End of Life Care
Current Awareness Bulletin
May 2018

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Title: "Some were certainly better than others" - Bereaved parents' judgements of healthcare providers in the paediatric intensive care unit: A grounded theory study

Citation: Intensive & Critical Care Nursing; Apr 2018; vol. 45; p. 18

Author(s): Butler, Ashleigh E; Copnell, Beverley; Hall, Helen

Objective: To explore bereaved parents’ judgements of healthcare providers, as part of a larger study examining their perceptions of the death of a child in the paediatric intensive care unit.

Research methodology: Constructivist grounded theory.

Setting: Four Australian paediatric intensive care units.

Main outcome measures: Semi-structured, audio recorded interviews were undertaken with 26 bereaved parents 6-48 months after their child’s death. Data were transcribed verbatim and analysed using open, focused and theoretical coding and the constant comparative method.

Findings: Bereaved parents judged healthcare providers as ‘good’ or ‘poor’ based on behaviours they exhibit. ‘Good’ behaviours were further subdivided by parents into four categories: ‘Better than others’, ‘good’, ‘very good’, and ‘fantastic’. Common behaviours identified as ‘good’ included provision of practical assistance, facilitation of parental presence, and sharing of information. In contrast, the concept of ‘poor’ had no subdivision: all identified behaviours, including diminishing parental concern, mishandling hope, adopting an unprofessional demeanour, judging the child’s worth, and mishandling communication, were equally detrimental.

Conclusions: Findings demonstrate that bereaved parents have clear opinions on what constitutes ‘good’ and ‘poor’ behaviours when their child is dying. These judgements provide clear examples for healthcare providers who provide end-of-life care, ensuring they provide high quality care.

Title: Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions.

Citation: BMC Palliative Care; Apr 2018; vol. 17 (no. 1)

Author(s): Baillie, Jessica; Anagnostou, Despina; Sivell, Stephanie; Van Godwin, Jordan; Byrne, Anthony; Nelson, Annmarie

Objectives: Symptom management is an essential aspect of palliative and end-of-life care, but evidence suggests that patients' symptoms may not always be relieved, causing significant harm to patients and magnifying their relatives' distress. A growing body of evidence focuses on symptom management at the end-of-life, but research funding for palliative care remains disproportionately low. It is therefore crucial that research funding is targeted at areas of importance to patients and relatives. The Palliative and end-of-life care Priority Setting Partnership (PeolcPSP) undertook a UK-wide free-text survey to establish research priorities within palliative and end-of-life care and disseminated its results in 2015. Much of the data were related more broadly to personal perceptions and experiences rather than specific research questions. The aim of this article is to report on a supplementary analysis exploring the experiences and questions of PeolcPSP survey respondents regarding symptoms, hydration and nutrition.

Methods: The PeolcPSP data (n = 1403) were coded by a team of qualitative researchers in a supplementary analysis. There were 190 responses that related to symptoms, nutrition and hydration. The data were analysed thematically using Braun and Clarke's approach.

Results: Five themes were identified: pain, breathlessness, agitation, nutrition and hydration. The majority of responses related to symptoms that were sub-optimally managed, in particular pain.
Nutrition and hydration were of significant concern, particularly for carers. Overall, respondents consistently asked about the most effective, evidence-based methods for managing symptoms and suggested areas where further research is necessary.

**Conclusions:** This study highlights the perceptions and experiences of patients, families and professionals within palliative care, highlighting the need for improved care, communication and further research to establish which treatments are most effective within a palliative care population. This is essential to reduce harm and distress for patients and families.

**Title:** Health service utilisation during the last year of life: a prospective, longitudinal study of the pathways of patients with chronic kidney disease stages 3-5.

**Citation:** BMC Palliative Care; Apr 2018; vol. 17 (no. 1); p. 1-1

**Author(s):** Chambers, Shirley; Healy, Helen; Hoy, Wendy E.; Kark, Adrian; Ratanjee, Sharad; Mitchell, Geoffrey; Douglas, Carol; Yates, Patsy; Bonner, Ann

**Background:** Chronic kidney disease (CKD) is a growing global problem affecting around 10% of many countries' populations. Providing appropriate palliative care services (PCS) to those with advanced kidney disease is becoming paramount. Palliative/supportive care alongside usual CKD clinical treatment is gaining acceptance in nephrology services although the collaboration with and use of PCS is not consistent.

**Methods:** The goal of this study was to track and quantify the health service utilisation of people with CKD stages 3-5 over the last 12 months of life. Patients were recruited from a kidney health service (Queensland, Australia) for this prospective, longitudinal study. Data were collected for 12 months (or until death, whichever was sooner) during 2015-17 from administrative health sources. Emergency department presentations (EDP) and inpatient admissions (IPA) (collectively referred to as critical events) were reviewed by two Nephrologists to gauge if the events were avoidable.

**Results:** Participants (n = 19) with a median age of 78 years (range 42-90), were mostly male (63%), 79% had CKD stage 5, and were heavy users of health services during the study period. Fifteen patients (79%) collectively recorded 44 EDP; 61% occurred after-hours, 91% were triaged as imminently and potentially life-threatening and 73% were admitted. Seventy-four IPA were collectively recorded across 16 patients (84%); 14% occurred on weekends or public holidays. Median length of stay was 3 days (range 1-29). The median number of EDP and IPA per patient was 1 and 2 (range 0-12 and 0-20) respectively. The most common trigger to both EDP (30%) and IPA (15%) was respiratory distress. By study end 37% of patients died, 63% were known to PCS and 11% rejected a referral to a PCS. All critical events were deemed unavoidable.

**Conclusions:** Few patients avoided using acute health care services in a 12 month period, highlighting the high service needs of this cohort throughout the long, slow decline of CKD. Proactive end-of-life care earlier in the disease trajectory through integrating renal and palliative care teams may avoid acute presentations to hospital through better symptom management and planned care pathways.

**Title:** Comparing unplanned and potentially planned home deaths: a population-based cross-sectional study.

**Citation:** BMC Palliative Care; May 2018; vol. 17 (no. 1)

**Author(s):** Kjellstadli, Camilla; Husebø, Bettina Sandgathe; Sandvik, Hogne; Flo, Elisabeth; Hunskaar, Steinar
Objective: There is little research on number of planned home deaths. We need information about factors associated with home deaths, but also differences between planned and unplanned home deaths to improve end-of-life-care at home and make home deaths a feasible alternative. Our aim was to investigate factors associated with home deaths, estimate number of potentially planned home deaths, and differences in individual characteristics between people with and without a potentially planned home death.

Methods: A cross-sectional study of all decedents in Norway in 2012 and 2013, using data from the Norwegian Cause of Death Registry and National registry for statistics on municipal health and care services. We defined planned home death by an indirect algorithm-based method using domiciliary care and diagnosis. We used logistic regressions models to evaluate factors associated with home death compared with nursing home and hospital; and to compare unplanned home deaths and potentially planned home deaths.

Results: Among 80,908 deaths, 12,156 (15.0%) were home deaths. A home death was most frequent in 'Circulatory diseases' and 'Cancer', and associated with male sex, younger age, receiving domiciliary care and living alone. Only 2.3% of home deaths were from 'Dementia'. In total, 41.9% of home deaths and 6.3% of all deaths were potentially planned home deaths. Potentially planned home deaths were associated with higher age, but declined in ages above 80 years for people who had municipal care. Living together with someone was associated with more potentially planned home deaths for people with municipal care.

Conclusion: There are few home deaths in Norway. Our estimations indicate that even fewer people than anticipated have a potentially planned home death.

Title: Reappraising 'the good death' for populations in the age of ageing.

Citation: Age & Ageing; May 2018; vol. 47 (no. 3); p. 328-330
Author(s): Pollock, Kristian; Seymour, Jane

Abstract: This is the second in an occasional series of paired commentaries in Age and Ageing, the Journal of the British Geriatrics Society and the Journal of the American Geriatrics Society (JAGS). The aim is to address issues of current significance and to foster dialogue and increased understanding between academics and clinicians working in comparative international settings. Both commentaries address the urgent need to improve palliative care for older people, with a critique of some stereotypes surrounding palliative care and the 'good death'. The companion commentary, published in JAGS, was written by Alexander Smith and Vyjeyanthi Periyakoil, and is grounded in their experience as academic clinicians (Smith AK, Periyakoil V. Should we bury 'The Good Death'? Journal of the American Geriatrics Society 2018; in press). In the present paper, we offer a perspective on the outcome and wider consequences of misalignment between current UK policy and aspirations for end of life care in relation to epidemiological trends and patient experience of death and dying.

Title: Staff preparedness for providing palliative and end-of-life care in long-term care homes: Instrument development and validation.

Citation: Geriatrics & Gerontology International; May 2018; vol. 18 (no. 5); p. 745-749
Author(s): Chan, Helen Y. L.; Chun, Gloria K. M.; Man, C. W.; Leung, Edward M. F.

Objective: Although much attention has been on integrating the palliative care approach into services of long-term care homes for older people living with frailty and progressive diseases, little is known about the staff preparedness for these new initiatives. The present study aimed to
develop and test the psychometric properties of an instrument for measuring care home staff preparedness in providing palliative and end-of-life care.

**Methods:** A 16-item instrument, covering perceived knowledge, skill and psychological readiness, was developed. A total of 247 staff members of different ranks from four care homes participated in the study. Exploratory factor analysis using the principal component analysis extraction method with varimax rotation was carried out for initial validation. Known group comparison was carried out to examine its discriminant validity. Reliability of the instrument was assessed based on test–retest reliability of a subsample of 20 participants and the Cronbach's alpha of the items.

**Results:** Exploratory factor analysis showed that the instrument yielded a three-factor solution, which cumulatively accounted for 68.5% of the total variance. Three subscales, namely, willingness, capability and resilience, showed high internal consistency and test–retest reliability. It also showed good discriminant validity between staff members of professional and non-professional groups.

**Conclusions:** This is a brief, valid and reliable scale for measuring care home staff preparedness for providing palliative and end-of-life care. It can be used to identify their concerns and training needs in providing palliative and end-of-life care, and as an outcome measure to evaluate the effects of interventional studies for capacity building in this regard.

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**Title:** Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care.

**Citation:** BMC Palliative Care; Apr 2018; vol. 17 (no. 1)

**Author(s):** Klop, Hanna T.; de Veer, Anke J.E.; van Dongen, Sophie I.; Francke, Anneke L.; Rietjens, Judith A.C.; Onwuteaka-Philipsen, Bregje D.

**Objective:** Homeless people often suffer from complex and chronic comorbidities, have high rates of morbidity and die at much younger ages than the general population. Due to a complex combination of physical, psychosocial and addiction problems at the end of life, they often have limited access to palliative care. Both the homeless and healthcare providers experience a lot of barriers. Therefore, providing palliative care that fits the needs and concerns of the homeless is a challenge to healthcare providers. This systematic review aims to summarize evidence about the concerns, palliative care needs and preferences of homeless people, as well as barriers and facilitators for delivering high quality palliative care.

**Methods:** PubMed, Embase, PsycINFO, CINAHL and Web of Science were searched up to 10 May 2016. Included were studies about homeless people with a short life expectancy, their palliative care needs and the palliative care provided, that were conducted in Western countries. Data were independently extracted by two researchers using a predefined extraction form. Quality was assessed using a Critical Appraisal instrument. The systematic literature review was based on the PRISMA statement.

**Results:** Twenty-seven publications from 23 different studies met the inclusion criteria; 15 studies were qualitative and eight were quantitative. Concerns of the homeless often related to end-of-life care not being a priority, drug dependence hindering adequate care, limited insight into their condition and little support from family and relatives. Barriers and facilitators often concerned the attitude of healthcare professionals towards homeless people. A respectful approach and respect for dignity proved to be important in good quality palliative care.

**Conclusions:** A patient-centred, flexible and low-threshold approach embodying awareness of the concerns of homeless people is needed so that appropriate palliative care can be provided timely. Training, education and experience of professionals can help to accomplish this.
Title: Caregiver informational support in different patient care settings at end of life.

Citation: Home Health Care Services Quarterly; Apr 2018; vol. 37 (no. 2); p. 97-112
Author(s): Lavalley, Susan A.

Abstract: Caregivers of the terminally ill face many complicated tasks including providing direct patient care, communicating with clinicians, and managing the logistical demands of daily activities. They require instructive information at all points in the illness process and across several settings where patients receive end-of-life care. This study examines how the setting where a patient receives end-of-life care affects caregivers’ informational support needs by thematically analyzing data from caregiver interviews and clinical observations. Caregivers providing care for patients at home received informational support related to meeting patients' mobility, medication, and nutritional needs. Caregivers who provided care remotely received informational support to navigate transitions between patient care settings or long-term care arrangements, including financial considerations and insurance logistics. The findings document that interventions designed to enhance information for caregivers should account for caregiving context and that health care providers should proactively and repeatedly assess caregiver information needs related to end-of-life patient care.

Title: A Practitioner's Guide to End-of-Life Intimacy: Suggestions for Conceptualization and Intervention in Palliative Care.

Citation: Omega: Journal of Death & Dying; May 2018; vol. 77 (no. 1); p. 15-35
Author(s): Morrissey Stahl, Kate A.; Bower, Kyle L.; Seponski, Desiree M.; Lewis, Denise C.; Farnham, Andrea L.; Cava-Tadik, Yasemin

Abstract: Sexuality and intimacy, including contact, tenderness, and love, are important at every life stage. Intimate expression is especially vital at the end of life, when relationships with loved ones are time limited. Unfortunately, care providers often ignore the potential need for sexual expression, especially at the end of life. In this article, we consider current research on sexuality and end-of-life care and situate these two fields in an ecological framework. We explore how end-of-life sexuality and intimacy can be supported by practitioners in multiple nested contexts and provide suggestions for theoretically-driven interventions. We also provide reflexive considerations for practitioners.

Title: Meaning of life for patients in palliative and end-of-life care.

Citation: British Journal of Healthcare Assistants; Apr 2018; vol. 12 (no. 4); p. 172-172
Author(s): Nyatanga, Brian


Citation: Gerontologist; Apr 2018; vol. 58 (no. 2); p. 290-299
Author(s): Ladin, Keren; Buttafarro, Katie; Hahn, Emily; Koch-Weser, Susan; Weiner, Daniel E.
Objective: Between 2000 and 2012, the incident dialysis population in the United States increased by nearly 60%, most sharply among adults 75 years and older. End-of-life (EOL) conversations among dialysis patients are associated with better patient-centered outcomes and lower use of aggressive interventions in the last month of life. This study examined how health literacy may affect engagement, comprehension, and satisfaction with EOL conversations among elderly dialysis patients.

Design and Methods: Qualitative/descriptive study with semi-structured interviews about health literacy, EOL conversations, and goals of care with 31 elderly dialysis patients at 2 centers in Boston. Themes were interpreted in the context of Nutbeam’s health literacy framework.

Results: Despite high mortality risk in this population, only 13% of patients had discussed EOL preferences with physicians, half had discussed EOL with their social network, and 25% of participants explicitly stated that they had never considered EOL preferences. Less than 30% of participants could correctly define terminology commonly used in EOL conversations. Analyses yielded 5 themes: (1) Misunderstanding EOL terminology; (2) Nephrologists reluctant to discuss EOL; (3) Patients conforming to socially constructed roles; (4) Discordant expectations and dialysis experiences; and (5) Reconciling EOL values and future care. Patients had limited understanding of EOL terminology, lacked of opportunities for meaningful EOL discussion with providers and family, resulting in uncertainty about future care. Implications: Limited health literacy presents a substantial barrier to communication and could lead to older adults committing to an intensive pattern of care without adequate information. Clinicians should consider health literacy when discussing dialysis initiation.

Title: Healthy dying: time for health promotion to get serious.

Citation: Health Promotion International; Apr 2018; vol. 33 (no. 2); p. 183-186
Author(s): Catford, John

Abstract: The author conveys his concerns about the concept of health promoting palliative care. Topics discussed include the three domains of a good death, empowerment of people receiving end-of-life care and care aimed at delaying death until late in the terminal phase, and a table that outlines countries where euthanasia and physician-assisted suicide is lawful including Switzerland, Belgium, and Canada.

Title: Sharing End-of-Life Care Preferences with Family Members: Who Has the Discussion and Who Does Not.

Citation: Journal of Palliative Medicine; Apr 2018; vol. 21 (no. 4); p. 463-472
Author(s): Peterson, Lindsay J.; Dobbs, Debra; Meng, Hongdao; Gamaldo, Alyssa; O’Neil, Kevin; Hyer, Kathryn

Objective: Research suggests that greater engagement in family discussions concerning end-of-life (EOL) care preferences could improve advance care planning and EOL outcomes. However, a substantial number of people have not had such discussions. The study’s objective was to understand attitudes and experiences influencing engagement in discussions of EOL care preferences with family members, including the role of healthcare providers in such discussions.

Methods: We conducted focus group interviews with 36 non-Hispanic White, African American, and Hispanic community-dwelling participants. Participants were divided among groups to explore differences between those who had or had not engaged in EOL care discussions. Atlas.ti version 7 was used to analyze data employing an open-coding method.
**Results:** Participants' mean age was 70 (range: 58–87); three-fourths were female (n = 27). Twenty were white, non-Hispanic; 10 were African American; and 6 were Hispanic. Four themes emerged from the data, (1) being proactive or passive/reactive; (2) perceiving discussion of death as normal or abnormal; (3) response to family resistance/disconnection; and (4) knowledge acquired. A fifth theme, the role of healthcare providers in family EOL care discussions, resulted from facilitators' questions. Theme examination led to identification of a central category, decision-making.

**Conclusions:** It is important to understand the differing experiences and attitudes of those who do or do not engage in EOL discussions. Research is needed on healthcare practitioners' use of decision-making tools to help patients discuss their EOL care preferences with family and others, the goal of which is to provide care consistent with patients' goals.

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**Title:** Tool will improve care for dying patients.

**Citation:** Nursing Standard; Mar 2018; vol. 33 (no. 1); p. 6-6

**Author(s):**

**Abstract:** The article discusses the University Hospitals Bristol National Health Service (NHS) Foundation Trust's end of life care tool that will enhance personalised support to dying patients in England as of April 2018.

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**Title:** Gaps in access and training limit care in last days of life.

**Citation:** Nursing Standard; Mar 2018; vol. 33 (no. 1); p. 51-54

**Author(s):** Dean, Erin

**Abstract:** The article presents a Nursing Standard-Marie Curie survey which shows that nurses and healthcare assistants in England struggled to provide good quality end of life care due to staffing levels, time constraints, and lack of end of life care community provisions as of 2018. Topics discussed include the comparatively greater strides made in Wales and Scotland, and nurses' difficulties in starting conversations with dying patients. Also noted is the need to train general nurses in this area.

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**Title:** Advice on setting out of hours staffing levels for specialist palliative care [including commentary by Eleanor Sherwen].

**Citation:** Nursing Standard; Mar 2018; vol. 33 (no. 1); p. 55-55

**Author(s):** Dean, Erin

**Abstract:** The article discusses the planned providing of 24-hour access to end of life care for people outside of hospitals in England by 2020. Topics covered include guidance on staffing levels needed for providing out of hours specialist palliative care issued in February 2018, and the challenges for nurses in out of hours settings. Also noted is end of life care nurse Eleanor Sherwen's observation on the dependence of 24-hour care access on an area's commissioning of services.
Title: Meeting the needs of carers of people at the end of life.

Citation: Nursing Standard; Mar 2018; vol. 33 (no. 1); p. 59-66
Author(s): Hardy, Beth

Abstract: Carers have a vital role in end of life care in all settings. They are essential in enabling people to live at home at the end of their lives. Carers give and receive care, and have a range of support needs related to this complex role. This article explores the context of caring at the end of life and considers the experience of carers, in particular those who have a non-professional and unpaid relationship with someone who is at the end of life, and the support they require.

Title: Palliative care for people with schizophrenia: a qualitative study of an under-serviced group in need.

Citation: BMC Palliative Care; Mar 2018; vol. 17; p. 1-1
Author(s): McNamara, Beverley; Same, Anne; Rosenwax, Lorna; Kelly, Brian

Objective: People with schizophrenia are at risk of receiving poorer end of life care than other patients. They are often undertreated, avoid treatment and are about half as likely to access palliative care. There are limited options for end of life care for this under-serviced group in need. This study aims to address the paucity of research by documenting possible need, experiences of health care service use and factors affecting palliative care use for people with schizophrenia who have advanced life limiting illness.

Methods: Semi-structured interviews were undertaken with 16 experienced health professionals caring for people with schizophrenia in Western Australia. The interviews focussed on their perceptions and experiences of end of life care, their patients’ unmet needs, palliative care options, and suggested services to support this vulnerable group and improve health care provision. The research used a qualitative design and thematic analyses.

Results: The participants all advocated strongly for their patients and recognised their extreme vulnerability. They identified a range of challenges and unmet needs experienced by people with schizophrenia at the end of life including: illness factors such as the impact of schizophrenia on information processing and communication; social factors such as stigma, isolation and the absence of a carer; and health care factors such as late diagnosis, delayed access to care, and mismanagement in care. Four themes were organised into two domains with the first exploring the individual and social circumstances of people with schizophrenia, including the challenges they experience in the health care system. The second domain covers themes that discuss barriers and facilitators to people with schizophrenia receiving palliative care and key features in palliative care provision, including recognising declining health, communication and planning, and collaboration and capacity building in the broader health, mental health and palliative care sectors.

Conclusions: To ensure people with schizophrenia are well supported at the end of life a model of palliative care is required that offers both specialised services and capacity building within the pre-existing health workforce. Resources are needed to address the stigma and lack of services faced by this vulnerable group.
Title: Meeting the needs of young adults with life-limiting conditions: A UK survey of current provision and future challenges for hospices.

Citation: Journal of advanced nursing; May 2018

Author(s): Knighting, Katherine; Bray, Lucy; Downing, Julia; Kirkcaldy, Andrew J; Mitchell, Tracy K; O'Brien, Mary R; Pilkington, Melissa; Jack, Barbara A

Objective: To seek views of UK children's and adult hospices on the availability and challenges of providing services for young adults with life-limiting conditions.

Background: Internationally there are a growing number of young adults with life-limiting conditions and/or complex needs which are degenerative, progressive and diverse and involve complex life-long symptom, medication management as well as palliative care. There are 55,721 young adults, aged 18-40 in England, which continues to increase. The hospice sector is experiencing demands to extend services for this population despite concerns about the appropriateness of adult hospices and their nursing staff to provide care for the complex and unfamiliar conditions of this patient group. Evidence is needed of hospices' views and the main challenges faced providing services for young adults.

Design: Descriptive cross-sectional survey.

Methods: Children and adult hospices completed an online survey exploring service provision and their views of respite care for young adults with life-limiting conditions from 18 years old and onward. Data were collected between October 2015-February 2016.

Findings: Respondents (N=76 hospices) reported that children's hospices predominantly provided short breaks and end-of-life care; adult hospices provided mainly symptom management, end-of-life care and day services. Main challenges were: a lack of existing adult respite services; lack of funding and capacity; lack of a skilled workforce in adult hospices; and the need for better integrated service provision.

Conclusion: Examples of good collaborative working were reported. With an increasing population of young adults and pressure on families, it is vital that services work together to find sustainable solutions to the challenges. This article is protected by copyright. All rights reserved.

Sources Used

The following databases are searched on a regular basis in the development of this bulletin:

British Nursing Index, Cinahl, Medline along with a number of other sources

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