## Evidence Search Service Results of your search request

**Recent research on bereavement care in acute hospital settings**

Thank you for requesting this evidence search. We hope you find the results useful. If you would like to discuss the findings or require an additional search, please contact: Alison McLaren [alisonmclaren1@nhs.net](mailto:alisonmclaren1@nhs.net)

Please acknowledge this work in any resulting paper or presentation as: *Evidence search: Recent research on bereavement care in acute hospital settings* Alison McLaren. (14 July 2020). East Surrey Hospital, UK: Surrey and Sussex Library and Knowledge Services.

## Summary

There is a great deal of research about bereavement care although much of it applies to hospices and primary care settings. During the COVID-19 pandemic, the Association for Palliative Medicine with the Northern Care Alliance has produced guidelines for palliative care in secondary settings which can be freely adapted with acknowledgement for local provision.[[1]](#footnote-2)

Research suggests that the current pandemic in which relatives are excluded from or limited in their interaction with the dying increases grief, distress and guilt, increasing the risk of mental disorders. Suggestions for improving bereavement care include the promotion of mental health literacy for the general public, [[2]](#footnote-3) addressing spiritual need, [[3]](#footnote-4) “advance care planning; proactive, sensitive, and regular communication with family members … enabling family members to say goodbye in person … supporting virtual communication; providing … emotional and spiritual support; and … sign-posting to bereavement services” [[4]](#footnote-5) and creative thinking in the management and delivery of care. [[5]](#footnote-6)

A recent rapid review into bereavement care in the acute setting found that staff training, education and communication skills to address gaps in knowledge and practice were essential to enhance pre and post bereavement services.[[6]](#footnote-7) An earlier systematic review concluded that “care provided by acute care nurses to patients and families during end-of-life care is crucial to bereavement” and further education and training is needed.[[7]](#footnote-8) Surveys of family members and carers identified a number of approaches to improve pre and post bereavement care in paediatric and adult palliative medicine. These include: communication, the flexibility to provide individualised care, emotional and spiritual support, and appropriate information at the right time in addition to ensuring that healthcare professionals are enabled to deliver compassionate bereavement care. [[8]](#footnote-9) [[9]](#footnote-10) [[10]](#footnote-11)

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## A. National and International Guidance

#### Association for Palliative Medicine of Great Britain and Ireland

**COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care: Role of the specialty and guidance to aid care** (2020)

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=8a7ccb214f01452591d72d7810fa6473)

Version 4: 20 April 2020 -- *check for updates:* [*https://apmonline.org/*](https://apmonline.org/) This guidance, which is been prepared for secondary care initially and is not intended to be comprehensive, has been prepared and collated locally by the Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland. While it is not nationally endorsed by the National Health Service, it may be useful to colleagues throughout the country when preparing their own guidance. Please feel free to use, adapt and share this guidance appropriately, acknowledging where specific individuals have been identified as contributing to discrete parts of the guidance.

#### National Institute for Health and Care Excellence (NICE)

**End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline [NG61]** (2019)

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=46127a74aa9c16c5dcd3f589060dae48)

This guideline covers the planning and management of end of life and palliative care in for infants, children and young people (aged 0-17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives. 1.4 Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person

## B. Systematic Reviews

#### Current Opinion in Supportive and Palliative Care

**What information and resources do carers require pre and post bereavement in the acute hospital setting? A rapid review** (2019)

Jackson B., McPeake J., Johnston B.

Purpose of review: This mixed-method, rapid review of published research from 2014 to 2019 aims to explore the experiences of pre and postbereaved carers, and the information that they receive in the acute hospital setting. The quality of articles was evaluated using a standardized quality matrix. The techniques of conceptual analysis and idea mapping were used to create a structured synthesis of the findings. Recent findings: From the initial search of 432 articles, ten studies met the inclusion criteria for this review. These studies generated data from 42 patients, 1968 family/carers and 139 healthcare staff. Themes that were generated from a synthesis of the included articles were clear and timely communication, workforce provision and environment. Summary: This review has highlighted the need for improvements in information provision for carers as part of end of life care. Furthermore, the need for specific staff education and training to enable staff to confidently communicate with dying patients and their relatives in the acute setting is also warranted. Understanding and addressing gaps in knowledge and practice are essential to develop strategies in this complex area. Simple strategies can be implemented to improve the care of carers both pre and post bereavement in acute care. Copyright © 2019 Wolters Kluwer Health, Inc. All rights reserved.

#### Journal of Clinical Nursing

**Understanding the bereavement care roles of nurses within acute care: a systematic review** (2017)

Raymond A. et al

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=e5ec70c28faf353e46cb6a89cbd5f302)

Aims and objectives: To investigate nurses' roles and responsibilities in providing bereavement care during the care of dying patients within acute care hospitals. Background: Bereavement within acute care hospitals is often sudden, unexpected and managed by nurses who may have limited access to experts. Nurses' roles and experience in the provision of bereavement care can have a significant influence on the subsequent bereavement process for families. Identifying the roles and responsibilities, nurses have in bereavement care will enhance bereavement supports within acute care environments. Design: Mixed-methods systematic review. Methods: The review was conducted using the databases Cumulative Index Nursing and Allied Health Literature Plus, Embase, Ovid MEDLINE, PsychINFO, CareSearch and Google Scholar. Included studies published between 2006-2015, identified nurse participants, and the studies were conducted in acute care hospitals. Seven studies met the inclusion criteria, and the research results were extracted and subjected to thematic synthesis. Results: Nurses' role in bereavement care included patient-centred care, family-centred care, advocacy and professional development. Concerns about bereavement roles included competing clinical workload demands, limitations of physical environments in acute care hospitals and the need for further education in bereavement care. Conclusions: Further research is needed to enable more detailed clarification of the roles nurse undertake in bereavement care in acute care hospitals. There is also a need to evaluate the effectiveness of these nursing roles and how these provisions impact on the bereavement process of patients and families. Relevance to clinical practice: The care provided by acute care nurses to patients and families during end-of-life care is crucial to bereavement. The bereavement roles nurses undertake are not well understood with limited evidence of how these roles are measured. Further education in bereavement care is needed for acute care nurses.

## C. Institutional Publications

#### Together for Short Lives

**Caring for a child at end of life: A guide for professionals on the care of children and young people before death, at the time of death and after death** (2019)

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=fc539b9d448959b8e931bb3ee95c4ded)

Together for Short Lives encourages a care pathway approach for children with life-threatening and life-limiting conditions, and their families, that puts children and their families at the centre of care. The care pathway provides a framework for providing care to children and families from diagnosis and throughout their illness, from diagnosis through to bereavement care. p21. Section 3: Care after death -- p32. Section 4 Bereavement support

## D. Original Research

1. **A New Perspective on Spiritual Care: Collaborative Chaplaincy and Nursing Practice.**  
   Donesky Advances in Nursing Science 2020;43(2):147-158.

Spirituality is a key focus and ethical obligation of nursing practice, but many nurses express uncertainty or discomfortwith this aspect of their role. The purpose of this article is to explore the domains of religion, spirituality, and culture as commonly conceptualized by chaplains, as a framework for nurses to provide spiritual care interventions to patients in acute care hospitals. Using anecdotes and illustrations from palliative care practice, this article discusses the enhanced benefits to patients and families when spiritual needs are addressed, with specialty-level chaplain interventions, primary spiritual interventions provided uniquely by nurses, or interventions that require the cooperation of both professions. Lessons learned from the inpatient palliative care team experience can also apply to chaplaincy and nursing care for patients in settings beyond the acute care hospital and in disciplines beyond palliative care.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=720bd2c950529c86ac7f0b7b00880251)

1. **Addressing Mental Health Care for the Bereaved During the COVID-19 Pandemic - PubMed**  
   Yankun Sun Psychiatry and clinical neurosciences 2020;74(7):406-407 .

Addressing Mental Health Care for the Bereaved During the COVID-19 Pandemic

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=4e3ad146496fb935fe7e97f74e93ef3f)

1. **Bereavement Support on the Frontline of COVID-19: Recommendations for Hospital Clinicians.**  
   Selman LE Journal of pain and symptom management 2020;:No page numbers.

Deaths due to COVID-19 are associated with risk factors which can lead to prolonged grief disorder, post-traumatic stress, and other poor bereavement outcomes among relatives, as well as moral injury and distress in frontline staff. Here we review relevant research evidence and provide evidence-based recommendations and resources for hospital clinicians to mitigate poor bereavement outcomes and support staff. For relatives, bereavement risk factors include dying in an intensive care unit, severe breathlessness, patient isolation or restricted access, significant patient and family emotional distress, and disruption to relatives' social support networks. Recommendations include advance care planning; proactive, sensitive, and regular communication with family members alongside accurate information provision; enabling family members to say goodbye in person where possible; supporting virtual communication; providing excellent symptom management and emotional and spiritual support; and providing and/or sign-posting to bereavement services. To mitigate effects of this emotionally challenging work on staff, we recommend an organizational and systemic approach which includes access to informal and professional support.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=4d6d804a6a90f9880340f9cf79bb9460)

1. **Caring for Bereaved Family Members During the COVID-19 Pandemic: Before and After the Death of a Patient.**  
   Morris SE Journal of pain and symptom management 2020;:No page numbers.

Bereavement care is considered an integral component of quality end-of-life care endorsed by the palliative care movement. However, few hospitals and health care institutions offer universal bereavement care to all families of patients who die. The current coronavirus disease 2019 pandemic has highlighted this gap and created a sense of urgency, from a public health perspective, for institutions to provide support to bereaved family members. In this article, drawing on the palliative care and bereavement literature, we offer suggestions about how to incorporate palliative care tools and psychological strategies into bereavement care for families during this pandemic.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=3be14663e748f096b326e3065d94ea6e)

1. **Development, validation and reliability testing of 'Perinatal Bereavement Care Confidence Scale (PBCCS)'.**  
   Kalu Women & Birth 2020;33(4):No page numbers.

Equipping midwives and nurses with confidence to provide bereavement care to parents who have experienced a perinatal loss is vital and impacts on the efficacy of the care received by grieving parents. In education and clinical practice environments there are shortages of bereavement care questionnaires specifically designed to measure midwives' and nurses' confidence and psychosocial factors that impact on their confidence to provide bereavement care. The purpose of the study was to develop a valid and reliable perinatal bereavement care confidence scale (PBCCS). The PBCCS was developed in 4 phases. Phase 1: Questionnaire development, 44 questions were formulated from the literature. Phase 2: Face and content validation of the PBCCS by an Expert Panel. Phase 3: A pilot study was conducted and included 10 cognitive pre-testing interviews and test-retest reliability assessment with a cohort of 26 midwives. Phase 4: Construct validity was assessed using factor analysis with 277 midwives and nurses. In order to avoid confusion with terminologies, the term midwife was used for both nurses and midwives who provided care to bereaved parents and participated in the study. Internal consistency reliability measurement was assessed with Cronbach's alpha. Ethical approval of the study was obtained from four maternity hospitals in Ireland. The PBCCS has 43 items. Bereavement care knowledge (15 items, 3 sub-scales). Bereavement care skills (9 items, 2 sub-scales). Self-awareness (8 items, 2 sub-scales). Organisational support (11 items, 2 subscales). The internal consistency reliabilities ranged from 0.753 to 0.871 except for one subscale 0.663. The PBCCS is a valid and reliable tool with good psychometric properties which can be used to measure midwives' confidence and the psychosocial factors thatimpact on their confidence to provide bereavement care.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=5a4008a225f2d9d6b90b6bb22dd28351)

1. **Dying during Covid-19.**  
   Moore Bryanna Hastings Center Report 2020;50(3):13-15.

I had been on the phone with Madeleine's mother for fifteen minutes, and she had sobbed throughout. She pleaded with me, "You won't even let our family visit her together. If you really want to help my daughter, you will let us stay with her." Madeleine, who was twenty-four years old, was dying of end-stage acute myeloid leukemia and was intubated in one of our intensive care units. Her intensivist had requested a clinical ethics consultation for potentially inappropriate medical treatment—in my world of clinical ethics consultation, routine stuff. Except that, in March 2020, nothing was routine anymore. The Covid-19 pandemic calls for creative thinking about ad hoc and post hoc bereavement efforts, and it may result in efforts to revise existing accounts of what constitutes a good death in order to accommodate patients' and families' experiences at the end of life during a pandemic.

1. **Experiences of spouses of patients with cancer from the notification of palliative chemotherapy discontinuation to bereavement: A qualitative study.**  
   Hisamatsu European Journal of Oncology Nursing 2020;45:No page numbers.

Many patients with advanced cancer choose palliative chemotherapy. Considering its purpose of palliation and not treatment, it is important to consider the life of family caregivers. Family caregivers who experience bereavement undergo extreme stress, which is particularly high among patients' spouses. The present study aims to clarify the experiences of the spouses of patients at the hospitals in Japan after the notification of palliative chemotherapy discontinuation until bereavement. We interviewed the spouses of 13 patients who received palliative chemotherapy using a semistructured interview guide. Each spouse was interviewed twice. The interviews were transcribed verbatim, and key concepts were identified using a grounded theory analytic approach. After the hospital's recommendation for palliative chemotherapy discontinuation, the spouses had "bewilderment over having to discontinue palliative chemotherapy" and experienced "difficulty in facing bereavement." The spouses having "difficulty to give up hope for the patient's survival," felt "bafflement over caregiving at the terminal stage," which would be their responsibility in the future. Further, they had "hesitation in being honest to the patient" and were engaged in "knowing how to live with the patient until bereavement." Nurses need to encourage the patients and spouses to honestly express how they feel from the early stages of palliative chemotherapy. Furthermore, nurses should help spouses with how they face bereavement. This result may help prevent anticipatory grief, which may lead to excessive stress and emotional distress on the family caregivers. • Spouses experienced the unavoidable reality of bereavement. • Honest expression of emotions toward patients was difficult for the spouses. • Nurses should encourage patients and their spouses to honestly express how they feel. • Nurses should help spouses with their manner of facing bereavement.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=8047b165cbabc46ce737ca79d5e01b00)

1. **Hospital-based bereavement care provision: A cross-sectional survey with health professionals**  
   Naef R. Palliative Medicine 2020;34(4):547-552.

Background: An in-hospital death is a profound experience for those left behind and has been associated with family members' psychological morbidity. Supporting bereaved family members is an essential part of end-of-life care and includes attentive presence, information-giving, and emotional and practical support. The actual adoption of hospital-based bereavement care, however, remains little understood. Aim(s): To investigate hospital-based bereavement care provision and associated barriers. Design(s): Cross-sectional survey using an online questionnaire. Setting/participants: Health professionals (n = 196) from two University-affiliated acute and psychiatric hospitals in Switzerland. Result(s): The most frequent bereavement services (40%) were viewing the deceased, giving information on available support, and making referrals; the most often named barriers were lack of time and organizational support. Acute care health professionals faced statistically significant more structural barriers (55.1% vs 21.4% lack of time, 47.8% vs 25.9% lack of organizational support) and felt insufficiently trained (38.4% vs 20.7%) compared to mental health professionals (p 0.05). Nurses provided more immediate services compared to physicians, such as viewing the deceased (71.3% vs 49.0%) and sending sympathy cards (37.4% vs 16.3%) (p 0.01). In contrast, physicians screened more often for complex bereavement disorders (10.2% vs 2.6%) and appraised bereavement care as beyond their role (26.5% vs 7.8%) (p 0.05). Conclusion(s): The study indicates that many barriers to bereavement care exist in hospitals. More research is required to better understand enabling and limiting factors to bereavement care provision. A guideline-driven approach to hospital-based bereavement care that defines best practice and required organizational support seems necessary to ensure needs-based bereavement care. Copyright © The Author(s) 2019.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=9bfcf20ede6d2d5e313046b2eecd2653)

1. **'It was peaceful, it was beautiful': A qualitative study of family understandings of good end-of-life care in hospital for people dying in advanced age.**  
   Gott Palliative Medicine 2019;33(7):793-801.

Background: Hospitals are important sites of end-of-life care, particularly for older people. A need has been identified to understand best practice in hospital end-of-life care from the service-user perspective. Aim: The aim of this study was to identify examples of good care received in the hospital setting during the last 3 months of life for people dying in advanced age from the perspective of bereaved family members. Design: A social constructionist framework underpinned a qualitative research design. Data were analysed thematically drawing on an appreciative enquiry framework. Setting/participants: Interviews were conducted with 58 bereaved family carers nominated by 52 people aged >80 years participating in a longitudinal study of ageing. Data were analysed for the 21 of 34 cases where family members were 'extremely' or 'very' satisfied with a public hospital admission their older relative experienced in their last 3 months of life. Results: Participants' accounts of good care aligned with Dewar and Nolan's relation-centred compassionate care model: (1) a relationship based on empathy; (2) effective interactions between patients/families and staff; (3) contextualised knowledge of the patient/family; and (4) patients/families being active participants in care. We extended the model to the bicultural context of Aotearoa, New Zealand. Conclusion: We identify concrete actions that clinicians working in acute hospitals can integrate into their practice to deliver end-of-life care with which families are highly satisfied. Further research is required to support the implementation of the relation-centred compassionate care model within hospitals, with suitable adaptations for local context, and explore the subsequent impact on patients, families and staff.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=735ffa4ace5d939c1dd2a44b4f8f37b4)

1. **Death in the emergency department: A rapid review.**  
   Anderson Emergency Nurse New Zealand 2019;:7-10.

Those who work in emergency departments rarely consider them a 'good' place to die. Recent New Zealand research suggests that palliative patients and their whānau/family -- particularly those living in more deprived areas -- can benefit from hospital admission at the end of life, and this often occurs via emergency departments. Inclusive and compassionate end-of-life care is associated with family involvement, relationship-building and detailed contextual knowledge of the patient and family. Patient death in the emergency department can have unique and varied features and challenges. Death may be sudden and unexpected, or there may be uncertainty about the cause of death. The patient's background, key relationships, cultural and spiritual priorities may not be known. This rapid review provides an overview of the evidence base exploring care of the dying and bereaved in the emergency department. It asks: What are the features of death in the emergency department setting? What are the barriers to quality care? Do we know what bereaved whānau/family need and value when their loved one dies in the emergency department? Research to-date suggests emergency department staff readily identify common challenges, and more researchinformed initiatives are needed to facilitate quality emergency care of the dying and bereaved.

1. **Dying in acute hospitals: voices of bereaved relatives.**  
   Ó Coimín BMC Palliative Care 2019;18(1):No page numbers.

Background: Internationally there is an increasing concern about the quality of end-of-life care (EoLC) provided in acute hospitals. More people are cared for at end of life and die in acute hospitals than in any other healthcare setting. This paper reports the views of bereaved relatives on the experience of care they and the person that died received during their last admission in two university adult acute tertiary hospitals. Methods: Relatives of patients who died were invited to participate in a post-bereavement postal survey. An adapted version of VOICES (Views of Informal Carers - Evaluation of Services) questionnaire was used. VOICES MaJam has 36 closed questions and four open-ended questions. Data were gathered in three waves and analysed using SPSS and NVivo. 356 respondents completed the survey (46% response rate). Results: The majority of respondents (87%: n = 303) rated the quality of care as outstanding, excellent or good during the last admission to hospital. The quality of care by nurses, doctors and other staff was highly rated. Overall, care needs were well met; however, findings identified areas of care which could be improved, including communication and the provision of emotional and spiritual support. In addition, relatives strongly endorsed the provision of EoLC in single occupancy rooms, the availability of family rooms on acute hospital wards and the provision of bereavement support. Conclusions: This research provides a powerful snapshot in time into what works well and what could be improved in EoLC in acute hospitals. Findings are reported under several themes, including the overall quality of care, meeting care needs, communication, the hospital environment and support for relatives. Results indicate that improvements can be made that build on existing good practice that will enhance the experience of care for dying persons and their relatives. The study adds insights in relation to relative's priorities for EoLC in acute hospitals and can advance care providers', policy makers' and educationalists' priorities for service improvement.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=db3b79ee897044822a3efe22f2a1ac09)

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=f7d2fff55df4fe4423b65f3c1cb119e9)

1. **Nursing Care at the End of Life: Optimizing care of the family in the hospital setting.**  
   Boyle Clinical Journal of Oncology Nursing 2019;23(1):13-17.

Most Americans prefer their home as a place of death, but most die in the hospital acute care setting. Nurses are the major providers of hospital-based end-of-life care; therefore, it is imperative to identify family preferences for nursing support during the end of life. An initiative was undertaken to create a blueprint for operationalizing research findings that identified family preferences for nursing support during the peri-death experience of a loved one within acute care. Seven components of an acute bereavement support protocol were delineated: developing room signage, assessing family prioritization parameters of support measures, offering advice on saying goodbye, performing an honoring ceremony, creating a memory keepsake, escorting the family out of the hospital, and sending a sympathy card following the loved one's death.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=302de0bd83616eef467580c37880332e)

1. **Perinatal bereavement and palliative care offered throughout the healthcare system**  
   Wool C. Annals of Palliative Medicine 2019;8:No page numbers.

The aims of this article are twofold: (I) provide a general overview of perinatal bereavement services throughout the healthcare system and (II) identify future opportunities to improve bereavement services, including providing resources for the creation of standardized care guidelines, policies and educational opportunities across the healthcare system. Commentary is provided related to maternal child services, the neonatal intensive care unit (NICU), prenatal clinics, operating room (OR) and perioperative services, emergency department (ED), ethics, chaplaincy and palliative care services. An integrated system of care increases quality and safety and contributes to patient satisfaction. Physicians, nurses and administrators must encourage pregnancy loss support so that regardless of where in the facility the contact is made, when in the pregnancy the loss occurs, or whatever the conditions contributing to the pregnancy ending, trained caregivers are there to provide bereavement support for the family and palliative symptom management to the fetus born with a life limiting condition. The goal for respectful caregiving throughout an entire hospital system is achievable and critically important. Copyright © Annals of Palliative Medicine. All rights reserved.

1. **Raising the bar: Development of a perinatal bereavement programme**  
   Steen S.E. International Journal of Palliative Nursing 2019;25(12):578-586.

The care a family receives at the time of perinatal loss can have a significant and lasting impact, hence it is important for healthcare providers to offer quality care that will meet the family's needs. Our hospital embarked on a journey to develop a perinatal bereavement programme that would give compassionate and excellent care to all families who experienced perinatal loss at any time during their pregnancy. Components of our bereavement programme include leadership, administrative and financial support, communication, well-educated and supported staff, and a process for individualised care. A perinatal bereavement programme can help institutions, large or small, to provide quality care for bereaved families and help them through this difficult experience. The purpose of this article is to discuss hospital-wide bereavement care, both on a large scale, detailing the specifics of programme development, and on a smaller scale, individualised care for families. Copyright © 2019 MA Healthcare Ltd.

[Available online at this link](https://www.knowledgeshare.nhs.uk/index.php?PageID=link_resolver&link=a6bcd272a83003311226e9a1982e4258)

1. **When a Child Dies in the PICU: Practice Recommendations From a Qualitative Study of Bereaved Parents.**  
   Butler Pediatric Critical Care Medicine 2019;20(9):No page numbers.

Objectives: Around the world, the PICU is one of the most common sites for hospitalized children to die. Although ensuring the best possible care experience for these children and their families is important, clear recommendations for end-of-life and bereavement care, arising from the parents themselves, remain limited within current literature. This report aims to describe bereaved parents' recommendations for improvements in end-of-life care and bereavement follow-up when a child dies in intensive care.Design: Thematic analysis of incidental data from a larger grounded theory study.Setting: Four Australian PICUs.Subjects: Twenty-six bereaved parents participated in audio-recorded, semi-structured interviews in 2015-2016. Interviews explored their experiences of having a child die in intensive care and their experiences of end-of-life care and bereavement follow-up. Data pertaining to this report were analyzed via thematic analysis.Interventions: None.Measurements and Main Results: Bereaved parents identified several areas for care delivery and improvement across three time periods: during hospitalization; during the dying phase; and during bereavement. During hospitalization, parents' recommendations focused on improved communication, changes to the physical environment, better self-care resources, and provision of family support. During the dying phase, parents suggested private, de-medicalized rooms, familiar staff members, and support to leave the hospital. Recommendations for care after death focused mainly on the provision of ongoing support from the hospital or local bereavement services, as well as improved information delivery.Conclusions: Findings from this study offer many concrete recommendations for improvements in care both during and after a child's death. These recommendations range from simple practice changes to larger organizational modifications, offering many potential avenues for change and improvement both on an individual healthcare provider level and within individual PICUs.

1. **Bereavement support standards and bereavement care pathway for quality palliative care.**  
   Hudson P. Palliative & supportive care 2018;16(4):375-387.

ABSTRACT Objective: Provision of bereavement support is an essential component of palliative care service delivery. While bereavement support is integral to palliative care, it is typically insufficiently resourced, under-researched, and not systematically applied. Our aim was to develop bereavement standards to assist palliative care services to provide targeted support to family caregivers. METHOD: We employed a multiple-methods design for our study, which included: (1) a literature review, (2) a survey of palliative care service providers in Australia, (3) interviews with national (Australian) and international experts, (4) key stakeholder workshops, and (5) a modified Delphi-type survey. RESULTS: A total of 10 standards were developed along with a pragmatic care pathway to assist palliative care services with implementation of the standards. SIGNIFICANCE OF RESULTS: The bereavement standards and care pathway constitute a key initiative in the evolution of bereavement support provided by palliative care services. Future endeavors should refine and examine the impact of these standards. Additional research is required to enhance systematic approaches to quality bereavement care.

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1. **Family members' experiences with intensive care unit diaries when the patient does not survive**  
   Johansson M. Scandinavian Journal of Caring Sciences 2018;32(1):233-240.

Objective: The aim of the study was to explore how family members experienced the use of a diary when a relative does not survive the stay in the intensive care unit (ICU). Method(s): A qualitative method with a hermeneutic approach was used. Nine participants who read/wrote eight diaries in total were interviewed. The collected data were analysed using a hermeneutic technique inspired by Geanellos. Finding(s): The analysis revealed an overall theme 'the diary was experienced as a bridge connecting the past with the future', which was a metaphor referring to the temporal aspect where there was the period with the diary up until the patient's death and then the postbereavement period. The diary contributed to both a rational and emotional understanding of the death of the patient and disclosed glimmers of light that still existed before the illness deteriorated. Further, the diary bridged the space between family members themselves and between family and nursing staff. It helped to maintain a feeling of togetherness and engagement in the care of the patient which family members found comforting. Conclusion(s): Family members of nonsurvivors had a need to have the ICU time explained and expressed. The diary might work as a form of 'survival kit' to gain coherence and understanding; to meet their needs during the hospital stay; and, finally, to act as a bereavement support by processing the death of the patient. Copyright © 2017 Nordic College of Caring Science

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1. **Family-centered bereavement practices in Danish intensive care units: A cross-sectional national survey**  
   Egerod Ingrid Intensive and Critical Care Nursing 2018;45:52-57.

Background: Mortality in Danish intensive care units (ICUs) continues at 27%, resulting in a large number of bereaved family members being cared for in the ICU. Objectives: To investigate the provision of bereavement care and follow-up services for bereaved families in Danish ICUs. Methodology: Self-administered computerized cross-sectional nation-wide survey of Danish ICUs. Results: Nurses at 46 of 48 (96%) ICUs in Denmark responded. Bereavement care at the time of patient death included viewing the patient in ICU (100%), and in the hospital mortuary (59%). Information about hospital-based follow-up for the family was provided in 72% of units, whereas only one unit provided information on community-based bereavement follow-up. Bereavement follow-up services after hospitalization were offered to families in 59% of ICUs and included an ICU visit, meeting with the staff present at the time of death, a letter of condolence, a phone call to the family, referral to a priest or clergyman, or referral to other counseling. Although many interventions were common, there were variations within the elements offered. Nurses and physicians were the most consistent health care staff involved in bereavement services. Conclusion: Most ICUs in Denmark offered bereavement follow-up services, but these varied in their approach, were not evidence-based, and lacked formal evaluation. More systematic quality improvement of bereavement practices is required. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

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1. **Filling the Void: Hospital Palliative Care and Community Hospice: A Collaborative Approach to Providing Hospital Bereavement Support**  
   Silloway C.J. Journal of Social Work in End-of-Life and Palliative Care 2018;14(2):153-161.

Bereavement services are often provided as components of hospice and palliative care plans, including emotional, psychosocial, and spiritual support provided to individuals and families to assist with grief, loss, and adjustment after the death of a loved one. Patient- and family-centered care is a hallmark of palliative care. Moreover, bereavement counseling is offered as a hospice care benefit that is covered by Medicare and various private insurance plans. However, not all hospital-based palliative care programs offer bereavement support. Many bereaved persons whose loved one dies in the hospital while receiving palliative care services may not have access to a bereavement support program. This practice concept article describes an innovative bereavement program designed to offer support to individuals whose loved one died in the hospital while receiving palliative care. The bereavement team, including clinical professionals from the inpatient palliative care team and two community hospices, developed the University of Florida (UF) Health Bereavement Program. The interprofessional team includes social workers, volunteers, chaplains, nurses, nurse practitioners, and physicians. The Bereavement Program incorporates grief support workshops, follow-up with participants, via postal mail at timed intervals, website access to grief resources, staff education, and an annual evening of remembrance program. Finally, interagency collaboration has extended the reach of bereavement services beyond UF Health into our community at large. Copyright © 2018, © 2018 Taylor & Francis Group, LLC.

1. **Pilot Study Assessing the Impact of Bereavement Support on Families of Deceased Intensive Care Unit Patients.**  
   McAdam JL American journal of critical care : an official publication, American Association of Critical-Care Nurses 2018;27(5):372-380.

BACKGROUND: Family members of patients who die in an intensive care unit (ICU) may experience negative outcomes. However, few studies have assessed the effectiveness of bereavement care for families. OBJECTIVE: To evaluate the effectiveness of bereavement follow-up on family members' anxiety, depression, posttraumatic stress, prolonged grief, and satisfaction with care. METHODS: A cross-sectional, prospective pilot study of 40 family members of patients who died in 2 tertiary care ICUs. Those in the medical-surgical ICU received bereavement follow-up (bereavement group); those in the cardiac ICU received standard care (nonbereavement group). Both groups completed surveys 13 months after the death. Surveys included the Hospital Anxiety and Depression Scale, Impact of Event Scale-Revised, Family Satisfaction With Care in the Intensive Care Unit, Prolonged Grief Disorder, and a bereavement survey. RESULTS: Of 30 family members in the bereavement group and 10 in the nonbereavement group, most were female and spouses, with a mean (SD) age of 60.1 (13.3) years. Significantly more participants in the nonbereavement group than in the bereavement group had prolonged grief. Posttraumatic stress, anxiety, depression, and satisfaction with care were not significantly different in the 2 groups. However, overall posttraumatic stress scores were higher in the nonbereavement group than the bereavement group, indicating a higher risk of posttraumatic stress disorder. CONCLUSIONS: Bereavement follow-up after an ICU death reduced family members' prolonged grief and may also reduce their risk of posttraumatic stress disorder. This type of support did not have a measurable effect on depression or satisfaction with ICU care.

1. **Bereavement service preferences of surviving family members: Variation among next of kin with depression and complicated grief**  
   Banyasz Alissa Journal of Palliative Medicine 2017;20(10):1091-1097.

Background: Research indicates that bereavement services reduce distress and support adjustment in the bereaved, particularly those experiencing significant levels of depression or grief. However, the service use of bereaved individuals and whether utilization differs among those experiencing depression and complicated grief currently remain unclear.Research is needed to clarify the preferences of the bereaved, including specific bereaved subgroups. Objectives: The purpose of this study was to explore the bereavement service preferences of bereaved family members whose loved one died in the hospital and identify group differences in service use among individuals with and without depression and complicated grief, considering time since the death of the patient. Design: In this cross-sectional study, self-report data were collected from family members primarily between 3 and 18 months following the death of the patient in the hospital. Setting: Academic medical center. Measurements: We explored helpfulness ratings and actual and projected service utilization of a comprehensive list of hospital and community bereavement services, and compared findings between those with and without depression and complicated grief, considering timing since patient death. Results: Services receiving the highest helpfulness ratings by the entire sample included time alone with the deceased, a quiet room to be alone after the death, sympathy cards from hospital staff, memorial services, chaplain support before/during time of death, an educational grief booklet, grief book recommendations, a check-in phone call from hospital staff, individual counseling, and a relationship-specific support group. Individuals with depression and complicated grief reported a greater willingness to utilize specific services, including a memorial website, support groups, a holiday workshop, and individual/family psychotherapy. Conclusion: Findings indicate a difference in the projected service use of the bereaved experiencing depression and/or complicated grief. Follow-up screenings 6–12 months post-bereavement are recommended to identify those in need of formal psychosocial support. (PsycINFO Database Record (c) 2017 APA, all rights reserved) (Source: journal abstract)

1. **Complicated Grief: Risk Factors, Interventions, and Resources for Oncology Nurses.**  
   Tofthagen CS Clinical journal of oncology nursing 2017;21(3):331-337.

BACKGROUND: When a loved one dies of cancer, complicated grief (CG) may occur because of the trauma associated with family caregivers' perceptions of their loved one's suffering, either from advanced cancer or from side effects of cancer treatment. OBJECTIVES: This article provides an overview of CG and existing interventions for family caregivers who may be at risk for CG following the loss of a loved one and the implications for oncology nurses who provide emotional support and guidance. METHODS: Current evidence related to the treatment of CG and information to assist with identification of individuals at risk for CG are presented, as well as resources for oncology nurses who encounter individuals who are at high risk for, or who are experiencing, CG. FINDINGS: Although therapy interventions for CG have been shown to be effective forms of treatment, these therapies are not widely available and often require an extended treatment period to yield results. Oncology nurses can provide early interventions, such as referrals to supportive care services and mental health professionals to facilitate effective treatment.

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1. **Empowering Bereaved Parents Through the Development of a Comprehensive Bereavement Program**  
   Snaman J.M. Journal of Pain and Symptom Management 2017;53(4):767-775.

Parents who experience the loss of a child have unique and valuable insights into the grief journey and can help health care providers identify key components intrinsic to the development, implementation, and maintenance of a comprehensive bereavement program. The bereavement program at St. Jude Children's Research Hospital was developed by pediatric palliative care experts in collaboration with bereaved parents to standardize and improve the institutional support provided to families around and after the death of a child. This article describes the components of a parent-derived bereavement program and presents early results on the effects of specific program components. The program, under the leadership of the bereavement coordinator, includes clinical and supportive interventions offered throughout the grief journey, parent-created bereavement support materials, and opportunities for parents and families to participate in research, quality improvement initiatives and educational interventions. Parents report that services and interventions provided through the bereavement program are beneficial to families after the death of their child. In addition, both health care providers and bereaved parents report that participation in educational interventions positively impacts their experiences as clinicians and parents, respectively. The innovative nature of this parent-driven, comprehensive bereavement program may serve as a paradigm for the development of bereavement programs in the fields of pediatrics, palliative oncology and hospice and palliative medicine. Copyright © 2017 American Academy of Hospice and Palliative Medicine

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1. **End-of-Life and Bereavement Care in Pediatric Intensive Care Units.**  
   Suttle ML Pediatric clinics of North America 2017;64(5):1167-1183.

Most childhood deaths in the United States occur in hospitals. Pediatric intensive care clinicians must anticipate and effectively treat dying children's pain and suffering and support the psychosocial and spiritual needs of families. These actions may help family members adjust to their loss, particularly bereaved parents who often experience reduced mental and physical health. Candid and compassionate communication is paramount to successful end-of-life (EOL) care as is creating an environment that fosters meaningful family interaction. EOL care in the pediatric intensive care unit is associated with challenging ethical issues, of which clinicians must maintain a sound and working understanding.

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1. **NICU Bereavement Care and Follow-up Support for Families and Staff.**  
   Levick J. Advances in neonatal care : official journal of the National Association of Neonatal Nurses 2017;17(6):451-460.

BACKGROUND: Experiencing the death of an infant in the neonatal intensive care unit (NICU) affects both families and staff, creating challenges and opportunities for best practices. PURPOSE: This practice-based article describes a comprehensive approach to delivering bereavement services to NICU families, as well as education and support to NICU staff. METHODS: Bereaved NICU parent and staff survey feedback, including quotes describing individual experiences and suggestions for improved service delivery. RESULTS: Bereaved NICU families and caregivers find meaning and purpose in the act of creating keepsake memories at the time of the infant's death. Mutual healing takes place with subsequent, individualized follow-up contacts by staff familiar to the bereaved parents over the course of a year. IMPLICATIONS FOR PRACTICE: Those staff involved in the care of a NICU infant and family, during and after the infant's death, attest to the value in providing tangible keepsakes as well as continuing their relationship with the bereaved parents. An effective administrative infrastructure is key to efficient program operations and follow-through. IMPLICATIONS FOR RESEARCH: Studying different methods of in-hospital and follow-up emotional support for NICU bereaved families. Identifying strategies for staff support during and after NICU infant loss, and the impact a formal program may have on staff satisfaction and retention.

1. **The Development of a Hospital-Wide Bereavement Program: Ensuring Bereavement Care for All Families of Pediatric Patients.**  
   Morris SE Journal of pediatric health care : official publication of National Association of Pediatric Nurse Associates & Practitioners 2017;31(1):88-95.

Although grief is a normal response to loss, the death of a child is believed to be one of the most difficult losses a person can endure, and bereaved parents are considered to be an "at-risk" group. Even though most deaths of children in the United States occur in hospitals, bereavement care provided by hospitals is highly variable, and little attention has been directed to how hospitals can best support grieving parents. In this article, we describe the development of a hospital-wide bereavement program at Boston Children's Hospital, where we conceptualize bereavement care as a preventive model of care. We identify the primary constructs of the program as education, guidance, and support and outline a template for use by other hospitals. We recommend that all pediatric hospitals implement basic, coordinated bereavement programs as the standard of care to ensure that all families receive bereavement care after the death of a patient.

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1. **Bereavement Services Offered in Adult Intensive Care Units in the United States**  
   McAdam JL American Journal of Critical Care 2016;25(2):110-117.

Losing a loved one in the intensive care unit (ICU) is stressful for family members. Providing bereavement support to them is recommended. However, little is known about the prevalence of bereavement services implemented in adult ICUs. Objective To describe current bereavement follow-up services in adult ICUs. Method A cross-sectional prospective study design was used. ICU nurse leaders completed a 26-item online survey posted in the American Association of Critical-Care Nurses e-newsletter. The survey contained questions about current practices in bereavement care. Data were collected for 1 month and were analyzed by using descriptive statistics and binary logistic regression. Results A total of 237 ICU nurse leaders responded to the survey. Hospital and ICU types were diverse, with most being community (n = 81, 34.2%) and medical (n = 61, 25.7%). Most respondents reported that their ICUs (n = 148, 62.4%) did not offer bereavement follow-up services, and many barriers were noted. When bereavement follow-up care was offered, it was mainly informal (eg, condolence cards, brochures). Multiple logistic regression indicated that ICUs in hospitals with palliative care were almost 8 times (odds ratio, 7.66) more likely to provide bereavement support than were ICUs in hospitals without palliative care. Conclusions The study findings provide insight into what type of bereavement evaluation methods are being used, what barriers are present that hinder use of bereavement follow-up services, and potential interventions to overcome those barriers in adult ICUs in the United States.

1. **Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys.**  
   Snaman JM Cancer 2016;122(17):2757-65.

BACKGROUND: Bereaved parents experience significant psychosocial and health sequelae, suggesting that this population may benefit from the ongoing extension of support and resources throughout the grief journey. The interaction of hospital staff with patients and families at the end of a child's life and after death profoundly affects parental grief, offering a unique opportunity for the medical community to positively impact the bereavement experience. The current study was conducted to explore the role of the health care team and medical institutions in the grief journeys of parents whose child died a cancer-related death. METHODS: Eleven bereaved parents participated in 2 focus groups. Responses to each of the 3 main prompts were coded and analyzed independently using semantic content analysis techniques. RESULTS: Four main concepts were identified within the parental narratives, including the importance of strong and ongoing relationships between providers and bereaved families, the importance of high-quality communication, the effect of negative experiences between providers and families on parental grief, and the importance of the institution's role in the grief journeys of bereaved parents. CONCLUSIONS: Bereaved parents consistently identified the critical role played by medical staff and medical institutions throughout the grief journey. Key components of bereavement support identified by parents should serve to guide the actions of providers as well as provide a template for the development of a comprehensive bereavement program within an institution. Cancer 2016. © 2016 American Cancer Society.

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1. **Nurses' experiences of caring for the suddenly bereaved in adult acute and critical care settings, and the provision of person-centred care: A qualitative study**  
   Walker W. Intensive and Critical Care Nursing 2016;33:39-47.

Aim: To explore nursing interventions for person-centred bereavement care in adult acute and critical care settings. Design(s): A descriptive exploratory study, involving focused, face-to-face interviews. Participants comprised nine registered nurses and one auxiliary nurse, working in environments where sudden death was known to occur, i.e. emergency, cardiac and critical care. Interviews were transcribed verbatim and data subjected to directed content analysis. The provision of person-centred care was examined by applying a validated Person-Centred Nursing Framework. Finding(s): Five main themes were identified. Participants' accounts contained descriptions of bereavement care and the presence of person-centred interventions. Contextual, professional and attitudinal factors influenced the degree to which person-centred care operated. Conclusion(s): Caring for suddenly bereaved families was important to nurses, but also a source of tension and unrest. An important consideration for person-centred practice is movement away from sudden bereavement as a 'here and now' event, towards a pathway of supportive care that envisions the longer-term. Further research is required to gain a deeper understanding of person-centred care for the suddenly bereaved and the perceived effectiveness of nursing interventions. Copyright © 2016 Elsevier Ltd.

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**Sources searched include**: CINAHL; EMCARE; Google (Advanced); NICE; PsychInfo; PubMed; TRIP PRO

This search was requested by a Palliative Care specialist and was not specifically related to COVID-19. As such it does not include a COVID-19 search hedge or strategy to ensure that research relevant in the palliative care setting was not excluded.

**Date range used** (5 years, 10 years): 2016-2020

|  | **Source** | **Criteria** | **Results** |
| --- | --- | --- | --- |
| 1. | EMCARE | exp "BEREAVEMENT SUPPORT"/ | 583 |
| 2. | EMCARE | (bereavement ADJ3 (support OR care)).ti,ab | 808 |
| 3. | EMCARE | (palliative ADJ3 (care OR support)).ti,ab | 22912 |
| 4. | EMCARE | (acute OR hospital).ti,ab | 613853 |
| 5. | EMCARE | (1 OR 2) | 1162 |
| 6. | EMCARE | (4 AND 5) | 198 |
| 7. | EMCARE | 6 [DT 2016-2020] [English language] | 74 |
| 8. | CINAHL | exp BEREAVEMENT/ | 15122 |
| 9. | CINAHL | (bereavement ADJ3 (support OR care)).ti,ab | 1238 |
| 10. | CINAHL | (palliative ADJ3 (care OR support)).ti,ab | 29574 |
| 11. | CINAHL | (acute OR hospital).ti,ab | 609415 |
| 12. | CINAHL | (8 OR 9) | 15412 |
| 13. | CINAHL | (11 AND 12) | 1045 |
| 14. | CINAHL | 13 [DT 2016-2020] [Languages eng] | 302 |
| 15. | PsycINFO | exp BEREAVEMENT/ | 14742 |
| 16. | PsycINFO | (bereavement ADJ3 (support OR care)).ti,ab | 804 |
| 17. | PsycINFO | (palliative ADJ3 (care OR support)).ti,ab | 9295 |
| 18. | PsycINFO | (acute OR hospital).ti,ab | 186230 |
| 19. | PsycINFO | (15 OR 16) | 14948 |
| 20. | PsycINFO | (18 AND 19) | 700 |
| 21. | PsycINFO | 20 [DT 2016-2020] [Languages English] | 106 |

**Google Advanced: hospital bereavement OR bereaved OR mourning OR grief OR grieving OR support "palliative care"**

**TRIP PRO: (hospital) (bereavement or bereaved or mourning or grief or grieving or support) ("palliative care") from:2016 to:2020**

**Date of request:** 3rd July, 2020  
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1. Association for Palliative Medicine of Great Britain and Ireland (2020) *COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care: Role of the specialty and guidance to aid care* [↑](#footnote-ref-2)
2. Yankun S (2020) Addressing Mental Health Care for the Bereaved During the COVID-19 Pandemic *Psychiatry and clinical neurosciences* [↑](#footnote-ref-3)
3. Donesky (2020 A New Perspective on Spiritual Care: Collaborative Chaplaincy and Nursing Practice *Advances in Nursing Science* [↑](#footnote-ref-4)
4. Selman LE (2020) Bereavement Support on the Frontline of COVID-19: Recommendations for Hospital Clinicians *Journal of pain and symptom management* [↑](#footnote-ref-5)
5. Moore B (2020) Dying during Covid-19 *Hastings Center Report* [↑](#footnote-ref-6)
6. Jackson B (2019) What information and resources do carers require pre and post bereavement in the acute hospital setting? A rapid review *Current Opinion in Supportive and Palliative Care* [↑](#footnote-ref-7)
7. Raymond A (2017) Understanding the bereavement care roles of nurses within acute care: a systematic review *Journal of Clinical Nursing* [↑](#footnote-ref-8)
8. Ó Coimín (2019) Dying in acute hospitals: voices of bereaved relatives *BMC Palliative Care* [↑](#footnote-ref-9)
9. Steen SE (2019) Raising the bar: Development of a perinatal bereavement programme *International Journal of Palliative Nursing* [↑](#footnote-ref-10)
10. Butler (2019) When a Child Dies in the PICU: Practice Recommendations From a Qualitative Study of Bereaved Parents *Pediatric Critical Care Medicine* [↑](#footnote-ref-11)