Review

A scoping review of bereavement risk assessment measures: Implications for palliative care.

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Abstract

Background: Palliative care standards and policies recommend that bereavement support be provided to family caregivers, yet uncertainty surrounds whether support currently offered by palliative care services throughout developed countries meets caregiver needs. The public health model of bereavement support, which aligns bereavement support needs with intervention, may address this gap between policy and practice.

Aim: The aim was to review the literature to identify bereavement risk assessment measures appropriate for different points in the caring and bereavement trajectories, evaluate their psychometric properties, and assess feasibility for use in palliative care.

Design: A scoping review was systematically undertaken following Arksey and O'Malley's (2005) methodological framework.

Data sources: PsycINFO, CINAHL, PubMed, and Cochrane Reviews databases, as well as grey literature including internet searches of Google, World Health Organisation, CareSearch, the Grey Literature Report, and OAIster were searched. Bereavement organisations and palliative care websites, reference lists in obtained articles, grief and bereavement handbooks were also scrutinised.

Results: Of 3,142 records screened, 356 records yielded 70 grief measures. Nineteen measures published between 1982 and 2014 were identified for inclusion in this review, and categorised for use with family caregivers at three points in time – before the

patient's death (n=5); in the period following the death (n=10), and for screening of prolonged or complex grief (n=4). The majority had acceptable psychometric properties; feasibility for use in palliative care varied substantially.

Conclusions: This review is an important preliminary step in improving the assessment of bereavement risk, and consequently better bereavement outcomes for palliative care family caregivers.

Keywords

Palliative care, bereavement, risk assessment, measures, instruments, family caregivers

Key Statements

What is already known/not known about the topic

- Improving bereavement care practices in palliative care is a high priority.
- The public health model of bereavement support aligns interventions with need across three groups – the bereaved population (universal), 'at risk' group (selective), and those with signs or symptoms of a disorder (indicated).

What this paper adds

- This is the first review to systematically identify existing bereavement risk measures for their use at three points in the caring and bereavement trajectories, evaluate their psychometric properties, and assess their feasibility for use in palliative care.

- The majority of measures exhibit acceptable psychometric properties, but their suitability for use in palliative care varies substantially.

Implications for practice, theory or policy

- Risk assessment is an essential step for the provision of bereavement support according to need.
- The systematic assessment of bereavement risk and provision of support will result in ~~a~~ more effective economical use of resources in palliative care.
- These findings may guide individual palliative care services towards evidence-based assessment and intervention, and inform palliative care practice standards.

Introduction

Standards and policies recommend support be provided to family caregivers of palliative care patients, and this-support should extend beyond the patient's death (1-5). Better bereavement outcomes is a goal of palliative care (6). However, bereavement support offered by palliative care services throughout developed countries is affected by a range of complex issues, including uncertainty about whether the supports provided by these services adequately meet the needs of bereaved family caregivers (7-10).

Of particular concern is that bereavement support in palliative care tends to be offered to all bereaved persons, irrespective of need (8, 10, 11). However, research indicates that, within the bereaved population, those experiencing greater distress, do not seek help (10, 12-14). This provision of blanket bereavement support means that some bereaved caregivers, possibly those in greatest need, may be overlooked, while others receive support they do not need (14, 15). As greater burdens are placed on the healthcare system, this approach is inappropriate and unsustainable (8, 10, 16). Providing bereavement support through effective assessment of need is required, and the public health model of bereavement support articulates a way to achieve this aim (10, 17).

The public health model of bereavement support

Public health approaches align interventions with need across three groups – the bereaved population (universal intervention), 'at risk' groups (selective), and those with signs or symptoms of a disorder (indicated) (10). Recent pilot testing in a community sample has provided preliminary empirical and theoretical support for the public health model in aligning bereavement support needs and intervention (11). By providing services appropriate to the needs of these three groups, palliative care services might better meet the support needs of the bereaved and use resources more efficiently (10).

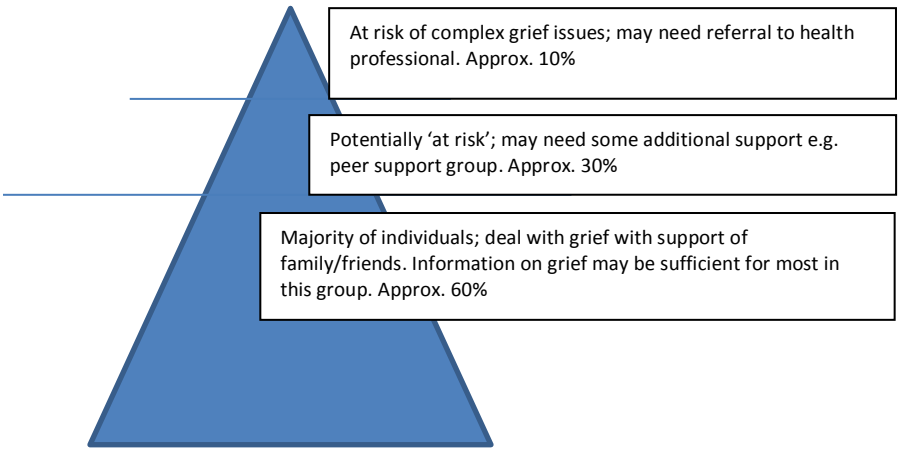

Figure 1. The Public Health Model (17).

Bereavement risk assessment is an essential initial step for the provision of bereavement support according to need. Various points along the care and bereavement trajectory are highlighted as being optimal for assessment (1, 2). The

first assessment should ideally be commenced between intake to the service, and the patient's death, in order to respond to mental health issues, or bereavement support needs in a timely manner. A second assessment should be conducted within three to six weeks after the death, to ascertain any trauma related to the death. In addition, a phone call to the family caregiver at 12 weeks post death is recommended, to determine if additional assessment or support is needed. For those identified as being at increased risk of prolonged or complicated grief in the initial assessments, a third assessment should be conducted approximately six months following the death (1, 2).

Extensive research has been conducted on complicated or prolonged grief, whereby bereavement distress triggers an intense grief reaction that can endure for an extended period, and may initiate ongoing physical or mental health disorders (18, 19). Such intense grief tends to interfere with integration and adjustment to the loss resulting in aversive symptoms, such as yearning for the deceased person, intrusive images and thoughts, rumination, inability to accept the death, a sense of meaninglessness, and feelings or behaviours which impede the bereaved person's social or occupational function (18, 19). This research has resulted in the inclusion of Persistent Complex Bereavement Disorder in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5)(20) as a condition for further study, and the removal of bereavement as an exclusion factor for the diagnosis of Major Depressive Disorder. Additionally, Prolonged Grief Disorder is proposed for inclusion in the

forthcoming revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-11) (21).

The objectives of the scoping literature review are to:

1) identify bereavement risk assessment measures that may be used to assess grief at different points in the caring and bereavement trajectories (pre-bereavement, following the death of the patient, and for complicated or prolonged grief):

2) evaluate measures on their psychometric properties; and

3) assess the feasibility of the measures for use in palliative care.

Methods

Selection of included studies

A scoping review of the literature, using the methodological framework set out by Arksey and O'Malley (22), was systematically undertaken to capture articles, or abstracts in English language citing bereavement measures between 1980 and August 2014. Databases searched were PsycINFO, CINAHL, PubMed, and Cochrane Reviews. Key search terms were grief, bereavement, mourning, family caregivers and caregivers, combined with measurement tool, measurement scale, instrument, rating scale, risk assessment, self-report questionnaire, and inventory.

Articles citing measures used for similar, but unrelated purposes were excluded. Such examples include end-of-life, dying, quality of life, satisfaction with care, survivorship, religion or spirituality, or other forms of loss unrelated to bereavement, such as divorce, employment or migration. Articles relating to grief measures used with infants, children and adolescents were also excluded.

Grey literature was also searched using the same search strategies. These included internet searches of Google, World Health Organisation, CareSearch (an online resource of evidence-based palliative care information), the Grey Literature Report, and OAIster. Bereavement and palliative care organisation websites were scrutinised for information on grief measures, as well as reference lists in obtained articles, and grief and bereavement handbooks.

Data extraction

Endnote software version 17 was used to create files for search results. Each database was allocated groups with search terms. Once files were downloaded from each database into EndNote, the articles were then assigned to sub-groups of duplicates of articles; relevant articles containing grief measures; and articles not-relevant. The relevant articles of interest were recorded on Microsoft Excel spread-sheets, listing authors, year and name of publication, country, and type of research.

The abstracts of articles of interest were perused for mention of a grief measure. If an abstract did not name measure/s, the full text article was read.

Measures were defined as a set of items, grouped in an instrument or tool, which evaluate how a person might feel about him/ ~~or~~ herself, in relation to his/ ~~or~~ her grief. Research articles identifying instruments used in the measurement of grief were then critically appraised in relation to reporting of psychometric properties, and clinical relevance of the information they might deliver, as well as for feasibility for use in palliative care. The measures were discussed by the research team and consensus reached on their inclusion in, or exclusion from, the search.

Results

Of the 3,142 records screened, 356 records yielded 70 grief measures. Of these, 19 grief measures, published between 1982 and early August 2014, were identified for inclusion in this review. Fifty-one measures were excluded due to a failure to address sufficient dimensions of grief relating to bereavement (n=30); were infrequently mentioned, unavailable, poorly described, may have been precursors to later, commonly used measures (n=15); or not available in English (n=6). A review flowchart is presented in Figure 2 (23). A summary of the properties of eligible measures are presented as appropriate for use with caregivers prior to the death of the patient (Table 1), in the period following the death (Table 2), and for assessing complicated or prolonged grief (Table 3).

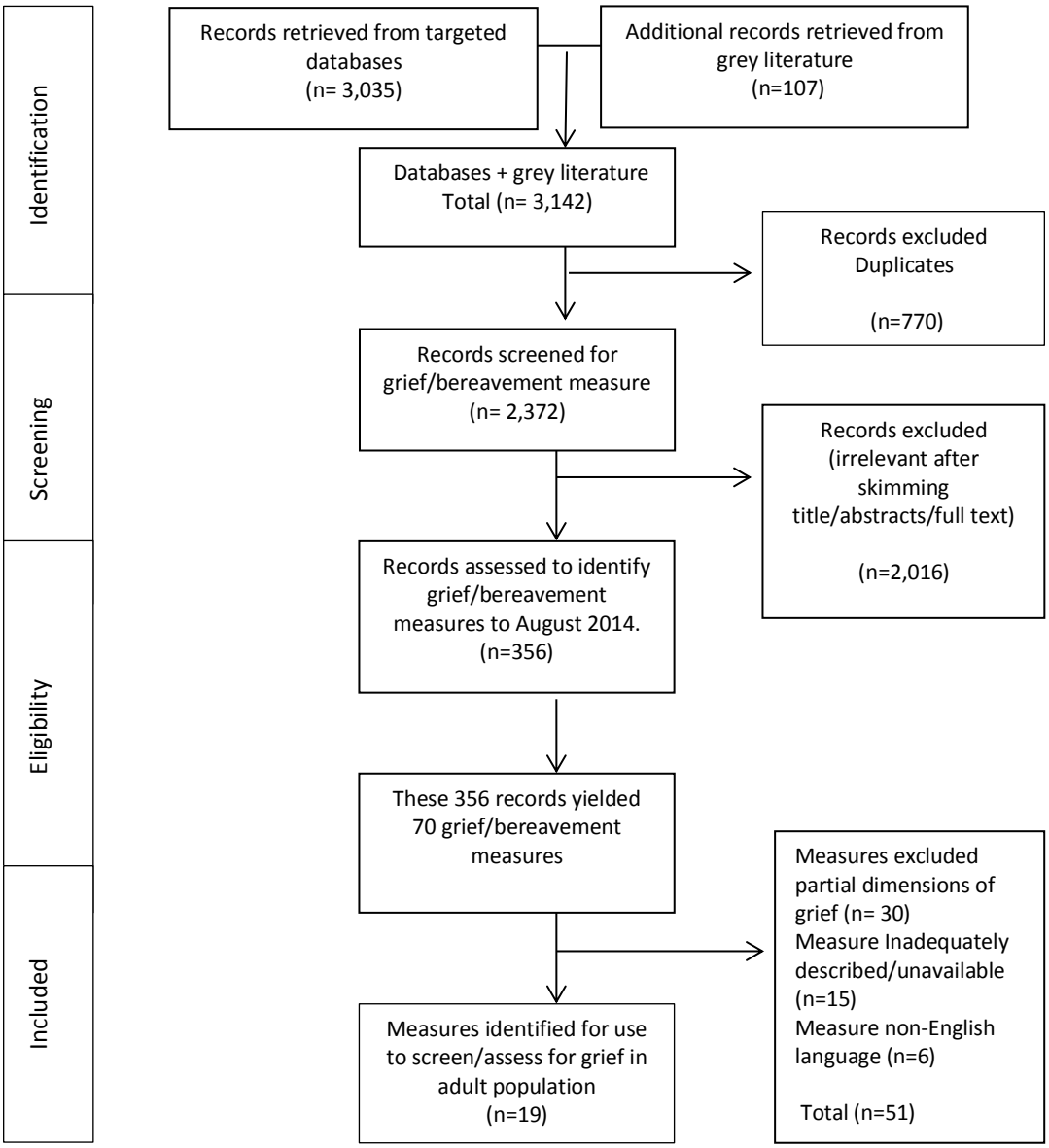

Figure 2. Flow diagram outlining selection of measures from relevant articles.

Pre-death measures of bereavement risk

Five measures were identified that were specifically designed to assess grief prior to a death (Table 1). These were three caregiver self-report measures and two staff-administered observational checklists. One checklist was the Bereavement Risk Assessment Tool (BRAT), developed by Canadian palliative care health professionals, based on ten case studies rated by 36 bereavement professionals, which demonstrated moderate inter-rater reliability. The items include both risk and protective factors stemming from the literature and clinical experience. It centres on staff observation, rather than direct enquiry of the caregiver's perceptions of his/her emotional state or coping. It also requires staff to be trained in its use, and has a large number of complex factors that staff rate subjectively (24).

The other checklist was the eight-item Bereavement Risk Index (BRI), which exhibited adequate internal consistency when tested for reliability in a community palliative care service. This assessment, which maps to a support protocol, is brief and user-friendly; however, it is based on staff observations, rather than directly asking the caregiver. A modified four-item version, had improved internal consistency and retained predictive validity when compared to the longer version (25). A modified version of the BRI was also used in a small longitudinal study of spousal bereavement, but the authors reported it to be unsuitable for prospective use without adaptation (26).

Two self-report measures were originally developed for use with dementia caregivers; the 50-item Marwit-Meuser Caregiver Grief Inventory (MMCGI), which also has a short form. Initial validation of the MMCGI showed three factors – personal sacrifice burden; heartfelt sadness and longing; and worry and felt isolation – each demonstrated high internal consistency reliability. The scores of the measures are highly correlated with scores on the Beck Depression Inventory (BDI), the Anticipatory Grief Scale (AGS), the Caregiver Strain Index (CSI), the Perceived Social Support-Family Questionnaire (PSSQ-FA), and the Well-Being Scale- Basic Needs (CWBS-BN) subscales (27), indicating good construct validity. This instrument has good internal consistency when used in caregivers of people with acquired brain injury, where it was found to be highly correlated with the same measures as in the original validation study cited above (28). While the measure requires modification for use outside dementia, one study conducted with cancer caregivers, demonstrated high internal consistency (29). A short form (18 items) of the MMCGI-SF, was also extracted from the longer version and had similar psychometric properties and high correlations with the measures in the original study (30).

The remaining self-report measure is the 12- item PG-12-Caregiver version, developed from the PG-13 (31), specifically to screen for pre-death susceptibility for Prolonged Grief Disorder (PGD) (19). It is brief and targets those at risk of prolonged

grief prior to the patient's death. In a study on caregiver burden in hospice caregivers, almost half were found to be at risk of PGD (32).

Table 1. Pre-death measures of bereavement risk (*n*=5).

Measure	Initial test population, and purpose of measure	Format and items	Psychometric data
Bereavement Risk Assessment Tool (BRAT) (24).	Palliative care family caregivers (N not reported). To identify those at risk of complex grief prior to patient's death.	40-item, staff observational checklist. Items based on 36 risk factors and 4 protective factors associated with bereavement)	Inter-rater reliability for agreement on measure items: Fleiss' kappa ranging between 0.05 and 0.97.
Bereavement Risk Index (BRI) (25, 26).	Palliative care family caregivers (N=150) (25). Longitudinal study of bereaved spouses (N=46) (26).	8-item, staff observational checklist completed by nurse at the time of patient's death (25) . Completed by researcher in a battery of 3 measures, before death, and twice following death (26).	Internal consistency: Cronbach's alpha 0.64 (25). BRI psychometric data not reported(26).
Marwit-Meuser Caregiver Grief Inventory (MM-CGI) (27-29).	Caregivers of people with dementia (N=166). To assess grief in caregivers (long term & acute) prior to death of a patient (27). Caregivers of people with acquired brain injury (N =28) (28). Caregivers of people with cancer (N=75) (29).	50-item self-report, 5 point Likert scale, consisting of 3 sub-scales.	Internal consistency: Cronbach's alpha 0.96 for total grief score, & ranging between 0.90 & 0.95 for sub-scales (27). Cronbach's alpha between 0.86 and 0.90 (28). Cronbach's alpha between 0.90 and 0.96(29).
Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF) (30).	Caregivers of people with dementia (N= 292). To develop a shortened version, for research, and for cases where attention span is reduced (30).	18-item self-report, 5 point Likert scale, consisting of 3 sub-scales.	Internal consistency: Cronbach's alpha ranging between 0.80 & 0.83 for subscales (30).
Prolonged Grief (PG-12) (31, 32).	Adult caregivers of people with dementia in residential aged care (N=315).	12-item self-report, 5 point Likert scale	Internal consistency: Cronbach's alpha 0.81 for 10 of the 12 items (31).

	To describe pre-death grief and differentiate between grief & depression (31). Adult caregivers of hospice patients (N=60). To measure incidence of PGD (32).

Measures of bereavement risk following a patient's death

Ten self-report measures, developed for a variety of purposes from research to clinical assessment, were identified for possible use to measure caregivers' bereavement support needs following patient death (Table 2).

The 67- item Bereavement Experience Questionnaire (BEQ), was modified to the Bereavement Experience Questionnaire – 24 (BEQ-24) to assess three loss domains – existential loss/emotional needs, guilt/blame/anger, and preoccupation with thoughts of the deceased – reflective of 'normal' grief (33).

Similarly, the 17-item Core Bereavement Items (CBI) scale was developed from an earlier Bereavement Phenomenology Questionnaire (BQ), which had been designed to map grief experience and intensity. The CBI has three subscales – images and thoughts, acute separation, and grief. The CBI exhibits high internal consistency and suitable convergent validity with the Texas Revised Inventory of Grief (TRIG) past and present scales (34). Researchers have used this measure to associate spiritual beliefs and grief resolution (35), bereavement outcomes in two ethnic groups (36), and the role of trauma and death anxiety in complicated grief (37). Being shorter in length

and therefore more practical for caregiver use, the CBI measure appears promising for use in palliative care; however, it is considered to be a generalised measure of grief (38), and therefore may not identify those caregivers at risk of poor bereavement outcomes.

The Grief Evaluation Measure (GEM) was developed to provide clinicians with readily accessible information for treatment planning, and in particular, to identify risk of complicated grief. Items were drawn from risk factors identified in the empirical literature. The 91-item instrument-covers demographic information, previous health issues and losses, relationships and resources, as well as peri-death circumstances that may impact bereavement distress. At the heart of the instrument are the *Experiences* (58 items), and the *Problems* (33 items) sections. A final section invites the caregiver to comment. Internal consistency reliability was high for the central *experiences* and *problems* sections, and correlated well with other measures such as the Inventory of Complicated Grief (ICG), and the Impact of Events Scale-Revised (IES-R) (39). The GEM is psychometrically sound and comprehensive, but its complexity and length makes it impractical for use in palliative care. Most palliative care services do not have face to face contact with caregivers following the patient's death, which reduces the likelihood that a complex and lengthy measure would be understood, completed, and returned to the service.

The Grief Experience Questionnaire (GEQ) was developed to compare grief in those who had lost someone to suicide, with those who had lost someone to natural or accidental causes. It comprises 11 sub-scales that cover somatic and general grief reactions, meaning making, social support, stigmatisation, guilt, responsibility for the death, shame, rejection, self-destructive behaviour and reactions exclusive to suicide survivors. While many of these are common grief experiences, Barrett and Scott state that some features are more pronounced or unique in those grieving a suicide loss (40). A subsequent study found that the measure was suitable for both clinical and research use in all grief, not suicide alone, but authors note that further research is needed before being applied to palliative care (41).

The Hogan Grief Reaction Checklist (HGRC) was based on data derived from focus groups with bereaved parents. Exploratory Factor analysis of this data yielded six factors – despair, panic behaviour, blame and anger, detachment, disorganisation, and personal growth (42). The 61-item HGRC would also seem to be very long and complex to be of practical use for post-death assessment by in palliative care services.

The 22-item Revised Grief Experience Inventory (R-GEI) was developed from the earlier, 135-item Grief Experience Inventory (GEI), with each item scored as a yes/no response. The four R-GEI subscales explore existential concerns, depression, feelings of tension and guilt, and physical distress. The R-GEI may have practical application in the palliative care context, although the authors state that it provides a

framework for clinicians to work with routine grief responses (43), which may not be suited to identifying 'at risk' caregivers.

The 34-item Inventory of Traumatic Grief (ITG) was developed to examine symptoms for 'pathological' grief, a term its developers originally used interchangeably with 'traumatic grief". The researchers saw two main symptom clusters of separation distress and traumatic distress. The ITG is an expanded version of the Inventory of Complicated Grief (ICG) which will be discussed in the next section (44, 45).

The Texas Revised Inventory of Grief (TRIG) was developed from the earlier Texas Inventory of Grief (TIG) as a brief measure of unresolved grief (46); however as the items were derived from both normative and atypical grief responses, it is considered to be a measure of 'normal' grief (38, 47, 48). The TRIG comprises two subscales, which may be used independently; *Past* behaviour scale (eight items) and the *Present* feelings scale (13 items) (38). The TRIG has been used to measure adjustment and grief intensity in hospice caregivers, from prior to the death until 13 months post-death (49).

Finally, the Two-Track Bereavement Questionnaire (TTBQ) was developed to assess grief responses across time. Factor analysis showed five factors that could be broadly categorised within two domains – the bereaved person's bio-psychosocial function (Track 1) and ongoing connections with the deceased (Track 2) (50). While

this measure is psychometrically sound and gathers comprehensive, clinically useful information, its complexity and length poses a problem for palliative care use. The TTBQ has recently been developed into a shorter 30-item measure, the TTBQ2-CG30, to assess complicated grief in terms of the ongoing relationship with the deceased and the impact on function (51). As services have limited to no contact with caregivers after the death, this shorter version may have application to palliative care and warrants further research to determine its suitability.

Other measures cited in the literature, and not included in this review, were the BPQ (52) as it was later incorporated into the CBI (34). Likewise, the TIG (46) was expanded into the TRIG (47), and the lengthy 135 item GEI by Sanders and colleagues, was modified to form the R-GEI (43). The BEQ by Demi in 1984, was revised to the BEQ-24 to address a number of theoretical issues in the earlier instrument (33). The Grief Measurement Scale (GMS), while being mentioned in some literature (48, 53, 54), has proved difficult to locate. The GMS included items relating to anxiety, depression and general grief, while omitting the more serious symptoms of complicated grief (48). The Impact of Events Scale (IES) and Impact of Events Scale-Revised (IES-R) were used as measures of grief in research studies (55), but were excluded in this review because they are measures of traumatic stress (56, 57), rather than grief.

Table 2. Measures of bereavement risk following a patient's death (*n*=10).

Measure	Initial test population, and purpose of measure	Format and items	Psychometric data
Bereavement Experience Questionnaire – 24 (BEQ-24)(33).	Bereaved adults within 2 years of bereavement (N=437) with additional validation study (N=297)(33).	24- item self-report, 4 point Likert frequency scale.	Internal consistency: Cronbach's alpha ranging between 0.70 & 0.84 (33).
Core Bereavement Items (CBI) (34)**.**	Bereaved adults (N=158)(34).	17- item self-report, 4 point Likert frequency scale.	Internal consistency: Cronbach's alpha total grief of 0.91 (34).
Grief Evaluation Measure (GEM)(39).	Bereaved adults: validation sample (N=92); reliability sample, one year later (N=23) To assess nature & severity of grief following loss (39).	91- item self-report, 6 point Likert scale consisting of 7 sections in total; 6 scaled sections, with one open narrative section.	Internal consistency in validation sample for *Experiences* section Cronbach's alpha 0.91; *Problems* section Cronbach's alpha 0.97 Test- retest correlation in reliability sample for *Experiences* section (*r=.*97); *Problems* section (*r*=.88)(39).
Grief Experience Questionnaire (GEQ)(40).	Conjugally bereaved adults to suicide, natural causes or accidental death at 2 to 4 years post-loss (N= 57). To differentiate grief related to suicide death from grief related to natural &/or accidental deaths (40).	55- item self-report, 5 point Likert scale consisting of 11 subscales.	Internal consistency: Cronbach's alpha ranges for subscales between 0.68 & 0.89, with a total alpha of 0.97 (40).
Hogan Grief Reaction Checklist (HGRC)(42).	Parentally bereaved people recruited from support groups (N=586) for an initial 100-item checklist. (N=209) in revised 61- item checklist. To gauge the multidimensional features of grief and bereavement over time (42).	61- item self-report, 5 point Likert scale consisting of 6 factors.	Internal consistency: Cronbach's alpha ranges for subscales between 0.79 & 0.90, with a total alpha of 0.90. Test-retest reliability correlations range between 0.56 & 0.85 (42).
Inventory of Traumatic Grief (ITG) (44).	Elderly widowed residents, 3.5 months following a loss (N= 76). To measure maladaptive symptoms of grief (44, 45).	34-item self-report, 5-point Likert scale consisting of 2 factors (44).	Internal consistency: Cronbach's alpha 0.95 (44).
	Bereaved adults within previous 3 years, who had help with their grief (N=250) (45).	Dutch version ITG 29-item self-report, 5 point scale, with one single	Internal consistency: Cronbach's alpha 0.94. Test-retest correlation

		factor (45).	(n=29) ranged between 0.41 & 0.91, with total 0.92 (45).
Revised Grief Experience Inventory (R-GEI) (43).	Hospice caregivers following the death of a loved one (N=418). To quantify grief in the context of various relationships (43).	22-item self-report, 6 point scale consisting of 4 subscales.	Internal consistency: Cronbach's alpha 0.93 (43).
Texas Revised Inventory of Grief (TRIG) (58).	Bereaved psychiatric outpatients between 2 months & >2 years post loss (N=57) (58). TIG Expanded: Bereaved adults (N=211) (59). Initially developed as a measure of unresolved grief (TIG) (46).	21-item self-report, 5 point Likert scale consisting of 2 standalone subscales, past (8 items) & present (13 items).	Limited information available for seminal TRIG research. Internal consistency: Cronbach's alpha 0.86; Split-half reliability *r* = .88 (TIG expanded which forms basis of present TRIG) (47).
Two Track Bereavement Questionnaire (TTBQ) (50).	Bereaved adults (N=354). To gauge grief reaction across time in relation to bio-psychosocial function and ongoing relationship with the deceased (50).	70-item self-report, 5 point Likert scale, consisting of five factors, divided into two domains.	Internal consistency: Cronbach's alpha ranged between 0.75 & 0.94 for the 5 factors, with a total alpha of 0.94 (50).
Two Track Bereavement Questionnaire (TTBQ2-CG30) (51).	Adults bereaved by traumatic deaths (N=412). To assess for complicated or prolonged grief (51).	30-item self-report, 5 point Likert scale consisting of four factors, across two domains.	Internal consistency: Cronbach's alpha 0.91 (51).

Measures of complicated or prolonged bereavement risk following a patient's death

Four self-report measures were developed specifically for complicated or prolonged grief, and may be suited to assess poor adjustment to bereavement six months post-death and beyond. Three of these measures were developed from research determining how the symptoms of complicated or prolonged grief are distinct from 'normal' grief, as well as depression and anxiety. These well-validated and

widely used measures (38) are the Inventory of Complicated Grief (ICG) (48), which also has a revised 15-item version (ICG-R) (19), and the PG-13, an algorithm for diagnostic criteria for Prolonged Grief Disorder (19). The ICG and the ICG-R were used to assess grief across various grieving populations such as spousal (48) and parental loss (60), those bereaved following traumatic events (61) and suicide (62), and in settings such as mental health (63), intensive care (64), palliative care (65) and oncology (66). The PG-13 has also been used across a variety of research including refugee populations (67), and Motor Neurone Disease (MND) caregivers (68).

The Brief Grief Questionnaire (BGQ) also known as the Brief Complicated Grief Questionnaire (BCGQ) was developed as a brief screening instrument for complicated grief following the 911 terrorist attacks in the USA (69). This measure has also been used to determine the prevalence of complicated grief in a large sample in Japan, demonstrating cross-cultural applicability. Its psychometric properties remain adequate across studies (70, 71).

Table 3. Measures of complicated or prolonged bereavement following a patient's death (*n*=4).

Measure	Initial test population, and purpose of measure	Format and items	Psychometric data
Brief Grief Questionnaire (BGQ) (69-71).	Recipients of crisis counselling following 911 terrorist attacks. (N=149). To provide a rapid screening measure of complicated grief > 6 months following the death (69). Bereaved community	5-item self-report, 3 point frequency scale.	Internal consistency: Cronbach's alpha 0.82(69). Internal consistency:

	dwelling adults bereaved between 6 months and 10 years (N=915) (70).		Cronbach's alpha 0.75 (70).
Inventory of Complicated Grief (ICG) (48).	Conjugally bereaved elders (N=97). To assess complicated grief symptoms as distinct from 'normal' grief (48).	19-item self-report, 5 point frequency scale, showing one single factor from original 22 item measure.	Internal consistency: Cronbach's alpha 0.94. Test-retest reliability: 0.80 (n=28).
Inventory of Complicated Grief-Revised (ICG-R) (19).	Data from Yale Bereavement Study (N=291). To validate criteria for diagnosis of prolonged or complicated grief (CG) (19).	15-item self-report, 5 point frequency scale	
	Conjugally bereaved elders (N=481). To assess complicated grief factors, & the relationship between CG & PTSD (72).	Shows 2 factors – separation anxiety & traumatic distress (72).	Internal consistency: Cronbach's alpha: Total 0.94 Ranging between .60 & .66 for separation anxiety, & .38 to .68 for traumatic distress(72)
	Bereaved people in general practice & palliative care (N=276). To identify people at risk of CG (73).		Internal consistency: Cronbach's alpha: Total 0.90 (73).
Prolonged Grief-13 (PG-13)(14, 74).	Adults (N=424). To compare grief across bereavement, divorce & job loss (74). Bereaved caregivers with PGD (N=86). To examine use of mental health services in people with PGD (14)	13- item self-report, 5 point Likert scale.	Internal consistency: Cronbach's alpha: Total 0.94(74). Internal consistency: Cronbach's alpha: Total 0.82(14).

Discussion

The primary aim of the scoping review was to identify bereavement measures that could be used by palliative care services, to screen for risk of poor bereavement outcomes in caregivers at three points in time – before the death of the patient, in the weeks following the patient's death, and six months following the patient's death (2).

These measures were evaluated based on their psychometric properties, and feasibility for use in palliative care settings with the intention of informing a bereavement risk assessment protocol based on the public health model of bereavement support that aligns bereavement risk with service provision.

It is notable that the majority of the bereavement measures had acceptable psychometric properties. However, validity and reliability were not always reported consistently. The measures were initially developed for a variety of purposes, ranging from screening to diagnosis, treatment planning, and assessment of efficacy of interventions in both clinical and research contexts. They were used ~~in~~ across a wide variety of populations and settings, and although some had been used in palliative care, or for family caregivers of people with life-limiting illnesses, only one had been developed specifically for palliative care (24). A number of measures were developed for the assessment or screening of complicated or prolonged grief later in the bereavement trajectory (19, 69).

There are a number of issues that need consideration when assessing bereavement risk in palliative care. Palliative care provides a window of opportunity to assess grief and bereavement needs in the lead up to the patient's expected death (75). Generic measures arguably should not require modification for use in palliative care if they are measuring a given construct in other populations (15). However, it is clear that situations faced by caregivers in palliative care are also unique, in that there

are often additional issues that may affect grief responses, assessment and the provision of support (6, 75, 76). As such, balancing the need for theoretically sound and empirically validated measures, with robust psychometric properties, alongside the practical need for a tool that is acceptable and feasible for use in busy clinical settings, remains a challenge.

Implications for palliative care practice

It is important to consider the model of care and funding source of a service, particularly in light of the rapidly changing environments we are presently witnessing. These include changes to how palliative care services are delivered, and to whom, alongside social and cultural changes inherent in any population (15). Community based services generally have longer contact with patients and caregivers, while inpatient or consultative services in hospitals may only have contact with patients and caregivers nearer end-of-life. Any bereavement risk assessment model needs to be developed within a range of referral pathways, not only counselling or therapy (10, 77).

A recent trend toward late referral to palliative care and shorter lengths of stay mean staff have little opportunity to build a comprehensive picture of patient needs, as was done previously with the use of staff observations and checklists (77, 78). While family caregivers are considered to be a part of the unit of care in a palliative care

service (5), and staff accept that bereavement support is important, the primary focus nevertheless remains on end-of-life care and the patient's comfort and symptom control (79). While lengthy measures are likely to extract comprehensive information, they are inappropriate when a family caregiver's time with the patient is limited, or when caregivers are focused on the needs of the dying patient (80).

The lead up to the death may be stressful to caregivers, and may become confounded with grief. Conflation of these constructs clouds the issue of assessment and must be taken into account when assessing grief and bereavement support needs (80). This raises the question as to what services need to assess in relation to what support they can, or should, provide.

Assessment following the patient's death often poses other challenges. Many services conduct follow-up via mail and/or telephone (8), which may not allow for caregivers to accurately convey responses about complex emotional states. In turn, this may impact the validity of their responses. Further, while standards recommend that bereaved former caregivers identified as being at increased risk of complicated or prolonged grief should be followed-up again at six months post-death (1,2) this is not yet established practice in palliative care (8). It is likely that staff would require upskilling so that they can undertake these assessments to identify and support caregivers pre and post bereavement appropriately.

With the above constraints in mind, we identified 19 grief measures as having adequate psychometric properties, and potential applicability for use in palliative care. Previous reviews have identified grief measures within a broad variety of instruments, from often overlapping domains, for use in palliative care (75, 83). This in itself is problematic, as it not only makes comparisons of measures difficult, but may possibly impede consensus on a bereavement risk assessment protocol (84). The present study has classified measures in line with recommended standards (1,2), as well as aligning bereavement needs with support in accordance with the public health model (17). If a more robust assessment of caregiver bereavement support needs can be made between admission and separation from the service, it is expected that the follow-up after the death will be more targeted to those in need of support, rather than following up the majority who integrate their loss over time.

Limitations and future directions

While hand searches of books, articles and organisations were conducted, and grey literature was searched, it is likely that sources were overlooked due to the immensity of the subject area. However, we are confident that the 19 measures included here were salient, as they were commonly cited in the literature. Psychometric properties, and/or the theoretical frameworks of measures have not been reported consistently in the searched articles, so there may be ambiguity for the reader

who is looking for clear comparisons between instruments and their utility along the caring and bereavement trajectories.

Future research is needed to investigate why palliative care services have not adopted existing bereavement risk assessment measures as routine practice (8, 75). Undoubtedly bereavement risk assessment is multifaceted and complex. As such implementing a bereavement risk assessment model for palliative care is a departure from current practice, and will not be without its challenges.

Conclusion

The aim of this scoping review was to identify bereavement risk assessment measures suitable for use in palliative care, congruent with the public health model of bereavement support. This review has centred on the assessment of grief, rather than a broad range of related palliative care domains, which have been the focus of other reviews (15, 83). We identified 19 frequently cited grief measures that were categorised for use with family caregivers at three points in time – before the patient's death; in the period following the death, and at six months post-death to screen for prolonged or complex grief issues. As stated above, the complexities of grief, bereavement and palliative care make it difficult to define the necessary attributes when considering measures for a bereavement risk assessment model. Issues relating to the unique conditions inherent in palliative care, such as conflation between

caregiver burden and grief, and service contact with caregivers, must be resolved before moving forward with a bereavement risk assessment model. This review is an important step in the process of moving toward appropriate assessment of bereavement risk, and better bereavement outcomes for people caring for a patient or family member in palliative care. Timely and suitable assessment and targeted support according to need would be a leap forward in the provision of ethical, effective, and cost-effective bereavement support in palliative care.

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Conflict of interest statement

The authors declare that there is no conflict of interest.

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