

Bereavement in Critical Care: a narrative review and practice exploration of current provision of support services and future challenges

Abstract

This special article outlines the background to bereavement in critical care and scopes the current provision and evidence for bereavement support following death in critical care. Co-authored by a family member and former critical care patient, we aim to draw out the current challenges and think about how and where support can be implemented along the bereavement pathway. We draw on the literature to examine different trajectories of dying in critical care and explore how these might impact bereavement, highlighting important points and risk factors for complicated grief. We present graphic representation of the critical junctures for bereavement in critical care. Adjustment disorders around grief are explored and the consequences for families, including the existing evidence base. Finally, we propose new areas for research in this field.

Bereavement in Critical Care: a narrative review and practice exploration of current provision of support services and future challenges

Background

This article aims to outline dying in critical care and why this presents unique challenges for families and staff providing services, summarise the research evidence and current bereavement services and suggest future areas of development. One of our co-authors is a patient and family representative to ensure that this view is an integral aspect to this article. In this article, we define family as anyone close to the patient, and concerned with their welfare, encompassing relatives, next of kin and friends.

Death in critical or intensive care (ICU) can be one of the most profound events for families. Experiencing what can be a sudden and traumatic death, and a lack of formalised bereavement follow-up, highlighted in a UK survey (1) creates a significant challenge for families who may well experience a difficult death. This can lead to complicated grief trajectories, prolonged grief disorder, and increased risk of post-traumatic stress disorders (2-6).

One in seven people admitted to UK ICUs die each year, this equates to 27,000 people (7). Critical illness onset, and death, may be sudden, unexpected, or it may be protracted and anticipated. Both can be traumatic for patients and families, although literature suggests the sudden nature of death can be more traumatic (8). Dying and death in critical care is arguably unique for several reasons, including the technologically-mediated nature of decline in critical care, which can lead to what has been termed a medicalised death (9). The rapidity of death and dying is also a factor.

Epidemiological data shows us that from admission to death is short, less than three days on average (10, 11) and withdrawal to death is very short (2.4 hours) (12). Moreover, patients are often ventilated and the mechanics of withdrawal can lead to a different death and subsequent bereavement experience, which cannot be captured in epidemiological studies.

The nature of the dying trajectory will affect dying, death and subsequent experience of grief for families. Four key trajectories for dying in critical care can be described (more detail is given in Figure 1):

1. **Rapid unexpected death**, where patients are unexpectedly deteriorating (and where end-of-life decisions are unlikely to have been made, nor end-of-life care plans initiated).

2. **Rapid expected death**, where the patient's condition deteriorates, and their death follows a clear decline in the patient's condition. This decline is often related to an acute episode related to a pre-existing chronic illness.
3. **Chronic unexpected death**, where people often have a period of protracted illness leading to an ICU admission.
4. **Chronic expected death**, where it is recognised that the patient is dying and this is likely to occur in critical care. Here, professionals have communicated this expectation to families, who have confirmed their understanding.

The speed with which rapid unexpected and chronic unexpected death occurs in critical care represents a particular burden for families. These quotes are from research with bereaved families of critically ill patients (13) (see Box 1.).

>>INSERT Box 1.

>>INSERT FIGURE 1

There is little evidence to understand the scale of the problem of grief for each of these trajectories, with the exception of chronic, expected death (particularly in the cancer/COPD literature). Several issues that arise in these dying trajectories that have a bearing on the patient's death, and subsequent bereavement and grief experiences, including adaptation and adjustment are:

- Prognostication (and timing thereof), the recognition of dying and the rapidity of death
- Process of transition to palliation and end-of-life (EoL) care in critical care (including transferring home to die), and ongoing support from these services once bereaved
- Interventions to support transitions, EoL care and anticipatory grief, including: Symptom management; Communication/Family Support; Continuity of Care; Raising awareness
- Presence of anticipatory grief, grief prior to loss (death), associated with expected death (14). In people who are also caregivers prior to death, anticipatory grief can be associated with poor bereavement outcomes, including complex and disordered grief trajectories (15), which can be contrary to the connotations of expected death, where it might be thought that a person was more prepared for death in knowing it was expected.
- Family context (such as social situation, family dynamics)
- Individual pre-existing mental health and well-being

- Social support and social networks/family structures

Consequences for families and societal impact

Bereavement and grief-related disorders

Bereaved family members often struggle to understand and adjust to events that occur in critical care leading up to and around the time of death. For this reason, some family members report experiencing intense grief that affects physical, mental, emotional and social health and wellbeing. Some authors argue grief models have shifted towards increasing medicalisation (16-18), particularly since the inclusion of grief disorders in diagnostic manuals (Diagnostic and Statistical Manual of Mental Disorders, DSM; International Classification of Diseases; ICD). Some of these authors advocate that grief should not be regarded as a problem to be resolved but a necessary process after loss (19). However, whilst it can be challenging to classify an individual's grief reaction as 'pathological', published frameworks provide a description of normal and disturbed grief (20).

In one such model, the bereavement process is understood to represent the accomplishment of tasks comprising personal, practical, spiritual and existential adjustments to loss (20): accepting the reality of the loss; processing the pain associated with grief; adjusting to a world without the deceased; and finding a way to remember the deceased whilst continuing to live the rest of one's life. Family members who have difficulties achieving these 'tasks' even after a period of time has passed may be experiencing a disturbance in the grieving process.

There is no clear, accepted definition of complicated grief currently, however there are clear definitions for prolonged grief disorder (in ICD-11) and persistent complex bereavement disorder (in DSM5). Complicated grief is a more widely used term but the official definitions are now linked to prolonged grief disorder (PGD) and persistent complex bereavement disorder. Shear suggests there is no consensus for criteria and naming of complicated grief, and that PGD is the natural successor to complicated grief (CG)(17).

Suggested diagnostic criteria for bereavement-related disorders include symptoms such as longing for and preoccupation with the person who died, emotional distress and significant functional impairment that persist beyond six months after the loss of a significant other (21). Three broad diagnostic concepts have been proposed to characterise bereavement-related disorders: prolonged grief disorder, persistent complex bereavement disorder and complicated grief (22). In this article, we focus on complicated grief as this has been associated with critical care bereavement (3).

Prevalence and risk factors for complicated grief

Emerging research within the field of critical care demonstrates that family members can experience high levels of complicated grief and other psychological morbidity. One such study evaluated these outcomes for families of 475 patients who died in 41 critical care units in France. This study found 52% experienced complicated grief and 44% had post-traumatic stress disorder symptomatology at 6 months after their loss (3). In contrast, the prevalence of complicated grief in the general population is 5-10% (23-25).

Factors associated with increased risk of developing complicated grief included the family member not able to say goodbye to the patient, witnessing the death, and the patient dying whilst intubated. Where a patient was involved in decision making and declined treatments, family members had a 76% reduction in odds of developing complicated grief (3). It is also of note that family members who found communication unsatisfactory with ICU staff had a three-times increase in odds of developing complicated grief. These findings suggest potential targets for research with interventions to improve care, including decision-making, which might impact on later psychological morbidity.

Fixed characteristics such as younger age of the decedent, and the person who has been bereaved being the spouse or living alone-also increased the risk of complicated grief (4). These non-modifiable characteristics could be used to identify family members at higher risk of morbidity and allow better targeting of bereavement support where and when it is needed, and to expand bereavement follow-up services.

Impact of complicated grief

Numerous studies conducted in general populations demonstrate that bereavement is associated with impacts on mental, physical and socioeconomic health and wellbeing. For example, bereaved family members seek more primary care consultations and receive more prescriptions for antidepressants (26). Research shows that bereaved spouses experience worse physical functioning and increased mortality (27-29). Furthermore, a recent Scottish study found that bereavement was associated with increased healthcare utilisation (including longer hospital stays when ill), shown by additional primary care consultations costing £2 million, and reduced employment in the two years after bereavement (30).

The consequences bereavement in the ICU, and hence associated costs for supporting families, are likely to be more severe due to the higher prevalence of complicated grief and psychological morbidity in families bereaved in critical care settings. However, UK-specific data are lacking to

identify family members at higher risk of complicated grief and to ensure their needs are met during their bereavement.

Current evidence for supporting families bereaved in ICU

Little evidence exists on ways to support ICU families through grief trajectories, from anticipatory grief during EoL decision-making, withdrawal, and dying, and in the months beyond (2, 31).

Recent reviews highlight insufficient evidence for specific interventions, models of delivery, or timing of support, as all studies were contextually bound, with no UK intervention studies reported (32, 33). Efstathiou et al's (32) systematic review identified 14 papers evaluating nine bereavement support interventions. Interventions included personal mementos, condolence letters, meetings with critical care staff after the death and story-telling. Adequately powered studies demonstrated no effect in a range of interventions, and one study even suggested worse psychological morbidity in families randomised to receive a personalised condolence letter compared with usual care. All the evidence reviewed was appraised as weak with little potential for generalisability. However, interventions were viewed as acceptable by bereaved families. Furthermore, a qualitative scoping review highlights the need to better understand bereaved critical care families' experiences in order to develop appropriate interventions grounded in a sound theoretical framework (34).

Most of the reviewed studies were conducted in countries other than the UK. However, findings from other countries may not be easily generalisable to the UK due to cultural differences. These differences are not limited to culturally-specific bereavement experiences, but extend to the practice of intensive care, where organisation, patient case-mix and outcomes differ substantially between countries (35). Despite this limitation, research in non-UK settings has not identified how we can better support bereaved families in critical care, in terms of models of service delivery or types of intervention, nor has it identified the appropriate timing of support. In particular, we do not understand bereavement needs of those affected by the death of family member in critical care settings.

Potentially, focused critical care interventions could reduce family burden, particularly in relation to returning to work while grieving (36). Given poor family experiences and outcomes after the death of a family member in critical care (37-39) current support mechanisms, including those post-critical care, do not meet families' needs. Crucially, evidence to understand and address these needs is also lacking.

Current provision and guidance for bereavement care in critical care

Recent guidance by the Faculty of Intensive Care Medicine written specifically to address end-of-life (EoL) care in critical care settings focusses on advanced care planning, EoL decisions and EoL care. It emphasises family involvement in EoL care to help prepare for bereavement and the role of the healthcare team in guiding the family toward an understanding of death from both individual and cultural perspectives. Bereavement care services were highlighted as invaluable for helping families who may struggle to understand death in critical care, particularly when compared to deaths in other environments (40). However, service provision guidance for UK critical care units does not specifically outline bereavement service configuration (41), nor does recent NICE guidance for EoL services (42). Current service models (1), or lack thereof, demonstrate how critical care units fail to meet national bereavement service standards (43). Berry et al's (1) survey conducted across 78% of eligible units (n=113/144) in England found limited, inconsistent provision of bereavement care. These were mainly information leaflets that signpost to bereavement services, (services which are predominantly based in the charity/third sector and not specific to critical care bereavement), and 17% of units provided no bereavement support services.

CRUSE, the largest bereavement charity in the UK, outlines seven key standards for bereavement service configuration: Planning, Awareness and Access, Assessment, Education and Training, Support and Supervision and Evaluation and Monitoring (44). However, these standards are not routinely considered in critical care related-bereavement, and primary care professionals may not fully understand the risk factors for complicated grief, as highlighted by Sealy (45), or implications following bereavement in critical care. Moreover, lack of data in this area means we do not know the scale of the problem. A multi-agency approach underpins UK bereavement services, with provision spanning acute care (palliative care and pastoral/spiritual care services) through to primary care and third sector (hospice/charity/volunteer groups), and variable access. This relies on much provision outside of the NHS, but may be partially/wholly commissioned by the NHS (see figure 2).

The National commissioning standards for bereavement support suggest three components of grief support for families (46):

- 1) Information about what to expect in bereavement, including normal trajectories of grief so families can understand that grief is to be expected and the forms that it can take, and what support is available to them
- 2) Formalised support and the opportunity to reflect on grief and bereavement experiences, which may involve lay support through volunteers
- 3) Access to specialist intervention through psychological support, mental health and counselling services, and palliative care/bereavement services.

Following death in critical care, there are additional challenges for families and staff as any bereavement service provision is usually disengaged from critical care services. In the absence of formalised critical care bereavement follow-up, bereavement care can fall to community services, in particular primary care, GPs and district nurses. This is problematic, due to GPs being ill-equipped to provide advice following bereavement in the ICU (even where GPs have expressed an interest to provide pro-active bereavement follow up), the time constraints in which they work, and increasing service pressures (47). Even where GPs were trained to deliver bereavement interventions, there was a lack of sustained improvement in families, and in GPs' ability a year later to recognise CG, suggesting these approaches may be limited (48).

Components of bereavement care in critical care units vary significantly. Options such as family meetings are generally focused on reviewing what happened to the patient (event review), rather than meaning-making and therapeutic interactions. Memorial services for former critical care patients have gained popularity in the UK, as a way of supporting families bereaved in critical care. Mementoes (locks of hair, electrocardiograms) are also increasingly used, alongside critical care diaries. Bereaved families can attend critical care support groups. However, we do not know whether initiatives like these offer support that help families grieving trajectory, as formalised research into the effect of these support mechanisms does not currently exist. As such, we do not understand what families' bereavement support needs are following death in critical care, nor how to meet individual and changing needs, and which interventions might be helpful to families, particularly in the UK.

We have mapped the current landscape for bereavement provision related to adult critical care in Figure 2.

>>INSERT Figure 2

Research directions

General bereavement care has been identified as a priority for research in several pieces of patient and family focused work, including the NIHR (49), and the James Lind Alliance priority setting exercises in both palliative (49, 50) and critical care (51). They specifically highlighted the impact of continuity of care across clinical settings, from tertiary specialist and secondary hospital care into the community via primary care and social care. However, there is a lack of research into pro family and

patient-centred interventions to achieve effective bereavement care, especially with patients who are acutely deteriorating and at-risk of dying.

Evidence to drive practice is limited, and more research is needed to understand experiences and meaning-making practice, but also to prevent long and short-term grief complications. The reasons for the lack of research are multifold, and include a reluctance to approach families for bereavement-related research, even when there is evidence to show that families find it cathartic and useful (52-54).

The heterogeneity of existing studies in critical care means it is hard to draw meaningful conclusions about effective practices, as recently outlined in a systematic review (32). Moreover, there is a tension between what happens in practice and what the limited evidence tells us we should be doing. A good example of this is sending condolence letters, a common practice in UK critical care, which Kentish Barnes et al's (4) randomised controlled trial identified was associated with increased depression and PTSD at six months. This emphasises how seemingly innocuous actions in early bereavement can have lasting consequences. The authors present a number of hypotheses for this finding, including the unique nature of ICU means this might exacerbate painful memories, but without qualitative understanding it is hard to draw definitive conclusions. Qualitative studies around end of life and bereavement suggest there may be value in certain practices, (such as creating mementoes) (33), which need to be explored in more depth across a range of critical care settings and in multi-centre studies. A broad range of research, encompassing mixed methods may improve understanding around the effectiveness, or not, of bereavement interventions. Theoretical frameworks of bereavement, such as the Integrated Risk Factors Framework (15), can also help in developing the evidence base as they provide comprehensive constructs to apply to what is a complex field, with social, familial, emotional, psychological, physical and societal components. We have to understand the mediating factors that influence bereavement and outcomes, in order to address them, therefore approaching research through a theoretical lens is also important. No core outcome set measures exist for EoL in critical care research currently, although development is underway for bereavement support research studies more broadly, which will help address these issues in the future (55).

Moreover, by looking to novel areas of practice in mental health, such as locally-commissioned mental health provision in GP practices (rather than requiring additional referrals to external mental health services) may be one way forward. Approaches such as social prescribing (where health professionals refer to community services, including voluntary sector, with a focus on

health/wellbeing) and by learning from areas such as paediatric critical care and maternity, bereavement care in adult critical care can potentially be advanced.

Conclusions

We have outlined how trajectories of death in critical care may impact on grief and complicated grief, in particular, and the unique nature of bereavement in this context. The patchy service provision, which falls well short of national guidance, and lack of UK centred-research means we do not fully understand the landscape of bereavement care, nor what optimal care looks like, following death in critical care. We have to work with patients, public and families and colleagues in driving forward services, and ensuring the care we provide is robustly underpinned with good evidence. In practice, we need to have mechanisms that ensure families' and public views in developing these services are fully integrated, requiring unit staff to know how and when to approach families, and knowing the appropriate things to ask.

Concluding view from a family member (CW, co-author):

“Just as the long and complex recovery and rehabilitation of critical care patients is often hidden from view from critical care staff (because it happens away from the unit), so are the repercussions for families after the death of their relative. There are particular facets to a death in critical care, which means general bereavement services are not sufficient, but the critical care expertise does not sit in the community. Family members may present to many different places seeking support or due to the consequences of what happened, but all this is hidden from view. This disconnect means that not only do services not improve for families while in critical care, but there is no impetus to improve the care afterwards. Investing in good quality research to know which interventions are effective pre and post death in ICU, is a necessity.”

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