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End-of-life and immediate postdeath acute hospital interventions: scoping review

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ABSTRACT

Background Hospital remains the most common place of death in the UK, but there are ongoing concerns about the quality of end-of-life care provision in this setting. Evaluation of interventions in the last days of life or after a bereavement is methodologically and ethically challenging.

Aim The aim was to describe interventions at the very end of life and in the immediate bereavement period in acute hospitals, with a particular focus on how these are evaluated.

Method A scoping review was conducted. Studies were restricted to peer-reviewed original research or literature reviews, published between 2011 and 2021, and written in the English language. Databases searched were CINAHL, Medline and Psycinfo.

Results From the search findings, 42 studies were reviewed, including quantitative (n=7), qualitative (n=14), mixed method (n=4) and literature reviews (n=17). Much of the current research about hospital-based bereavement care is derived from the intensive and critical care settings. Three themes were identified: (1) person-centred/family-centred care (memorialisation), (2) institutional approaches (quality of the environment, leadership, system-wide approaches and culture), (3) infrastructure and support systems (transdisciplinary working and staff support). There were limited studies on interventions to support staff.

Conclusion Currently, there are few comprehensive tools for evaluating complex service interventions in a way that provides meaningful transferable data. Quantitative studies do not capture the complexity inherent in this form of care. Further qualitative studies would offer important insights into the interventions.

BACKGROUND

The death of a loved one is associated with increased morbidity and mortality in both the short-term and long term,

particularly in the event of unexpected bereavement.¹ Hospital remains the most common place of death in the UK^{2 3} with up to a third of hospital inpatients being thought to be in the last year of life at any one time.⁴ However, there are ongoing concerns about the quality of end-of-life care provision in this setting. When patients die in the hospital setting, they and their families may receive input from a variety of palliative and support services, both generalist and specialist. Challenges in end of life and bereavement care in acute settings are well established but services remain understudied⁵⁻⁷ and notably, the services that provide support at this time are not well evaluated.⁸ What is known is that patients and their loved ones express a need for clear communication about death,⁹ timely provision of information¹⁰ and compassionate support before and after the death.¹¹

A small proportion of people who die in hospital are known to specialist palliative care services, but not all.¹² Deaths take place in every clinical area and some of these are sudden or unexpected. Much end-of-life support is provided by staff who are not specialists in palliative and end-of-life care. Effective interventions that offer meaningful support to patients, families and staff must take this into consideration. Evaluation of interventions in the last days of life or after a bereavement is methodologically and ethically challenging,¹³ and consequently there is little evidence on which to base generalist palliative care interventions. Little is known about the context and mechanisms of such services, and the circumstances in which they achieve specific outcomes. Services not directly involved in clinical care, such as chaplaincy, face particular challenges in evaluation especially in multicultural settings.¹⁴ The benefits of aspects of care such as enabling relatives

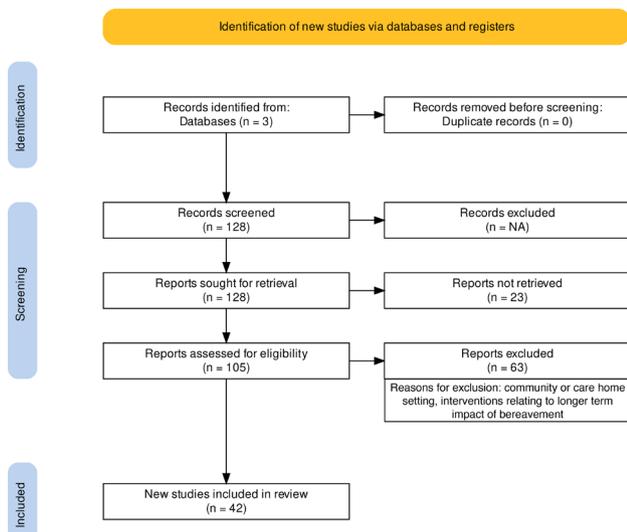


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

to visit their loved one after death are also difficult to evaluate empirically.¹⁵

Aim and objectives

The motivation for this review arises from the need to appraise the current state of evidence relating to interventions and services in the last days of life and shortly after death. Because this is a broad area of study rather than a discrete intervention, a scoping review was considered the most appropriate approach. Scoping reviews generally aim to assess the potential size and scope of available research literature and identify the extent of research evidence.¹⁶ The aim of this scoping review was to describe services and interventions at the very end of life and in the immediate bereavement period in acute hospitals, with a particular focus on how these are evaluated.

This review has been reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews as listed in the Enhancing the Quality and Transparency Of Health Research network (online supplemental file 1).

METHOD

The scoping review followed Arksey and O’Malley’s five-stage framework¹⁷: identifying the scope of the review, identifying relevant studies, selecting the studies, documenting data and reporting the results. The two central questions guiding the review were ‘what services and interventions exist in acute hospitals for supporting patients, families and staff in the period immediately before and after death?’ and ‘what methods are used to evaluate these?’

We were particularly interested in research related to ‘immediate’ interventions, where individuals or professionals become involved at the time of death

Table 1 Scoping review criteria

Inclusion criteria	Exclusion criteria
Studies set within acute hospital care setting	Studies based in community, long-term or care home setting
Studies involving end-of-life care and bereavement	Studies focusing on specialist palliative care interventions for example, symptom control
Interventions or services	Disease or condition-specific interventions
Primary research, systematic reviews	

or immediately afterwards. The scope of this review includes research that explores the mechanisms of bereavement interventions (these may be theoretical or empirical), the impact of care before and at the time of death on outcomes related to family and staff, and the contextual conditions that facilitate or impede the provision of such care. Outcomes include both intended and unintended consequences of the interventions included.

The search strategy included palliative, end-of-life care and bereavement. There were two issues concerning timescales that influenced the scope of the study. The first relates to the period considered to be the ‘end of life’. In UK policy,¹⁸ the ‘end-of-life’ is generally taken to refer to the last 12 months of life and therefore much of the literature relates to this period. Further, the literature relating to bereavement interventions tends to concentrate on longer-term interventions rather than support at the time of death and immediately afterwards. For the purposes of this study, we were interested in the last days of life, the time around death and immediately afterwards. Therefore, we used a ‘sift-and-sort’ approach to identify the literature that potentially included studies from outside this period, but only if it provided insight into service evaluation that could be transferable to the period of interest.

A search was conducted using the following search terms:

Bereavement OR end-of-life OR palliative OR care after death
 AND
 Intervention OR service OR support OR strateg*
 AND
 Impact OR outcome OR mechanism OR evaluation OR realist

Studies were restricted to peer-reviewed original research or literature reviews, between the years 2011 and 2021, written in the English language. Databases searched were CINAHL, Medline and Psycinfo. The PRISMA diagram (figure 1) summarises the search strategy, and table 1 describes inclusion and exclusion criteria. Following retrieval of 128 records, a process of sifting and sorting was undertaken. Although the focus of the review is on acute hospital care, this was

not a restriction in the literature search because we wished not to exclude relevant studies from settings such as hospice. This was to ascertain their methods of evaluation rather than to examine the interventions themselves. On applying sifting and sorting criteria, there were no additional methods used outside the acute hospital setting so it was decided not to include those studies reporting on other care settings.

Overall, 2421 studies were identified in the initial search. Duplicates were removed, titles were screened and a total of 128 study abstracts were reviewed for inclusion. Additional sifting and sorting criteria were applied. Studies looking at sudden and unexpected death as well as expected death were included, recognising that the needs of families and staff will vary according to the nature of the loss. Because the focus of the review is on care immediately before and after death, studies on longer-term bereavement support were excluded, unless they specifically discussed approaches to service evaluation. Studies that focused on the community and care home setting were excluded, as the review aimed to look at what works in the acute healthcare context.

RESULTS

Following the original search and a subsequent process of sifting and sorting, 42 studies were selected for inclusion. Online supplemental table 1 summarises the studies, including methods and key findings, and indicating the international nature of the studies selected. Of these, 7 were quantitative, 14 were qualitative, 4 were mixed methods and the remaining 17 were literature reviews. Of the mixed method studies, one was a critical realist evaluation. Most of the quantitative studies were satisfaction questionnaires or surveys. Nine studies reported on paediatric end of life and bereavement care.

To assist in a structured approach to findings, and to inform the development of our planned realist evaluation, three themes were identified: person and family centred care, institutional approaches and infrastructure. First, the evaluation methods of the interventions are summarised.

Evaluation methods

In terms of methods of evaluation, the literature highlights a broad range of methods, including self-devised questionnaires, qualitative interviews and the use of data collection instruments such as grief inventories and depression scales. Much research on bereavement focuses on long-term interventions and there is next to no evidence to support practices in the immediate aftermath of death. In many cases, information is collected at a single time point—on completion of the programme or intervention. Across both adult and children's bereavement services, formal evaluation appears to be ad hoc and may not provide the quality of information required for robust service development.

An examination of how bereavement programmes were evaluated identified 38 studies that reported specifically on approaches to bereavement service evaluation.¹⁹ Outcomes were generally related to use of crisis services, participation in ongoing bereavement support groups and identification of those who would benefit from services. The included studies primarily used questionnaires or surveys for data collection. More detail on these approaches is provided within the themes below.

Patient-centred/Family-centred care

This theme contains studies that reported on how individuals experience end of life and bereavement care interventions, including families and loved ones. The interventions include actions to support memorialisation, such as creation of mementoes (letters, pictures), hand and lip prints or locks of hair and provision of comfort items such as twinned knitted hearts, one of which remains with the deceased person while the other is kept by loved ones. The interactions that take place in the context of end of life and bereavement care are a key consideration in terms of how they contribute to the overall experience. This relates not only to the kinds of therapeutic relationships required when caring for patients and families but also to how staff work together to provide compassionate care. This theme includes the interpersonal aspects of interventions and how they are evaluated.

The studies report on family experiences, both directly and as a proxy for patient experience. In the UK, families' experiences of end-of-life care have been evaluated using satisfaction surveys, with one of the most prominent modes of data collection in the UK being the 'Views of Informal Carers—Evaluation of Services' ('VOICES') survey.^{20–22} This retrospective quantitative survey includes data relating to demographics, the quality of clinical care, covering issues such as compassionate communication and symptom control. There are also free-text questions to gather descriptive data. The survey is recommended as best practice in enhancing hospital-based end-of-life care,²³ and has been widely used on institutional, Trust and national levels to support and inform service development. However, while a profile of the quality of end-of-life care is essential, the VOICES questionnaire provides minimal information about what works, for whom and in what circumstances.

Efstathiou *et al*²⁴ described nine bereavement interventions within the literature, including personal mementos, condolence letters, debriefs for staff and story-telling. The quality of evidence of effectiveness is considered weak and not generalisable; the success (or otherwise) of such interventions appears to be highly dependent on the role and way such interventions are delivered. There is some evidence that acts of remembrance and memorialisation are valued by bereaved family members.^{25–29} These studies have primarily used

qualitative methods to find out families' perceptions of having received mementoes (such as ECGs, locks of hair or handprints) following the death of a loved one.

There appears to be a clear role for hospital-based bereavement care, particularly in the support of families of children.³⁰ Much of the current research about hospital-based bereavement care is derived from the intensive care unit (ICU) and critical care unit settings, where deaths can be unexpected and sudden. A scoping review of memory-making in adult ICU³¹ identified seven studies presenting research on this intervention, using both qualitative and quantitative methods. The acceptability and comfort offered by the interventions was largely ascertained by proxy, for example, by asking nursing staff for their opinions, rather than directly from families.

Several studies examining family perceptions of care made use of surveys and questionnaires for the purpose of evaluation.^{32–34} Some questionnaires had been developed specifically to evaluate a single service, while other studies made use of existing, validated tools such as the 'Satisfaction With Bereavement Experience Questionnaire' and the 'Quality of Dying and Death in the Intensive Care Unit survey'.³⁵ One of the challenges in using quantitative instruments for the purposes of evaluating services is that they do not capture the complexity inherent in this form of care. For example, of 52 studies identified in a review by Garstang *et al*³⁶ on parents' needs following sudden death of a child, fewer than a quarter used qualitative methods.

While quantitative instruments such as surveys play an important role in evaluation, avoiding some of the ethical complexity of more iterative research approaches, they can limit the level of detail obtained, in particular the generation of new insights into how an intervention might work in particular situations. A further consideration is the variable reliability in different survey instruments in different populations. Evaluations may be prone to bias as users of such services are a self-selecting group, so findings of such studies may not indicate the value of interventions for people who decline or are not afforded access to services, and who may be highly vulnerable to the adverse impact of grief.¹³

The use of qualitative methods provides a more nuanced insight into these kinds of individual interventions. In the field of paediatric intensive care, Bloomer *et al*^{37–39} describe how observations of practice reveal several ways in which nurses support families in the period leading up to a child's death. Again, respecting the child as a person and collecting and creating mementoes appears to be an important part of nursing care, and appears to empower parents and families to be a part of the process rather than just onlookers.

There is little research that focuses specifically on the interpersonal nature of care in the context of specific interventions. One small Australian study by

Clark *et al*¹¹ highlights the ramifications of the interpersonal encounters between them and the health-care providers. The study combined the use of the Quality of Death and Dying tool with semistructured interviews to evaluate experiences of bereavement in the acute hospital settings. Two studies sought to describe the role of staff in providing immediate care following a death. Raymond *et al* undertook a systematic review⁴⁰ and suggested that nurses provide vital patient-centred and family-centred care at the end of life and that this continues into the bereavement period. Naef *et al*⁴¹ described ways in which health professionals in Switzerland provide immediate support following a death in acute and psychiatric care settings, via a cross-sectional online questionnaire (n=196). Roles included enabling viewing of the deceased, sending condolence cards, providing information on funerals and other support, and referring onwards. Nurses provided more immediate care, while physicians were involved in screening for bereavement risk factors. Notably, participants observed that such aspects of their roles are rarely evaluated and there is a need for support and education. The value of volunteers in the provision of hospital end-of-life support was the subject of a literature review by Bloomer and Walshe,⁴² with the emphasis being on 'being with' the dying person in a non-specialist capacity. The psychosocial aspect of the role was considered to be particularly valuable, alongside the clinical care provided by the core healthcare team.

Several studies report on interventions that sustain or maintain personhood in the face of dying. A systematic review of 21 studies by Kochen *et al*⁴³ summarises a range of interventions to support families when a child dies. The studies point to the importance of acknowledging and recognising a child who has died through the creation of keepsakes by hospital staff. In general, the literature in this area suggests that this is appreciated by bereaved loved ones. However, the authors conclude that the interventions lacked an empirical evidence base and suggested that one approach to evaluating them is to do so against theoretical concepts such as theories of grief and loss.

Institutional approaches

Many of the interventions described in the theme 'Person-centred/Family-centred care' were implemented on an individual ward level, rather than across entire institutions. This theme addresses changes across institutions, which were perceived to impact on the quality of end of life and bereavement support.

The 'VOICES' survey reports on the quality of the hospital environment and repeatedly, the importance of privacy, dignity and sensitive care after death are highlighted.²¹ Coombs *et al*'s⁴⁴ scoping review of family experiences of end-of-life care in ICU identified the impact of flexibility in terms of family perceptions of support, including hospital parking, visiting hours

and privacy. Particularly in critical care of children, the importance of the hospital environment is emphasised, such as in the grounded theory study by Butler *et al.*⁴⁵ Moss *et al.*⁴⁶ note that three existing randomised controlled trials of bereavement interventions omitted key bereavement outcomes, including communication and connectedness, finding balance, and relationships and social functioning.

Where service developments take place across entire institutions, it is important to obtain information about staff perceptions. Walker and Deacon⁴⁷ attest to the impact on staff of caring for the suddenly bereaved. Through a series of interviews with staff, they identified that staff find this role simultaneously important and a source of unrest. Participants in the study identified the context of care as a key influencing factor in staff's perceptions of this aspect of their role; this includes attitudes to death and dying, professional support from colleagues, and the culture of care on that ward or shift. Participants indicated that care provision was less challenging when departmental guidelines about visiting times and numbers of visitors were relaxed. Participants identified a number of aspects of this type of care that they perceived to be rewarding, including 'person-centred moments', informal debriefs with colleagues and the ability to establish priorities of care with families and members of the multidisciplinary team. Bristowe *et al.*⁴⁸ identified tangible changes in practice from the views of relatives when new models of care such as the Amber care Bundle were put into practice, notably in relation to the effectiveness of open and honest communication from clinicians.

A review by Harrop *et al.*⁴⁹ appraised bereavement support during the COVID-19 pandemic, identifying that organisational culture and prioritisation of bereavement care across the entirety of the institution is highly valued by staff in those clinical settings where death occurs.

Bristowe *et al.*⁵⁰ examined healthcare professionals' views of a complex intervention to improve care towards the end of life (the "AMBER" care bundle) and although the intervention itself relates to decision-making in relation to escalation of treatment and advance care planning, both of which fall somewhat outside the remit of the review and fit more with the role of the specialist palliative care team, this is a useful study in terms of looking at approaches to evaluation for complex interventions relating to the end of life. Understanding perceptions can help to shape implementation plans and education to ensure consistent use of a service or model. One of the findings of Bristowe's evaluation was that the implementation of the AMBER care bundle appeared to have an impact on staff through serving a symbolic purpose—it indicated that the patients in receipt of the intervention were at a particular point on their illness trajectory (in this case, at a point where recovery is uncertain) and the fact of

being identified as an appropriate patient for the use of the bundle led to staff awareness of the wider context of their situation becoming apparent. This idea of symbolic relevance may be an important element of large-scale changes in institutions.

Walsh *et al.*⁵¹ undertook an evaluation of a whole-hospital approach bereavement services through secondary analysis of qualitative data from focus groups with bereaved people and staff (n=21). The approach they evaluated took place in one Irish hospital and included appointment of a dedicated bereavement coordinator, whose role included staff support and training across the institution. Improved practices in a number of areas were identified, such as the establishment of 'memory bags', closer working between services such as organ transplantation, ward and mortuary staff and bereavement care coordination. Staff reported a sense of pride in the development of the bereavement services. The central role of management and leadership was also identified as contributing to the success of the service changes.

Using a case-study approach to evaluation can help to make sense of large-scale innovations. Della Penna *et al.*⁵² undertook a quality improvement study of an inpatient palliative care service across a large health-care organisation in the USA. Through interviews with national, regional and local leaders, a number of factors were identified that were thought to contribute to the widespread uptake of the innovation across the organisation. Alongside evidence of improved patient satisfaction (as identified through surveys), the impact of leadership and support on creating a change in culture appears to be pivotal.⁵³

Infrastructure and support systems

This theme addresses interventions that appear to act on service infrastructure and support systems. In contrast to the 'institutions' theme above, they propose ways in which support systems can be strengthened through service development.

Observational research suggests that acute hospital staff may need support after patient deaths, particularly around sudden or unexpected deaths³⁸; a need for education alongside the intervention has been established in other evaluations of end-of-life care innovations. The need for support for staff is well established^{38 54 55} particularly in those clinical settings where there are more unexpected or traumatic deaths.^{47 56} There are times when staff need immediate advice and support in relation to unfamiliar or particularly challenging end-of-life situations. Role-modelling and expertise-in-action may therefore also be an important contextual factor in the acceptability and action of the individuals supporting patients and their loved ones.³⁸ There is little research on interventions to support staff in the immediate aftermath. A small, anonymised survey on a 'sacred pause' in a single ICU

in the USA suggested taking time to reflect on deaths permits closure and builds resilience within the team.⁵⁷

Shariff *et al.*'s narrative overview of ICU nurses⁵⁵ focused on the needs of the 'suddenly bereaved', and the particular challenges that this poses both to relatives and to the staff providing care. An ethos of caring support between staff was seen as fundamental to being able to enact this difficult part of the job. Contextual factors that impeded the provision of care included manpower resources, the conflicting demands of other patients and the brevity of the encounter with the person who has died and their families. Where death had not been discussed, or there was conflicting information provided by members of the multidisciplinary team, staff reported finding bereavement care more difficult as death felt more like a failure and was unanticipated. The literature identified in Shariff *et al.*'s review⁵⁵ further supported the importance of small acts of humanity—making a cup of tea, providing physical and temporal space, remembrance and gentle conversation—on the experiences of the suddenly bereaved.

Transdisciplinary working is generally considered to be an important component of the success of services around the end of life, given that it is a time of such uncertainty and unpredictability, with patients often requiring input from a variety of services in a variety of care settings.⁵⁸ Efstathiou *et al.*⁵⁹ undertook a realist evaluation of a coordinated end-of-life care service. They concluded that the service's acceptability and success was partly related to the way in which expectations about pre-existing services and traditional roles were challenged. However, the authors also considered that challenging traditional boundaries brought with it the need to establish and maintain clear and realistic expectations, as well as investment in recruiting, educating and developing the workforce.

Research that incorporates observation of service provision has had somewhat more success in capturing the kinds of mechanisms and contexts of care at this time of life. Woodthorpe and Komaromy⁶⁰ explored the role of mortuary staff in hospital-based bereavement care services through undertaking an ethnographic study of one mortuary team. The study included observation and interviews, and participants were keen to describe the barriers and facilitators to the provision of mortuary services. They challenged existing perceptions that the dead person's body should be kept hidden, suggesting instead that it is important to promote visibility of death and dying to counter stigma. Becoming more integrated into multidisciplinary teams was a common wish expressed by participants, as well as recognition for their 'bridging' role between clinical care of the living person, and care of the dead person. This study also describes the use of interventions such as enabling viewing of the deceased person³⁴ but did not provide information on how this is valued by the bereaved. A qualitative approach, such as that taken by Chapple and Ziebland,¹⁵ is able to

provide insight into relatives' perceptions of being able to view the body of a deceased loved one following traumatic death.

Structural features of organisations and institutions have not been well evaluated in terms of their impact on end-of-life care and bereavement. It is difficult to evaluate cost-effectiveness, not least because of the lack of clarity about outcome measures.⁶¹ One example identified in this review was a realist evaluation of a single-point coordinated end-of-life care service,⁵⁹ which suggested that several mechanisms contributed to success: the presence of coordinated services, the recruitment and development of the workforce, articulation of clear roles and the management of expectations. One approach to evaluate effectiveness of an intervention is to investigate the impact of an intervention on a particular outcome. In a stepped-wedge cluster trial by Aoun *et al.*,⁶² researchers investigated whether involvement of palliative care before death had an impact on whether the patient achieved their preferred place of death, and how carers perceived their level of grief. These findings in end-of-life care are mirrored in a recent narrative review on bereavement by Harrop *et al.*,⁴⁹ examining the relative success of elements of systems approaches to mass bereavement. The latter highlighted that those characteristics of successful system-level responses were that they were proactive and centrally organised, with an emphasis on psychosocial support. It is perhaps unsurprising that the elements of success in end of life and bereavement care show such overlap.

DISCUSSION

It is essential that services are evaluated to ensure efficiency and efficacy of provision, but evaluation of end of life and bereavement services is notoriously challenging. In part this is an inevitable consequence of the ethical, logistical and theoretical obstacles inherent in trying to evaluate services at such a potentially vulnerable time. Undertaking service evaluation with bereaved family members and service users presents challenges such as the appropriateness of asking for their time, the reliability of recall under stress and the lack of other comparable experiences on which to base their opinions. Further, it is important to distinguish between satisfaction and the effectiveness of an intervention.

Satisfaction surveys as a measure of effectiveness of interventions are problematic.¹⁴ If provided to a bereaved person too soon, there is no means of evaluating the enduring effectiveness of support provided to families along the trajectory of their experiences. If administered too late, bereaved loved ones' experiences of grief may be shaped by any number of factors additional and extrinsic to the support provided around the time of death—for example, existing support networks, resilience factors, support from other health and social care services.

Further, there are theoretical difficulties in understanding what constitutes efficacy of interventions at such a sensitive time. It is not possible to undertake empirical research and so there is no way to compare interventions and services with one another. There are no studies reporting on patient experiences, likely due to practical and ethical obstacles, although observational research may provide a valuable means of evaluation here. Current MORECare guidance⁶³ on evaluating end-of-life care services recommends the use of research designs that extend beyond randomised trials and mixed methods to capture the nuanced nature of complex interventions, including paying attention to implementation aspects of services.

Among other indicators of success are the perceptions of family members and professionals, and satisfaction surveys. Dias *et al*⁸ appraised the quality of research relating to end-of-life care processes and outcomes in a hospital setting, highlighting that of 416 studies meeting eligibility criteria for evaluation the majority (n=351) were descriptive and of those that evaluated interventions, just 18 met the Effective Practice and Organisation of Care taxonomy design criteria. The use of stakeholder views, while providing valuable evaluation for individual services, does not necessarily provide a sense of transferability. Elements of a service that work in one context may be less effective or less well received in another context, as demonstrated by the attempt to implement a US-based evaluation of chaplaincy services in a multicultural UK context.¹⁵ A stakeholder engagement event reported by Harrop *et al*⁴⁹ sought to clarify a set of outcomes for evaluating support received by bereaved people, identifying the importance of communication and connectedness, finding meaning and finding balance between grief and life moving forwards. Although this approach to developing outcomes is valuable, the stakeholders were those who had been involved with bereavement service provided by a hospice, therefore their views related to experiences of expected death and longer-term support. It is not clear from this study which, if any, of these outcomes might be applicable to those experiencing sudden loss.

Measurement of outcomes is challenging in this area of practice, and it is necessary to develop new ways to conceptualise efficacy and effectiveness. One important means of doing this may be through insight into the kinds of processes that lead to the outcomes observed. Without evaluation, we cannot know whether interventions are effective, and whether they represent a good use of resources in an increasingly competitive healthcare environment. Schut and Stroebe⁶⁴ propose that instead of seeking to establish empirical criteria for success in such services, stakeholders should instead consider efficacy as the extent to which a service was able to protect the bereaved from the 'unnecessary consequences of the loss'. This is to say that bereavement is distressing in all cases, for all involved, but that there is potential for services

Table 2 Summary of key themes and findings

Person-centred and family-centred care	'Whole person' concerns
	Acts of remembrance and memorialisation
	Maintaining dignity
	The 'little things'
Institutional approaches	Preparation
	Flexibility
	Culture of care
	Leadership
	Adoption across institutions
	Symbolic; visibility of death; conversations
	Continuity—end of life through to mortuary care
Infrastructure	Education and staff support; community of practice
	Professional roles and boundaries
	Interdisciplinary and transdisciplinary working

or individuals to inadvertently add to the suffering of the bereaved if care is not delivered in an appropriate, compassionate and family-centred way. Adopting this perspective means that the success of a service relates to the extent to which it can help to mitigate against these unintended additional stressors for the bereaved, and for those who work with them.

This review has highlighted limitations in the quality and quantity of research available in relation to evaluating services and interventions at the end of life. However, from the literature identified, there are key mechanisms that appear to be of value in the implementation success of interventions at the end of life, at the time of death and during the immediate bereavement period (see [table 2](#)).

Limitations

As a scoping review we were concerned with seeking out published studies and reports but have not excluded the literature because of quality concerns as we were keen to include a broad range of literature covering a variety of aspects of practice.

CONCLUSION

Dying and grief are profoundly individual experiences. Currently, there are few comprehensive tools for evaluating complex service interventions in a way that answers the question of what works, and for whom, and in what circumstances. Qualitative research in this area is therefore an important part of understanding the impact of services and interventions. This review has provided an overview of the current state of research relating to interventions at the end of life and around and after the time of death in acute hospitals. The interventions related to person-centred and family-centred care, institutional approaches and the necessary infrastructure. A variety of approaches to evaluation have been described and appraised, highlighting limitations in the quality and quantity of research available in relation to evaluating services and interventions at the end of life.

Evaluating such interventions requires approaches that can accommodate the need for transparency and reliability and yet provide nuanced data describing what works to support people through dying and early grief. Evaluating the effectiveness of bereavement interventions presents major theoretical, ethical and practical challenges. Findings from this review highlights some of the key considerations that must be addressed when evaluating end-of-life care. These include what methods to use, the recruitment of participants, what to measure to demonstrate effectiveness, adapting measures to reflect cultural and other diversities, and how to deal with variables likely to influence the delivery and outcomes of the intervention.

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Contributors All authors contributed to the planning of this review. LG: prepared manuscript, undertook review and led writing. LB: provided detailed feedback on study selection and structure, manuscript review and editing, wrote abstract. AS-L: reviewed and provided detailed comments and edited all versions of manuscript.

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Supplementary Table - Summary of findings

Authors and Location	Research Focus	Method	Findings
Aiyelaagbe et al. 2017 [UK]	Parents' experiences following perinatal bereavement	Quantitative; questionnaires, pilot study	Parents valued: Sensitivity and kindness of staff. Time spent with baby. Involvement of partners and wider family. Information about post-mortem process.
Aoun et al. 2018 [Australia]	The impact of supporting family caregivers before bereavement on outcomes after bereavement: adequacy of end-of-life support and achievement of preferred place of death.	Quantitative; telephone survey to evaluate carer support needs assessment tool (CSNAT)	The CSNAT intervention positively impacts on bereaved family caregivers' perceived adequacy of support and achievement of preferred place of death. There are benefits to being involved in early and direct assessment of support needs prior to death.
Beiermann et al. 2017 [US]	Family Members' and Intensive Care Unit Nurses' Response to the ECG Memento© During the Bereavement Period.	Quantitative; survey using questionnaires: Bereavement Experience Questionnaire and the Quality of Dying and Death in the	Families often found the death to be unexpected. ECG mementos are highly valued by families as an "image of life" - transitional object.

		Intensive Care Unit survey	
Bloomer et al. 2016 [Australia]	Nurses' endeavours to create normality amidst the sadness and grief for children dying in paediatric and neonatal ICU	Qualitative; interviews and focus groups with nurses	Four themes: respecting the child as a person, creating opportunities for family involvement and connection, collecting mementos, planning for death. The activities were perceived to empower parents to care for their children as death approached.
Bloomer & Walshe 2020 [Australia]	The role and experience of volunteers in hospital-based end of life care	Systematic review and narrative synthesis	Volunteers have diverse roles, some involving 'hands-on' care but often focused on 'being with' patients. Roles seen as complementary to health professionals. Volunteers faced unique challenges too.
Bloomer (et al) 2013 [Australia]	Exploration of nurses recognition of dying and response to dying patients in two acute medical wards	Qualitative observational followed by focus groups and individual interviews	Nurses provide passive care until dying is declared by medical doctor. Ward design, nurse allocation and attitudes to death impacts on patient care.
Bloomer et al 2013 [Australia]	Describes the ways in which ICU nurses care for families of dying patients during and after death	Qualitative descriptive study; focus groups	Organisational constraints impact on the provision of 'ideal' care. Nurses rely on peer support and role modelling to enhance care. Nurses value time spent with families and highlight importance of ensuring families are able to be with the patient before and after death.

Bristowe et al. 2015 [UK]	The experience of care supported by the AMBER care bundle compared to standard care in the context of clinical uncertainty, deterioration and limited reversibility	Mixed methods: Semi-structured interviews with patients and follow-back survey with NOK of deceased patients	Evaluation of a complex intervention - use of AMBER care bundle was associated with increased frequency of discussions about prognosis between clinicians and patients, higher awareness of prognosis by patients, and lower clarity of information received about their condition.
Bristowe et al. 2018 [UK]	Healthcare professionals' perceptions of a complex intervention (AMBER care bundle) to improve care for people approaching the end of life and their understandings of its purpose within clinical practice	Qualitative; interviews with healthcare professionals	Value of categorising patients, use of tool to change care delivery, symbolic purpose indirectly affecting behaviour of individuals and teams. Required education and sufficient exposure to the intervention to embed its practices.
Butler et al. 2019 [Australia]	Bereaved parents' recommendations for EOL and bereavement care follow-up when a child dies in intensive care	Grounded theory; semi-structured interviews with bereaved parents (Thematic analysis of incidental data from larger study)	Areas for care delivery and improvement identified: During hospitalization: improved communication, changes to the physical environment, better self-care resources, and provision of family support. During the dying phase: private, de-medicalized rooms, familiar staff members, and support to leave the hospital. Care after death: ongoing support from the hospital or local bereavement services, as well as improved information delivery.

Clark et al (2015) [Australia]	Exploration of the experiences of family members whose relative had died on a medical ward	Mixed methods; QoDD tool and one-to-one interviews	Families reported the need for time spent with their loved one before death, the provision of information, and sensitive care after death
Coombs et al (2015)	Family experiences of end-of-life care on ICU	Scoping review	Most studies US based, single site. Families need support during transition from active treatment to end of life care.
Dias et al. 2019 [US]	Current state of knowledge related to interventions for bereaved parents	Systematic literature review	Varied interventions for bereaved parents ranging from single-model interventions, such as expressive arts therapy and telephone support, to multimodal interventions that combine resources (eg Overall, state of the science on interventions for bereaved parents is poor
Donnelly et al (2018) [Ireland]	Post-bereavement survey conducted in two acute hospitals in Ireland	Postal survey, qualitative analysis of free-text data	Two themes relate to how care needs were met and the impact of environment of care, three themes report on interpersonal context of care eg dignity and respect.
Donovan et al. 2015 [Australia]	Services offered to bereaved families in perinatal, neonatal, and pediatric hospital settings	Systematic review of qualitative, quantitative and mixed method studies	Families felt cared for and supported by staff, reduced isolation and improved coping and personal growth. Bereavement services have most impact for parents with more complex mourning. There is a value in transitional services/interventions for families from hospital.
Efstathiou 2020[UK]	Realist evaluation of a single point of contact EoLC service, to explore whether coordinated EoLC would	Realist evaluation: activity/performance indicators,	Rates of advance care planning and achievement of preferred place of death used as indicators of success. Mechanisms and contexts: single point of contact,

	support patients being cared for or dying in their preferred place in their preferred place and avoid unwanted hospital admissions	observations, documentation analysis, satisfaction survey and interviews with service providers and users	coordinating services across providers, development of workforce, understanding and clarifying new roles, managing expectations
Efstathiou et al.2019 [UK]	Bereavement support in adult ICU globally and the availability and effectiveness of bereavement support interventions.	Systematic review and narrative synthesis	All identified interventions were well accepted by bereaved families but reviewed evidence was weak. Specific interventions: personal mementoes, handwritten condolence letter, post-death meeting, storytelling, research participation and ICU diary.
Garstang et al. 2014 [UK]	What bereaved parents want from professionals following unexpected death of a child.	Systematic review (mixed studies)	Parents want permission, time and privacy to say goodbye, explanation of why their child died, follow-up appointments, emotional support and continuing contact with healthcare professionals
Goebel et al. 2017 [Germany]	Evaluation perceptions of receiving a one-year anniversary bereavement card.	Quantitative; questionnaire non-validated	Positive response to receiving card. Few that were less pleased - may relate to grief rather than the card itself
Harrop et al. 2020 [UK]	System level responses to mass bereavement events	Rapid systematic review and narrative synthesis	Key features of service delivery include proactive outreach approach, centrally organised but locally delivered interventions, event-specific professional competencies,

			emphasis on psycho-educational content. Limitations in quantity and quality of evidence
Kapoor et al. 2018 [US]	The impact of the "sacred pause" intervention on ICU physicians' and nurses' attitudes and behaviour following a death.	Quantitative; Likert survey, plus free text comments (completed by physicians and nurses)	The majority believed that a "sacred pause" brings closure, prevents cumulative grief and distress, builds resilience, promotes team effort, and improves professional satisfaction of ICU team. It may lower burnout syndrome in ICU but further studies needed.
Kentish-Barnes et al. 2017 [France]	Bereaved family members experiences of receiving a letter of condolence from physician in charge of their relative	Qualitative; telephone interviews (Part of larger mixed methods study)	1) a feeling of support, 2) humanization of the medical system, 3) an opportunity for reflection, 4) an opportunity to describe their loved one, 5) continuity and closure, and 6) doubts and ambivalence. Possible difficulties emerged, notably the re-experience of the trauma, highlighting the absence of further support.
Kentish-Barnes et al. 2019 [France, US, Canada]	Family members' experience of organ donation request after brain death in the critical care setting	Narrative review	Research in this area is both family-orientated and clinician-orientated. Family experience of organ donation is complex, Principles of care and respect are key - balance between "gift of life" and "sacrifice of body". No clear indication of value of specific approaches
Kochen et al. 2020 [Netherlands]	Parent-focused bereavement interventions delivered by	Systematic review	15 interventions identified Five key concepts: acknowledgement of parenthood of child's life, establishing keepsakes, follow-up contact, education and information,

	healthcare professionals when a child dies		remembrance activities. Focus was on conduct and experiences of the interventions but not effectiveness.
Luta et al. 2021 [Switzerland, UK]	Evidence on the economic value of end-of life and palliative care interventions	Narrative review of reviews	Most evidence on cost effectiveness relates to home interventions, suggesting they offer substantial savings to the health system, including decreased healthcare costs, resource use and improvement in patient and caregivers' outcomes. Hospital-based outcome measures hampered by lack of consistency in outcome reporting measures
Mayland et al. 2017 [UK]	Views of bereaved relatives on quality of care provided to dying patients and families in acute hospitals	Quantitative; CODE questionnaire (completed by bereaved relatives)	Majority of relatives evaluated care positively but a small minority perceived poor quality care with clearer and more timely communication needed. Acceptable and feasible method of obtaining information from relatives, however see Higginson et al re issues with post-death evaluation of care.
McCourt et al. 2013 [UK]	General nurses' experiences of providing EoLC to patients in acute hospital setting	Literature review	Themes: lack of education and knowledge, lack of time with patients, barriers arising in the culture of the health-care setting, communication barriers, symptom management, and nurses' personal issues. Educational needs must be addressed and culture must enable individualised care
Moss et al. 2021 [Canada]	Outcomes of bereavement interventions in ICU, intended to improve informal caregivers' ability to cope with grief	Systematic review (RCTs only) Bereavement interventions categorized	Sparse evidence available. One trial examining the effect of family presence at brain death assessment found no significant improvement in emotional or psychological distress. Two other trials assessed a condolence letter intervention, which did not decrease grief symptoms and

		according to the UK National Institute for Health and Care Excellence three-tiered model of bereavement support.	may have increased symptoms of depression and post-traumatic stress disorder, and a storytelling intervention that found no significant improvements in anxiety, depression, post-traumatic stress, or complicated grief.
Naef et al. 2020 [Switzerland]	Hospital-based bereavement care provision and associated barriers	Quantitative, survey of healthcare professionals	Most bereavement interventions take place around and following the death. The most frequent bereavement services were viewing the deceased, giving information on available support, and making referrals. The most often named barriers were lack of time and organizational support. Structural barriers impact on compassionate care.
Neville et al. 2020 [US, Canada]	Description and characterisation of keepsakes created as part of the "3W" (3 wishes) project in US.	Qualitative; secondary analysis of interview data (from bereaved families)	Keepsakes may be tangible reminders of deceased person's presence e.g. lock of hair or thumbprints, or technology-assisted e.g. digital photographs. Highly valued by family members and the creation of the keepsake with clinical staff is valued and viewed as a gesture of compassion.
Ó Coimín et al. 2019 [Ireland]	The views of bereaved relatives on the experience of care they and the person that died received during their last hospital admission	Mixed method; survey with closed and open-ended questions (Adapted	Key areas for improvement are communication and the provision of emotional and spiritual support around the time of dying and afterwards. Relatives strongly supported single rooms for EoLC, family rooms and bereavement support.

		version of VOICES questionnaire), bereaved relatives	
Raymond et al. 2017 [Australia]	Nurses' roles and responsibilities in providing bereavement care during the care of dying patients within acute care hospitals .	Systematic review (mixed methods)	Bereavement within acute care is often sudden, unexpected and managed by nurses with limited access to experts. Key role which impacts on bereaved loved ones' future experiences. Nursing role includes patient-centred care and advocacy, family-centred care, professional development. Concerns about the role include competing workload demands, limitations of physical environment of care in acute hospital setting, and the need for education and support.
Riegel et al. 2019 [Australia]	Memory-making in end-of-life care in the adult intensive care setting and outcomes	Scoping review	Memory-making activities included: word cloud images, patient's ECG, patient diaries including photos. Limited evidence from peer reviewed research but existing studies suggest families value memory-making opportunities - further research needed into healthcare staff competence / confidence, and how memory-making impacts on adjustment to loss after bereavement
Robinson et al (2021) [New Zealand]	Bereaved family's experiences of care at the end of life	Qualitative analysis of free text data in questionnaire	Families report that uncertainty around dying has an ongoing impact on the process of bereavement. It helps to be explicit about what is happening to loved ones.

Schaefer et al. 2020 [US]	The impact of legacy artwork on grief experiences of bereaved parents in pediatric oncology.	Qualitative; semi-structured interviews with parents and healthcare professionals	Legacy artwork allow family bonding and opens up communication about death and dying, provides opportunity for parents to engage in life review and meaning making. Artworks are frequently displayed in parents' homes after the child has died, and are a source of comfort. Experience of being with other families was beneficial - created a community.
Shariff et al. 2017 [Canada]	Challenges and facilitators that nurses experience in delivering bereavement support during and after sudden or unexpected death in ICUs.	Narrative review	Four themes: hospital policies and organisational constraints, significance of time and trust, level of knowledge and staff support, nurses inner conflict, moral distress and personal ways of coping.
Thornton et al. 2020 [Australia]	The significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of loss following neonatal loss.	Qualitative; grounded theory; semi-structured interviews with bereaved parents	Key theme of "Creating evidence" to affirm the life of the baby. Included taking photographs, creating mementos, as well as involving friends and family during the baby's time in the Neonatal Unit.
Walker and Deacon 2016 [UK]	Nurses' experiences of caring for the suddenly bereaved in adult acute and critical care settings, and the provision of person-centred care:	Qualitative; interviews with nursing staff	Caring for suddenly bereaved families was important to nurses but was also a source of tension and unrest. Importance of seeing the bigger picture - moving away from death as a single event to seeing a pathway of supportive care for the suddenly bereaved,

Waller et al. 2017 [Australia]	Improving hospital-based end of life care processes and outcomes	Systematic review of studies described as descriptive, measurement or intervention studies.	Most studies reported benefits for end-of-life processes including end-of-life discussions and documentation. Impact on end-of-life outcomes was mixed, with some benefit for psychosocial distress, satisfaction and concordance in care
Walsh et al. 2013 [Ireland]	Staff's views of bereavement care in a large hospital setting.	Qualitative; focus groups and interview with staff	Staff training enabled a sense of confidence and pride in bereavement work. Whole hospital approach to bereavement care may be a viable alternative to individual clinical services. Some management-led initiatives were seen as helpful e.g. patient belongings bags.
Wilson et al. 2017 [Canada, Spain]	Bereavement service evaluations and their efficacy	Scoping review	Outcomes include level of grief, stress/distress, grief knowledge, depression, and somatic symptoms. Most bereavement services evaluated as a whole rather than piecemeal, so individual service effectiveness not readily evaluated. Most services appear to have some evidence for effectiveness but measures are heterogenous.
Woodthorpe and Komaromy 2013 [UK]	The role of mortuary staff in hospital-based bereavement services.	Qualitative; ethnography; Direct observation and interviews with mortuary team	Mortuary staff provide an important link with the rest of the hospital team, providing continuity in patient-centred care from the point of death until the deceased person leaves the hospital site. Staff value being part of the wider team and believe that they are also valued in terms of the support they give to clinical and ancillary staff.

