

Summary of Proposed Research Program for Doctor of Philosophy

Title

The Conceptualisation of 'Normal' Grief: Using Mixed Methods to Reconcile Community Expectations with Actual Experiences of Grief

Abstract

It has been recognised that the provision of helpful, timely social support is one of the strongest determinants of positive psychosocial outcomes following the death of a loved one. Despite this acknowledgement, there is little evidence to suggest what factors influence community recognition of grief and intentions to provide social support to grieving persons. The purpose of this research is to examine how societal norms impact on support of people who are bereaved, and how this support or lack thereof, in turn, shapes the experience of grief. The study will 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. This mixed methods research will be conducted across three phases, comprising a systematic review, an online community questionnaire, and face-to-face interviews. The findings of each phase will inform the next with the aim to form a snapshot of the nature of grief-related norms in Australia and their effects, both helpful and unhelpful, on the experience of grief. The outcomes of this study will provide valuable insight for practice with people who are bereaved as well as general community-wide grief education.

Objectives

1. Investigate community norms for grief following bereavement by conducting a systematic review of existing literature exploring community responses to bereavement.
2. Address gaps in the existing literature through exploring expectations of, beliefs about, and intentions to support people who are bereaved, and whether these differ dependent on personal experience with grief.
3. Examine the level of community agreement with current proposals to include pathological forms of grief in diagnostic classification systems.
4. Evaluate how people who are bereaved reconcile their own expectations, and that of those around them, with their actual experience of grief.
5. Inform clinical practice with people who are bereaved and make recommendations to contribute to best practice grief education for the general public.

Background

Bereavement is a universal experience that will inevitably affect all people at some point during their lifetime. It is widely recognised that grief is both a normal and healthy emotional reaction to the loss of someone to whom the person was closely attached (Shear et al., 2011). Despite this recognition, evidence suggests that people who are bereaved do not consistently receive the quality or quantity of social support that they require (Harris, 2009). There is a general consensus that such behaviours towards bereaved people stem from a reluctance to talk about death and loss (Jalland, 2013; McConnell, Moules, McCaffrey, & Raffin Bouchal, 2012), in combination with rigid societal expectations of the circumstances under, and manner in which, grief is permitted (Doka, 1989, 2002). The dominant argument in the grief literature is whether 'pathological' responses to bereavement can be differentiated from what is considered a 'normal' or 'typical' grief reaction, without increasing stigmatisation and other negative outcomes for people who are bereaved.

Grief in Diagnostic Nosology

The latest edition of the Diagnostic and Statistical Manual of Mental Disorders has proposed a diagnostic classification for further study termed Persistent Complex Bereavement Disorder (DSM-5; American Psychiatric Association [APA], 2013). This classification recommends diagnosis for children after six months and adults after one year following a death if the following are present: prolonged yearning, intense emotion, and preoccupation with the deceased and the manner in which they died. The individual must also exhibit at least six indicators of pathological grief causing significant distress and impairment to everyday functioning. Prolonged Grief Disorder has also been proposed for inclusion in the upcoming edition of the International Classification of Disease (ICD-11), with specific classification criteria still under development (Maercker et al., 2013; Prigerson et al., 2009).

The final criterion for Persistent Complex Bereavement Disorder 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). There is surprisingly limited research examining these norms, or the extent to which the general public, and specifically people who have been bereaved, agree with proposals to diagnose grief. Two core studies in this area have demonstrated levels of support for grief as a mental illness ranging from 51% (Rüsch, Evans-Lacko, & Thornicroft, 2012) to 75% (Penman, Breen, Hewitt, & Prigerson, 2014a). However, other research has shown that people are less likely to classify symptoms as indicative of depression or recommend professional support when the context of a negative life event, such as bereavement, is given (Holzinger, Matschinger, Schomerus, Carta, & Angermeyer, 2011).

The first known study to explore opinions held by people who have been bereaved found that of 135 adults, the majority thought that a diagnosis would bring them relief (96.3%) and were receptive to the idea of receiving treatment for their grief (98.5%; Johnson et al., 2009). Subsequent qualitative research observed that of eight bereaved adults, although some reported a strong resonance of the complicated grief label to their own experiences, others failed to identify with an arbitrary label and proposed that an understanding of the phenomenon was more important (Ghesquiere, 2013). Evidently, the evidence for and against a diagnosis for grief is both mixed and limited in scope. An understanding of these attitudes is particularly important, given that many people are unaware that they are experiencing what might be considered pathological grief, and therefore do not access formal support services (Cherlin et al., 2007; Lichtenthal et al., 2011).

The Legitimation of Loss

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'. The main discourse of grief has been constructed on the assumption that grief is a finite, short-term experience that must be worked through following a predictable pattern across a series of quasi-linear stages, eventually culminating in detachment from the deceased and meaning taken from the death (Breen & O'Connor, 2007). Despite widespread acceptance, there have been robust theoretical and empirical challenges to these ideas, suggesting that stage and task-based models merely perpetuate unrealistic expectations and a sense of inadequacy in those who fail to detach, move on, and 'resolve' their grief (Breen & O'Connor, 2007; Breen & O'Connor, 2011; Wortman & Silver, 1989, 2001). Rather, there is greater evidence for variation in the timing, intensity, and expression of grief dependent on a complex interplay of factors including the attachment to the deceased person, anticipation of the death, past experiences, coping style, and the level of social support perceived by the person who is bereaved (Centre for the Advancement of Health, 2004).

The understanding of grief in terms of community norms stems from Doka's (1989, 2002) coining of the term 'grieving rules', referring to a series of principles that guide who should grieve, when they should grieve, where the grief should occur, how they should grieve, for how long they should continue grieving, and finally, for whom should they grieve. Through the specification of these implicit rules, a dichotomy is created whereby a loss is appraised as either enfranchised and legitimate, or disenfranchised and illegitimate. Where an individual's grief 'sits' on this dichotomy will depend on others' perceptions of the nature of the loss, the relationship to the deceased, and the bereaved person's ability to grieve (Doka, 1989). For people whose grief is enfranchised, they are afforded what Harris (2009) 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. Those who exhibit little distress are not perceived to be resilient, but rather are assumed to be denying the loss or suppressing emotion, both societal indicators of poor coping (Boerner, Wortman, & Bonanno, 2005). Conversely, when death is disenfranchised, others will not recognise or validate the loss, and social support will not be offered (Doka, 1989, 2002).

There is little empirical evidence for the origins of these grieving rules. It has been proposed that grief is set within a historical, political, social, and cultural climate and the norms and practices of grief change according to these (Breen & O'Connor, 2010). Death was once accepted as a familiar, inevitable part of living and talking about and dressing according to one's grief were not uncommon one year 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 in Western society (Jalland, 2013; Kübler-Ross, 1969). With increases in life expectancy and declines in communicable diseases, death was reconstructed to represent a failure in the medical system to prolong life (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 endorsement of "a stiff upper lip" to boost public morale (Jalland, 2013, p. 17). Although it could be argued that today's Western society encourages a more liberal, expressive

style of grief, the traditional mourning practices embedded in our history continue to influence social constructions of bereavement and what it means to grieve in an appropriate manner.

Unpacking Specific Norms for Grief

Research exploring the factors that influence community responses towards bereavement has spanned over three decades. Studies in this area commonly present participants with a hypothetical bereavement vignette and explore the impact of manipulated factors on expectations of, judgments of, and intentions to act towards people who are bereaved.

Gender. Calhoun, Selby, and Gribble (1979) observed that female respondents were more socially rejecting of a bereaved family than males; while in contrast, Versalle and McDowell (2005) found that women offered greater sympathy to people who were bereaved than did men. Further studies of gender have observed that respondents are more willing to interact with bereaved women than men, but this depends both on the expectation of the death and the level of trauma surrounding the death (Kubitz, Thornton, & Robertson, 1989; Penman, Breen, Hewitt, & Prigerson, 2014b). Other studies again have found that the grief of male and female target figures is rated equally appropriate (Miller, 2014; Versalle & McDowell, 2005). Evidence for the impact of gender on the actual experience of grief is equally varied. While some research suggests differences in the expression of grief and bereavement outcomes between genders (Sidmore, 2000; Stroebe, 1998, 2001), other studies have found no evidence (Lawrence, Jeglic, Matthews, & Pepper, 2006).

Circumstances of the death. Another factor under exploration is the degree to which certain bereavements are expected to be more difficult to cope with than others. Research has indicated greater dislike of and blame towards parents bereaved by suicide, than by illness (Calhoun, Selby, & Faulstich, 1980, 1982; Rudestam & Imbroll, 1983; Thornton, Whitemore, & Robertson, 1989). It has been observed that, by its nature, the general public perceive bereavement by suicide to be more difficult to cope with, offer sympathy to, and talk about (Calhoun, Selby, & Abernathy, 1984). In line with this, respondents in Costa's (2007) study rated expected deaths as easier to adjust to than sudden deaths, with the belief that certain aspects of grief should be resolved prior to the death. Despite these evaluations, research indicates that the nature of the death is not as important as once thought, with few quantitative differences in the perceived difficulty of grieving between those bereaved by suicide and other types of death (Clark, 2001). As identified by Clark, this myth condemns people bereaved by suicide to grieve in a certain way, based on the expectation that their bereavement is the 'worst' kind.

Expectations of time. Based on the grief work hypothesis, there is a strong push for people who are bereaved to work through their grief, according to the prescribed stages, and in the quickest time possible (Granek, 2010). Studies have identified a paradox in evaluations of time with respondents emphasising the importance of allowing people to grieve in their own way, yet simultaneously imposing timeframes for when grief has persisted too long (Costa et al., 2007). For example, one study reported an average of 1.5 years as the longest expected time for recovery (Vickio, Cavanaugh, & Attig, 1990). Other studies have indicated the gradual dissolution of symptoms between six weeks, one year, and five years (Rubin & Schechter, 1997); two weeks, six months, and 15 months (Penman et al., 2014b); and one month and one year (Miller, 2014). These findings, however, sit in contrast to extensive evidence suggesting that emotional thoughts about and conversations with the deceased person commonly persist for many years following the death (Carnelley, Wortman, Bolger, & Burke, 2006; Zisook & Shuchter, 1985).

The Impact of Norms on the Experience of Grief

The risk of such a strong-held dominant discourse of grief is that people who are bereaved are open to being judged, and judging themselves against, a dominant prescription that is not necessarily congruent with the unique circumstances of their own bereavement (Breen & O'Connor, 2007). Studies of people who are bereaved have documented their reluctance to think or talk about grief outside the context of a death, resulting in the preservation of naïve beliefs and unrealistic expectations which may complicate the first bereavement experience (Costa et al., 2007). Respondents in Costa and colleague's study reported awareness of experiencing too little or too much distress, comparing the self to others, and feeling a sense of failure when symptoms of grief did not resolve within an expected timeframe. Similarly, bereaved adults in Ghesquiere's (2013) reported that their intensity and duration of grief symptoms significantly exceeded both their own and others' expectations, resulting in self- and other-critical judgements when their grief was perceived to be greater than what the bereavement necessitated. Consequently, some individuals may engage in a process of self-disenfranchisement, where the person bereaved will discount their own loss as unjustified

and not warranting support (Cordaro, 2012; Kauffman, 1989, 2002); while others wilfully reject the norms and instead withdraw from friends and family around whom they cannot grieve naturally (Breen & O'Connor, 2011).

The Impact of Norms on Social Support

Although most people will accommodate their loss, research has indicated that a subset (approximately 15%) will remain consumed by their loss, experiencing persistent debilitating symptoms long after the death (Bonanno & Kaltman, 2001; Prigerson et al., 2009; Shear et al., 2011). The question of how to protect bereaved individuals from developing pathological grief reactions has long been contested in bereavement research. Research has identified factors prior to the death (e.g., attachment style), associated with the death (e.g., level of trauma surrounding the death), and after the death (e.g., perceived social support) as key predictors of complicated grief (Lobb et al., 2010). The assumption that social support or lack thereof, is an important factor in bereavement outcomes has received widespread acceptance in bereavement research and practice (Hibberd, Elwood, & Galovski, 2010); however, there have been few empirical studies to explore what predicts or influences the quality of social support. The only study to have done so found that behavioural beliefs, followed by control beliefs and past behaviours were the strongest predictor of social support intentions, with normative beliefs having no effect (Bath, 2009). This suggests that people's perceived efficacy of and control over their supportive behaviours, and the consequences of these for themselves and others have a greater influence on intentions than perceptions of what others will think.

The costs and benefits of social support. Studies have found an association between positive support and symptoms of pathological grief, with those with lower perceived social support more likely to ruminate over the loss, resulting in more intense grief, depressive symptoms, and lower mood (van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2010). Further, the effects of social support have been found to be particularly positive when the support is offered by someone who has experienced a significant bereavement (Costa et al., 2007). Behaviours rated as most helpful by people who have been bereaved include being able to tell their story; informing others of what happened by mentioning the deceased person's name and speaking truthfully about the death; and explicitly clarifying personal needs for support (Dyregrov, 2004). Additionally, unconditional acceptance of grief has been rated as particularly important, with the most helpful social supports still available months or years after the death (Costa et al., 2007).

Despite these benefits, it has been consistently identified that not all social support is perceived by people who are bereaved to be positive or indeed helpful. Many people describe practical and emotional assistance to be plentiful immediately after the death, but this steadily decreases within just a few weeks to leave the bereaved with little or no contact (Begley & Quayle, 2007; Breen & O'Connor, 2011; Ghesquiere, 2013). 'Empathic failure' (Neimeyer & Jordan, 2002) and 'social ineptitude' (Dyregrov, 2004) are terms that have been derived to describe the inability of bereaved persons' social networks to understand the meaning of their experience and respond appropriately. A study of 90 adults bereaved by AIDS-related causes, explored the effects 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 were found to contribute significantly to levels of depression, beyond that of grief alone, and led to isolating behaviours by the bereaved person as a means of self-protection. Studies have identified that many people will lose relationships through their grief experience due to others feeling unable to support the bereaved person or perceiving the bereavement as a timely reminder of their own mortality (Breen & O'Connor, 2011; Costa et al., 2007). As such, the breakdown of social networks due to unsupportive friends and family becomes a type of secondary loss, compacting and complicating the nature of the primary loss. Given that a lack of, or inappropriate, social support for grief can have just as a significant effect as appropriate, helpful social support, it is important to understand the beliefs and assumptions that underpin supportive behaviours in bereavement.

Limitations and Rationale

One decade ago, the Centre for Advancement of Health (2004) identified the impact of support systems on bereavement outcomes as a priority area for continued research; however, evaluation of the literature indicates persistent gaps in this area. As identified by Bath (2009), very few factors that have been found to complicate the grieving process (e.g., suddenness of death and attachment to the deceased) can be modified *after* the fact, to the extent that social support can. Although there has been some independent investigation of the norms of grief (e.g., Breen & O'Connor, 2010; Costa et al., 2007) and predictors of social support for

people who are bereaved (Bath, 2009), there have been few connections between the two. Research to date has predominately used university samples to represent broader community perceptions, and has focused on white, middle- to-late-aged women bereaved by the death of a spouse when reporting on general bereavement outcomes. Greater diversity in research samples is needed to capture broader societal norms for grief, and the effects of these norms on various types of bereavement.

The proposed study endeavours to address these shortcomings by uncovering the reasons why people may or may not be offered appropriate social support, and the effect that this has on their experience of grief. There are two key ways in which this project is innovative: (1) being the first known study of its kind to explore whether experiencing a significant bereavement results in more or less helpful responses towards other people who are bereaved; (2) going beyond the description of unhelpful social supports, to evaluate how people who are bereaved accommodate their own beliefs as well as the expectations imposed by others, all the while trying to cope with the loss itself. Regardless of if, when, or how, a bereavement-related disorder is 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, believe in, support, and would utilise such a diagnosis. The findings of this study will promote a clearer understanding of societal norms for grief and will offer valuable insight into how people who are bereaved can best be supported.

Significance

Recommendations from past research call for greater community-wide grief education to support the natural helpers of people who are bereaved, including their family, friends, and colleagues (Breen & O'Connor, 2007; Hansson & Stroebe, 2003). Reconciling community expectations of grief (what it 'should' be) with the reality of bereavement experiences (what it actually *is*) offers the potential to enfranchise and legitimise a greater range of grief responses. Secondary gains of this include an increased awareness in people who are bereaved of the variable nature of grief, reducing the internalisation of dominant grief expectations and critical self-evaluations of right and wrong ways of responding (Breen & O'Connor, 2007). Given the increasing emphasis on social support as a protective factor against pathological grief, an understanding of the mechanisms behind when and how society responds to bereavement is of critical importance. Only with an understanding of this will it be possible to (a) improve prediction of bereavement outcomes; (b) mobilise social supports at a time when they are needed most; (c) develop interventions that take into account the presence (or absence) of social support; and (d) correct erroneous beliefs and expectations held by bereavement practitioners, researchers, the media, and laypersons alike. It is anticipated that the proposed research will raise awareness of the secondary losses that people may encounter when the nature of their bereavement and associated grief is not considered 'normal' as judged by those closest to them.

Research Method

Research Aims

The first aim of the proposed study is to explore whether community norms for grief, beliefs about social support, intentions to provide social support, and attitudes towards the diagnosis of grief differ dependent on past bereavement experiences. The following hypotheses are proposed:

H1: Past behaviours providing social support will be significantly correlated with future intentions to provide social support.

H2: Controlling for social desirability, expected levels of grief and intentions to provide social support will decrease as the time since death increases.

H3: Controlling for social desirability, expected levels of grief and intentions to provide social support will be lower when the person evaluated is male, compared to female.

H4: Controlling for social desirability, expected levels of grief and intentions to provide social support will decrease as the age at death increases.

H5: Controlling for social desirability, expected levels of grief and intentions to provide social support will be higher if the evaluator has been significantly affected by bereavement, than if they have not been significantly affected by bereavement, or if they have never experienced bereavement.

H6: There will be a significant difference in beliefs about social support between people who have been significantly affected by bereavement, people who have not been significantly affected by bereavement, and people who have never experienced bereavement.

H7: There will be a significant difference in opinions towards the diagnosis of grief between people who have been significantly affected by bereavement, people who have not been significantly affected by bereavement, and people who have never experienced bereavement.

The second aim is 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. Taken together, these aims will examine the current nature of grief-related norms in Australia and the impact of such norms on the experience of grief.

Research Design

The proposed study will adopt a mixed methods research design conducted across three phases. The first phase will involve a systematic review of previous literature exploring community responses towards bereavement, as indicated by expectations of, beliefs about, evaluations of, and intentions to act towards bereaved people. Based on the findings of this review, the second phase will involve a quantitative exploration of some of the less well-researched areas in a sample of the Australian public. This phase will employ random allocation to 1 of 54 fictional bereavement vignettes in order to evaluate how individuals typically respond to another person dependent on the type of bereavement situation. The first part will be addressed using a between-groups fully randomised 3 x 3 x 3 x 2 factorial design to explore the impact of manipulations on expectations of grief symptomatology and intentions to provide social support. Subsequent scales will utilise past bereavement experiences to explore differences in beliefs about social support and opinions towards the diagnosis of grief. Stemming from these findings, the third phase will follow up with semi-structured interviews to evaluate the impact of these grief-related norms on the experience of grief.

The three phases of this study will be integrated using a pragmatist perspective, recognising that no single methodology or world view can account for the complexity of this phenomenon, nor respond to the range of contexts – historical, political, social, and cultural – in which grief is constructed (Creswell, Plano Clark, Gutmann, & Hanson, 2003; Denscombe, 2008). Sequential components of the study will be weighted equally to inform current understandings of societal norms for grief and their impact on bereavement experiences.

Phase One

The first phase will be conducted in accordance with the Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). A research protocol will be developed and published documenting chosen search terms derived from the research question, key limiters, and a list of databases to be searched. Inclusion and exclusion criteria will be developed and a search flow diagram will be designed to track the number of articles identified and excluded at each stage of the search process.

Phase Two

Participants. Participants in the second and third phases will be English-speaking adults aged over 18 years. The second phase will recruit Australian residents who have Internet access. Past research has demonstrated no difference in demographic variables or ratings of grief between online and offline samples, but greater variability in bereavement characteristics (e.g., relationship to death, cause of death and time since death; Tolstikova & Chartier, 2010). Recruitment will occur using a combination of convenience and purposive sampling through community newspapers, Curtin radio advertising, community noticeboards, and online noticeboards and discussion forums. In line with previous research (e.g., Penman et al., 2014b), participants will be asked to refrain from participating in the study if they expect to experience significant distress as a result of participation. Based on an *a priori* power analysis (Faul, Erdfelder, Lang, & Buchner, 2007), 10 participants per group will be required for an 80% chance of detecting a relatively small ($f = .168$) 4-way interaction at an alpha-level of .05. A total sample size of 540 participants will be sought (180 in each bereavement experience group).

Measures. Eighteen versions of a vignette will be developed to reflect a common bereavement and will vary only by levels of the manipulated factors. Manipulations will be informed based on the outcomes of the systematic review in phase one; however, the most likely choices will be the time that has passed since the death, the gender of the bereaved person, and the age of the deceased person. In line with Penman and colleagues (2014b), the vignettes will be designed to provide participants with sufficient information to answer the questions, but will offer no information that might stray participant judgements (e.g., indications of current coping). Multiple choice questions in the form of manipulation checks will also be included to

ensure that participants are attending to key details in the vignette. The responses of participants who respond incorrectly to these items will be screened out.

The first two scales in the questionnaire will assess participants' expectations of and intentions to support the person in the vignette. Expectations of grief symptomatology will be assessed using a modified version of the Prolonged Grief Disorder scale (PG-13; Prigerson & Maciejewski, 2009), previously published by Penman and colleagues (2014b) as a 12-item scale. Responses to all items are measured on a 5-point Likert-type scale from 1 (*never*) to 5 (*always*), with higher overall scores indicating an expectation of more intense grief. The scale has demonstrated unidimensionality and acceptable internal consistency reliability ($\alpha = .87$; Penman et al., 2014b). Intentions to provide social support will be measured using a 4-item subscale of the Theory of Planned Behaviour for Social Support of Grieving Persons scale (Bath, 2009). This scale explores intentions to support grieving persons in general, so the wording will be modified to make judgements specific to the person in the vignette. Responses to items are measured on a 7-point Likert-type scale from 1 (*strongly disagree*) to 7 (*strongly agree*), with higher overall scores reflecting greater intentions to support. This scale has demonstrated unidimensionality and internal consistency reliability ($\alpha = .71$; Bath, 2009). A single item exploring past behaviours of providing social support, from the same scale, will also be used. This item will be measured on a 7-point scale from 1 (*none of the possible times*) to 7 (*all of the possible times*) with a higher score reflecting more frequent past support.

The remaining scales will ask questions unrelated to the vignette. Beliefs about supporting people who are bereaved will be assessed using the 64-item Support-Intended Statements Scale (Rack, Burlison, Bodie, Holmstrom, & Servaty-Seib, 2008). This scale explores the perceived helpfulness of a number of support-intended statements with responses measured on a 5-point scale from 1 (*very harmful*) to 5 (*very helpful*), with a midpoint of 3 (*neither*). Higher scores on each construct indicate a higher perceived helpfulness rating. Each of the 16 subscales has demonstrated adequate internal consistency reliability, ranging from $\alpha = .69$ to $.92$. Opinions towards the diagnosis of grief will be measured using a 2-item scale modified from Penman and colleagues (2014b). The first item asks participants to rate the extent to which they agree that certain forms of grief could be considered a mental disorder. Response options have been modified from *yes/no* to a 5-point 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 will then ask participants to explain how they believe that a diagnosis could help or hinder the experience of grief.

Finally, as a covariate for the previous scales, social desirability will be measured using a 10-item version of the Crowne-Marlow Social Desirability scale (Strahan & Gerbasi, 1972). Past research has deemed this scale to be a good fit to the original 33-item scale by Crowne and Marlowe (1960) and has rated it as preferred over other short forms (Fischer & Fick, 1993). This scale is commonly used alongside self-report measures to control for tendencies to respond in a socially desirable way. Responses to items are measured on a *yes/no* scale (with five items keyed true and five false). Higher scores on this scale indicate more socially desirable responding. This scale has demonstrated reliability with Strahan and Gerbasi (1972) reporting Kuder-Richardson formula 20 reliability coefficients of $.59$ to $.70$, and Fischer and Fick (1993) reporting internal consistency reliability of $\alpha = .84$.

Procedure. Following ethics approval, an online information sheet will be circulated to all interested participants, with a direct link to the questionnaire (Appendix A) for those who consent to participate. The questionnaire is expected to take 15-20 minutes. Following completion, participants will be directed to a debrief page and will be provided with information for relevant support contacts.

Proposed analysis. Each of the scales will first be examined using a series of Confirmatory Factor Analyses to determine whether each scale conforms to its previously established factor structure. Several generalised linear mixed models (GLMMs) will be implemented using the Statistical Package for the Social Sciences (SPSS version 20; IBM Corporation, 2011) to examine changes on the outcome measures. To optimise the likelihood of convergence, separate GLMM analyses will be run for each of the four dependent variables (DVs): expectations of grief symptomatology, intentions to provide social support, beliefs about social support, and opinions towards the diagnosis of grief. These DVs are conceptually independent; therefore, statistical significance can be evaluated at the conventional per-test alpha-level of $.05$. Due to their independence, analysing each outcome independently of the others is not expected to inflate the family-wise error rate. For H2-5, random allocation to groups will be necessary to ensure the greatest likelihood of group equivalence. For the bereavement experience of rater condition, however, it will not be possible to randomly allocate participants to groups. To address potential non-equivalence, each of the three groups will be

examined to determine whether they differ in terms of potentially confounding participant characteristics (e.g., age and gender). Where differences occur, these variables will be included as covariates in the GLMMs. The follow-up open-ended question will be analysed using content analysis, as per Hsieh and Shannon 's (2005) proposed conventions.

Phase Three

Participants. Participants for phase three will be adults residing in the Perth metropolitan area who have been bereaved by the death of a person. No constraints will be placed on the time that has passed since the death; rather, it has been decided on theoretical grounds that participants should decide when they feel prepared to discuss their bereavement (Williams, Woodby, Bailey, & Burgio, 2008). Although the progression of time may impact on the accuracy of recall (Williams et al., 2008), the focus of this study will be on capturing the participants' experiences of bereavement at the time of interviewing, rather than testing their ability to recall feelings at the time of death. Theoretical sampling will be used to select individuals, and sampling will occur concurrent to transcription and analysis, with the focus on emerging theoretical constructs from interim analyses (Boeije, 2002). Participants will be recruited through palliative care services, bereavement support groups, community noticeboards, and newspapers. These strategies have been fruitful in previous studies of bereavement (e.g., Breen & O'Connor, 2011; Costa et al., 2007; Schlernitzauer et al., 1998). Onwuegbuzie and Leech (2007) propose a sample size estimate that is located within the range used in similar past studies. Based on their recommendation, a sample of 15-20 participants is proposed as an estimate; however, the final number will be determined by the point at which theoretical saturation occurs (as defined by Strauss & Corbin, 1998).

Measures. Phase three will employ the aforementioned original PG-13 (Prigerson & Maciejewski, 2009) as a demographic measure of current levels of grief. The PG-13 is a 13-item self-report scale designed to assess the severity of an individual's maladaptive symptoms of grief over the past month. Responses are on a 5-point likert-type scale from 1 (*not at all*) to 5 (*several times a day or overwhelmingly*), with two questions structured as forced choice *yes/no*. The scale has demonstrated unidimensionality and adequate internal consistency reliability ($\alpha = .82$; Prigerson et al., 2009). The Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q-18; Ritsner, Kurs, Gibel, Ratner, & Endicott, 2005) will also be used as a demographic measure of quality of life, enjoyment, and satisfaction. The Q-LES-Q-18 is an 18-item self-report scale covering the five domains of leisure time activities, social relationships, subjective feelings, and physical health. Questions are answered on 5-point likert-type scales from 1 (*not at all or never*) to 5 (*frequently or all the time*). Quality of life is measured by summing the items, with higher scores representing higher quality of life. The Q-LES-Q-18 scale has demonstrated good construct and concurrent validity, high internal consistency reliability ($\alpha = .82$ to $.96$), and high test-retest reliability (ICC = $.71$ to $.83$; Ritsner et al., 2005).

The interviews will be guided by a semi-structured interview schedule, based on the second research aim and will be structured in such a way as to permit the discovery of new concepts and themes. The key focus of the questions will be on: (a) perceived reactions to the loss by people in their social environment; (b) types of support that were needed but not given; (c) personal reactions to how others in their social environment responded to their loss; (d) evaluation of the helpfulness of their own pre-existing beliefs; and (e) reflections on how the experience has impacted them and what suggestions they would give for helpful supports.

Procedure. For phase three, the research opportunity will be circulated to potential participants with an accompanying information sheet and consent form. Interested participants will be asked to contact the researcher to schedule an interview. Interviews are expected to take approximately one hour and will be conducted following a semi-structured interview schedule (Appendix B). Participants may choose to take a break or withdraw from the study at any time without consequence. Upon completion of the interview, participants will complete the PG-13 (Prigerson & Maciejewski, 2009) and the Q-LES-Q-18 (Appendix C; Ritsner et al., 2005). Finally, participants will be offered contacts in community mental health should they require additional support. The interviews will be audio recorded and transcribed verbatim using Playscript transcription.

Proposed analysis. Data will be analysed using the constant comparative method (CCM) to develop a conceptualisation of the phenomenon that is grounded in the data (Glaser, 1965; Glaser & Strauss, 1967). At the core of CCM is a continual process of comparing and contrasting across the four phases of: forming categories from incidents within interviews, integrating conceptually related categories across interviews, identifying boundaries around categories, and developing core themes that are embedded in and consistent

with the data (Glaser, 1965). NVivo version 10 (QSR International, 2012) will be used to manage the transcripts and will act as a platform for the coding and categorisation of data. CCM is increasingly being used as a methodological technique outside of Grounded Theory (Fram, 2013). In this way, CCM is not used to inductively generate a theory as Glaser and Strauss (1967) originally proposed, but rather it is a method of systematically processing data and producing a complete account of a social phenomenon (Lincoln & Guba, 1985). Variations of the CCM method have been used previously in bereavement research, and it is well suited for a topic such as this where no theory exists, but where there is a clear link between sociocultural processes and individual experiences of the phenomenon. Following analysis, participants will also be invited to engage in respondent validation of themes.

Statement of Thesis Format and Proposed Publications

The proposed research will be formatted according to a thesis by publication. It has been determined that this will better suit the three-phase design of the research. Proposed publications resulting from the research are outlined in Table 1.

Table 1.
Proposed Titles and Journals for Publication

Proposed title	Primary journal	Secondary journal
A systematic review of community responses towards bereavement: Implications for theory and practice	Personality and Social Psychology Review (IF 8.195)	Social Science & Medicine (IF 2.558)
Legitimising grief: A comparison of responses to grief in bereaved and non-bereaved individuals	Journal of Health and Social Behavior (IF 3.333)	The Journal of Nervous and Mental Disease (IF 1.812)
Grief in the public arena: Reconciling expectations with experiences in bereaved adults	Qualitative Health Research (IF 2.181)	Qualitative Research in Psychology (IF 1.487)
The future of community grief education: Towards the normalisation, acceptance, and support of people who are bereaved	Health & Social Care in the Community (IF 1.151)	International Perspectives on Stress and Coping (IF 0.718)

Ethical Issues

Careful consideration will be made to ensure the ethical and safe treatment of participants. The National Statement on Ethical Conduct in Human Research (The National Health and Medical Research Council, 2007) and Code of Ethics (Australian Psychological Society, 2007) will be adhered to in the design, collection, and reporting of data. Participants will be aged over 18 years will give informed consent. In both phases, participants will be given the opportunity to withdraw from the study up until data analysis. Participants in both phases will be known only by a participant ID number which will be cross-referenced to demographic information stored separately in a locked cabinet at Curtin University.

It is expected that the potential benefits of this research will outweigh any potential risks. No constraints will be placed on the time that has passed since the death, rather, potential participants will be asked to exclude themselves if they expect to experience significant distress as a result of participation. During the interviews in phase three, participant distress will be carefully monitored. At any time during the interview participants will be invited to choose to take a break, terminate the interview and continue at another time, or withdraw from the study without consequence. Given the sensitive nature of the topic, all participants across both phases will be offered an information sheet with community mental health supports. As an acknowledgement of time and effort, participants in phase two will be given the opportunity to enter a prize draw to win one of four Amazon or iTunes gift voucher to the value of AUD\$50. Participants in phase will be sent a letter of appreciation alongside a Coles Group and Myer gift card to the value of AUD\$15. In both cases, participants will be given the opportunity to substitute the voucher for a donation to a charity of their choosing.

Facilities and Resources

Year	Item	Total Cost
2014	Books	
	Qualitative Inquiry and Research Design	\$80
	Designing and Conducting Mixed Methods Research	\$70
	In-depth interviews master class	\$50
2015	Advertising	\$900
	Fuel for interviews	\$300
	Participation vouchers	\$500
	Transcription costs	\$2400
2016	National conference attendance and travel (ACGB)	\$1500
2017	International conference attendance and travel (ICGB)	\$2500
	Thesis printing and binding	\$200
TOTAL COST:		\$8500

Data Storage

All audio recordings, digital transcripts, and datafiles will be stored in a private file on a password protected computer at Curtin University. For phase three, all identifying information will be stored in a locked cabinet separate to the interview transcripts. All data will be stored for a minimum period of seven years, after which time they will be destroyed.

Timeline

2014	
Prepare candidacy document	January – September
School candidacy presentation	October
Submit candidacy and ethics	November
Conduct systematic review (Phase One)	October – January
2015	
Manuscript preparation and submission (#1)	February
Participant recruitment to conduct Phase Two	March – May
Data analysis of questionnaires	May – July
Manuscript preparation and submission (#2)	August
Participant recruitment and interviews for Phase Three	September – March (2015)
Transcription and analysis of interview data	September – May (2015)
2016	
Continued recruitment, interviews, and analysis	January – May
Present at ACGB national conference (Sydney)	March
Secondary level analysis of interviews	May – July
Synthesis of findings from three phases	August – October
Manuscript preparation and submission (#3)	December
2017	
Manuscript preparation and submission (#4)	January – April
Writing and compilation of thesis	February – November
Present at ICGB international conference (Lisbon, Portugal)	July
Submit thesis for marking	December

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