seib, H. L. (2008).
Bereaved adults' evaluations of grief management messages: Effects of message

person centeredness, recipient individual differences, and contextual factors. *Death Studies, 32*, 399-427. http://dx.doi.org/10.1080/07481180802006711

Rando, T. A. (1993). *Treatment of complicated mourning*. Champaign, IL: Research Press.

Rando, T. A. (2012). Is it okay for you to be okay? In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Creative practices for counseling the bereaved* (pp. 147-158). New York, NY: Routledge.

Rando, T. A., Doka, K. J., Fleming, S., Franco, M. H., Lobb, E. A., Parkes, C. M., & Steele, R. (2012). A call to the field: Complicated grief in the DSM-5. *Omega: Journal of Death and Dying, 65*, 251-255. http://dx.doi.org/10.2190/OM.65.4.a

Range, L. M., Bright, P. S., & Ginn, P. D. (1985). Public reactions to child suicide: Effects of child's age and method used. *Journal of Community Psychology, 13*, 288-294. http://dx.doi.org/10.1002/1520-6629

Range, L. M., & Thompson, K. E. (1987). Community responses following suicide, homicide, and other deaths: The perspective of potential comforters. *Journal of Psychology, 121*, 193-198. http://dx.doi.org/10.1080/00223980.1987.9712657

Range, L. M., Walston, A. S., & Pollard, P. M. (1992). Helpful and unhelpful comments after suicide, homicide, accident, or natural death. *Omega: Journal of Death and Dying, 25*, 25-31. http://dx.doi.org/10.2190/b5nl-dcby-28q5-kj8d

Ray, M. (1990). Phenomenological method for nursing research. In N. L. Chaska (Ed.), *The nursing profession: Turning points* (pp. 173–179). St. Louis: C.V. Mosby.

Regehr, C., & Sussman, T. (2004). Intersections between grief and trauma: Toward an empirically based model for treating traumatic grief. *Brief Treatment and Crisis Intervention, 4*, 289–309. http://dx.doi.org/10.1093/brief-treatment/mhh025

Reynolds, F. M. T., & Cimbolic, P. (1988). Attitudes toward suicide survivors as a function of survivors' relationship to the victim. *Omega: Journal of Death and Dying, 19*, 125-133. http://dx.doi.org/10.2190/kr1x-qng3-2ygm-udyq

Ritsner, M., Kurs, R., Gibel, A., Ratner, R., & Endicott, J. (2005). Validity of an abbreviated quality of life enjoyment and satisfaction questionnaire (Q-LES-Q-18) for schizophrenia, schizoaffective, and mood disorder patients. *Quality of Life Research, 14*, 1693-1703. http://dx.doi.org/10.1007/s11136-005-2816-9

Roberts, L. R., & Lee, J. W. (2013). Autonomy and social norms in a three factor grief model predicting perinatal grief in India. *Health Care for Women International, 35*, 285-299. http://dx.doi.org/10.1080/07399332.2013.801483

Robson, P., & Walter, T. (2012). Hierarchies of loss: A critique of disenfranchised grief. *Omega: Journal of Death and Dying, 66*, 97-119. http://dx.doi.org/10.2190/om.66.2.a

Romano, J. L., & Hage, S. M. (2000). Prevention and counseling psychology: Revitalizing commitments for the 21st century. *The Counseling Psychologist, 28*, 733-763. http://dx.doi.org/10.1177/0011000000286001

Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2015). Informal caring networks for people at end of life: Building social capital in Australian communities. *Health Sociology Review, 24*, 29-37. http://dx.doi.org/10.1080/14461242.2014.999400

Rosenberg, J. P., Mills, J., & Rumbold, B. (2016). Putting the 'public' into public health: Community engagement in palliative and end of life care. *Progress in Palliative Care, 24*, 1-3. http://dx.doi.org/ 10.1080/09699260.2015.1103500

Rosenberger, K. L. (1996). *Evaluations of typical and atypical grief* (Unpublished doctoral dissertation, Indiana University of Pennsylvania, USA).

Rosenblatt, P. (1995). Ethics of qualitative interviewing with grieving families. *Death Studies, 19*, 139-155. http://dx.doi.org/10.1080/07481189508252721

Rubin, S. S. (1981). A two-track model of bereavement: Theory and application in research. *American Journal of Orthopsychiatry, 51*, 101-109. http://dx.doi.org/10.1111/j.1939-0025.1981.tb01352.x

Rubin, S. S., Malkinson, R., & Witztum, E. (2012). *Working with the bereaved: Multiple lenses on loss and mourning*. New York: Routledge.

Rubin, S. S., Nadav, O. B., Malkinson, R., Koren, D., Goffer-Scnarch, M., & Michaeli, E. (2009). The two-track model of bereavement questionnaire (TTBQ): Development and validation of a relational measure. *Death Studies, 33*, 305-333. http://dx.doi.org/10.1080/07481180802705668

Rudestam, K. E., & Imbroll, D. (1983). Societal reactions to a child's death by suicide. *Journal of Consulting and Clinical Psychology, 51*, 461-462. http://dx.doi.org/10.1037/0022-006x.51.3.461

Rumbold, B., & Aoun, S. (2014). Bereavement and palliative care: A public health perspective. *Progress in Palliative Care, 22*, 131–135. http://dx.doi.org/10.1179/1743291x13y.0000000079

Rumbold, B., & Aoun, S. (2015). An assets-based approach to bereavement care. *Bereavement Care, 34*, 99–102. http://dx.doi.org/10.1080/02682621.2015.1115185

Rüsch, N., Evans-Lacko, S., & Thornicroft, G. (2012). What is a mental illness? Public views and their effects on attitudes and disclosure. *Australian & New Zealand Journal of Psychiatry, 46*, 641-650. http://dx.doi.org/10.1177/0004867412438873

Rynearson, E. K., Correa, F., Favell, J., Saindon, C., & Prigerson, H. (2006). Restorative retelling after violent dying. In E. Rynearson (Ed.), *Violent death: Resilience and intervention beyond the crisis* (pp. 195-216). New York, NY: Routledge.

Sallnow, L., & Paul, S. (2014). Understanding community engagement in end-of-life care: Developing conceptual clarity. *Critical Public Health, 25*, 231-238. http://dx.doi.org/10.1080/09581596.2014.909582

Sallnow, L., Richardson, H., Murray, S. A., & Kellehear, A. (2016). The impact of a new public health approach to end-of-life care: A systematic review. *Palliative Medicine, 30*, 200-211. http://dx.doi.org/10.1177/0269216315599869

Sand, E., Gordon, K. H., & Bresin, K. (2013). The impact of specifying suicide as the cause of death in an obituary. *Crisis, 34*, 63-66. http://dx.doi.org/10.1027/02275910/a000154

Sayer, D. (2010). Who's afraid of the dead? Archaeology, modernity and the death taboo. *World Archaeology, 42*, 481–491. http://dx.doi.org/10.1080/00438243.2010.498665

Schneider, B., Grebner, K., Schnabel, A., & Georgi, K. (2011). Is the emotional response of survivors dependent on the consequences of the suicide and the support received? *Crisis, 32*, 186-193. http://dx.doi.org/10.1027/0227-5910/a000081

Schut, H., Stroebe, M. S., Boelen, P. A., & Zijerveld, A. M. (2006). Continuing relationships with the deceased: Disentangling bonds and grief. *Death Studies, 30*, 757–766. http://dx.doi.org/10.1080/07481180600850666

Schut, H., Stroebe, M. S., van den Bout, J., & Terheggen, M. (2001). The efficacy of bereavement interventions: Determining who benefits. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 705-727). Washington, DC: American Psychological Association.

Scott, D. P. (2016). Healing through internal compassion. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Assessment and intervention* (pp. 186-189). New York, NY: Routledge.

Scott, S. B., Bergeman, C. S., Verney, A., Longenbaker, S., Markey, M. A., & Bisconti, T. L. (2007). Social support in widowhood: A mixed methods study. *Journal of Mixed Methods Research, 1*, 242–266. http://dx.doi.org/10.1177/1558689807302453

Sealey, M., Breen, L. J., O'Connor, M., & Aoun, S. M. (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliative Medicine, 29*, 577-589. http://dx.doi.org/10.1177/0269216315576262

Servaty-Seib, H. L. (2004). Connections between counseling theories and current theories of grief and mourning. *Journal of Mental Health Counseling, 26*, 125–145. http://dx.doi.org/10.17744/mehc.26.2.p9aukha7v8fqkc9g

Servaty-Seib, H. L., & Burleson, B. R. (2007). Bereaved adolescents' evaluations of the helpfulness of support-intended statements: Associations with person centeredness and demographic, personality, and contextual factors. *Journal of Social and Personal Relationships, 24*, 207-223. http://dx.doi.org/10.1177/0265407507075411

Servaty-Seib, H. L., & Taub, D. J. (2010). Bereavement and college students: The role of counseling psychology. *The Counseling Psychologist, 38*, 947-975. http://dx.doi.org/10.1177/0011000010366485

Shakespeare, W. (1923). *The work of Shakespeare: Much ado about nothing*. London, UK: Cambridge University Press.

Shaver, P., & Tancredy, C. (2001). Emotion, attachment, and bereavement: A conceptual commentary. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.),

Handbook of bereavement research: Consequences, coping and care (pp. 63−88). Washington, DC: American Psychological Association.

Shear, M. K., Boelen, P. A., & Neimeyer, R. A. (2011). Treating complicated grief: Converging approaches. In R. A. Neimeyer, D. L. Harris, H. R. Winokuer, & G. F. Thornton (Eds.), *Grief and bereavement in contemporary society: Bridging research and practice* (pp. 139–162). New York, NY: Routledge.

Shear, M. K., Frank, E., Houck, P. R., & Reynolds, C. F. (2005). Treatment of complicated grief: A randomized controlled trial. *Journal of the American Medical Association, 293*, 2601-2608. http://dx.doi.org/10.1001/jama.293.21.2601

Shear, M. K., Simon, N., Wall, M., Zisook, S., Neimeyer, R. A., Duan, N., . . . Keshaviah, A. (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety, 28*, 103-117. http://dx.doi.org/10.1002/da.20780

Shumaker, S. A., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. *Journal of Social Issues, 40*, 11–36. http://dx.doi.org/10.1111/j.1540-4560.1984.tb01105.x

Silverman, P. (2000). Research, clinical practice, and the human experience: Putting the pieces together. *Death Studies, 24*, 469–478. http://dx.doi.org/10.1080/07481180050121453

Silverstein, S. (2011). *Every thing on it*. New York, NY: Harper.

Smith, N. G., Tarakeshwar, N., Hansen, N. B., Kochman, A., & Sikkema, K. J. (2009). Coping mediates outcome following a randomized group intervention for HIV-positive bereaved individuals. *Journal of Clinical Psychology, 65*, 319-335. http://dx.doi.org/10.1002/jclp.20547

Sofka, C. J. (2007). Death education: Ethical and legal issues. In D. Balk (Ed.), *Handbook of thanatology* (pp. 355-367). London, UK: Routledge.

Somhlaba, N. Z., & Wait, J. W. (2008). Psychological adjustment to conjugal bereavement: Do social networks aid coping following spousal death? *Omega: Journal of Death and Dying, 57*, 341-366. http://dx.doi.org/10.2190/OM.57.4.b

Spinelli, E. (2000). *Tales of un-knowing: Therapeutic encounters from an existential perspective*. London, UK: Gerald Duckworth.

Spino, E., Kameg, K. M., Cline, T. W., Terhorst, L., & Mitchell, A. M. (2016). Impact of social support on symptoms of depression and loneliness in survivors bereaved by suicide. *Archives of Psychiatric Nursing, 30*, 602-606. http://dx.doi.org/10.1016/j.apnu.2016.02.001

Stolorow, R. (2011). From mind to world, from drive to affectivity: A phenomenological contextualist psychoanalytic perspective. *Attachment: New directions in psychotherapy and relational psychoanalysis, 5*, 1–14. http://dx.doi.org/10.1037/e635372012-001

Strahan, R., & Gerbasi, K. C. (1972). Short, homogenous versions of the Marlow-Crowne social desirability scale. *Journal of Clinical Psychology, 28*, 191-193. http://dx.doi.org/10.1002/1097-4679

Stroebe, M. S. (2001). Gender differences in adjustment to bereavement: An empirical and theoretical review. *Review of General Psychology, 5*, 62–83. http://dx.doi.org/10.1037/1089-2680.5.1.62

Stroebe, M. S., Gergen, M. M., Gergen, K. J., & Stroebe, W. (1992). Broken hearts or broken bonds: Love and death in historical perspective. *American Psychologist, 47*, 1205–1212. http://dx.doi.org/10.1037/0003-066x.47.10.1205

Stroebe, M. S., Hansson, R. O., Stroebe, W., & Schut, H. (2001). Introduction: Concepts and issues in contemporary research on bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 3-22). Washington, DC: American Psychological Association.

Stroebe, M. S., & Schut, H. (1999). The dual process model of grief: Rationale and description. *Death Studies, 23*, 197-224. http://dx.doi.org/10.1080/074811899201046

Stroebe, M. S., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *Omega: Journal of Death and Dying, 61*, 273-289. http://dx.doi.org/10.2190/OM.61.4.b

Stroebe, M. S., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *Lancet, 370*, 1960-1973. http://dx.doi.org/10.1016/s0140-6736(07)61816-9

Stroebe, M. S., Stroebe, W., & Hansson, R. O. (1988). Bereavement research: An historical introduction. *Journal of Social Issues, 44*, 1–18. http://dx.doi.org/10.1111/j.1540-4560.1988.tb02073.x

Stroebe, M. S., van Son, M., Stroebe, W., Kleber, R., Schut, H., & van den Bout, J. (2000). On the classification and diagnosis of pathological grief. *Clinical Psychology Review, 20*, 57-75. http://dx.doi.org/10.1016/s0272-7358(98)00089-0

Stroebe, W. (2008). Does social support help with marital bereavement? *Bereavement Care, 27*, 3-6. http://dx.doi.org/10.1080/02682620808657706

Stroebe, W., Zech, E., Stroebe, M. S., & Abakoumkin, G. (2005). Does social support help in bereavement? *Journal of Social and Clinical Psychology, 24*, 1030–1050. http://dx.doi.org/10.1521/jscp.2005.24.7.1030

Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology*. Thousand Oaks, CA: SAGE.

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research. Integrating quantitative and qualitative approaches in the social and behavioural sciences*. Thousand Oaks, CA: SAGE.

Tedrick Parikh, S. J., & Servaty-Seib, H. L. (2013). College students' beliefs about supporting a grieving peer. *Death Studies, 37*, 653-669. http://dx.doi.org/10.1080/07481187.2012.684834

The 100-Member Committee. (2012). The campaign to build a dementia-friendly community. In L. Sallnow, S. Kumar, & A. Kellehear (Eds.), *International perspectives on public health and palliative care* (pp. 123-138). Abingdon, UK: Routledge.

Thieleman, K., & Cacciatore, J. (2013). The DSM-5 and the bereavement exclusion: A call for critical evaluation. *Social Work, 58*, 277-280. http://dx.doi.org/10.1093/sw/swt021

Thoits, P. A. (1985). Self-labeling processes in mental illness: The role of emotional deviance. *American Journal of Sociology, 91*, 221-249. http://dx.doi.org/10.1086/228276

Thomas, K., Hudson, P., Trauer, T., Remedios, C., & Clarke, D. (2014). Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in

palliative care: A longitudinal study. *Journal of Pain and Symptom Management, 47*, 531–541. http://dx.doi.org/10.1016/j.jpainsymman.2013.05.022

Thompson, B. E. (2012). Mindfulness training. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Creative practices for counseling the bereaved* (pp. 39-41). New York, NY: Routledge.

Thompson, K. E., & Range, L. M. (1990). Recent bereavement from suicide and other deaths: Can people imagine it as it really is? *Omega: Journal of Death and Dying, 22*, 249-259. http://dx.doi.org/10.2190/10BD-WFE4-YAD3-ARY3

Thompson, N., & Lund, D. A. (2017). *Loss, grief, and trauma in the workplace*. New York, NY: Routledge.

Thornton, G., Robertson, D. U., & Mlecko, M. L. (1991). Disenfranchised grief and evaluations of social support by college students. *Death Studies, 15*, 355-362. http://dx.doi.org/10.1080/07481189108252440

Thornton, G., Whittemore, K. D., & Robertson, D. U. (1989). Evaluation of people bereaved by suicide. *Death Studies, 13*, 119-126. http://dx.doi.org/10.1080/07481188908252289

Toller, P. (2011). Bereaved parents' experiences of supportive and unsupportive communication *Southern Communication Journal, 76*, 17-34. http://dx.doi.org/10.1080/10417940903159393

Tolstikova, K., & Chartier, B. (2010). Internet method in bereavement research: Comparison of online and offline surveys. *Omega: Journal of Death and Dying, 60*, 327-349. http://dx.doi.org/10.2190/OM.60.4.b

Torrance, H. (2012). Triangulation, respondent validation, and democratic participation in mixed methods research. *Journal of Mixed Methods Research, 6*, 111-123. http://dx.doi.org/10.1177/1558689812437185

Umphrey, L. R., & Cacciatore, J. (2011). Coping with the ultimate deprivation: Narrative themes in a parental bereavement support group. *Omega: Journal of Death and Dying, 63*, 141-160. http://dx.doi.org/10.2190/OM.63.2.c

Utz, R. L., Swenson, K. L., Caserta, M., Lund, D., & deVries, B. (2014). Feeling lonely versus being alone: Loneliness and social support among recently bereaved persons.

The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 69, 85-94. http://dx.doi.org/10.1093/geronb/gbt075

Vachon, M. L. S., & Stylianos, S. K. (1988). The role of social support in bereavement. *Journal of Social Issues, 44*, 175–190. http://dx.doi.org/10.1111/j.1540-4560.1988.tb02084.x

Vale-Taylor, P. (2009). "We will remember them": A mixed-method study to explore which post-funeral remembrance activitiesare most significant and important to bereavedpeople living with loss, and why those particular activities are chosen. *Palliative Medicine, 23*, 537-544. http://dx.doi.org/10.1177/0269216309103803

van der Houwen, K., Stroebe, M. S., Schut, H., Stroebe, W., & van den Bout, J. (2010). Mediating processes in bereavement: The role of rumination, threatening grief interpretations, and deliberate grief avoidance. *Social Science & Medicine, 71*, 1669-1676. http://dx.doi.org/10.1016/j.socscimed.2010.06.047

van der Houwen, K., Stroebe, M. S., Stroebe, W., Schut, H., van den Bout, J., & Meij, L. W.-D. (2010). Risk factors for bereavement outcome: A multivariate approach. *Death Studies, 34*, 195–220. http://dx.doi.org/10.1080/07481180903559196

Van Humbeeck, L., Dillen, L., Piers, R., Grypdonck, M., & Van Den Noortgate, N. (2016). The suffering in silence of older parents whose child died of cancer: A qualitative study. *Death Studies, 40*, 607-617. http://dx.doi.org/10.1080/07481187.2016.1198942

Vanderwerker, L. C., Jacobs, S. C., Parkes, C. M., & Prigerson, H. G. (2006). An exploration of associations between separation anxiety in childhood and complicated grief in later life. *Journal of Nervous and Mental Disease, 194*, 121-123. http://dx.doi.org/10.1097/01.nmd.0000198146.28182.d5

Vaughans, D. C. (2016). Grief etiquette coaching. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Assessment and intervention* (pp. 294-296). New York, NY: Routledge.

Versalle, A., & McDowell, E. E. (2004). The attitudes of men and women concerning gender differences in grief. *Omega: Journal of Death and Dying, 50*, 53-67. http://dx.doi.org/10.2190/R2TJ-6M4F-RHGD-C2MD

Vickio, C. J., Cavanaugh, J. C., & Attig, T. W. (1990). Perceptions of grief among university students. *Death Studies, 14*, 231-240. http://dx.doi.org/10.1080/07481189008252364

Villa, D. P. (2010). *The differential impact of suicide type on provision of social support: A qualitative comparison* (Doctoral dissertation, The University of California, USA). Retrieved from https://escholarship.org/content/qt4qt7w4f7/qt4qt7w4f7.pdf

Wagner, K. G., & Calhoun, L. G. (1991). Perceptions of social support by suicide survivors and their social networks. *Omega: Journal of Death and Dying, 24*, 61–73. http://dx.doi.org/10.2190/3748-g16y-yebf-qd10

Wågø, S. S., Byrkjedal, I. K., Sinnes, H. M., Hystad, S. W., & Dyregrov, K. (2017). Social support and complicated grief: A longitudinal study on bereaved parents after the Utøya terror attack in Norway. *Scandinavian Psychologist, 4*, 1-19. http://dx.doi.org/10.15714/scandpsychol.4.e10

Walter, T., Hourizi, R., Moncur, W., & Pitsillides, S. (2011-2012). Does the Internet chaneg how we die and mourn? Overview and analysis. *Omega: Journal of Death and Dying, 64*, 275-302. http://dx.doi.org/10.2190/OM.64.4.a

Wegleitner, K., Heimerl, K., & Kellehear, A. (Eds.). (2016). *Compassionate communities: Case studies from Britain and Europe*. New York, NY: Routledge.

Whiteley, J. M. (1984). Historical periods in the development of counseling psychology. *The Counseling Psychologist, 12*, 3-5. http://dx.doi.org/10.1177/0011000084121001

Wijngaards-de Meij, L., Stroebe, M. S., Schut, H., Stroebe, W., van den Bout, J., van der Heijden, P., & Dijkstra, I. (2007). Neuroticism and attachment insecurity as predictors of bereavement outcome. *Journal of Research in Personality, 41*, 498−505. http://dx.doi.org/10.1016/j.jrp.2006.06.001

Wiles, R., Jarrett, N., Payne, S., & Field, D. (2002). Referrals for bereavement counselling in primary care: A qualitative study. *Patient Education and Counseling, 48*, 79-85. http://dx.doi.org/10.1016/s0738-3991(02)00068-x

Williams, B. R., Woodby, L. L., Bailey, F. A., & Burgio, K. L. (2008). Identifying and responding to ethical and methodological issues in after-death interviews with next-of-kin. *Death Studies, 32*, 197-236. http://dx.doi.org/10.1080/07481180701881297

Wilsey, S. A., & Shear, M. K. (2007). Descriptions of social support in treatment narratives of complicated grievers. *Death Studies, 31*, 801-819. http://dx.doi.org/10.1080/07481180701537261

Winnicott, D. W. (1965). *The maturational process and the facilitating environment*. New York, NY: International Universities Press.

Wittouck, C., Van Autreve, S., De Jaegere, E., Portzky, G., & van Heeringen, K. (2011). The prevention and treatment of complicated grief: A meta-analysis. *Clinical Psychology Review, 31*, 69-78. http://dx.doi.org/10.1016/j.cpr.2010.09.005

Worden, J. W. (1982). *Grief counselling and grief therapy: A handbook for the mental health practitioner*. New York, NY: Springer.

Worden, J. W. (1991). *Grief counselling and grief therapy: A handbook for the mental health practitioner* (2nd ed.). New York, NY: Springer.

Worden, J. W. (2002). *Grief counselling and grief therapy: A handbook for the mental health practitioner* (3rd ed.). New York, NY: Springer.

Worden, J. W. (2009). *Grief counseling and grief therapy. A handbook for the mental health practitioner* (4th ed.). New York: Springer Publishing.

World Health Organization. (2017). *6B72 prolonged grief disorder*. Retrieved from http://id.who.int/icd/entity/1183832314

Wortman, C. B., & Boerner, K. (2007). Beyond the myths of coping with loss: Prevailing assumptions and scientific evidence. In H. S. Friedman (Ed.), *The Oxford handbook of health psychology*. Oxford, UK: Oxford University Press.

Wortman, C. B., & Silver, R. C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology, 57*, 349-357. http://dx.doi.org/10.1037//0022-006x.57.3.349

Yalom, I. D. (1980). *Existential psychotherapy*. New York, NY: Basic Books.

Yalom, I. D. (2009). *Staring at the sun: Overcoming the terror of death*. San Francisco, CA: Jossey-Bass.

Yamanaka, A. (2015). Japanese undergraduates' attitudes toward student survivors of parental suicide: A comparison with other stigmatized deaths. *Omega: Journal of Death and Dying, 71*, 82-91. http://dx.doi.org/10.1177/0030222814568290

Zisook, S. (1987). Unresolved grief. In S. Zisook (Ed.), *Biopsychosocial aspects of bereavement* (pp. 23-34). Washington, DC: American Psychiatric Press.

Zisook, S., & Shuchter, S. R. (1985). Time course of spousal bereavement. *General Hospital Psychiatry, 7*, 95–100. http://dx.doi.org/10.1016/0163-8343(85)90017-9

APPENDICES

Appendix A   HREC Approvals

MEMORANDUM

Curtin University
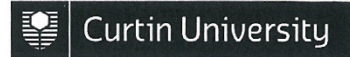
To:	A/Prof Jenny Thornton
	School of Psychology and Speech Pathology
CC:	Ms Emma Penman
From:	Professor Peter O'Leary, Chair HREC
Subject	Ethics approval
	Approval number: RDHS-12-15
Date:	15-Jan-15

Office of Research and
Development
Human Research Ethics Office

TELEPHONE   9266 2784
FACSIMILE   9266 3793
EMAIL   hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Office for the project: 5868

The conceptualisation of 'normal grief': using mixed methods to reconcile community expectations with actual experiences of grief

Your application has been approved through the low risk ethics approvals process at Curtin University.

Please note the following conditions of approval:

1. Approval is granted for a period of four years from   **20-Jan-15** to   **20-Jan-19**
2. Research must be conducted as stated in the approved protocol.
3. Any amendments to the approved protocol must be approved by the Ethics Office.
4. An annual progress report must be submitted to the Ethics Office annually, on the anniversary of approval.
5. All adverse events must be reported to the Ethics Office.
6. A completion report must be submitted to the Ethics Office on completion of the project.
7. Data must be stored in accordance with WAUSDA and Curtin University policy.
8. The Ethics Office may conduct a randomly identified audit of a proportion of research projects approved by the HREC.

Should you have any queries about the consideration of your project please contact the Ethics Support Officer for your faculty, or the Ethics Office at hrec@curtin.edu.au or on 9266 2784. All human research ethics forms and guidelines are available on the ethics website.

Yours sincerely,

Professor Peter O'Leary
Chair, Human Research Ethics Committee

MEMORANDUM

To:	A/Prof Jenny Thornton
	School of Psychology and Speech Pathology
CC:	Ms Emma Penman
From:	Dr Catherine Gangell, Manager Research Integrity
Subject	Amendment approval
	Approval number: RDHS-12-15
Date:	26-Oct-15

Thank you for submitting an amendment to the Human Research Ethics Office for the project:

RDHS-12-15   The conceptualisation of 'normal grief': using mixed methods to reconcile community expectations with actual experiences of grief

The Human Research Ethics Office approves the amendment to the project.

Amendment number: RDHS-12-15/AR01

Approval date: 26-Oct-15

The following amendments were approved:

Provision of recruitment material.

Please ensure that all data are stored in accordance with WAUSDA and Curtin University Policy.

Yours sincerely

Dr Catherine Gangell
Manager, Research Integrity

01-Sep-2016

Name: Jenny Thornton
Department/School: School of Psychology and Speech Pathology
Email: J.Thornton@curtin.edu.au

Dear Jenny Thornton

RE: Amendment approval
Approval number: RDHS-12-15

Thank you for submitting an amendment request to the Human Research Ethics Office for the project **The conceptualisation of 'normal grief': using mixed methods to reconcile community expectations with actual experiences of grief**.

Your amendment request has been reviewed and the review outcome is: **Approved**

The amendment approval number is RDHS-12-15-02 approved on 01-Sep-2016.

The following amendments were approved:

Addition of 2 sets of materials not previously developed:

1. A two-page Support Services List that will be offered to interview respondents on the day of the interview.

2. Three documents of text for advertising the study and recruiting respondents. The first is a poster for distribution in general community spaces, the second is a blurb to be distributed in online spaces (e.g., social media, blogs, online noticeboards), and the third is a blurb to be read aloud on Curtin FM as an oral advertisement.

Any special conditions noted in the original approval letter still apply.

Standard conditions of approval

1. Research must be conducted according to the approved proposal
2. Report in a timely manner anything that might warrant review of ethical approval of the project including:
   - proposed changes to the approved proposal or conduct of the study
   - unanticipated problems that might affect continued ethical acceptability of the project
   - major deviations from the approved proposal and/or regulatory guidelines
   - serious adverse events
3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants)

4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval and a completion report submitted on completion of the project
5. Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
6. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
7. Changes to personnel working on this project must be reported to the Human Research Ethics Office
8. Data and primary materials must be retained and stored in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
9. Where practicable, results of the research should be made available to the research participants in a timely and clear manner
10. Unless prohibited by contractual obligations, results of the research should be disseminated in a manner that will allow public scrutiny; the Human Research Ethics Office must be informed of any constraints on publication
11. Ethics approval is dependent upon ongoing compliance of the research with the Australian Code for the Responsible Conduct of Research, the National Statement on Ethical Conduct in Human Research, applicable legal requirements, and with Curtin University policies, procedures and governance requirements
12. The Human Research Ethics Office may conduct audits on a portion of approved projects.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Dr Catherine Gangell
Manager, Research Integrity

Appendix B   Publishing Agreement: What Determines Supportive Behaviours Following Bereavement? A Systematic Review and Call to Action

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Appendix D Phase One: Systematic Review Protocol

UNIVERSITY *of York*
Centre for Reviews and Dissemination

NHS
National Institute for
Health Research

PROSPERO International prospective register of systematic reviews

A systematic review of the determinants of perceptions of and behavioural responses towards bereaved people

Emma Penman, Jenny Thornton, Lauren Breen

Review question(s)

What are the determinants of perceptions of and behavioural responses towards people who are bereaved?

Searches

We will search the following electronic databases: PubMed, EMBASE, ProQuest, CINAHL Plus, PsycINFO, and The Cochrane Database of Systematic Reviews. In addition, we will complete hand searches of key journals in this field and citation searches using Web of Science (science and social science citation index). Grey literature, including published abstracts, conference proceedings, reports, theses, and dissertations, will be searched using sources such as ProQuest Dissertations and Theses, NHS Evidence, and Open Grey. Finally, experts in the field will be consulted to identify any further potentially relevant papers.

The search strategy for PubMed is available from the authors on request. The search terms will be adapted for use with other bibliographic databases. There will be no language or date restrictions. The searches will be re-run prior to final analyses and further studies retrieved for inclusion.

Types of study to be included

Inclusion:

• Articles where full texts are available in English or English translation is available.

• No restrictions on study design will be imposed. Qualitative evidence will be incorporated alongside quantitative in the review.

• Studies presenting quantitative and/or qualitative analysis on the topic of interest, i.e., interview/focus group, questionnaire.

• Studies for inclusion must present original data. When results are published multiple times, the data will be used only once.

• Study describes or manipulates one or more determinants which affect an individual's perception of and/or intended behaviours towards a bereaved person. Determinants may relate to the bereaved person (e.g., age at which bereavement occurred), the deceased person (e.g., cause of death), or the respondent of the study (e.g., gender).

• Study describes the impact of this determinant on some kind of response outcome, i.e., perception of (e.g., expectations, beliefs, or evaluations) or intended behaviour towards (e.g., provision of practical or emotional support) the bereaved person.

• Responses must be as reported by the individual community members, and not the bereaved person.

Exclusion:

• Non-English articles.

• No full text available (once all efforts have been exhausted to obtain a full text copy).

• Any articles not describing a determinant and its impact on a specified response-related outcome.

• Any article describing responses to bereavement from the viewpoint of the bereaved person.

Condition or domain being studied

Past research has highlighted the receipt of social support as a key contributor to positive bereavement outcomes. Despite this acknowledgement, there is little recognition of the full range of factors that influence community recognition of grief and intentions to provide social support to grieving persons. Given that a lack of, or inappropriate, social support for grief can have just as a significant effect as helpful social support, it is important to understand the beliefs and assumptions that underpin supportive behaviours in bereavement. This review will examine community norms for grief following bereavement by exploring the factors that determine if, when, and how individuals respond to bereaved people. The purpose of the review will be to raise awareness of what society expects of grief and bereavement in order to further educate bereavement practitioners as well as the general community in how they respond to grief and loss.

Participants/ population

Members of the general public who may or may not have experienced a personal bereavement in their lifetime.

Intervention(s), exposure(s)

Dependent on the study design, an intervention may or may not be present. Across all studies, there must be some description or manipulation of one or more determinants which affect an individual's perception of and/or intended behaviours towards a bereaved person (whether fictional or non-fictional).

Comparator(s)/ control

None.

Context

Studies in general community settings exploring the determinants of responses towards grief and bereavement.

Outcome(s)

Primary outcomes

• We aim to identify all possible factors that determine if, when, and how individuals respond to bereaved people. Uncovering these determinants will offer insight into the circumstances under which bereaved people are most likely to be offered social support, and as a consequence, the likely nature of their grief experience.

• As described above, determinants may relate to the bereaved person, the deceased person, or the respondent and their impact may range from expectations or evaluations of the bereaved person, to intentions to provide practical or emotional support.

Secondary outcomes
None.

Data extraction, (selection and coding)

Articles will be imported and managed using EndNote software. Titles and abstracts of studies retrieved using the search strategy and those from additional sources will be screened to identify studies that potentially meet the inclusion criteria outlined above. A minimum of 10% of the total studies retrieved will be screened independently by two review authors and any disagreement will be resolved through discussion and/or consultation with a third reviewer. The remaining studies will be screened by one reviewer, applying the established standard for screening. Any identified duplicates will be removed. The full text of these potentially eligible studies will then be retrieved and assessed for eligibility. Again the first 10% will be independently assessed by two reviewers and any disagreement will be resolved before assessment of the remaining studies. A flow chart will be used to summarise the number of papers included and excluded at each stage of the review process.

A standardised, pre-piloted form will be used to extract data from the included studies for assessment of study quality and evidence synthesis. Extracted information will include: study design; study location; study population and participant demographics; sampling methods; description of the determinants; study methodology; outcomes; information for assessment of risk of bias. A minimum of 10% of the studies will be fully double extracted and any discrepancies resolved by discussion. In the case of incomplete data, one attempt will be made to contact the corresponding author by email.

Risk of bias (quality) assessment
Two review authors will independently assess the risk of bias in included studies using the McMaster review forms.

Strategy for data synthesis
It is expected that there will be considerable heterogeneity in the reporting of outcomes. For this reason, we will conduct a narrative synthesis of the findings, combining both qualitative and quantitative data, structured around the types of determinants and their relative impact on community responses as a whole.

Analysis of subgroups or subsets
This is a narrative synthesis and while subgroup analyses may be undertaken, it is not possible to specify the groups in advance.

Dissemination plans
Findings from this review will be submitted to a leading peer-reviewed journal in this field. EP will lead the writing as this will constitute the first publication towards her PhD at Curtin University. This systematic review forms the first stage of a three-phase study so will also be included in a final paper making recommendations for improved community-wide grief education and practice.

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Organisational affiliation of the review
Curtin University

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Review team
Ms Emma Penman, Curtin University
Associate Professor Jenny Thornton, Curtin University
Dr Lauren Breen, Curtin University

Anticipated or actual start date
05 January 2015

Anticipated completion date
05 July 2015

Funding sources/sponsors
No funding

Conflicts of interest

Two of the reviewers (EP and LB) have written peer-reviewed journal articles and presented at conferences on this topic which may emerge in the process of searching. The other author declares no known conflicts of interest.

Language

English

Country

Australia

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Bereavement; Humans; Social Perception

Stage of review

Ongoing

Date of registration in PROSPERO

22 January 2015

Date of publication of this revision

22 January 2015

Stage of review at time of this submission	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Appendix E   Phase Two: Participant Information Sheet and Consent Form

HREC Project Number:	RDHS-12-15
Project Title:	The Conceptualisation of 'Normal' Grief: Using Mixed Methods to Reconcile Community Expectations with Actual Experiences of Grief
Principal Investigator:	Dr Lauren Breen, Senior Lecturer
Student researcher:	Ms Emma Logan, PhD Candidate
Version Number:	2.1
Version Date:	08/01/2015

What is the Project About?
- Bereavement is a universal experience that affects all people at some point during their lifetime. However, there is little evidence to suggest what influences community recognition of grief and intentions to support grieving persons.
- The purpose of this research is to examine how societal expectations impact on support of people who are bereaved, and how this support, in turn, shapes the experience of grief.
- The outcomes of this study will provide valuable insight for practice with people who are bereaved.
- We will recruit adults from the general Australian public to take part in this project.

Who is doing the Research?
- The project is being conducted by Ms Emma Logan.
- The results of this research project will be used by Ms Emma Logan to obtain a Doctor of Philosophy (Counselling Psychology) at Curtin University and is funded by the University.
- There will be no costs to you and you will not be paid for participating in this project. At the end of the questionnaire, you will be invited to enter an optional prize draw in recognition of your time.

Why am I being asked to take part and what will I have to do?
- We are looking for members of the general Australian public who are aged 18 years and over.

- If you chose to participate, we will ask you to complete a single online questionnaire. We will ask you questions about grief and how you might respond to someone who is bereaved.
- The questionnaire will take approximately 15-20 minutes and can be completed on your personal computer or mobile device.
- There will be no cost to you for taking part in this research and you will not be paid for taking part. At the end of the questionnaire, you will be invited to enter an optional prize draw to win one of four Amazon or iTunes gift vouchers valued at AUD$50. You may choose to substitute this voucher for a donation to a charity of your choosing.

Are there any benefits' to being in the research project?
- There may be no direct benefit to you from participating in this research. Sometimes, people appreciate the opportunity to discuss their opinions.
- We hope the results of this research will offer us a clearer understanding of societal norms for grief and will offer valuable insight into how people who are bereaved can be best supported.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?
- It is not expected that completing the questionnaire will cause you any distress. Should you feel anxious about any of the questions you do not need to answer them and can discontinue your participation at any time by simply closing your web browser.
- Sometimes just thinking about death and loss can be upsetting. If you chose not to be in this research but feel distressed from considering it then please contact Lifeline on 13 11 14.
- Apart from giving up 15-20 minutes of your time to complete the questionnaire, we do not expect that there will be any risks or inconveniences associated with taking part in this study.

Who will have access to my information?
- The information collected in this research will be non-identifiable (anonymous). This means that information is anonymous and will not include a code number or name. No one, not even the research team will be able to identify your information. Any information we collect and use during this research will be treated as confidential. The contact details you provide for the prize draw will not be linked to your responses in the questionnaire.
- The following people will have access to the information we collect in this research: Ms Emma Logan, Associate Professor Jenny Thornton, Dr Lauren Breen, Dr Robert Kane, and Curtin University Ethics Committee.
- Electronic data will be password-protected on a computer at Curtin University.
- The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed.
- You have the right to access, and request correction of, your information in accordance with relevant privacy laws.
- The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?
- We are not able to send you any results from this research as we do not collect any personal information to be able to contact you. However, a summary of

the results will be published on this website upon completion of the study. Results will not be individual but based on all the information we collect and review as part of the research. If you wish to view these results, please take note of the URL now.

Do I have to take part in the research project?
- Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project by simply closing your web browser. You do not have to give us a reason. If you chose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues.
- If you chose to leave the study, we will be unable to destroy your information because it has been collected in an anonymous way

What happens next and who can I contact about the research?
- For further information, please contact Ms Emma Logan at Emma.Logan@postgrad.curtin.edu.au. Alternatively, you may wish to contact Emma's supervisors:
    - Email. Dr Lauren Breen (Lauren.Breen@curtin.edu.au), Associate Professor Jenny Thornton (J.Thornton@curtin.edu.au) or Dr Robert Kane (R.T.Kane@curtin.edu.au)
- At the start of the questionnaire, available via the link provided, there is a checkbox to indicate you have understood the information provided here in the information sheet.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number RDHS-12-15). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

CONSENT FORM

I have received information regarding this research and had an opportunity to ask questions. I believe I understand the purpose, extent and possible risks of my involvement in this project and I voluntarily consent to take part.
O I agree
O I do not agree

Appendix F   Phase Two: Questionnaire

Q1 What is your age? (in years)

Thank you for agreeing to take part in this questionnaire. Once you have answered each question, please do not attempt to return to any previous pages, as this will end your session. On the next page, you will read a fictional scenario about someone who has experienced the death of someone close to them. Please take your time to read the story and then answer the questions with the scenario in mind. Please note that there is no right or wrong answer. We are interested in your personal opinion.

[One of the following four vignettes randomly displayed]

A.L's spouse died unexpectedly after a sudden illness. A.L lives alone and appears to have little support from family or friends.

A.L's spouse died unexpectedly after a sudden illness. A.L lives alone and appears to have a lot of support from family and friends.

A.L's spouse died expectedly after a lengthy illness. A.L lives alone and appears to have little support from family or friends.

A.L's spouse died expectedly after a lengthy illness. A.L lives alone and appears to have a lot of support from family and friends.

Q2 At this point in time, please rate how often you think the person in the scenario would be experiencing the following...
This rating scale ranges from 1 (Never) to 5 (Always)

	1	2	3	4	5
Feelings of longing or yearning for the person lost	O	O	O	O	O
Intense feelings of emotional pain, sorrow, or pangs of grief related to the lost relationship	O	O	O	O	O
Avoiding reminders that the person lost is gone	O	O	O	O	O
Feeling stunned, shocked, or dazed by the loss	O	O	O	O	O
Feeling confused about their role in life or feeling like they don't know who they are (i.e., feeling like a part of themselves has died)	O	O	O	O	O
Having trouble accepting the loss	O	O	O	O	O
Finding it hard to trust others since the loss	O	O	O	O	O
Feeling bitter over the loss	O	O	O	O	O
Feeling that moving on (e.g., making new friends, pursuing new interests) would be difficult now	O	O	O	O	O
Feeling emotionally numb since the loss	O	O	O	O	O
Feeling that life is unfulfilling, empty, or meaningless	O	O	O	O	O
Experiencing a significant reduction in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)	O	O	O	O	O

Q3 Assuming the person in the scenario was someone you knew, at this point in time, please rate the likelihood you would perform the following...
This rating scale ranges from 1 (Strongly Disagree) to 7 (Strongly Agree)

	1	2	3	4	5	6	7
I would support this person, such as giving words of sympathy or an offer of help	O	O	O	O	O	O	O
I plan to give this person support, such as words of sympathy or an offer of help	O	O	O	O	O	O	O
I will make an effort to give this person support, such as words of sympathy or an offer of help	O	O	O	O	O	O	O
I intend to give this person support, such as words of sympathy or an offer of help	O	O	O	O	O	O	O

Q4 Thinking about yourself...
This rating scale ranges from 1 (None of the possible times) to 7 (All of the possible times)

	1	2	3	4	5	6	7
In the past, you have given support or words of sympathy to a grieving person you have known	O	O	O	O	O	O	O

Q5 At the beginning of the questionnaire, you read a scenario about a person who had been bereaved. The questions below explore your attention to specific parts of the story.

a. Please answer according to which statement you remember to be true:

	Little support from family or friends	A lot of support from family and friends
How was the bereaved person's social network described?	O	O

b. Please answer according to which statement you remember to be true:

	Expected	Unexpected
How was the death described?	O	O

Q6 The next section of the questionnaire does not relate to the scenario, but instead asks about general perceptions. Please rate the degree to which you perceive each of the statements below would be either helpful or harmful, if said to a person who is bereaved by the death of someone close to them...
This rating scale is as follows: 1 (Very Harmful), 3 (Neither), 5 (Very Helpful)

	1	2	3	4	5
You should read self-help books	O	O	O	O	O
It should not affect you	O	O	O	O	O
What was it like before?	O	O	O	O	O
Do you need help cleaning out possessions?	O	O	O	O	O
You have done a nice job of looking after everyone	O	O	O	O	O
You shouldn't let this get you down	O	O	O	O	O
I really want to know how you are doing	O	O	O	O	O
He/she was fun to be around	O	O	O	O	O
I can imagine what it might be like for you	O	O	O	O	O
Would you like to come to dinner so you don't have to cook?	O	O	O	O	O

Would you like to come with us to the football game?	O	O	O	O	O
He/she always had a kind word for everyone	O	O	O	O	O
You should keep busy	O	O	O	O	O
He/she no longer has any worries	O	O	O	O	O
Would you like to talk about it?	O	O	O	O	O
Do not take it so hard	O	O	O	O	O
I am here for you	O	O	O	O	O
Everything that happens is for a purpose, you just don't see it	O	O	O	O	O
Would you like to talk to someone who has been through this?	O	O	O	O	O
I am proud of you for being so brave	O	O	O	O	O
I have some friends who this happened to; would you like to talk with them?	O	O	O	O	O
Everything has a time and a place and a purpose	O	O	O	O	O
It cannot be that bad	O	O	O	O	O
It is God's will	O	O	O	O	O
Do you remember how it was before this happened?	O	O	O	O	O
How about a movie?	O	O	O	O	O
I can arrange for you to meet with someone in your position	O	O	O	O	O
I know it must really hurt right now	O	O	O	O	O
Would you like me to run to the store for you?	O	O	O	O	O
If you want to talk, I will listen	O	O	O	O	O
You are being so strong	O	O	O	O	O
We are not always meant to understand God's purpose	O	O	O	O	O
Do you remember when…?	O	O	O	O	O
Someday you will reconnect	O	O	O	O	O
I am concerned about how you feel	O	O	O	O	O
I care about what happens to you	O	O	O	O	O
Was he/she in much pain?	O	O	O	O	O
You must get on with your life	O	O	O	O	O
He/she is no longer suffering	O	O	O	O	O
You were so helpful during this difficult time	O	O	O	O	O
I would be happy to stay with you if you'd like company	O	O	O	O	O
I know how you feel	O	O	O	O	O
I am a good listener if you need one	O	O	O	O	O
I really enjoyed spending time with him/her	O	O	O	O	O
In time, your spirits will reunite	O	O	O	O	O
Put your faith in God	O	O	O	O	O
Do you have errands I can run for you?	O	O	O	O	O
I am nearby if you need me	O	O	O	O	O
Going through this pain makes you appreciate the good in life	O	O	O	O	O
Some things we just can't control in this world	O	O	O	O	O
We usually go to the movies on Fridays, why don't you come?	O	O	O	O	O
When you feel bad you should exercise	O	O	O	O	O
I really care about how you are doing	O	O	O	O	O
I really liked your (e.g., parent, sibling)	O	O	O	O	O
The Lord works in mysterious ways	O	O	O	O	O
I really care about how you are doing	O	O	O	O	O
I know a group that meets to discuss loss. Would you like to talk with them?	O	O	O	O	O

Your souls will always be united	O	O	O	O	O
I remember when he/she did…(some event)	O	O	O	O	O
Your spirits will always be together	O	O	O	O	O
He/she is no longer in any pain	O	O	O	O	O
If you need company, I am here for you	O	O	O	O	O
Do you want to come to a friend's party with me?	O	O	O	O	O

Q7a In the field of mental health, there is a current proposal to include a grief-related classification in the Diagnostic and Statistical Manual of Mental Disorders (DSM). This classification would be given to a person when they show a complex set of symptoms that indicate difficult adjustment to the death.

To what extent do you believe that these symptoms could be considered a mental disorder?

Strongly Disagree	O
Disagree	O
Unsure	O
Agree	O
Strongly Agree	O

Q7b How do you think a grief-related classification (as described above) might affect an individual's grieving experience?

Q8 Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it pertains to you personally.

	True	False
I'm always willing to admit it when I make a mistake	O	O
I always try to practice what I preach	O	O
I never resent being asked to return a favour	O	O
I have never been irked when people expressed ideas very different from my own	O	O
I have never deliberately said something that hurt someone's feelings	O	O
I like to gossip at times	O	O
There have been occasions when I took advantage of someone	O	O
I sometimes try to get even rather than forgive and forget	O	O
At times I have really insisted on having things my own way	O	O
There have been occasions when I felt like smashing things	O	O

Please answer a few questions about yourself

Q9a Which of these statements best applies to you?

I have not experienced the death of someone close to me	O
I have experienced the death of someone close to me that had and/or continues to have a significant impact on my life	O
Although I have experienced the death of someone close to me, I do not think that this death has had a significant impact on my life	O

Q9b Thinking of the bereavement that you have been most significantly affected by (or most recently affected by, if you have experienced more than one significant bereavement), how long ago (in months and years) was this death?

Q9c What was your relationship to the deceased person? The deceased person was my…

Spouse/partner	O
Child	O
Sibling	O
Parent	O
Extended family member	O
Friend	O
Colleague	O
Other (please tell us)	O

Q10 What is your gender?

Male	O
Female	O
Other (please tell us)	O

Q11 Where were you born?

Australia	O
Outside Australia (please tell us)	O

Q12 What religion do you identify with?

None	O
Christianity	O
Islam	O
Hindu	O
Buddhism	O
Other (please tell us)	O

Q13 What is your highest level of completed education?

Equivalent of Year 11 or below	O
Year 12 (high school)	O
Vocational education/training	O
Tertiary undergraduate	O
Tertiary postgraduate	O

Q14 What is your primary occupational status?

Work full-time	O
Work part-time	O
Away from work	O
Unemployed	O

Q15 What is/was your area of profession?

Professional	O
Clerical/Administrative Worker	O
Technician/Trade Worker	O
Manager	O
Community/Personal Service Worker	O
Labourer	O
Sales Worker	O
Machinery Operator/Driver	O

Q16 Has your professional life included any exposure to, or training in, grief or bereavement?

No	O
Yes (please tell us)	O

Expectations of Grief Symptomatology Scale (Q2):
> Penman, E. L., Breen, L. J., Hewitt, L. Y., & Prigerson, H. G. (2014). Public attitudes about normal and pathological grief. Death Studies, 38, 510-516. http://dx.doi.org/10.1080/07481187.2013.873839

Intentions to Support Scale (Q3-4):
> Bath, D. M. (2009). Predicting social support for grieving persons: A theory of planned behavior perspective. *Death Studies, 33*, 869-889. http://dx.doi.org/10.1080/07481180903251547

Support-Intended Statements Scale (Q6):
> Rack, J. J., Burleson, B. R., Bodie, G. D., Holmstrom, A. J., & Servaty-Seib, H. L. (2008). Bereaved adults' evaluations of grief management messages: Effects of message person centeredness, recipient individual differences, and contextual factors. *Death Studies, 32*, 399-427. http://dx.doi.org/10.1080/07481180802006711

Crowne-Marlowe Social Desirability Scale (Q8):
> Strahan, R., & Gerbasi, K. C. (1972). Short, homogenous versions of the Marlow-Crowne social desirability scale. *Journal of Clinical Psychology, 28*, 191-193. http://dx.doi.org/10.1002/1097-4679

Appendix G   Phase Three: Participant Information Sheet and Consent Form

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	RDHS-12-15
Project Title:	The Conceptualisation of 'Normal' Grief: Using Mixed Methods to Reconcile Community Expectations with Actual Experiences of Grief
Principal Investigator:	Dr Lauren Breen, Senior Lecturer
Student researcher:	Ms Emma Logan, PhD Candidate
Version Number:	2.1
Version Date:	08/01/2015

What is the Project About?
- Bereavement is a universal experience that affects all people at some point during their lifetime. However, there is little evidence to suggest what influences community recognition of grief and intentions to support grieving persons.
- The purpose of this research is to examine how societal expectations impact on support of people who are bereaved, and how this support, in turn, shapes the experience of grief.
- By talking to bereaved people, we hope to gain an understanding of how bereaved and non-bereaved people respond to loss.
- We will recruit 15-20 adults from the general Australian public who have been bereaved to take part in this project.

Who is doing the Research?
- The project is being conducted by Ms Emma Logan.
- The results of this research project will be used by Ms Emma Logan to obtain a Doctor of Philosophy (Counselling Psychology) at Curtin University and is funded by the University.
- There will be no costs to you and you will not be paid for participating in this project. As an appreciation of your time, you will be offered a Coles Group and Myer Gift Card valued at AUD$15. You may choose to substitute this voucher for a donation to a charity of your choosing.

Why am I being asked to take part and what will I have to do?
- We are looking for members of the general Australian public who are aged 18 years and over. You must have experienced the death of a person close to you, whether recently or in the past, that had and/or continues to have an impact on your life. It is up to you to decide whether you feel ready to discuss your bereavement.
- You will be invited to participate in a face-to-face interview with a researcher. The study will take place at a mutually convenient location. Interviews usually last around one hour, but may take longer. We will ask you questions about your loss and your experience of social support during this time. We will also ask you about your current levels of coping and how your loss is impacting on you.
- We will make a digital audio recording so we can concentrate on what you have to say and not distract ourselves with taking notes. After the interview we will make a full written copy of the recording.

Are there any benefits' to being in the research project?
- There may be no direct benefit to you from participating in this research. Sometimes, people appreciate the opportunity to discuss their loss experiences.
- We hope the results of this research will give us a clearer understanding of how people who are bereaved can be best supported.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?
- It is possible that discussing the death of your loved one could be emotionally upsetting.
- You may choose to have a family member or friend sit with you during the interview. You may choose to not answer any question.
- If you are experiencing a significant amount of distress, you may choose to take a break, terminate the interview and continue at another time, or withdraw completely from the study without consequence. At the end of the interview, you will also be given a list of resources and services, should you wish to seek further support.
- Sometimes just thinking about your loss can be upsetting. If you chose not to be in this research but feel distressed from considering it then please contact Lifeline on 13 11 14.
- Apart from giving up your time to complete the interview, we do not expect that there will be any risks or inconveniences associated with taking part in this study.

Who will have access to my information?
- The information collected in this research will be re-identifiable (coded). This means that we will remove identifying information on any data or sample and replace it with a code. Only the research team have access to the code to match your name if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project unless otherwise specified. The following people will have access to the information we collect in this research: Ms Emma Logan, Dr Lauren Breen, Associate Professor Jenny Thornton, Dr Robert Kane, and Curtin University Ethics Committee.
- Electronic data will be password-protected and hard copy data (including audio tapes) will be in locked storage.

- The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed.
- You have the right to access, and request correction of, your information in accordance with relevant privacy laws.
- The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?
- Once analysis of the data is complete, we will contact you and invite you to read over the findings. We will seek agreement from as many participants as possible before publishing the findings.
- We will also write to you at the end of the research (in about one year) and let you know the results of the research. Results will not be individual but based on all the information we collect and review as part of the research.

Do I have to take part in the research project?
- Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just tell us that you want to stop. Please let us know you want to stop so we can make sure you are aware of any thing that needs to be done so you can withdraw safely. You do not have to give us a reason. If you chose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues.
- If you chose to leave the study, we will destroy any information we have collected from you.

What happens next and who can I contact about the research?
- For further information, please contact Ms Emma Logan at Emma.Logan@postgrad.curtin.edu.au. Alternatively, you may wish to contact Emma's supervisors:
  - Email. Dr Lauren Breen (Lauren.Breen@curtin.edu.au), Associate Professor Jenny Thornton (J.Thornton@curtin.edu.au, or Dr Robert Kane (R.T.Kane@curtin.edu.au)
- If you decide to take part in this research we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number RDHS-12-15). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

CONSENT FORM

HREC Project Number:	RDHS-12-15
Project Title:	The Conceptualisation of 'Normal' Grief: Using Mixed Methods to Reconcile Community Expectations with Actual Experiences of Grief
Principal Investigator:	Dr Lauren Breen, Senior Lecturer
Student researcher:	Ms Emma Logan, PhD Candidate
Version Number:	2.1
Version Date:	08/01/2015

- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – updated March 2014.
- I understand I will receive a copy of this Information Statement and Consent Form.

Participant Name	
Participant Signature	
Date	

Declaration by researcher: I have supplied an Information Letter and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Researcher Name	
Researcher Signature	
Date	

Appendix H   Phase Three: Interview Guide

<u>Interview Guide</u>

I would like to hear about your experience of bereavement. For some, this might be a distressing topic. Some of these questions may represent your first opportunity to think about these concepts. Please take your time to respond. There are no right or wrong answers; I am interested in your unique perspective. There may also be questions that you do not wish to answer and that is fine too.

I would like to spend some time exploring your loss, your experience of social support following the death, and your current reflections on grief. I hope that the information I collect today will assist in our understanding of the role of informal supports in what happens following a bereavement.

<u>The bereavement</u>
- Who the deceased was
- Circumstances of the death
- Own reactions to the death
- Others' reactions to the death

<u>Reactions of others</u>

- Forms of support/help (practical/financial, emotional, informational) and who provided it (family, friends, colleagues, health professionals, emergency services, other)
    - o Helpful/unhelpful? How?
- Prior expectations of support from others
- Reflecting back, what you wished they had done/said at the time

<u>Others' beliefs and expectations</u>
- Perceived beliefs or expectations held by others of your grief
    - o What was said directly/indirectly?
    - o Helpful/unhelpful? How?
    - o Responses by you to the helpful/unhelpful reactions of others

<u>Personal beliefs and expectations</u>
- Beliefs or expectations held of own grief
    - o Possible origins
- Any impact on grief

<u>Current reflections</u>
- Understandings of grief: then versus now
- Nature of interactions with other bereaved people since this bereavement
- Personal learnings/advice that might be of interest/help to others (bereaved or supporter)

This brings us to the end of the formal questions. Is there anything else you would like me to know or wish that I had asked?

Thank you for your participation in this research today.

Appendix I   Phase Three: PG-13 Questionnaire

Center for Psychooncology & Palliative Care Research
Prolonged Grief Disorder (PG – 13) ©
Holly G. Prigerson, Ph.D., Paul K. Maciejewski, Ph.D.

PGD is a newly defined syndrome that is a specific reaction to the loss of someone loved very much. There are a particular set of PGD symptoms – feelings, thoughts, actions – that must be elevated at 6 months post-loss and that must be associated with significant impairment in order for a person to meet criteria for PGD.

INSTRUCTIONS
Below lie instructions for how to score (diagnose) Prolonged Grief Disorder (PGD). Each of the requirements for Criteria A-E must be met for an individual to be diagnosed with PGD.

A. Event Criterion: In order to complete the PG-13, we assume the respondent has experienced bereavement (i.e., the loss of a loved person).

B. Separation Distress: The respondent must experience PG-13 questions #1 or 2 at least daily.

C. Duration Criterion: The symptoms of separation distress must be elevated at least 6 months after the loss. That is, PG-13 question #3 must be answered as "Yes".

D. Cognitive, Emotional, and Behavioral Symptoms: The respondent must experience 5 of the PG-13 questions #4-12 at least "once a day" or "quite a bit".

E. Impairment Criterion: The respondent must have significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities). That is, PG-13 question #13 must be answered as "Yes".

PG-13 is a diagnostic tool. If a respondent meets criteria for PGD, this would suggest that he or she should seek a more thorough evaluation from a mental health professional. Only an in-person assessment by a mental health professional can determine for certain, the clinical significance of the reported symptoms, and provide recommendations or referrals for treatment.

PART I INSTRUCTIONS: **FOR EACH ITEM, PLACE A CHECK MARK TO INDICATE YOUR ANSWER.**

1. In the past month, how often have you felt yourself longing or yearning for the person you lost?
    _____ 1= Not at all
    _____ 2 = At least once
    _____ 3 = At least once a week
    _____ 4 = At least once a day
    _____ 5 = Several times a day

2. In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to the lost relationship?
    _____ 1= Not at all
    _____ 2 = At least once
    _____ 3 = At least once a week
    _____ 4 = At least once a day
    _____ 5 = Several times a day

3. For questions 1 or 2 above, have you experienced either of these symptoms at least daily and after 6 months have elapsed since the loss?
    _____ No
    _____ Yes

4. In the past month, how often have you tried to avoid reminders that the person you lost is gone?
    _____ 1= Not at all
    _____ 2 = At least once
    _____ 3 = At least once a week
    _____ 4 = At least once a day
    _____ 5 = Several times a day

5. In the past month, how often have you felt stunned, shocked, or dazed by your loss?
    _____ 1= Not at all
    _____ 2 = At least once
    _____ 3 = At least once a week
    _____ 4 = At least once a day
    _____ 5 = Several times a day

PART II INSTRUCTIONS: FOR EACH ITEM, PLEASE INDICATE HOW YOU CURRENTLY FEEL. CIRCLE THE NUMBER TO THE RIGHT TO INDICATE YOUR ANSWER.	Not at all	Slightly	Somewhat	Quite a bit	Overwhelmingly
6. Do you feel confused about your role in life or feel like you don't know who you are (i.e., feeling that a part of yourself has died)?	1	2	3	4	5
7. Have you had trouble accepting the loss?	1	2	3	4	5
8. Has it been hard for you to trust others since your loss?	1	2	3	4	5
9. Do you feel bitter over your loss?	1	2	3	4	5
10. Do you feel that moving on (e.g., making new friends, pursuing new interests) would be difficult for you now?	1	2	3	4	5
11. Do you feel emotionally numb since your loss?	1	2	3	4	5
12. Do you feel that life is unfulfilling, empty, or meaningless since your loss?	1	2	3	4	5

PART III INSTRUCTIONS: FOR EACH ITEM, PLACE A CHECK MARK TO INDICATE YOUR ANSWER.

13. Have you experienced a significant reduction in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)?

_____ No

_____ Yes

Prolonged Grief Disorder Scale (PG-13):

Prigerson, H. G., & Maciejewski, P. K. (2009). Prolonged grief disorder: PG-13. Boston, MA: Center for Psychooncology and Palliative Care Research.

Appendix J   Phase Three: Q-LES-Q-18 Questionnaire

During the past week, how much of the time have you…
This rating scale ranges from 1 (Not at all or never) to 5 (Frequently or all the time)

	1	2	3	4	5
1. Felt in at least very good physical health?	O	O	O	O	O
2. Been free of worry about your physical health?	O	O	O	O	O
3. Felt good physically?	O	O	O	O	O
4. Felt full of pep and vitality?	O	O	O	O	O
5. Felt satisfied with your life?	O	O	O	O	O
6. Felt happy or cheerful?	O	O	O	O	O
7. Felt able to communicate with others?	O	O	O	O	O
8. Felt able to travel about to get things done when needed (walk, use car, bus, train, or whatever is available as needed)?	O	O	O	O	O
9. Felt able to take care of yourself?	O	O	O	O	O

The following questions refer to leisure time activities such as watching T.V., reading the paper or magazines, tending house plants or gardening, hobbies, going to museums or the movies, or to sports events, sports, etc.
This rating scale ranges from 1 (Not at all or never) to 5 (Frequently or all the time)

	1	2	3	4	5
10. How often did you enjoy leisure activities?	O	O	O	O	O
11. How often did you concentrate on the leisure activities and pay attention to them?	O	O	O	O	O
12. If a problem arose in your leisure activities, how often did you solve it or deal with it without undue stress?	O	O	O	O	O

During the past week how often have you…
This rating scale ranges from 1 (Not at all or never) to 5 (Frequently or all the time)

	1	2	3	4	5
13. Looked forward to getting together with friends or relatives?	O	O	O	O	O
14. Enjoyed talking with co-workers or neighbours?	O	O	O	O	O
15. Felt affection towards one or more people?	O	O	O	O	O
16. Joked or laughed with other people?	O	O	O	O	O
17. Felt you met the needs of friends or relatives?	O	O	O	O	O

Taking everything into consideration, during the past week how satisfied have you been with your…

This rating scale ranges from 1 (Not at all or never) to 5 (Frequently or all the time)

	1	2	3	4	5
18. Medication (if not taking any check here _____ and leave item blank)	O	O	O	O	O
19. Social relationships?	O	O	O	O	O
20. Ability to function in daily life?	O	O	O	O	O
21. Economic status?	O	O	O	O	O
22. Overall sense of well being?	O	O	O	O	O
23. How would you rate your overall life satisfaction and contentment during the past week?	O	O	O	O	O

Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q-18):

Ritsner, M., Kurs, R., Gibel, A., Ratner, R., & Endicott, J. (2005). Validity of an abbreviated quality of life enjoyment and satisfaction questionnaire (Q-LES-Q-18) for schizophrenia, schizoaffective, and mood disorder patients. *Quality of Life Research*, *14*, 1693-1703. http://dx.doi.org/10.1007/s11136-005-2816-9

Appendix K   Phase Three: Demographics Form

Participant ID: _____

ABOUT YOU

Age: _____

Gender:
O Male
O Female
O Other _____

Place of birth:
O Australia
O Outside Australia   _____

Religious identification:
O None
O Christianity
O Islam
O Hindu
O Buddhism
O Other _____

Education:
O Equivalent of year 11 or below
O Year 12 (high school)
O Vocational education/training
O Tertiary undergraduate
O Tertiary postgraduate

Postcode: _____

ABOUT YOUR BEREAVEMENT

Time since the death: _____ years _____ months

Relationship to the deceased (he/she was my…): _____

Gender:
O Male
O Female
O Other _____

Age: _____

Email address/address (for summary of findings): _____

Appendix L   Phase Three: Support Service List

Bereavement Support Services

Local Psychologists
Can be accessed via your GP under the Better Access initiative. Through this initiative, Medicare rebates are available for selected mental health services (up to 10 individual and 10 group allied mental health services per calendar year).

Contact*:* See your local GP

Lifeline
Lifeline provides 24/7 access to telephone crisis support, suicide prevention, and mental health support services.

Website: www.lifeline.org.au
Phone: 13 11 14

The Samaritans
Samaritans are volunteers who are specially trained to offer sympathetic, caring, and confidential emotional support to people who are feeling desperate, lonely, or suicidal. This 24-hour service is available 365 days a year.

Email: support@samaritanscrisisline.org.au
Website: www.thesamaritans.org.au
Phone: 13 52 47

The Salvation Army
National, 24-hour, 7-day week telephone counselling line for those bereaved through suicide.

Website: www.suicideprevention.salvos.org.au
Phone: 13 72 58

Mensline Australia
24-hour support for Australian men anywhere, any time. Includes online and vide counselling.

Website: www.mensline.org.au
Phone: 1300 789 978

Cancer Council Western Australia
Offers counselling and bereavement support groups facilitated by Cancer Council counsellors.

Website: www.cancerwa.asn.au
Phone: 13 11 20

Cancer Support Association
One to one counselling and/or family counselling for people who have lost someone to cancer.

Website: www.cancersupportwa.org.au
Phone: (08) 9384 3544

Compassionate Friends
A non-religious self-help group for bereaved parents, grandparents, children, and siblings of any age. Has a statewide network of contacts for both telephone and group support.

Website: www.compassionatefriendswa.org.au
Phone: (08) 9486 8711

SIDS and KIDS
Provides bereavement support services for anyone affected by the sudden, unexpected death of a child from conception to 12 years of age. Services include: 24-hour telephone support, free counselling, peer support, crisis services, information and library access, newsletters, memorial services, education, and research.

Website: www.sidsandkids.org/wa
24-hour support line: 1300 308 307
General inquiries: (08) 9474 3544
Country (free call): 1800 199 466

Solace Australia (WA)
Bereavement support for anyone grieving the death of a partner. Services include: group meetings, telephone support, and courses provided by trained support workers.

Email: solacewa@eftel.net.au
Website: www.solace.org.au
Phone: (08) 9474 3297

ARBOR (Anglicare WA)
Offers short to medium-term counselling, referral, peer support, and support groups to people bereaved by suicide.

Email: arbor@anglicarewa.org.au
Website: www.anglicare.org.au
Phone: (08) 9263 2150

Centrelink
Provides information about eligibility for bereavement payments following the death of a partner, child, or person you have cared for.

Website: www.humanservices.gov.au
Phone: 13 10 21

Australian Centre for Grief and Bereavement: www.grief.org.au
Good Grief: www.goodgrief.org.au
GriefLine: www.griefline.org.au
My Grief Assist: www.mygriefassist.com