

# Bereavement needs assessment in specialist palliative care: a review of the literature

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## Abstract

Bereavement needs assessment for specialist palliative care services has been highlighted as important by NICE guidance on palliative care for adults with cancer. Identifying and implementing appropriate bereavement measurement tools has remained a challenge. This paper identifies and reviews bereavement measurement tools to determine their suitability for use within bereavement services and hospice settings. Cochrane, MEDLINE, PsycINFO and CINAHL, electronic databases were searched, yielding 486 papers. From fifty-nine full text papers appraised, 10 measurement tools were analysed in detail. Some tools had been tested on specific populations which limited transferability to specialist palliative care settings; some lacked adequate theoretical links and were not effective in discriminating between normal and complicated grief reactions; and some lacked clear evidence of validity or reliability. Based on these criteria, conclusions are drawn about the suitability of particular tools for UK bereavement services and hospice settings where intervention is delivered by both trained professionals and volunteers.

## Keywords

bereavement, literature review, needs assessment, palliative care

## Introduction

Grief is a natural response to human loss. Each loss is unique and the requirement for bereavement support varies according to the resilience and diverse needs of each person and family affected. Although most individuals have sufficient inner and informal resources to adapt to this life transition, some are more vulnerable and may be at risk of developing lasting physical or mental health problems or complicated bereavement.<sup>1</sup> Reviews of the risk factors that influence grief<sup>2–4</sup> conclude that differences in health outcome are affected by the unique predisposing characteristics and circumstantial factors that may determine the bereaved person's vulnerability to loss or their adjustment to bereavement.<sup>2</sup>

Providing a universal bereavement service is unnecessary and offering therapy to resilient individuals is known to be unhelpful or indeed harmful.<sup>5–11</sup>

Therefore, bereavement support should be offered in response to individually assessed need.<sup>2,12</sup> According to the National Institute for Clinical Excellence (NICE) Guidance for Supportive and Palliative Care for Adults with Cancer,<sup>13</sup> (p. 157) 'Professionals are often not adept at assessing, predicting and responding to families' and carers' bereavement needs, both before and after death'.

Recommendations for the development of bereavement support services in UK palliative care settings have been highlighted nationally.<sup>11–14</sup> Organizations are challenged to implement reliable methods of screening and assessing bereavement outcomes based on the three component model of bereavement support in the NICE Guidance.<sup>13</sup>

## Patterns of bereavement response

The death of a person with whom an individual has a significant relationship is challenging.<sup>15</sup> The expression

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of normal grief is evident through emotional, cognitive, physical and behavioural features.<sup>16</sup> Key events may be anticipatory grief if a death is expected, the immediate news of the death, the stages of acute grief, and in some cases, the complications of bereavement.<sup>17</sup> Normal and abnormal responses to bereavement span a spectrum in which intensity of reaction, presence of a range of related grief behaviours, and time course determine the differentiation.<sup>17</sup>

A large proportion of the bereaved experience common grief reactions where normal life functioning is interrupted with depressive symptoms. Distress is present for several months and gradually alleviates over time. There is adjustment to loss and bereavement by individuals utilizing their own inner personal strengths, existing informal resources and support systems.<sup>7</sup> Non-involvement of professional services (component one of the NICE bereavement model) is balanced against duty of care which may be met by the provision of information on common grief reactions and the availability of formal bereavement support services. This approach, which aims to promote resilience, respects that not all bereaved individuals experience acute distress by their loss and recognizes that many are able to maintain relatively stable, healthy levels of psychological and physical functioning.<sup>18</sup>

Component two of the NICE model recognizes that a minority of individuals, who may find bereavement difficult without formal support, are known to be more vulnerable, more at risk of lasting physical or mental health consequences,<sup>13,14,19</sup> and more likely to suffer impairments in social, family and occupational functioning.<sup>20-22</sup> They often need an opportunity to review their loss experience and volunteers or self-help and community groups may offer much of this support. Service providers however must establish a process for onward referral if more complicated or specialist bereavement needs emerge.

Component three recognizes that a minority of individuals will require specialist interventions for complicated grief reactions. Complicated grief is characterized by distressing symptoms lasting at least 6 months following the death of a significant person or relative. Specialist service responses are likely to include: referral to mental health services, psychological support, counselling or psychotherapy services; provision of specialist palliative care and general bereavement services; and specialist intervention to meet the needs of bereaved children and young people.<sup>13</sup>

In this paper we review existing bereavement assessment tools which facilitate objective decision-making about the type and level of bereavement service that may be needed. We focus on two types of bereavement assessment: (1) assessment commencing at the point of

referral or admission to palliative care, and continuing into early bereavement and (2) assessment conducted when an individual presents requesting formal bereavement support and is screened for normal or complicated grief.

### *Bereavement assessment practice*

Bereavement risk assessments have been incorporated into hospice practice since the 1970s with the work of Parkes.<sup>5</sup> The advantage of referral to palliative care is that anticipated death is usually acknowledged and the time interval between referral and death may offer an opportunity to engage in complicated bereavement risk assessment practice.<sup>2</sup> According to Kissane<sup>17</sup> (p. 1141) as palliative care teams are involved continuously from the patient's admission, they are ideally placed to recognize those at increased risk of complicated grief and to plan preventive interventions in an endeavour to reduce morbidity. Empirical evidence confirms that when preventive interventions are targeted to those at risk, benefits ensue.<sup>23</sup>

In most services, nurses use their clinical judgement, and formal bereavement assessments, applying written checklists of established risk factors, are used in 40% of UK hospices.<sup>24</sup> These checklists, usually completed by nursing staff in conjunction with multidisciplinary discussions, are used to assess the perceived needs of bereaved individuals. They are central to demonstrating the decision-making process surrounding the type, level and timing of support to be offered,<sup>11</sup> to ensuring accuracy of information collected and to facilitating audits of practice.<sup>2,5,6,8,24-28</sup>

As in other spheres of health and social care, anxieties have been expressed about the reliability of such checklists in 'measuring' accumulated risk factors or in predicting outcomes.<sup>29</sup> It has been found that assessments completed before or around the time of a patient's death, frequently reduced to a series of tick boxes, are often incomplete or inaccurate. Information is limited due to brief hospice stays, reluctance by nursing staff to ask 'intrusive' questions,<sup>30</sup> poor user involvement and limited staff training in psychosocial care.<sup>11</sup>

Specialist palliative care teams are well placed to undertake bereavement risk assessments around the time of the patient's death. However, formal methods, such as Parkes' Risk Index,<sup>31</sup> show limited reliability to predict bereavement outcome.<sup>32,33</sup> Many formal assessments also neglect ethical issues around assessment practice and have not altered the widely applied model of universal, proactive service delivery by specialist palliative care teams or hospices. Although some individuals may self-refer for additional support, there may be a more reliable method of assessment

which specialist palliative care teams might use to screen for risk of complicated bereavement. Such a measure might enable specialist palliative care to focus support on those in greatest need.

Ellifrit et al.<sup>34</sup> found consensus among American bereavement professionals regarding the prioritization of risk factors and concluded that it is possible to assess bereavement risk in carers of seriously ill patients, prior to their loss. However, this requires professionals who are confident in clarifying concerns, assessing risk and offering preventive interventions. Similarly, in Australia Aranda and Milne<sup>2</sup> reported that most studies in complicated bereavement focused on the measurement of psychological distress and ill health to determine outcomes post-bereavement, therefore medicalizing grief, with the disadvantages of not exploring social vulnerability and adjustment factors or differentiating between grieving styles. Whilst Aranda and Milne<sup>2</sup> do not endorse a particular bereavement risk assessment tool, they do recommend that family members of dying individuals should be involved in their assessment; that risk of complicated bereavement assessment forms be part of the palliative care team's duty of care; that assessment be commenced at the point of referral to palliative care and continue into early bereavement; and that assessment should involve the illness, care and nature of death, the characteristics of the bereaved, the interpersonal relationships, the family functioning and the characteristics of the deceased.

Self-referral post-bereavement is in line with NICE guidance<sup>13</sup> and offers information on common grief reactions and support services to all bereaved families, and an assessment is only conducted when an individual requests bereavement support. Such a model requires that the individual is able to recognize their need for support and have the courage and motivation to self-refer. The advantage of such an approach is that the individual can provide accurate information based on how they have been coping with their bereavement and can identify their current informal and formal support networks. In this way, resilience is encouraged and the individual is more actively involved in the assessment and care planning process. According to Reith and Payne<sup>35</sup> (p. 139) this approach promotes individual choice regarding service uptake, respects the capacity of the bereaved individual to determine their point of entry into service provision, is less likely to create stigma based on a deficit model of assessment and will moderate the tendency of professionals to decide who needs bereavement support. A number of bereavement assessment tools can be used, some of which are self-assessment methods and some of which have been validated to predict or confirm complicated grief reactions.

### *Theory underpinning bereavement assessment*

The subscales of the majority of bereavement measurement tools<sup>36–39</sup> were originally developed applying the tenets of attachment theory.<sup>40</sup> The Colorado Bereavement Services Project<sup>41</sup> assessment tool is based on Four Tasks of Mourning identified by Worden,<sup>42</sup> whose theoretical interpretation of grief responses has contributed to a simplified approach to grief. However, Machin<sup>43</sup> (p. 72) warns that whilst this simplification has made complex ideas more accessible and practitioners more confident to work with grief, it has also led to distortion and misunderstanding of the rich knowledge base contributed by theorists and researchers and to a culture of care that does not recognize the wide variations in the uniqueness of grief experiences. In our post-modernist climate, which recognizes human diversity, theories within which diversity is not sacrificed for simplicity and no theoretical concepts deemed too complex for clinical application<sup>43</sup> (p.72) have been created and applied at the forefront of practice.

Such post-modern theoretical developments suggest the need for an integrative approach to assessment which examines both risk factors and coping styles.<sup>11,44–46</sup> For example the Integrative Risk Factor Framework,<sup>46</sup> which attempts to address the limitations of earlier theoretical models, encourages a more systematic analysis of factors contributing to outcome by regarding grieving as an active and fluctuating process, incorporating both avoidance and confrontation. This framework, derived from the Dual Process Model<sup>44</sup> and Cognitive Stress Theory<sup>47</sup> highlights that factors relating to adjustment cannot be evaluated in isolation but need to be understood in relation to each other, to enable 'oscillation' between loss and restoration type stressors.<sup>48</sup> Other theoretical frameworks, comparable to the notion of fluctuation or oscillation, are evident in the work of Horowitz et al.<sup>49</sup> who understood the impact that painful life events have on individuals through intrusive thoughts or avoidant responses, in the work of Martin and Doka<sup>50</sup> who differentiate between intuitive grievers and instrumental grievers, and in the work of Machin<sup>45</sup> who conceptualized the 'Range of Response to Loss' model of grief based on three broadly different reactions to bereavement on a continuum from overwhelmed, controlled to resilient. Greater resilience is indicated when there is a capacity to embrace competing forces of grief.<sup>43,51</sup> Models of coping identified by Lazarus and Folkman<sup>47,52</sup> emphasise how pre-existing coping mechanisms and perspectives become operational in the face of stress and will be used to appraise the nature of the current life event. Positive emotions, which offer respite or

diversion from the distress of a life event, are now acknowledged to play a role in sustaining the coping process and leading to a positive outcome.<sup>52</sup>

According to Machin<sup>43</sup> (p. 45)

‘A significant conceptual shift has taken place, in which the theoretical dominance of grief work formulated with the psychodynamic tradition, has given way to understanding grief from the position of new empirical and cross-cultural evidence.’

The principles of bereavement needs assessment require that an integrative approach is used which includes the investigation of coping styles and risk factors, in line with more recent theoretical developments.

### Aims of this review

In this review the aim is to identify and evaluate two main types of bereavement assessment tool: (1) measures developed for use in specialist palliative care settings where bereavement needs are assessed continuously; and (2) measures available for use by bereavement services who respond to requests for bereavement support. The purpose of such tools is to differentiate between normal and complicated grief and thereby inform support offered. These measures operate in line with components two and three of the NICE guidance bereavement service model.<sup>13</sup>

## Methods

### Literature identification

A search of published literature relating to bereavement, risk assessment and grief was performed. The search strategy used search terms from subject heading lists in CINAHL, MEDLINE, PsycINFO and the Cochrane Database of Systematic Reviews.

### Search strategy

**CINAHL** (1982 to April Week 3 2008) was searched using the search terms *bereavement*, *research instruments*, *research measurement*, *psychometrics* and *risk assessment*. From a total of 110 results, 45 articles were selected for further study.

**MEDLINE** (1996 to April Week 2 2008) was searched using the search terms *bereavement*, *research* and *risk assessment*. From 250 results, a total of 24 articles were selected for further study.

**PsycINFO** (2000 to April Week 3 2008) was searched using the search terms *grief*, *risk assessment* and *experimentation*. From 53 abstracts, three articles were selected for further study.

**Cochrane Database of Systematic Reviews** was searched using search terms *risk assessment*, *research*, *bereavement* and *grief*. From 73 abstracts, 11 were selected for further study.

### Selection criteria

The search was limited to English-language articles and reviews published between the dates outlined under each database above on palliative care or bereavement services only. Reports involving children, deaths by suicide, murder, natural disasters, terrorist attacks, Alzheimer’s disease, HIV and Sudden Infant Death Syndrome were excluded due to the additional dimensions associated with such losses. Reference lists of retrieved manuscripts and recently published books were hand searched. Articles selected for inclusion in this review met the following criteria:

- Focused on adult bereavement.
- Published measurement tools used in research and/or service settings.
- Reported on bereavement assessments employing qualitative and/or quantitative methods.
- Showed evidence of transferability to a palliative care setting.
- Reported on measurement tools tested for reliability and/or validity.
- Reported on bereavement measurement tools influenced by theory.

### Data extraction

We evaluated the bereavement assessment tools systematically. A framework for analysis of included tools was developed from Gabriel and Kirschling’s<sup>53</sup> review of existing measures and incorporated the following seven dimensions: administration, breadth of application, theoretical basis, information yielded, reliability, validity and accessibility.

**(a) Administration:** Some assessment tools require specific training for use and interpretation. User involvement in assessment ensures that an instrument is meaningful and that it covers the areas important to those participating in the assessment process. It is essential to recognize the benefits and limitations of different methods of completion and to know the estimated time required for completion, the number of items and the brevity or thoroughness of the assessment tool.

**(b) Breadth of application:** It is important to have knowledge of where and how an instrument has been used previously as this will give guidance for future use and whether it is appropriate for use within hospice or

specialist palliative care settings, where the majority of bereavement support services are provided by trained professionals and volunteers.

(c) **Theoretical basis:** It is important that conceptual or theoretical frameworks underpin assessment tools to ensure that content is comprehensive and outcome measures are evidence based.

(d) **Information yielded:** An assessment tool must provide sufficient information within measurement scales. Normative data should be available on the instrument's development and use to enable future users to compare their client population with a larger, representative group of bereaved persons.

(e) **Reliability:** Reliability was determined by one or more of the following: parallel forms (equivalence); test-retest (stability); split halves (internal consistency); or coefficient alpha (internal consistency).<sup>54</sup>

(f) **Validity:** Three types of validity were considered: content validity (expert judgement or face validity); criterion-related validity (concurrent validity and predictive validity); and construct validity (theoretical relationships).<sup>54</sup>

(g) **Accessibility:** All tools were accessed by the authors for the purposes of this review.

To assist with the evaluation process, original and review articles of measurement tools were examined.<sup>6,10,21,26,48,53,55-59</sup> To promote rigour a second reviewer participated in the evaluation process.

## Results

Our search yielded 486 results (110 in CINAHL; 250 in MEDLINE; 53 in PsycINFO; and 73 in Cochrane). Titles and abstracts were examined for the identification of bereavement assessment tools. When a tool was named or described, full papers ( $n=83$ ) were obtained and examined for further information. The reference lists in these papers were searched manually. Fifty-nine articles met the inclusion and exclusion criteria, and referred to 14 measurement tools. On further examination a number of measurement tools were excluded: one was only suitable for use by GPs (Grief Diagnostic Instrument)<sup>60</sup> one was designed for use regarding traumatic and sudden deaths (Hogan Grief Reaction Checklist)<sup>38</sup> and two were developed for research purposes (Assessing Widow's Grief<sup>61</sup>, Grief Experience Inventory<sup>62</sup>).

Included tools were separated into two groupings.

### (1) Continuous bereavement screening and assessment tools

Professional screening or assessment tools, suitable for use from the point of a patient's admission and continuing into early bereavement:

- Bereavement Risk Index (BRI);<sup>8,36</sup>
- Colorado Bereavement Services Project;<sup>41</sup>
- Family Relationships Index (FRI);<sup>63</sup>
- Matrix of Range of Responses to Loss;<sup>11</sup>
- Risk Assessment of Bereavement.<sup>39</sup>

### (2) Normal or complicated bereavement assessments

Assessments undertaken around 6 months into bereavement to determine whether a person is experiencing normal or complicated grief, and to clarify the type and level of support required:

- Adult Attitude to Grief Scale (AAG);<sup>45</sup>
- Core Bereavement Items (CBI);<sup>37</sup>
- Grief Evaluation Measure (GEM);<sup>59</sup>
- Inventory of Traumatic Grief (ITG);<sup>64</sup>
- Texas Revised Inventory of Grief (TRIG).<sup>65</sup>

Based on Gabriel and Kirschling's review,<sup>53</sup> descriptives are presented for continuous bereavement screening and assessment tools in Table 1, and for normal or complicated bereavement assessment tools in Table 2. We now discuss their key features.

### Continuous bereavement screening and assessment tools

*BRI*<sup>36</sup>, which derived from the Risk Index<sup>31</sup> and was revised by Kristjanson<sup>8</sup>, is completed by nursing staff and is based on observations or information collected during discussions with the multi-disciplinary team. It is used to screen and offer a proactive service within a preventive health care model and has been widely adapted for use within specialist palliative care settings. Whilst brief and simple to use, its mode of completion excludes direct service user involvement raising issues of consent and accuracy regarding the assessment and decision-making process. Briefer admissions to hospice and limited knowledge of relatives could also lead to incomplete assessments. This tool has been reported to have limited reliability in predicting bereavement outcome.<sup>32,33</sup>

*Colorado Bereavement Services Project*<sup>41</sup> is completed by trained staff or volunteers and uses an asterisk scoring system to identify risk assessment/stressors and

Table 1. Continuous bereavement screening/assessment tools

Instrument	Administration	Breadth of application	Theoretical basis	Information yielded	Reliability	Validity
Bereavement Risk Index <sup>8,36</sup>	Professional assessment based on observations and contact with family. 8 items/4 items 6 point scale Measures: high, moderate and low risk. Brief. Requires 4 hours training.	Tested on 150 bereaved families who received structured bereavement support in hospice setting.	Parkes <sup>36</sup>	Measures clinging/ pinning; anger; self-approach; perceived coping <sup>8</sup>	Internal consistency Chronbach's alpha coefficient 0.80 with short four-item version. Internal consistency low and unreliable <sup>33</sup>	Good face, content and predictive validity. Convergent and discriminant validity not reported.
Colorado Bereavement Services Project <sup>41</sup>	Self assessment: 20 items 3 point scale 5* items or suicidal ideation equals high risk. Professional assessment: 23 items Scores: high, medium and low risk. Training 1 day.	Tested in urban and rural populations in Colorado hospices. Adaptable to families from different racial and cultural backgrounds.	Worden <sup>42</sup>	Helps providers tailor services to identified needs based on combination of self assessment and professional assessment information. Qualitative and quantitative approaches blended.	Further testing planned.	Good content and construct validity.
Family Relationships Index <sup>63</sup> Derived from Family Environment Scale <sup>66</sup>	Self-completion screening tool used to identify families, where a relative is dying, who may be at risk of poor bereavement outcome. It can be used to rule out families that are not at risk. 12 items True/False scale Where possible, information is collected from both patient in palliative care setting and their carer/relative.	Tested against the Family Assessment Device (FAD) <sup>71</sup> on 257 families who consented to screening <sup>67</sup> in a RCT study involving patients in a palliative care setting who had less than 6 months to live. Tested against the Family Assessment Device - General Functioning (FAD-GF) <sup>72</sup> on 48 families of adult patients with cancer and 99 adult relatives <sup>73</sup>	Family focused grief therapy <sup>74</sup>	Measures individual perceptions of family functioning, interpersonal relationships and organisational structure. Subscales measure: Cohesiveness Expressiveness Conflict Scores describe five classes of family: Supportive Conflict-resolving Intermediate Sullen Hostile	Diagnostic accuracy was tested against the general functioning scale of the Family Assessment Device. The predictive power indicates the FRI has an 86% likelihood of identifying dysfunctional families, but of these only 50% proved to be true cases. The authors were willing to tolerate this misclassification in a screening instrument to avoid missing any at risk family <sup>74</sup>	FRI demonstrated good sensitivity (0.86), moderate specificity (0.45); PPV indicated 50% families considered at risk were identified by the FRI. The NPV suggested there was a high degree of concordance between individuals identified as not being at risk by both measures (NPV = 0.84). <sup>74</sup> Measured against FAD-GF <sup>73</sup> FRI demonstrated 100% sensitivity; lacked specificity but was sensitive to family dysfunction, depression and anxiety; diagnostic accuracy varied between 0.38 and 0.52

<p>Matrix of 'Range of Responses to Loss'<sup>11</sup></p> <p>Professional assessment. Five items repeated in each category of overwhelmed, controlled and resilient. Bias towards responses in the bottom half indicates formal bereavement support is unlikely and multiple agreements with factors in the top half indicates the potential need for bereavement support.</p> <p>Completed based on information gathered through observation and discussion with the family during a patient's admission to hospice or palliative care setting.</p>	<p>This is a recently developed tool which is targeted for use in hospice or specialist palliative care settings. It has not yet been tested for reliability or validity, but it is based on the Range of Responses to Loss which was validated in a study of bereaved people.<sup>45</sup></p>	<p>Range of Responses to Loss.<sup>45</sup> Overwhelmed Controlled Resilient Vulnerable</p>	<p>Captures responses to: Feelings, thoughts, behaviours, life perspective and social support. Also records vulnerability or resilience factors to personal capacity or circumstantial risk. What happened and when (external narrative) The impact of events on the person (internal narrative) How they are making sense (or not) of their experience (reflexive narrative)</p>	<p>Matrix not yet tested.</p>	<p>Consistently valid with other well established theories.</p>
<p>Risk assessment of bereavement in a palliative care setting<sup>39</sup></p> <p>Professional nursing assessment based on knowledge of main carer. 11 items Easy to administer. Training 1 day.</p>	<p>Piloted for 1 year in a UK hospice. Identifies high, medium and low risk categories. Transferable between hospice and community palliative care settings.</p>	<p>Worden<sup>42</sup> Parkes<sup>16</sup></p>	<p>Time in hospice, mode of death, knowledge of illness, kinship, spirituality, anticipatory grief, known traumatic life experiences, physical/mental health, reaction at time of death, perceived coping.</p>	<p>Not reported.</p>	<p>Good face and content validity based on feedback from service users and staff.</p>

Table 2. Normal and complicated bereavement measurements

Instrument	Administration	Breadth of application	Theoretical basis	Information yielded	Reliability	Validity
Adult Attitude to Grief scale <sup>45</sup>	Self-assessment with professional. 9 items 5 point scale 3 categories of response to loss: overwhelmed; resilient; controlled. Qualitative and quantitative data collected. Requires 1 day training.	Tested on 94 people seeking bereavement counselling. <sup>45</sup> Tested on 17 bereaved people seeking bereavement counselling. <sup>51</sup> Adaptable to therapeutic settings and different types of loss.	Attachment. <sup>40,76</sup> Range of response to loss. <sup>45</sup> Dual Process Model. <sup>44</sup> Intuitive and instrumental mode of grief. <sup>50</sup>	Promotes narrative account of grief and explores grief within wider social context and history of losses experienced. Profiles individual grief, how person reacted to it and identifies aspects to address in bereavement support. Reflects changes in emotional and cognitive perspectives over time.	Significant correlation between 'overwhelmed' and the Leiden 'detachment' scale. <sup>77</sup> Negative correlation between 'resilient' items on AAG scale and distress, as measured by Beck Depression Inventory, <sup>78</sup> Impact of Event Scale, <sup>49</sup> and Leiden Detachment Scale. <sup>77</sup>	Good face and content validity: positive reception by clients and affirmation of its therapeutic effectiveness by practitioners. <sup>51,75</sup> Consistently valid with other well established theories.
Core Bereavement Items <sup>37</sup>	Self-assessment or professional assessment. 17 items 5 point scale 3 subscales Rapid screening device. Training not reported.	Tested prospectively on 158 subjects in different community samples: bereaved partners, spouses under 70 and adult children. Best suited to normal grief.	Attachment Theory. <sup>76</sup>	Attachment emotions and behaviours invoked by reminders of deceased; ongoing behaviour; parameters of resolution. Assesses intensity of bereavement reaction.	Internal consistency 0.91. <sup>36</sup> Chronbach's alpha coefficient for 17 item CBI scale 0.91 compared to 21 item TRIG (8 item) and 0.86 (13 item). <sup>56</sup> Test-retest not reported.	Good face and discriminant validity. Good construct validity demonstrated using factor analysis. Convergent and discriminant validity not reported.
Grief Evaluation Measure <sup>59</sup>	Self-assessment 58 items 7 sections 6 point scale Takes 30–35 minutes to complete.	Tested on 92 bereaved persons. Test-retest reliability based on 23 persons.	Not based on any model or theory of grieving.	Qualitative and quantitative approaches blended. Screens for complicated grief in adults.	Test-retest: experiences section 0.97; problems section 0.88. <sup>79</sup> Internal reliability 0.82 (problems) 0.74. Chronbach's alpha: experiences 0.91; problems 0.97.	Construct validity good. Concurrent validity GEM and ICG 0.82 (problems) 0.74. Good predictive validity for adjustment 1 year after initial evaluation.



Inventory of Traumatic Grief <sup>64</sup>	Self-assessment 30 items 5 point scale Total score calculated by summation of item scores. Rapid screening device.	Tested on 250 adults aged 18–70 years who suffered first-degree loss (partner, parent, child or sibling) three years previously and accessed bereavement support.	Not stated.	Measures maladaptive grief symptoms. Distinguishes between normal/pathological grief.	Favourable internal consistency 0.94. Chronbach's alpha and test–retest reliability 0.80 over six months of bereavement. <sup>70</sup> Test–retest correlation ranged 0.41–0.91 with ITG total score 0.92. <sup>20</sup>	Construct and factorial validity very favourable. Convergent and discriminant validity 0.87 with TRIG part II but ITG better discriminates good from poor outcome.
Texas Revised Inventory of Grief <sup>65</sup>	Self-assessment 21 items 2 sub scales 5 point scale. Comprehensive rapid screening device. Training and time to complete not reported.	Tested on 260 bereaved persons (mean age 38 years). Test–retest on 328 persons (mean age 33 years). Adaptable to multi-cultural research subjects.	Based on literature of normative and atypical grief reactions.	Measures change in grief over time. Focusing on past behaviour and present feelings with additional un-scaled items: nature of relationship, perceived closeness to deceased, length of time since death, and other related factors.	Split half and coefficient alphas 0.87 initial adjustment; 0.89 present levels of grief. Internal consistency (Part I) Chronbach's alpha 0.77–0.87, <sup>80</sup> 0.78–0.89; (Part II) 0.69–0.89 and 0.90–0.93. <sup>80</sup> Test–retest not reported.	Good construct and factorial validity. Exploratory factor analysis with retention of items loading 0.40. <sup>80</sup> Convergent and discriminant validity ITG 0.87.

resources/strengths. Starred items are considered to be of major significance and five or more starred items generally indicate high risk. Suicidal ideation is automatically considered high risk. Otherwise the ranking of low, moderate or high risk is subjective, based on the items ticked and the professional undertaking the assessment. It is easily administered and has been tested for content and construct validity.

*FRI*<sup>63</sup> is a simple and effective 12-item, true–false response scale which was derived from the short-form Family Environment Scale.<sup>66</sup> It has been used in palliative care settings as a screening tool that identifies dysfunctional families. The FRI is a well-validated measure of an individual's perception of their family's functioning, including such constructs as interpersonal relationships and organizational structure.<sup>63</sup> The cohesiveness, expressiveness and conflict subscales generate the FRI, a global measure of family interaction.<sup>67</sup> Scores are used to describe five classes of family: supportive, conflict-resolving, intermediate, sullen and hostile. Kissane et al.<sup>68</sup> suggest that a family may be at risk of poor outcome if one or more members scores nine or less out of 12, or less than four on cohesiveness, namely those identified as hostile, sullen or intermediate. Kissane et al.<sup>67,69</sup> found the level of family functioning to be a powerful predictor of bereavement outcome and they suggest that clinicians assess family issues in practice.

*Matrix of 'Range of Responses to Loss'*<sup>11</sup> was adapted from the theoretical concepts underpinning Machin's Adult Attitude to Grief Scale.<sup>45</sup> The matrix provides a framework for professionals to understand the coping responses and to assess the vulnerability factors of individuals facing bereavement. Assessment using the matrix requires observations of family reactions and engagement in conversations about how individuals are dealing with their situation. The concepts of overwhelmed, controlled and resilient can be considered alongside the traditional risk factors to help understand individual differences in coping. Whilst based on Machin's Range of Response to Loss, the matrix has not been tested for validity or reliability.

*Risk Assessment of Bereavement*<sup>39</sup> relies on completion by hospice nursing staff based on their observations and information gathered during the patient's admission and is used to inform the nature of bereavement follow-up services. Although underpinned by theories of Parkes<sup>16</sup> and Worden<sup>42</sup> and piloted in a UK hospice prior to implementation it has not been tested for validity or reliability.

### Normal versus complicated grief assessment tools

*AAG*<sup>45</sup> profiles qualitative and quantitative responses to nine attitudinal statements reflecting the spectrum

of emotional and cognitive perspectives of loss: overwhelmed, resilient or controlled. The AAG has evidence of reliability and validity. Being self-completed, it promotes a narrative account of the service user's grief perspective within their wider social context addressing issues about consent, accuracy and partnership in care planning. It can be used to identify complicated grief reactions and the proposed hierarchy of vulnerability can be used as guidance in the selection of a therapeutic approach; it measures change when repeated and has been tested in palliative care settings.

*CBI*<sup>37</sup> refers to commonly occurring symptoms about images and thoughts, acute separation and grief. It can be used as a self- or professional assessment. Whilst tested on 150 subjects in Australia who experienced a close bereavement, critics suggest it is best suited to the study of normal grief responses rather than complicated grief.<sup>56</sup>

*GEM*<sup>59</sup> provides a self-report quantitative and qualitative assessment of the nature and severity of individual grief reactions. Whilst the GEM demonstrates good concurrent validity for established measures and good predictive validity for mourner adjustment 1 year after initial assessment, it was tested on a convenience sample of individuals who had already sought bereavement counselling. This measure takes 30–35 minutes to complete and training is not accessible in the UK.

*ITG*<sup>64</sup> developed from the Inventory of Complicated Grief<sup>70</sup> is a rapid screening self-assessment device to measure symptoms of grief and to distinguish between normal and pathological forms of grief. Completion is normally 6 months into bereavement. Whilst it is the only tool demonstrated to have strong predictive validity for the development of future grief related problems<sup>59</sup> it was only tested on adults who had suffered a first-degree loss and accessed professional bereavement support.

*TRIG*<sup>65</sup> is the most commonly used self-assessment measure in the empirical literature which focuses on past behaviour and present feelings. Although developed from the literature and clinical experience of the authors, some TRIG items are reported to be benign or redundant, do not permit variation or overlap extensively with the measure of depression.

## Discussion

In this work we have reviewed two types of bereavement assessment tools. Whilst reviews of a range of bereavement measurement tools are available, few have evaluated their transferability to UK specialist palliative care settings where pre-bereavement support is offered by qualified social workers and nursing staff and post-bereavement support is offered by trained

bereavement professionals and volunteers in line with NICE guidance.<sup>13</sup>

Whilst five measurement tools reviewed were developed for use in palliative care settings (BRI,<sup>36</sup> Risk Assessment,<sup>39</sup> Colorado Project,<sup>41</sup> Matrix of Range of Responses to Loss,<sup>11</sup> FRI<sup>63</sup>) where death is anticipated, information is collected based on observations by professionals rather than direct user participation, which could lead to inaccurate or incomplete assessments. The Matrix<sup>11</sup> and the Family Relationships Index,<sup>63</sup> however, are completed based on observations and narratives with individual family members. Both identify the potential for poor psychological outcome in individuals anticipating bereavement.

Six tools are claimed to be adaptable to different settings, populations or types of loss (BRI,<sup>36</sup> CBI,<sup>37</sup> AAG Scale,<sup>45</sup> Colorado Project,<sup>41</sup> ITG,<sup>64</sup> Matrix of Range of Responses to Loss<sup>11</sup>). Even though written formal methods of bereavement needs assessment are widely accepted and encouraged in practice,<sup>2,5,6,8,11,24–28</sup> identifying a valid and reliable assessment tool suitable for use in UK specialist palliative care settings has remained a challenge. This is complicated further by briefer hospice stays, limited training opportunities and a perceived reluctance by nursing staff to ask ‘intrusive’ questions.<sup>30</sup>

### Administration

The bereaved need to be receptive to and formally engaged in any assessment and intervention process to ensure their consent, as well as the accuracy and use of information. All of the assessment tools reviewed for use to distinguish between normal and complicated grief promoted self-completion (CBI,<sup>37</sup> AAG Scale,<sup>45</sup> GEM,<sup>59</sup> ITG,<sup>64</sup> TRIG<sup>65</sup>). However, self-completion assessments require appropriately skilled staff to interpret the results, alongside professional judgement, to determine whether an individual is experiencing complicated grief.

The estimated time required to complete assessments and the number of items to be completed varied. The number of items directly asking the service user about his or her bereavement experience in the identified tools ranged from 8 (BRI)<sup>36</sup> to 58 (GEM).<sup>59</sup> Whilst some may criticize brief measures, this review included two ‘longer’ tools (ITG,<sup>64</sup> TRIG<sup>65</sup>) which were reported to be rapid screening devices for individuals presenting for bereavement support.

### Theoretical basis

Two tools were not explicitly linked to any theoretical model (GEM,<sup>59</sup> ITG<sup>64</sup>), five were based on traditional theoretical perspectives which may not reflect more

recent developments in our understanding of grief (BRI,<sup>36</sup> Colorado Project,<sup>41</sup> Risk Assessment,<sup>39</sup> CBI,<sup>37</sup> TRIG<sup>65</sup>), and three were explicitly underpinned by modern theoretical concepts which consider coping styles and family dynamics (Matrix of Range of Responses to Loss,<sup>11</sup> AAG Scale,<sup>45</sup> FRI<sup>63</sup>). Five measurement tools were reported to be effective in identifying complicated grief reactions (GEM,<sup>59</sup> AAG Scale,<sup>45</sup> TRIG,<sup>65</sup> FRI,<sup>63</sup> ITG<sup>64</sup>). Whilst the FRI<sup>63</sup> and the ITG<sup>64</sup> are the only tools validated to predict the development of future grief-related problems, the FRI is validated as a screening tool to rule out families not at risk and it over-predicted the number of high risk individuals, and the ITG is an assessment tool to be used at least 6 months into bereavement.

### Psychometric properties

Three measures reviewed had undergone minimal testing for reliability or validity (Risk Assessment,<sup>39</sup> Colorado Project,<sup>41</sup> Matrix<sup>11</sup>) and one measure showed low and unreliable internal consistency (BRI<sup>36</sup>). However, five tools had undergone psychometric testing against other established measurement tools (TRIG,<sup>65</sup> CBI,<sup>37</sup> AAG Scale,<sup>45</sup> ITG,<sup>64</sup> FRI<sup>63</sup>) and the majority had good content and construct validity (TRIG,<sup>65</sup> BRI,<sup>36</sup> CBI,<sup>37</sup> AAG Scale,<sup>45</sup> ITG,<sup>64</sup> FRI,<sup>63</sup> Colorado Project,<sup>41</sup> GEM<sup>59</sup>).

Where sample sizes for testing were provided, respondents ranged from 92 (GEM<sup>59</sup>) to 260 (TRIG<sup>65</sup>). In two cases (Risk Assessment,<sup>39</sup> Colorado Project<sup>41</sup>) tools were tested in hospice teams over a 12-month period.

Measurement tools, blending qualitative and quantitative responses, promote narrative elaboration on personal thoughts and feelings about the experience of loss, and may help to identify complicated grief and measure change. Five of the measurement tools included in this review used such a blended approach (TRIG,<sup>65</sup> AAG Scale,<sup>45</sup> ITG,<sup>64</sup> Colorado Project,<sup>41</sup> GEM<sup>59</sup>).

### Conclusion

The aim of this review was to identify screening or bereavement assessment tools suitable for use within UK specialist palliative care settings. This review identified two groups of assessment: continuous assessment from the point of a patient’s admission into early bereavement (Table 1) and post-bereavement to differentiate between normal and complex grief (Table 2). In the first group, the BRI<sup>36</sup>, despite criticisms about its completion and reliability, is most commonly used across the UK. The FRI<sup>63</sup> which has been validated as a screening tool to identify families at risk of poor

bereavement outcome, offers a structured approach to identify individuals who may not be at risk of poor bereavement outcome, however, it is uncertain how many UK palliative care services offer family focused grief therapy and this tool has been predominantly used in research studies. The Matrix,<sup>11</sup> based on more modern theoretical concepts, demonstrates great potential for UK-wide implementation into specialist palliative care settings, particularly given the changing diversity of our population, the need to involve service users in the assessment process and the benefits of having a continuous assessment of bereavement needs to target resources to those in greatest need.

In relation to assessing bereavement risk when an individual actively presents for support, the ITG<sup>64</sup> and the TRIG<sup>65</sup> are the most widely tested tools to distinguish between normal and complicated grief; however, they are complex, were developed in the USA and may not be suitable for use by bereavement volunteers even if trained. The AAG Scale<sup>45</sup> seems more appropriate for assessing need by a UK hospice bereavement support service. It promotes user involvement by empowering bereaved individuals to engage actively in their own assessment and care planning process, and ensures that any intervention is based on accurate information shared by the individual. Its content, clarity, brevity and face-validity make it user-friendly. The qualitative and quantitative components ensure clarity, flexibility and measurability, and its theoretical basis is modern and familiar to trained professionals and bereavement volunteers. It may, however, be useful to explore the applicability of some validated screening and assessment tools in practice, using evaluative research methods.

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