Exploration of clinicians' perspectives of using a bereavement risk screening tool in a palliative care setting: a qualitative study

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Abstract: To minimise the adverse outcomes of prolonged complex bereavement, health professionals need effective risk screening tools to identify those at risk. However, existing tools can be challenging to implement in the clinical setting. This qualitative study aimed to explore clinicians' perspectives and experiences of using the Bereavement Risk Index (BRI) screening tool, including identifying barriers and enablers regarding its use and what they perceived as important domains in bereavement risk screening. Data was collected through semi-structured group and individual interviews and deductively analysed using the Theoretical Domains Framework. Eleven participants employed in one regional palliative care service were interviewed. The results revealed three key implications: 1) a risk screening tool is highly beneficial, however contextual factors can limit its implementation; 2) clinician confidence in the tool and perception of the tool's comprehensiveness are significant factors in its use; 3) feedback is needed as to whether clinicians' assessment of bereavement risk remains accurate and valid in the longer term.

Keywords: bereavement risk, prolonged complex bereavement, risk screening, bereavement risk index

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Introduction

It is internationally recognised that bereavement risk assessment is best practice in palliative care services (Breen, Aoun, O'Connor, & Rumbold, 2014). The Australian Palliative Care Standards highlight the need for palliative care services to adequately screen for those who might be at risk of 'experiencing a complex response to bereavement'and to ensure access to on-going assistance for family caregivers of palliative care patients if indicated (Palliative Care Australia [PCA], 2018, Changes: p. 19). Moreover, accurate assessment can reduce adverse health outcomes in the bereaved (Hudson et al., 2010).

A recent scoping review identified the feasibility of measures to assess bereavement risk for use in palliative care settings and to inform bereavement care practices (Sealey, Breen, O'Connor, & Aoun, 2015). Nineteen different measures with adequate psychometric properties were identified and these were divided into those that can be used before the patient's death (n=5), in the period following death (n=10), and for screening of prolonged or complex grief (n=4). Two of the pre-death measures could be used in the palliative care context – the Bereavement Risk Index (BRI) (Parkes & Weiss, 1983) and the Bereavement Risk Assessment Tool (BRAT) developed by the Victoria Hospice Society in 2008 (Uchida, Satake, Nakaho, Inoue, & Saito, 2018).The BRI was developed by Parkes and Weiss (1983) as a predictor of bereavement outcomes, 'comprising assessment for eight risk factors (identified by its authors) that contribute to poor bereavement outcomes' (Levy et al.,1992, p. 227). The BRI discriminates between bereaved spouses at high and low risk of psychological distress pre-death and post-death (Robinson, Nuamah, Lev, & McCorkle, 1995). The BRAT is a 40-item risk assessment tool developed in Canada in 2008. It was found to have only moderate reliability (Rose, Wainwright, Downing, & Lesperance, 2011). Both tools rely on clinician ratings and observations rather than directly questioning the bereaved (Sealey, Breen, et al., 2015). Sanderson et al.'s (2015) review also highlighted the challenge of incorporating bereavement risk assessment tools that are both empirically validated as well as acceptable and feasible for use in busy clinical contexts, as reported elsewhere (Blackburn & Dwyer, 2017).

The challenges experienced by clinicians when implementing bereavement risk screening tools have been explored within palliative care settings. Sealey, O'Connor, Aoun, and Breen (2015) interviewed key healthcare professionals from five palliative care sites and identified several barriers to assessment using existing measures including reluctance to ask intrusive or sensitive questions pre-death and the logistics of contacting bereaved caregivers. This study also examined systems issues such as differences in models of service which affect clinicians' contact with patients along the illness trajectory and the challenges of conducting assessments when a patient is near death. Other researchers have identified obstacles to bereavement risk screening in palliative care such as time constraints to conduct adequate assessment and ethical considerations in creating medical records for bereaved caregivers (Thomsen, Guldin, Nielsen, Ollars, & Jensen, 2017). Furthermore, other investigators have commented that clinician administered tools are not reliable and self-reporting tools are difficult to validate and lack clinical utility (Roberts et al., 2017).

Despite their challenges, multiple bereavement risk assessment tools are utilised by specialist palliative care services. The BRI is commonly used across the United Kingdom within specialist palliative care settings (Agnew, Manktelow, Haynes, & Jones, 2010). However, studies have found the BRI has limited reliability to sufficiently predict a bereavement outcome (Agnew et al., 2010). Research undertaken by Kristjanson, Cousins, Smith, and Lewin (2005) aimed to test validity, reliability and feasibility of the modified version of Parkes (1993) Bereavement Risk Index (BRI) and bereavement support protocol in an Australian home hospice setting. The results revealed the modified four item version had improved internal consistency when compared with the longer eight item version (Kristjanson et al., 2005; Sealey, Breen, et al., 2015). Notwithstanding these findings the eight item version of the BRI has been implemented in some palliative care services across Australia.

When implementing a bereavement risk screening tool, it is pertinent to obtain both expert and user feedback regarding its use and items (Roberts et al., 2017). There is currently limited research regarding health professionals' experiences of using the BRI in contexts where it is embedded as standard practice. Within one specialist palliative care service in Queensland, Australia, discussions emerged regarding the usefulness of the BRI within their setting. This led to the current research which aimed to explore palliative care clinicians' perspectives and experiences of systematically using the BRI screening tool over an extended period of time. Specifically, the research aimed to answer the questions : 1) What are the barriers and enablers that clinicians report in using the BRI in the local palliative care context? and 2) What are the factors that clinicians perceive to be important in a bereavement risk screening tool for the local palliative care context?

Method

Study design

In order to understand local contextual factors influencing bereavement risk assessment, a qualitative case study was designed. In-depth semi-structured, group and individual interviews were conducted to explore the individuals' perspectives regarding the barriers and enablers to bereavement risk screening. The Theoretical Domains Framework (TDF), a comprehensive behaviour change sensitising tool, (Atkins et al., 2017), guided our data collection and analysis, enabling us to identify contextual factors and generate empirical and theory informed recommendations.

Setting

This study was conducted in a 16 to 20 bed specialist palliative inpatient care unit in a large tertiary hospital and health service in regional Australia. It should be recognised that the average length of stay in the palliative care unit fell over the period the BRI was in use and patient admissions, discharges and deaths increased. Since 2011, social workers employed by the unit routinely utilised the eight item BRI as the bereavement risk screening tool for all bereaved and pre-bereaved family caregivers. Emergent discussions had been occurring for some years regarding the usefulness of the tool, formulating the foundational rationale for this study.

Recruitment of participants

Purposive sampling was used to recruit participants as key stakeholders possess significant knowledge and are willing to share it (Barratt, Ferris, & Lenton, 2014). Within this specialist palliative care service, clinicians are expected to attend a weekly mortality meeting. Attendees include palliative care consultant doctors, registrars, nurses, psychologists, pharmacists and social workers. A written participant information sheet was provided to each of the attendees at this meeting, with an explanation of the purpose of the research. Willing participants were emailed a written consent form to sign. The participants were recruited over a two-week period.

Participants and procedure

Group interviews and one individual interview were conducted. To accommodate participant preference and availability, one medical practitioner was interviewed separately, and the remaining 10 participants were interviewed in group settings. The Theoretical Domains Framework (TDF) (supplementary online material) was applied in the question design and data analysis. The TDF is a model comprising 14 theoretical domains, with each of the domains containing a series of constructs relating to behaviour change theories (Kirk, Sivertsen, Petersen, Nilsen, & Petersen, 2016). The constructs can be applied to identify barriers and enablers regarding implementation of new concepts or interventions in a health service (Kirk et al., 2016; Cane, O'Connor, & Michie, 2012), as well as existing healthcare interventions or practices in order to enhance future implementation (Debono et al., 2017; McLellan, O'Carroll, Cheyne, & Dombrowski, 2019; Steinmo et al., 2016), as applied in the present study. The interviews were conducted from June 2017 to August 2017 within the health service clinical setting. The group interviews and individual interview were facilitated by one of the researchers (LJ), with a second researcher, (CN or RW) present to assist with audio equipment, provide feedback to the facilitator and observe the group interactions. The duration of the interviews was approximately 60 minutes. The semi-structured questions were designed by two of the researchers (LJ and CN), then put to three other researchers for feedback and input.

To obtain responses to the second research question at the time of interview, participants were presented with three risk assessment tools to generate discussion about risk factors: 1) the Bereavement Risk Index (BRI) 2) the Bereavement Risk Assessment Tool (BRAT) and 3) the Complicated Bereavement Risk Assessment Tool (CBRAT) (Aranda & Milne, 2000). The tools were chosen as the BRI and BRAT are validated in the clinical context and the CBRAT was a more recently developed tool.

Participants were invited to provide their viewpoints regarding the most useful and least useful items and offer suggestions regarding important risk factors. The data from the group interviews and individual interview were audiotaped and transcribed verbatim by a paid research assistant.

Data analysis

After transcription, the data was imported into the QSR NVivo computer programme and meaning units were coded by researchers into nodes (QSR International, 2015). The nodes were categorised in accordance with the 14 TDF domains using deductive coding to answer the first research question, with additional nodes being added using inductive coding to address the second research question and also for data that did not fit into the TDF domains. Under each node labelled with the 14 TDF domains, sub-nodes, titled 'enablers' and 'barriers' were added. The majority of the coding was undertaken by one of the researchers (EP), however, this researcher met regularly with a second researcher (LJ) who is not a palliative care health practitioner to double-check decisions made and to monitor for potential bias. Reflective notes were written throughout the data analysis process to help researchers to reflect on how their own experiences could possibly impact. The reflections were shared and discussed as a research team. To uphold rigour, four of the researchers met on multiple occasions to discuss categories and work together to obtain consensus on categorisations. These meetings also created an opportunity to discuss coding and ensure there was mutual understanding of each domain within the framework. This shared understanding was particularly pertinent for data that did not align to the TDF categories. However, these data were minimal and did not represent a dominant theme. A consensus was reached by the research team not to include this data in the results presented.

Ethical considerations

The study gained ethical clearance (HREC/17/QGC/96). One researcher who was a former clinician within the palliative care service participated in the focus groups, so could not be a part of the data analysis process. A further researcher was also a clinician within the service. Two health service employed research fellows were members of the research team however had no history of any direct clinical contact with the palliative care service team. A further research team member collaborated on the study from a partner university.

Results

Eleven health professionals were interviewed comprising palliative care consultant doctors, registrars, nurses, psychologists, pharmacists and social workers, all of whom on average had at least five years' experience in palliative care.

Participants reported several barriers and enablers regarding the use of the BRI. The majority of the comments were coded within the 14 domains of the TDF. Within the interviews, participants repeatedly referred to the BRI as only one component of the wider multidisciplinary process of determining risk during their weekly mortality meeting.

Beliefs about consequences

This TDF domain was predominantly identified as a barrier by all participants who routinely use the BRI tool in their practice. Participants questioned the justification of some of the tool's sections. One clinician stated:

> 'It's the number of children under 14 at home. I think it's an inappropriate emphasis. A parent might have one child at home but the way they're feeling about helping that child through the grief; that is a more important focus rather than just "the more children you've got, the worse it is".' (Participant 10, allied health)

Another clinician suggested that there were important factors that were not captured by the tool. For example:

> 'One of the things this tool doesn't take into account is people's protective factors, how resilient they are.' (Participant 9, allied health)

At the same time this domain was identified as an enabler, with one participant stating the tool was '*theoretically valid, evidence-based and applicable for use in the Australian context*'. This participant also stated that it was currently embedded into core business within the service and had some credibility as it had been '*tested here*'. (Participant 1, medicine and nursing)

Knowledge

Knowledge barriers to utilising the tool included participants not knowing the rationale for the risk factors and whether the scoring system assigned to the items accurately predicted the risk of grief complication. A lack of knowledge about the tool's rigour and validity was also expressed.

> 'I have completed this form and I was thinking … low risk, but the only thing that jumped up the mark was … "semi-skilled manual" … why would that automatically make them a moderate bereavement risk, just because of their employment?'(Participant 5, allied health)

Only one participant described a knowledge enabler, stating that the tool supported new staff to assess bereavement risk.

Optimism

The optimism domain was exclusively identified as a barrier by the participants. Clinicians expressed reservations about their confidence that the tool's risk factors would lead to an accurate score.

> ' I have always wondered from the first time we started using this – what is it measuring? Because we are trying to get it filled in pre-death ideally, then what it might be measuring is acute grief so I'm very ambivalent about this tool.' (Participant 10, allied health)

Environmental context and resources

Most participants reported that a key barrier related to environmental context and resources was that the tool is filled out by a single profession, namely social work. If there are no social work resources, the tool is not completed.

> 'There were a number of these that weren't acted on or weren't even done because we didn't have the social worker capacity.' (Participant 1, medicine and nursing).

Workload constraints such as time to conduct the necessary assessment to inform the tool's completion due to short lengths of stay, coupled with staff reluctance to enquire about certain sensitive factors when a depth of relationship did not exist with the bereaved, were also described as barriers under this domain.

> 'Not knowing the people when doing this. When you are doing a bereavement call you don't want to be asking them about employment, so it's going to impact your ability to use this.' (Participant 5, allied health).

In contrast, other participants highlighted environmental context and resources as an enabler, citing the BRI's ease of use. Some mentioned the tool as being a valuable basis for discussion at the weekly mortality meeting. One participant believed the tool allowed the targeted use of limited clinical resources.

> 'Because of the constraints for bereavement care in this service, that is the reason to start using this bereavement risk assessment.' (Participant 10, allied health)

Skills

The skills domain was only referred to as an enabler. Clinicians described that being able to use their clinical judgement to comment on how the bereaved will cope on the BRI tool allowed them to apply their bereavement assessment skills acquired through practice.

> 'People are scoring "moderate", but they have significant social support. I have documented that the "BRI states moderate, but my clinical judgement is they are low risk"; and list my reasons why they don't require follow-up.' (Participant 5, allied health)

Beliefs about capabilities

As with skills, this TDF domain was also considered as an enabler, with participants highlighting the ability to draw on intuitive clinical skills to assist in decision-making. One clinician reflected on this, stating:

> 'The question in the end is usually – "Does this person need bereavement follow-up or is this a complicated risk?" From there, with an inherent special expertise, they have picked up clues and generally, they are right.' (Participant 1, medicine and nursing)

Behavioural regulation

Participants frequently described enabling factors related to behavioural regulation including improving the monitoring of bereavement risk, facilitating audit processes, promoting responsibility to assess bereavement risk by clinicians and action planning in response to BRI scores. Overall, participants were encouraging a systematic approach to the assessment of bereavement risk and delivery of care to those most at risk.

> 'The BRI ultimately takes a lot of things that are common sense and allocates essentially a risk, a score; once you reach a certain score I guess we should do something.' (Participant 1, medicine and nursing)
>
> 'Because the social workers fill in the BRI; if the social workers retain that responsibility, it's easy to monitor as a team, the social work team, such as an internal audit.' (Participant 10, allied health)

Health practitioners' identification of important risk factors to assess

Participants described 11 key factors as important in a bereavement risk screening tool. All participants agreed 'circumstances of the death' was an important factor, particularly in relation to a family's perception of the quality of care in the dying phase. One clinician commented:

> 'I think "circumstances leading up to the death" is important and if the family perceived the care as inadequate this can possibly lead to more complicated grief.' (Participant 10, allied health)

Communication with the treating team and the opportunity to prepare for and anticipate the death were also reported to be pivotal to bereavement outcomes.

> 'So when something is not explained or understood, and it happened fast, it can be a lot harder. How the person died … if they died really suffering.' (Participant 2, medicine and nursing)

Coping strategies and style were referred to as essential by the majority of participants including coping prior to the death, self-perception of coping, expressed anger, guilt and self-reproach in family caregivers. An example was provided by a participant who talked about a family member's feelings *'of self-blame and guilt.'* The participant elaborated by adding:

> 'The daughter fed her mother and she deteriorated really suddenly and it's totally unrelated but she keeps saying, "if I hadn't given mum anything, it would have been okay."' (Participant 7, medicine and nursing)

Concurrent stressors such as financial hardship, childcare and other secondary losses were identified as important by most interviewees*:*

> 'If the sole wage earner dies and you have got no income: that would affect, impact bereavement.' (Participant 11, allied health)

Supports and relationships including family functioning and family communication styles elicited a substantial number of comments by participants:

> 'People can feel guilty if they had problems in their relationship with that person who died, I think that makes it hard.' (Participant 2, medicine and nursing)

There were multiple comments suggesting stage within the lifespan as an essential consideration.

> 'We had a recent patient who passed away and the daughter was only 20 so had limited life experiences and…lack of maturity…I think age is a really important thing to identify.' (Participant 6, allied health)

Religion or spirituality was described as being important to finding meaning:

> 'I have experienced that, for those who are bereaved, if they have got some sort of spiritual belief system whereby they can find meaning in the loss: that's important.' (Participant 8, allied health)

Other significant risk factors referred to by participants were the nature of the relationship with the deceased including attachment and dependence, length of time in the caregiving role, bereavement and mental health history of the bereaved, opportunity for additional information as well as identification of protective factors.

Discussion

To the best of our knowledge, this is the first study to examine palliative care clinicians' perspectives of the barriers and enablers to using the BRI risk screening tool in an inpatient setting. The TDF enabled us to systematically explore clinicians' experiences of using the BRI tool as part of their clinical practice. The principal findings were that while staff noted that the BRI enabled a systematic approach to assessing bereavement risk, their ability to make a comprehensive assessment was hampered by both a lack of knowledge about the underlying rationale for components of the tool and contextual constraints of the model of service.

Clinicians reported that overall, the BRI facilitated targeted bereavement risk assessment and follow-up in a resource constrained environment. For example, participants described that the BRI: 1) enabled improved monitoring of bereavement risk; 2) had the potential to facilitate audit processes; 3) promoted responsibility to assess bereavement risk by clinicians; 4) helped in action planning in response to BRI scores; and 5) enabled a systematic approach to the assessment of bereavement risk and delivery of bereavement care. This is consistent with Roberts et al. (2017) who acknowledged the need to track identified 'at-risk' families to allocate limited bereavement resources (p. 59).

Some participants described the BRI as a useful tool for further developing their bereavement risk assessment skills. Using screening tools, such as the BRI, to provide guidance and support for clinical practice, especially for novice practitioners with limited experience, is well documented in the literature (Benner, 1984). Most participants in our study were experienced practitioners, and thus less likely to rely on rules or guidelines to take appropriate action (Gobet & Chassy, 2008). Even so, we identified that while experienced practitioners drew on their expert judgement, the validity of these judgements is not fully understood, as the resources and processes required to report back the accuracy of the assessments were not in place.

In the clinical context of this study, social work holds responsibility for the completion of the BRI. Having one health professional assigned to assess bereavement complexities via a screening tool was considered by the participants to be an enabling factor. Indeed, social workers' clinical expertise in bereavement risk assessment has been acknowledged by Bosma et al. (2010). Conversely, some participants noted that this could also act as a barrier to consistent bereavement risk screening. If social work resources are compromised, the BRI may not be completed.

Other barriers reported by participants include challenges to understanding the rationale behind the tool's scoring system and this led to doubts concerning its validity and reliability. These findings corroborate previous research (Sealey, O'Connor, et al., 2015; Blackburn & Dwyer, 2017). For example, Sealey, O'Connor, et al. (2015) report that participants expressed uncertainty about what was being measured in pre-death assessments. To address this uncertainty, Blackburn and Dwyer (2017) recommend that clinicians not only be educated about the risk assessment tool being used but also about theories of loss and grief.

Workload constraints noted by participants including later referrals to the palliative care service and shorter stays in the palliative care unit do not allow clinicians to engage adequately with family caregivers, as previously described by Aranda and Milne (2000). This is an important finding because it suggests that bereavement risk assessment should not occur in palliative care settings alone. Consideration must be given to how the bereavement needs of family caregivers can be best supported earlier in the continuum of care, such as in the non-palliative care settings of acute and chronic care.

Some participants' beliefs about the consequences of using the BRI were also described as a barrier, including doubts regarding the usefulness of some of the existing risk factors on the BRI. This factor might be a reflection of the changes in socio-cultural practices since the introduction of the BRI 35 years ago. For example, the key person delivering care now is less likely to be a spouse.

Lastly, clinicians identified the absence of certain risk factors on the BRI as another dominant barrier to using the tool in their clinical practice. For example, all participants noted that 'circumstances of the death' was essential in determining bereavement outcomes and this confirmed findings by other researchers (Rose et al., 2011; Roberts et al., 2017). This risk factor is absent from the BRI. Perceived sub-standard quality of care and undue suffering in the dying phase can lead to grief complications (Sanderson et al., 2013). Other missing risk factors identified by clinicians as important determinants of bereavement outcomes were concurrent stressors, the nature of the bereaved's relationship with the deceased, bereavement history, mental health history, religion/spirituality and the stage in the lifespan of the bereaved. These factors have previously been identified to be important by other researchers (Blackburn & Dwyer, 2017; Roberts et al., 2017). Clinicians in this study also identified protective factors of the bereaved as a useful domain to include on a bereavement risk screening tool, which is included in other risk assessment tools such as the BRAT and CBRAT. Identifying the strengths of the bereaved such as the existence of firm social supports will lend weight to the bereavement risk assessment.

Clinical implications and future research

This study has three key implications for practice for the effective use of a bereavement risk screening tool in the palliative care context. First, the study highlights that while there are important benefits to using risk screening tools, consideration needs to be given to contextual practicalities of their implementation. This includes examining issues such as shorter lengths of stay in palliative care inpatient settings which impacts on the time available to assess factors which influence bereavement risk (Aranda & Milne, 2000). This may be addressed through the addition of other tools which include assessment of bereavement needs earlier in the illness trajectory. For example, preliminary research in Australia investigating the use of a carer support needs assessment tool (CSNAT) has shown positive results (Aoun, Ewing, Grande, Toye, & Bear, 2018). Furthermore, adequate training about how to use the risk screening tool and information about theories of loss and grief may assist clinicians' confidence in implementing tools within their context.

Second, risk screening items need to be informed by clinicians' experience and observations of important risk factors and also be supported by theories of grief and loss. For example, the BRI included or somewhat included three out of 11 items considered important by clinicians in our local palliative care context. Other tools exist that meet the majority of these 11 domains including the BRAT (Rose et al., 2011).

Lastly, our participants identified the importance of having their assessments of bereavement risk verified, in terms of accuracy and validity. These results suggest the importance of service specific feedback about the longitudinal accuracy of those identified as more at risk.

Given that the BRI was first developed over 30 years ago, there may be a need for further research regarding the tool's current validity in an ever-changing socio-cultural context. This presents an opportunity for future research.

Strengths and limitations

This study investigated clinicians' perspectives of the barriers and enablers to using the BRI risk screening tool in an inpatient palliative care setting. The use of the TDF to inform data collection and analysis enabled a comprehensive understanding of the barriers and enablers for clinicians from diverse professional groups. However, the study took place in a single acute care setting within a tertiary hospital which may limit the broader applicability of its findings. Even so, the participants' rich descriptions combined with the finding's resonance with existing literature may enhance the study's potential transferability (Creswell, 2009; Lincoln & Guba, 1985). The study relied on individual accounts of using the BRI rather than observations. We aimed to increase the study's dependability through sample specificity (i.e. participants engaged in bereavement care in a palliative care setting) and by being theory informed (i.e. using the TDF) (Lincoln & Guba, 1985; Varpio, Ajjawi, Monrouxe, O'Brien, & Rees, 2017). There would have been value in exploring the perspectives of the bereaved, however, this was not within the scope of this study.

Conclusion

The BRI was perceived to be easy to use and facilitated monitoring of bereavement risk, however staffing resources, clinician confidence in the tool's ability to accurately identify at risk people and perception of the tool's comprehensiveness may influence its implementation in some clinical settings. Multiple drivers impacting shorter lengths of stay and other contextual practicalities in palliative care settings affect the implementation of risk screening tools. This points to the need for earlier risk screening by clinicians in the continuum of care.

While the BRI was noted as only one part of the risk assessment process in this palliative care setting, by systematically exploring barriers and enablers to its use, the study highlights the value of seeking clinician feedback about the use of a bereavement risk screening tool in practice. ■

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