

# End of Life Care Current Awareness Bulletin

June 2020

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**Title: Hospital-based bereavement care provision: A cross-sectional survey with health professionals**

**Citation:** Palliative Medicine; Apr 2020; vol. 34 (no. 4); p. 547

**Author(s):** Naef, Rahel; Peng-Keller, Simon; Rettke, Horst; Rufer, Michael; Petry, Heidi

**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:** To investigate hospital-based bereavement care provision and associated barriers.

**Design:** Cross-sectional survey using an online questionnaire.

**Setting/participants:** Health professionals (n = 196) from two University-affiliated acute and psychiatric hospitals in Switzerland.

**Results:** The most frequent bereavement services ( $\geq 40\%$ ) 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 ( $p \leq 0.05$ ). 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%) ( $p \leq 0.01$ ). 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%) ( $p \leq 0.05$ ).

**Conclusion:** 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.

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**Title: End-of-life nursing care practice in long-term care settings for older adults: A qualitative systematic review**

**Citation:** International Journal of Nursing Practice; Apr 2020; vol. 26 (no. 2)

**Author(s):** Nasu, Katsumi; Konno, Rie; Fukahori, Hiroki

**Aim:** To synthesize qualitative evidence on nurses' end-of-life care practices in long-term care settings for older adults.

**Background:** Qualitative evidence on how nurses describe their own end-of-life care practice has not been reviewed systematically.

**Design:** Qualitative systematic review.

**Data Sources:** Databases MEDLINE, CINAHL, PsycINFO, EMBASE, Mednar, Google Scholar, and Ichushi were searched for published and unpublished studies in English or Japanese.

**Methods:** The review followed the Joanna Briggs Institute approach to qualitative systematic reviews. Each study was assessed by two independent reviewers for

methodological quality. The qualitative findings were pooled to produce categories and synthesized through meta-aggregation.

**Results:** Twenty studies met all inclusion criteria. Their 137 findings were grouped into 10 categories and then aggregated into three synthesized findings: playing multidimensional roles to help residents die with dignity, needing resources and support for professional commitment, and feeling mismatch between responsibilities and power, affecting multidisciplinary teamwork.

**Conclusion:** Nurses play multidimensional roles as the health care professionals most versed in residents' complex needs. Managers and policymakers should empower nurses to resolve the mismatch and help nurses obtain needed resources for end-of-life care that ensures residents die with dignity.

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**Title: Nurses' perceptions of and barriers to the optimal end-of-life care in hospitals: A cross-sectional study**

**Citation:** Journal of Clinical Nursing; Apr 2020; vol. 29 (no. 7-8); p. 1209

**Author(s):** Chan, Carmen W H; Chow, Meyrick C M; Chan, Sally; Robert Sanson-Fisher; Waller, Amy; Lai, Theresa T K; Kwan, Cecilia W M

**Aims and objectives:** To assess nurses' perceptions of what constitutes optimal end-of-life (EOL) care in hospital and evaluate nurses' perceived barriers to EOL care delivery.

**Background:** Care of dying patients is common in hospitals. However, little is known about the important elements of and barriers to optimal EOL care from key service providers' perspective, which is crucial for quality EOL care in hospital settings.

**Method:** This is a cross-sectional survey. Nurses practising in hospitals recruited by convenience sampling completed self-report survey questionnaires. STROBE checklist was used in study reporting.

**Results:** One hundred and-seventy-five nurses participated in the survey. The majority (70%) had experience in caring for dying patients. The five most highly perceived factors constituting optimal EOL care included the following: "families know and follow patient's EOL wishes"; "patients emotional concerns identified and managed well"; "patients participating in decision-making"; "EOL care documents stored well and easily accessed"; and "provide private rooms and unlimited visiting hours for families of dying patients". Top five barriers were "doctors are too busy"; "nurses are too busy"; "insufficient private room/space"; "nurses have limited training in EOL care"; and "families have unrealistic expectations of patient's prognosis." Multivariate regression analysis identified that nurses without experience in caring for dying patients reported a significantly higher number of perceived barriers towards EOL care ( $p = .012$ ). Those with postgraduate degree training reported significantly fewer perceived barriers ( $p = .007$ ).

**Conclusion:** Findings identified essential elements for optimal hospital EOL care not only involving patients and families in EOL decision and care, but also documentation and environmental issues in the healthcare system level and the needs for strengthening manpower and expertise at palliative care policy level.

**Relevance to clinical practice:** This study revealed quantitative data to inform health service managers and policy makers in terms of training and service development/ re-design for EOL care in hospital settings.

**Title: End of life in acute hospital setting—A systematic review of families' experience of spiritual care**

**Citation:** Journal of Clinical Nursing; Apr 2020; vol. 29 (no. 7-8); p. 1041

**Author(s):** Hennessy, Nora; Neenan, Kathleen; Brady, Vivienne; Sullivan, Melissa; Eustace-Cooke, Jessica; Timmins, Fiona

**Aims and objectives:** To systematically review qualitative studies exploring families' experiences of spiritual care at the end of life in acute hospital settings.

**Background:** Although there is a widespread belief that the consideration of spiritual and religious needs is outdated in the context of secularism, from a practical perspective patients and families appear to benefit from spiritual support at the end of life.

**Methods:** Six key databases, CINAHL, MEDLINE, EMBASE, Global Health Library, Web of Science and Applied Social Sciences Index and Abstracts (ASSIA), were searched, and three reviewers independently extracted the data and coded them into themes and subthemes. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used as a reporting framework.

**Results:** Five main themes emerged: anticipating needs; honouring the family by honouring the patient; personal connection; lack of sensitivity; and making space for religious and spiritual practices.

**Conclusions:** Families experiencing end-of-life care in acute hospital settings may benefit from spiritual care. While this can also be considered as fundamental care, understanding this through the lenses of spiritual care allows for incorporation of religious and spiritual practices that many seek at this time, irrespective of their faith perspectives.

**Relevance to clinical practice:** Although hospice care is well established internationally, many families experience end-of-life care in acute hospital settings. Nurses usually get to know families well during this time; however, the demands of the clinical environment place restrictions on family care and perceptions of lack of communication, limited support and/or limited sensitivity can compound families' suffering. Consideration of families' spiritual needs can help to support families during this time. Nurses are ideally placed for this and can anticipate and plan for patient and family needs in this regard, or refer to a specialist, such as the Healthcare Chaplain.

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**Title: Experiences at the End of Life From the Perspective of Bereaved Parents: Results of a Qualitative Focus Group Study.**

**Citation:** American Journal of Hospice & Palliative Medicine; Jun 2020; vol. 37 (no. 6); p. 424-432

**Author(s):** Sedig, Laura K.; Spruit, Jessica L.; Paul, Trisha K.; Cousino, Melissa K.; Pituch, Kenneth; Hutchinson, Raymond

**Background:** Palliative care principles are known to support the experiences of children and their families throughout the illness trajectory. However, there is little knowledge of the parental perceptions of care delivered and gaps experienced by families receiving end-of-life care. We report the most helpful aspects of care provided during the end of life and identify opportunities to improve care delivery during this critical time.

**Methods:** This study consists of 2 one-hour focus group sessions with 6 participants each facilitated by a clinical psychologist to explore the experiences of bereaved parents of

pediatric oncology patients at the end of their child's life. The data were transcribed and coded using constant comparative analysis and evaluated for inter-rater reliability using intraclass correlation coefficient.

**Results:** Four common themes were identified through qualitative analysis: (1) valued communication qualities, (2) valued provider qualities, (3) unmet needs, and (4) parental experiences. The most prevalent of these themes was unmet needs (mentioned 51 times). Subthemes were identified and evaluated. Parents described struggling with communication from providers, loss of control in the hospital environment, and challenges associated with transition of care to hospice services.

**Conclusion:** Interventions that support the complex needs of a family during end-of-life care are needed, especially with regard to coordination of care.

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**Title: Palliative care in the pediatric emergency department: Findings from a qualitative study**

**Citation:** Dimensions of Critical Care Nursing; May 2020; vol. 39 (no. 3); p. 164-164

**Author(s):** Côté, A.; Payot, A.; Gaucher, N.

**Abstract:** The researchers in this qualitative study sought to explore challenges in providing palliative care for children in the emergency department (ED) and roles for the ED in caring for children with complex medical issues. A secondary aim of this study was to propose solutions for implementation of palliative care for children while they were in the ED. The researchers state that medically complex children who visit the ED are at risk of fragmented care related to issues with communication, care coordination, and case management. They further state that an acute event may change a family's preference with end-of-life care. The researchers conducted semistructured interviews (n = 58) with health care professionals from the ED, palliative care, complex care, and intensive care to explore their perspective on palliative care in the ED. Some of the barriers reported in providing palliative care in the ED included ED's culture of care and emotions when caring for children with complex medical issues, continuity of care, pressures to be efficient, lack of expertise with pediatric palliative care, and discomfort with communication on palliative care with families of medically complex children. The researchers found that communication between the teams was essential in providing care for these children including transmitting information on these children and their family's preference for end-of-life care. Study findings also included the necessity of preparing families and medically complex children for potential ED visits and the need to strengthen the relationship between the ED, the primary care providers, and case management.

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**Title: The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system.**

**Citation:** Anaesthesia; May 2020

**Author(s):** Madden, S; Collett, D; Walton, P; Empson, K; Forsythe, J; Ingham, A; Morgan, K; Murphy, P; Neuberger, J; Gardiner, D

**Abstract:** Organ transplantation saves and transforms lives. Failure to secure consent for organ retrieval is widely regarded as the single most important obstacle to transplantation. A soft opt-out system of consent for deceased organ donation was introduced into Wales in

December 2015, whilst England maintained the existing opt-in system. Cumulative data on consent rates in Wales were compared with those in England, using a two-sided sequential procedure that was powered to detect an absolute difference in consent rates between England and Wales of 10%. Supplementary risk-adjusted logistic regression analysis examined whether any difference in consent rates between the two nations could be attributed to variations in factors known to influence UK consent rates. Between 1 January 2016 and 31 December 2018, 8192 families of eligible donors in England and 474 in Wales were approached regarding organ donation, with overall consent rates of 65% and 68%, respectively. There was a steady upward trend in the proportion of families consenting to donation after brain death in Wales as compared with England and after 33 months, this reached statistical significance. No evidence of any change in the donation after circulatory death consent rate was observed. Risk-adjusted logistic regression analysis revealed that by the end of the study period the probability of consent to organ donation in Wales was higher than in England (OR [95%CI] 2.1 [1.26-3.41]). The introduction of a soft opt-out system of consent in Wales significantly increased organ donation consent though the impact was not immediate.

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**Title: Opt-out organ donation in England.**

**Citation:** The Lancet. Respiratory medicine; May 2020; vol. 8 (no. 5); p. 443

**Author(s):** Burki, Talha Khan

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**Title: Children, organ donation, and Islam: A report of an engagement day of Islamic scholars, young Muslims and pediatric transplant and donation professionals.**

**Citation:** Pediatric transplantation; May 2020; vol. 24 (no. 3); p. e13677

**Author(s):** Aktas, Mikail; Randhawa, Gurch; Brierley, Joe

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**Title: Management of the neurologically deceased organ donor: A Canadian clinical practice guideline**

**Citation:** Canadian Medical Association. Journal; Apr 2020; vol. 192 (no. 14); p. E361

**Author(s):** Ball, Ian M, MD MSc; Hornby, Laura, MSc; Rochweg, Bram, MD MSc; Weiss, Matthew J, MD; Gillrie, Clay, RN MSN; Chassé, Michael, MD PhD; D'Aragon, Frederick, MD MSc; Meade, Maureen O, MD MSc; Soliman, Karim, MD; Ali, Aadil, Bsc; Arora, Samantha, MD; Basmaji, John, MD; Boyd, J Gordon, MD PhD; Cantin, Bernard, MD PhD; Chaudhury, Prosanto, MD MSc; Cypel, Marcelo, MD MSc; Freed, Darren, MD; Frenette, Anne Julie, PharmD PhD; Hruska, Pam, RN MSc; Karvellas, Constantine J, MD SM; Keenan, Sean, MD; Kramer, Andreas, MD; Kutsogiannis, Demetrios James, MD; Lien, Dale, MD; Luke, Patrick, MD; Mahoney, Meagan, MD; Singh, Jeffrey M, MD; Wilson, Lindsay C, MHA; Wright, Alissa, MD MSc; Zaltzman, Jeffrey, MD MSc; Shemie, Sam D, MD

**Abstract:** In 2006, the Canadian Council for Donation and Transplantation produced the first Canadian recommendations for organ donor management, the result of a 2004 forum in collaboration with the Canadian Critical Care Society, the Canadian Association of Transplantation and the Canadian Society of Transplantation. The 2006 guideline had an influence on organ donation recommendations internationally; however, it had not been

updated to incorporate emerging evidence in organ donor management and critical care medicine and the many advances in guideline development methodology. Here, Ball et al discuss the existing Canadian recommendations for the medical management of neurologically deceased adult and pediatric potential donors for the purposes of single- or multi-organ recovery for transplantation.

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**Title: Measuring Attitudes Toward Organ Donation.**

**Citation:** Progress in Transplantation; Jun 2020; vol. 30 (no. 2); p. 182-183

**Author(s):** Feeley ; Harris, Katy E.; Yang, Janet Z.

**Abstract:** The authors discuss the type of items that can be reliable measures of attitudes and barriers to organ donation, with topics mentioned such as confirmatory factor analysis, kurtosis, and organ transplantation.

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**Title: Delirium at the end of life.**

**Citation:** Age & Ageing; May 2020; vol. 49 (no. 3); p. 337-340

**Author(s):** Agar, Meera R

**Abstract:** Delirium is highly prevalent in people with advanced life limiting illness(es), and current evidence can inform how we provide best delirium care in this setting. Whilst strategies to prevent and reverse delirium are the cornerstones of optimal care, the care for delirious patients who are approaching the end of life and their families pose specific challenges particularly if delirium is refractory flagging a grave prognosis. These include addressing additional supportive care needs, clinical decision-making about the degree of investigation and intervention, minimising distress from the symptoms of delirium itself and considering other concurrent problems contributing to agitation. A fine balance is needed to address other symptoms such as pain whilst minimizing psychoactive medication load. There is need for regular and clear information and communication about prognosis and goals of care. Witnessing a delirium episode in a loved one in close proximity to death requires consideration of the needs of the family into bereavement care. Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease; who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise quality of life. It is an approach which can be provided regardless of setting and diagnosis, and by both specialist palliative care teams and other health professionals.

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**Title: Organ Donation During the Coronavirus Pandemic: An Evolving Saga in Uncharted Waters.**

**Citation:** Transplant international : official journal of the European Society for Organ Transplantation; Apr 2020

**Author(s):** Moris, Dimitrios; Shaw, Brian I; Dimitrokallis, Nikolaos; Barbas, Andrew S

**Abstract:** Coronavirus 2 (SARS-CoV-2) is the cause of an ongoing pandemic of respiratory illness, known as coronavirus disease 2019 (COVID-19). The risk of developing COVID-19 from a SARS-CoV-2 infected organ donor is unknown. Therefore, extreme caution is necessary when considering transplantation. Transmission is affected by epidemiological risk factors, incubation period, degree of viraemia, and viability of SARS-CoV-2 in blood and organ compartments. Recent guidelines from NHSBT recommend that all potential donors be tested for SARS-CoV-2 and donation suspended from those who test positive. Donation is discouraged for asymptomatic individuals who have been in a COVID-19-affected area in the last 28 days.

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**Title: Integration of Routine Parental Request of Organ Donation in End-of-Life Care of Children with Neurologic Disorders in the UK: Unresolved Medical, Legal, Cultural, and Religious Challenges.**

**Citation:** Neurocritical care; May 2020

**Author(s):** Rady, Mohamed Y

**Abstract:** The UK adopted the opt-out system (deemed or presumed consent) in end-of-life organ donation enforceable in May 2020. Presumed consent applies to adults but not children. Transplant advocates have recommended that all children on end-of-life care should be referred for potential organ donation to increase the supply of transplantable organs in the UK. To buttress this objective, a UK survey of parents of deceased children mostly with neurologic disorders secondary to severe brain injuries recommended the integration of routine parental discussion of donation regardless of donation eligibility in end-of-life care. Donation discussions emphasize the utility and suitability of organs in dying children for transplantation to maximize consent rate. To ensure that this recommendation does not harm children and parents, contemporary medical, legal, cultural, and religious challenges to end-of-life organ donation should be disclosed in parental discussion of donation and resolved appropriately. To that effect, it is urged that: (1) practice guidelines for the diagnosis and treatment of neurologic disorders secondary to severe brain injuries in children are updated and aligned with recent advances in neuroscience to eliminate potential errors from premature treatment discontinuation and/or incorrect diagnosis of death by brain(stem) criteria, (2) transparent and non-biased disclosure of all empiric information when discussing donation to ensure informed parental decision-making, and (3) a societal dialogue is conducted on the legal, cultural, and religious consequences of integration of routine donation discussion and referral in end-of-life care of children in the UK.

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**Title: Current status of organ donation after brain death in the UK.**

**Citation:** Anaesthesia; May 2020

**Author(s):** Manara, A R; Thomas, I

**Abstract:** Organ donation after brain death remains the deceased organ donation pathway of choice. In the UK, the current identification and referral rate for potential donation after brain death donors is 99%, the testing rate for determining death using neurological criteria is 86% and the approach to families for donation is 91%. Increasing donation after brain death donation will primarily require a large increase in the current consent rate of 72% to one matching the consent rate of 80-90% achieved in other European countries. Implementing the use of evidence-based donor optimisation bundles may increase the



number of organs available for transplantation. Alternatively, the UK will need to look at more challenging ways of increasing the pool of potential donors after brain death. The first would be to delay the withdrawal of life-sustaining treatment in patients with devastating brain injury to allow progression to brain death after the family have given consent to organ donation and with their consent to this delay. Even more challenging would be the consideration of re-introducing intensive care to facilitate organ donation programmes that have been so successful at increasing the number of organ donors elsewhere.

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**Title: Dyadic Decision-Making in Advanced Parkinson's Disease: A Mixed Methods Study**

**Citation:** Western Journal of Nursing Research; May 2020; vol. 42 (no. 5); p. 348

**Author(s):** Habermann, Barbara; Ju Young Shin; Shearer, Gretchen

**Abstract:** People with advanced Parkinson's disease (PD) are living at home being cared for by a family member. Decisions about health care and living preferences are made in a family context. The aims of the study were to (a) examine the types and timing of the decisions being made by dyads (person with Parkinson's [PWP] and caregiver) in advanced PD; and (b) explore perceived decision quality relative to specific decisions made. A mixed methods design of semi-structured dyad interviews followed by individual completion of decision measures twice at six months apart was utilized. Decisions involved obtaining more services in the home, moving into assisted living communities, maintaining as is, and initiating hospice. There was high decision quality as reflected by low decisional conflict and regret without statistical differences within the dyad. The findings provide insight into the nature of decisions dyads face and suggest ways that health care providers can support decision-making.

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**Title: Optimising compassionate nursing care at the end of life in hospital settings.**

**Citation:** Journal of Clinical Nursing (John Wiley & Sons, Inc.); Jun 2020; vol. 29 (no. 11/12); p. 1788-1796

**Author(s):** Robinson ; Moeke-Maxell, Tess; Parr, Jenny; Slark, Julia; Black, Stella; Williams, Lisa; Gott, Merryn

**Background:** An urgent need to improve palliative care in hospital has been identified. Moreover, service users consistently report care delivered by nurses in hospital as lacking compassion. Compassion is a fundamental component of nursing care, and promoting compassionate care has been identified as a policy priority in many countries. To help address this within the hospital context, we recently completed research exploring bereaved family experiences of good end of life care in hospital. We found that family accounts of good care aligned with Nolan and Dewar's compassionate care framework and subsequently extended the framework to the bi-cultural context of Aotearoa, New Zealand.

**Aims and objectives:** In this discussion paper, we explore synergies between our newly developed Kapakapa Manawa Framework: a bi-cultural approach to providing compassionate care at the end of life and the Fundamentals of Care. We argue that our framework can be used to support the implementation of the relational component of the Fundamentals of Care and the delivery of compassionate nursing practice in hospitals in Aotearoa, New Zealand.

**Design:** Discussion paper.

**Methods:** Review of relevant literature and construction of two vignettes describing good end of life care from the perspectives of bereaved family—one Māori and one non-Māori. The vignettes provide practical examples of how the values of the Kapakapa Manawa Framework can be enacted by nurses to provide compassionate care in alignment with the relationship component of the Fundamentals of Care.

**Conclusions:** Whilst the Kapakapa Manawa bi-cultural compassionate care framework has grown out of research conducted with people nearing the end of their lives, it has the potential to improve nursing care for all hospital inpatients. Relevance to clinical practice: Addressing the wider policy and health system factors detailed in the Fundamentals of Care will support its implementation in the clinical setting.

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**Title: End of life care in the emergency department.**

**Citation:** Emergency Medicine Journal; May 2020; vol. 37 (no. 5); p. 273-278

**Author(s):** Dawood

**Abstract:** The importance of end of life care (EoLC) for patients and their families is well documented, however, the skills and knowledge of emergency clinicians in delivering EoLC is not widely understood but it is clear from the existing literature that we fall short in delivering consistently good EoLC although there is recognition of the need to improve. This paper will acknowledge the challenges of delivering good EoLC in the emergency department (ED) but more importantly consider practical ways of improving EoLC in the ED in line with best practice guidelines on EoLC.

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**Title: Optimizing Quality of Life With Cognitive Impairment: A Study of End-of-Life Care in Assisted Living.**

**Citation:** Journal of the American Medical Directors Association; May 2020; vol. 21 (no. 5); p. 692-696

**Author(s):** Arneson, Laura; Bender, Alexis A.; Robert, Maggi N.; Perkins, Molly M.

**Abstract:** Assisted living (AL) is an expanding site of end-of-life (EOL) care in the United States. Understanding determinants of quality of life (QoL) for AL residents near EOL is vital to optimize care for this growing population, most of whom have some degree of cognitive impairment (CI). This analysis aimed to identify factors associated with QoL in a diverse sample of AL residents with CI approaching EOL. Observational cross-section design. Data are from a 5-year study funded by the National Institute on Aging examining EOL care of residents in 7 diverse AL communities in metropolitan Atlanta (n = 67). CI was assessed with the Montreal Cognitive Assessment (scores  $\leq 26$ ) and QoL was determined with the self-reported QoL in Alzheimer's disease survey adapted for use in AL. Psychological distress was assessed using the Patient Health Questionnaire-4 and fatigue was assessed using the 13-item Functional Assessment of Chronic Illness Therapy Fatigue Scale. Initial descriptive analyses were followed by backward stepwise regression analyses to select a best-fitting model of QoL. The final model predicted 27% of the variance in QoL. CI was not significantly correlated with QoL and was not retained in the final model. Pain and functional limitation also did not meet inclusion criteria ( $P \leq .10$ ) and were sequentially removed, producing a final

model of QoL in terms of psychological distress ( $\beta = -0.28$ ,  $P = .032$ ), fatigue ( $\beta = -0.26$ ,  $P = .048$ ), and race ( $\beta = 0.21$ ,  $P = .063$ ). The lack of a significant correlation between degree of CI and self-reported QoL suggests that AL residents have the potential to experience high QoL, despite CI. Interventions to reduce psychological distress and manage fatigue could be implemented during EOL care to attempt to improve QoL for AL residents with CI. The correlation between race and QoL warrants investigation into possible racial disparities in AL and EOL care.

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**Title: Primary care service use by end-of-life cancer patients: a nationwide population-based cohort study in the United Kingdom.**

**Citation:** BMC Family Practice; Apr 2020; vol. 21 (no. 1); p. 1-13

**Author(s):** Gao, Wei; Gulliford, Martin; Morgan, Myfanwy; Higginson, Irene J.

**Background:** End of life (EoL) care becomes more complex and increasingly takes place in the community, but there is little data on the use of general practice (GP) services to guide care improvement. This study aims to determine the trends and factors associated with GP consultation, prescribing and referral to other care services amongst cancer patients in the last year of life.

**Methods:** A retrospective cohort study of cancer patients who died in 2000–2014, based on routinely collected primary care data (the Clinical Practice Research DataLink, CPRD) covering a representative sample of the population in the United Kingdom. Outcome variables were number of GP consultations (primary), number of prescriptions and referral to other care services (yes vs no) in the last year of life. Explanatory variables included socio-demographics, clinical characteristics and the status of palliative care needs recognised or not. The association between outcome and explanatory variables were evaluated using multiple-adjusted risk ratio (aRR).

**Results:** Of 68,523 terminal cancer patients, 70% were aged 70+, 75% had comorbidities and 45.5% had palliative care needs recognised. In the last year of life, a typical cancer patient had 43 GP consultations (Standard deviation (SD): 31.7; total = 3,031,734), 71.5 prescriptions (SD: 68.0; total = 5,074,178), and 21(SD: 13.0) different drugs; 58.0% of patients had at least one referral covering all main clinical specialities. More comorbid conditions, prostate cancer and having palliative care needs recognised were associated with more primary care consultations, more prescriptions and a higher chance of referral (aRRs 1.07–2.03). Increasing age was related to fewer consultations (aRRs 0.77–0.96), less prescriptions (aRR 1.09–1.44), and a higher chance of referral (aRRs 1.08–1.16) but less likely to have palliative care needs recognised (aRRs 0.53–0.89).

**Conclusions:** GPs are very involved in end of life care of cancer patients, most of whom having complex care needs, i.e. older age, comorbidity and polypharmacy. This highlights the importance of enhancing primary palliative care skills among GPs and the imperative of greater integration of primary care with other healthcare professionals including oncologists, palliative care specialists, geriatricians and pharmacists. Research into the potential of deprescribing is warranted. Older patients have poorer access to both primary care and palliative care need to be addressed in future practices.

**Title: Practice Recommendations for End-of-Life Care in the Intensive Care Unit.**

**Citation:** Critical Care Nurse; Jun 2020; vol. 40 (no. 3); p. 14-22

**Author(s):** Jensen ; Halvorsen, Kristin; Jerpseth, Heidi; Fridh, Isabell; Lind, Ranveig

**Topic:** A substantial number of patients die in the intensive care unit, so high-quality end-of-life care is an important part of intensive care unit work. However, end-of-life care varies because of lack of knowledge of best practices.

**Clinical Relevance:** Research shows that high-quality end-of-life care is possible in an intensive care unit. This article encourages nurses to be imaginative and take an individual approach to provide the best possible end-of-life care for patients and their family members.

**Purpose of Paper:** To provide recommendations for high-quality end-of-life care for patients and family members.

**Content Covered:** This article touches on the following domains: end-of-life decision-making, place to die, patient comfort, family presence in the intensive care unit, visiting children, family needs, preparing the family, staff presence, when the patient dies, after-death care of the family, and caring for staff.

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**Title: The experiences of, and need for, palliative care for people with motor neurone disease and their informal caregivers: A qualitative systematic review.**

**Citation:** Palliative Medicine; Jun 2020; vol. 34 (no. 6); p. 708-730

**Author(s):** Flemming ; Turner, Victoria; Bolsher, Samantha; Hulme, Bill; McHugh, Elizabeth; Watt, Ian

**Background:** Despite being a terminal neurodegenerative disease, the role of palliative care is less recognised for motor neurone disease than for other life-limiting conditions. Understanding the experiences of, and need for, palliative care for patients and carers is key to configuring optimal policy and healthcare services.

**Aim:** To explore the experiences of, and need for, palliative care of people with motor neurone disease and their informal carers across the disease trajectory.

**Design:** A systematic review of qualitative research conducted using Thematic Synthesis – PROSPERO registration CRD42017075311.

**Data Sources:** Four electronic databases were searched (MEDLINE, CINAHL, PsycINFO, Social Science Citation Index) using terms for motor neurone disease, amyotrophic lateral sclerosis, palliative care, and qualitative research, from inception to November 2018. Included papers were data extracted and assessed for quality.

**Results:** A total of 41 papers were included, representing the experiences of 358 people with motor neurone disease and 369 caregivers. Analytical themes were developed detailing patients' and carers' experiences of living with motor neurone disease and of palliative care through its trajectory including response to diagnosis, maintaining control, decision-making during deterioration, engaging with professionals, planning for end-of-life care, bereavement.

**Conclusion:** The review identified a considerable literature exploring the care needs of people with motor neurone disease and their carers; however, descriptions of palliative care were associated with the last days of life. Across the disease trajectory, clear points were identified where palliative care input could enhance patient and carer experience of the disease, particularly at times of significant physical change.

**Title: The Mitori project: End of life care in the United Kingdom and Japan – intersections in culture, practice and policy.**

**Citation:** Progress in Palliative Care; Jun 2020; vol. 28 (no. 3); p. 189-191

**Author(s):** Clark ; Takenouchi, Hirobumi

**Abstract:** The article focuses on the Mitori, a Japanese word referring to the practice of accompanying someone towards the end of their life. It provides an orientating concept to unlock deep cultural assumptions about where, how and in what circumstances people should die; and mentions the Mitori Project has tried to instantiate a watching brief on end of life issues in the Great Britain and Japan.

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**Title: Management of endocrine conditions at the end of life.**

**Citation:** British Journal of Hospital Medicine (17508460); May 2020; vol. 81 (no. 5); p. 1-9

**Author(s):** de Bray ; Tomas, Jon; Gittoes, Neil; Hassan-Smith, Zaki

**Abstract:** An important facet to end-of-life care is deprescribing. This can be challenging when reviewing life-sustaining endocrine medications but, unlike for diabetes, there is no national guidance to support patients and clinicians faced with care planning. This article reviews the limited current evidence to highlight areas for further discussion and research with the aim of moving towards consensus opinion. Discontinuation of certain endocrine medications, including corticosteroids, desmopressin and levothyroxine, is likely to precipitate an 'endocrine-driven mechanism of death', while it may be reasonable to discontinue other endocrine medications without the risk of hastening death or causing unnecessary symptoms. However, the over-arching theme should be that early discussion with patients regarding conversion or discontinuation of endocrine medications or monitoring is central to care planning.

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**Title: Palliative care and infection management at end of life in nursing homes: A descriptive survey.**

**Citation:** Palliative Medicine; May 2020; vol. 34 (no. 5); p. 580-588

**Author(s):** Tark ; Estrada, Leah V; Tregallo, Mary E; Quigley, Denise D; Stone, Patricia W; Agarwal, Mansi

**Background:** Infections are common occurrences at end of life that are associated with high rates of morbidity and mortality among frail elderly individuals. The problem of infections in nursing homes has led to a subsequent overuse and misuse of antibiotics in this already-frail population. Improving palliative care in nursing homes has been proposed as a key strategy to reduce the use of antibiotics.

**Aim:** The aim of this study was to describe the current status of how nursing homes integrates palliative care and infection management at end of life across the nation.

**Design:** This is a cross-sectional survey of nationally representative US nursing homes.

**Setting/participants:** Between November 2017 and October 2018, a survey was conducted with a nationally representative random sample of nursing homes and 892 surveys were

completed (49% response rate). The weighted study sample represented 15,381 nursing homes across the nation.

**Results:** Most nursing homes engaged in care plan documentation on what is important to residents (90.43%) and discussed spiritual needs of terminally ill residents (89.50%). In the event of aspiration pneumonia in terminally ill residents, 59.43% of nursing homes responded that resident would be transferred to the hospital. In suspected urinary tract infection among terminally ill residents, 66.62% of nursing homes responded that the resident will be treated with antibiotics.

**Conclusion:** The study found wide variations in nursing home palliative care practices, particularly for timing of end-of-life care discussions, and suboptimal care reported for antibiotic usage. Further education for nursing home staff on appropriate antibiotic usage and best practices to integrate infection management in palliative care at the end of life is needed.

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**Title: Physical restraining of nursing home residents in the last week of life: An epidemiological study in six European countries.**

**Citation:** International Journal of Nursing Studies; Apr 2020; vol. 104

**Author(s):** Pivodic, Lara; Smets, Tinne; Gambassi, Giovanni; Kylänen, Marika; Pasman, H. Roeline; Payne, Sheila; Szczerbińska, Katarzyna; Deliens, Luc; Van den Block, Lieve

**Abstract:** End-of-life care in nursing homes holds several risk factors for the use of physical restraints on residents, a practice shown to be neither safe nor effective. To determine the frequency of physical limb and/or trunk restraint use in the last week of life of nursing home residents in six European countries and its association with country, resident and nursing home characteristics. Epidemiological survey study. Proportionally stratified random sample of nursing homes in Belgium (BE), England (ENG), Finland (FI), Italy (IT), the Netherlands (NL), and Poland (PL). Nursing home staff (nurses or care assistants). In all participating nursing homes, we identified all residents who died during the three months prior to measurements. The staff member most involved in each resident's care indicated in a structured questionnaire whether trunk and/or limb restraints were used on that resident during the last week of life 'daily', 'less frequently than daily' or 'not used'. In 322 nursing homes, staff returned questionnaires regarding 1384 deceased residents (response rate 81%). Limb and/or trunk restraints were used "daily" in the last week of life in 8% (BE), 1% (ENG), 4% (FI), 12% (IT), 0% (NL), and 0.4% (PL) of residents; and "less frequently than daily" in 4% (BE), 0% (ENG), 0.4% (FI), 6% (IT), 0% (NL), and 3.5% (PL) of residents. Restraint use was associated with country ( $p = 0.020$ ) and inversely associated with residents' age ( $p = 0.017$ ; odds ratio 0.96, 95% confidence interval 0.93 to 0.99). Restraint use was not significantly associated with resident's gender, dementia, functional status, staffing level, or the level of dependency of residents within the nursing home. In all but one of the six countries studied, staff reported that nursing home residents were restrained through limb and/or trunk restraints in the last week of life. The proportion of restrained residents was highest in Italy and Belgium. Organizational and resident characteristics may not be relevant predictors of restraint use at the end of life in this setting. National policy that explicitly discourages physical restraints in nursing home care and suggests alternative practices may be an important component of strategies to prevent their use.

**Title: A Qualitative Study of Pulmonary and Palliative Care Clinician Perspectives on Early Palliative Care in Chronic Obstructive Pulmonary Disease.**

**Citation:** Journal of Palliative Medicine; Apr 2020; vol. 23 (no. 4); p. 513-526

**Author(s):** Iyer, Anand S.; Dionne-Odom, James Nicholas; Khateeb, Dina M.; O'Hare, Lanier; Tucker, Rodney O.; Brown, Cynthia J.; Dransfield, Mark T.; Bakitas, Marie A.

**Background:** Guidelines recommend that pulmonary clinicians involve palliative care in chronic obstructive pulmonary disease (COPD); however, integration before advanced stage, that is, early palliative care, is rare.

**Objective:** To explore and compare pulmonary and palliative care clinician perspectives on barriers, facilitators, and potential referral criteria for early palliative care in COPD.

**Design:** Qualitative descriptive formative evaluation study.

**Setting/Subjects:** Pulmonary and palliative care clinicians at a tertiary academic medical center.

**Measurements:** Transcribed interviews were thematically analyzed by specialty to identify within- and across-specialty perspectives on barriers, facilitators, and referral criteria.

**Results:** Twelve clinicians (n = 6 pulmonary, n = 6 palliative care) participated. Clinicians from both specialties agreed that early palliative care could add value to disease-focused COPD care. Perspectives on many barriers and facilitators were shared between specialties along broad educational, clinical, and operational categories. Pulmonary and palliative care clinicians shared concerns about the misconception that palliative care was synonymous to end-of-life care. Pulmonologists were particularly concerned about the potential risks of opioids and benzodiazepines in COPD. Both specialties stressed the need for clearly defined roles, consensus referral criteria, and novel delivery models. Although no single referral criterion was discussed by all, frequent hospitalizations and emotional symptoms were raised by most across disciplines. Multimorbidity and poor prognosis were discussed only by palliative care clinicians, whereas medication adherence was discussed only by pulmonary clinicians.

**Conclusions:** Pulmonary and palliative care clinicians supported early palliative care in COPD. Continued needs include addressing pulmonologists' misconceptions of palliative care, establishing consensus referral criteria, and implementing novel early palliative care models.

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**Title: Multidimensional emotion regulation strategies among hospice nurses.**

**Citation:** Death Studies; Sep 2020; vol. 44 (no. 8); p. 463-468

**Author(s):** Barnett ; Cantu, Christina; Clark, Kametrice A.

**Abstract:** The purpose of this study was to investigate relationships between four emotion regulation strategies (intrinsic affect-improving, intrinsic affect-worsening, extrinsic affect-improving, and extrinsic affect-worsening) and compassion fatigue, job satisfaction, and life satisfaction among 90 hospice nurses who completed an online survey. Intrinsic affect-improving was associated with higher life satisfaction. Intrinsic affect-worsening was associated with higher compassion fatigue and lower life satisfaction. Extrinsic affect-worsening was associated with lower job satisfaction. Overall, these findings support a multidimensional approach to understanding emotion regulation among hospice nurses.

**Title: What factors predict the confidence of palliative care delivery in long-term care staff? A mixed-methods study.**

**Citation:** International Journal of Older People Nursing; Jun 2020; vol. 15 (no. 2); p. 1-14

**Author(s):** Frey ; Balmer, Deborah; Robinson, Jackie; Boyd, Michal; Gott, Merryn

**Background:** Research has indicated that clinical staff in long-term care often lack self-confidence in palliative care delivery, particularly at the end of life.

**Goals:** (a) To examine the contribution of age, palliative care education, palliative care work-related experience and psychological empowerment to palliative care delivery confidence and (b) to explore the social reality shaping those factors for long-term care staff.

**Design:** Explanatory sequential design.

**Setting:** Twenty long-term care facilities in two district health boards in New Zealand.

**Participants:** Phase 1:139 clinical staff. Phase 2:46 clinical staff who provided care in the last month of a residents' life.

**Methods:** Phase 1: Cross-sectional survey. Phase 2: Individual semi-structured interviews.

**Results:** Phase 1: Previous experience ( $\beta = .319$ ) and psychological empowerment ( $\beta = .311$ ) contribute most to predicting an increase in palliative care delivery confidence. Phase 2: Four factors underlay palliative care delivery confidence, (a) mentorship by hospice nurses or colleagues (b) contextual factors (organisational culture, resources and experience), (c) maturity and (d) formal education.

**Conclusion:** Organisational leadership should use multiple strategies (e.g. power-sharing, increased opportunities for mentorship) to improve staff palliative care delivery confidence.

**Implications for Practice:** This study adds to the literature in understanding the predictors of palliative care delivery confidence specific to long-term care staff. The results indicate that educational interventions must be contextually appropriate to achieve sustainable improvements in palliative care confidence and ultimately in resident care at the end of life.

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**Title: Role of nurses in medication management at the end of life: a qualitative interview study.**

**Citation:** BMC Palliative Care; May 2020; vol. 19 (no. 1); p. 1-11

**Author(s):** Huisman ; Geijteman, Eric C. T.; Dees, Marianne K.; Schonewille, Noralie N.; Wieles, Margriet; van Zuylen, Lia; Szadek, Karolina M.; van der Heide, Agnes

**Background:** Patients in the last phase of their lives often use many medications. Physicians tend to lack awareness that reviewing the usefulness of medication at the end of patients' lives is important. The aim of this study is to gain insight into the perspectives of patients, informal caregivers, nurses and physicians on the role of nurses in medication management at the end of life.

**Methods:** Semi-structured interviews were conducted with patients in the last phase of their lives, in hospitals, hospices and at home; and with their informal caregivers, nurses and physicians. Data were qualitatively analyzed using the constant comparative method.

**Results:** Seventy-six interviews were conducted, with 17 patients, 12 informal caregivers, 15 nurses, 20 (trainee) medical specialists and 12 family physicians. Participants agreed that the role of the nurse in medication management includes: 1) informing, 2) supporting, 3) representing and 4) involving the patient, their informal caregivers and physicians in



medication management. Nurses have a particular role in continuity of care and proximity to the patient. They are expected to contribute to a multidimensional assessment and approach, which is important for promoting patients' interest in medication management at the end of life.

**Conclusions:** We found that nurses can and should play an important role in medication management at the end of life by informing, supporting, representing and involving all relevant parties. Physicians should appreciate nurses' input to optimize medication management in patients at the end of life. Health care professionals should recognize the role the nurses can have in promoting patients' interest in medication management at the end of life. Nurses should be reinforced by education and training to take up this role.

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**Title: Communication can reduce opioid misuse in home hospice care.**

**Citation:** Modern Healthcare; May 2020; vol. 50 (no. 19); p. 34-34

**Author(s):** Brady, Michael

**Abstract:** The article discusses the importance of patient education and communication in preventing the diversion or misuse of drugs critical to end-of-life care according to experts. Topics covered include significance of opioid treatment agreements to patients and providers, the use of the Opioid Risk Tool by Bluegrass Care Navigators to assess all patients who receive controlled substances, and ways to limit medications.

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**Title: Factors influencing engagement in an online support group for family caregivers of individuals with advanced cancer.**

**Citation:** Journal of Psychosocial Oncology; May 2020; vol. 38 (no. 3); p. 235-250

**Author(s):** Washington ; Oliver, Debra Parker; Benson, Jacquelyn J.; Rolbiecki, Abigail J.; Jorgensen, Lucas A.; Cruz-Oliver, Dulce M.; Demiris, George

**Objective:** To explore factors that influenced engagement in an online support group (OSG) for family caregivers of hospice patients with cancer.

**Design:** Secondary qualitative data analysis.

**Sample:** 58 family caregivers of hospice patients with advanced cancer.

**Methods:** Template analysis of individual family caregiver interviews.

**Findings:** Emotional isolation and caregiving downtime positively influenced engagement, while reluctance to share personal information, a short timeframe of participation in the OSG, and caregiving commitments were negatively influential. While the group facilitation and secure privacy settings of the OSG were viewed positively, reactions to the OSG platform and group tone were mixed. Information on pain and the dying process was found to be particularly engaging.

**Practice implications:** Providers offering OSGs for family caregivers should maximize factors that promote meaningful member engagement, responding to changes in activity and tone over time.

**Title: Disease trajectories, place and mode of death in people with head and neck cancer: Findings from the 'Head and Neck 5000' population-based prospective clinical cohort study.**

**Citation:** Palliative Medicine; May 2020; vol. 34 (no. 5); p. 639-650

**Author(s):** Mayland ; Ingarfield, Kate; Rogers, Simon N; Dey, Paola; Thomas, Steven; Waylen, Andrea; Leary, Sam D; Pring, Miranda; Hurley, Katrina; Waterboer, Tim; Pawlita, Michael; Ness, Andy R

**Background:** Few large studies describe initial disease trajectories and subsequent mortality in people with head and neck cancer. This is a necessary first step to identify the need for palliative care and associated services.

**Aim:** To analyse data from the Head and Neck 5000 study to present mortality, place and mode of death within 12 months of diagnosis.

**Design:** Prospective cohort study.

**Participants:** In total, 5402 people with a new diagnosis of head and neck cancer were recruited from 76 cancer centres in the United Kingdom between April 2011 and December 2014.

**Results:** Initially, 161/5402 (3%) and 5241/5402 (97%) of participants were treated with 'non-curative' and 'curative' intent, respectively. Within 12 months, 109/161 (68%) in the 'non-curative' group died compared with 482/5241 (9%) in the 'curative' group. Catastrophic bleed was the terminal event for 10.4% and 9.8% of people in 'non-curative' and 'curative' groups, respectively; terminal airway obstruction was recorded for 7.5% and 6.3% of people in the same corresponding groups. Similar proportions of people in both groups died in a hospice (22.9% 'non-curative'; 23.5% 'curative') and 45.7% of the 'curative' group died in hospital.

**Conclusion:** In addition to those with incurable head and neck cancer, there is a small but significant 'curative' subgroup of people who may have palliative needs shortly following diagnosis. Given the high mortality, risk of acute catastrophic event and frequent hospital death, clarifying the level and timing of palliative care services engagement would help provide assurance as to whether palliative care needs are being met.

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**Title: Incidence and prevalence of pressure ulcers in cancer patients admitted to hospice: A multicentre prospective cohort study.**

**Citation:** International Wound Journal; Jun 2020; vol. 17 (no. 3); p. 641-649

**Author(s):** Jakobsen, Tina Bull Tafteberg; Pittureri, Cristina; Seganti, Patrizia; Borissova, Elena; Balzani, Isabella; Fabbri, Samanta; Amati, Piero; Donigaglia, Sara; Gallina, Silvia; Fabbri, Elisabetta

**Abstract:** Pressure ulcers lead to discomfort for patients and may have an important impact on a patient's quality of life. Measure the incidence and prevalence of pressure ulcers in a Hospice environment; evaluate the risk factors associated with pressure ulcers; and calculate the incidence of Kennedy Terminal Pressure Ulcers. This multicentre prospective cohort study enrolled 440 cancer patients in advanced phase, consecutively admitted to five hospices of the AUSL della Romagna (Italy), during a period of 1 year. Five hundred more patients were excluded from the study because of inability to sign the consent form or refusal to participate. All patients were adults above 18 years of age. The National Pressure Advisory Panel Classification System was used to evaluate the pressure ulcers. Potential

risk predictors were evaluated through the Braden Scale, the Numerical Scale, and the Pain Assessment in Advanced Dementia Scale. Starting in September 2016, 214 (48.6%) females and 226 (51.4%) males were analysed. The incidence of pressure ulcers in the total population was 17.3%. The risk factors that influence the development of pressure ulcers were age, proximity to death, and duration of stay in Hospice. The incidence of Kennedy Terminal Pressure Ulcers was 2.7%. This study demonstrates that 17.3% of all patients admitted to a hospice setting developed a pressure ulcer. The longer the patients stay in hospice and the clinical condition deteriorates, the higher the risk of developing a pressure ulcer.

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**Title: Pharmacovigilance in Hospice/Palliative Care: De-Prescribing Combination Controlled Release Oxycodone-Naloxone.**

**Citation:** Journal of Palliative Medicine; May 2020; vol. 23 (no. 5); p. 656-661

**Author(s):** Clark, Katherine; Byrne, Paul G.; Hunt, Jane; Brown, Linda; Rowett, Debra; Watts, Gareth; Lovell, Melanie; Currow, David C.

**Background:** Pharmacovigilance studies in hospice/palliative care provide extra information to improve medication safety. Combination controlled release oxycodone-naloxone offers an alternative opioid with less risk of opioid-induced constipation.

**Objective:** To examine why palliative care clinicians chose to cease oxycodone-naloxone and to explore immediate and short-term benefits and harms of this medication change.

**Design:** A consecutive cohort study.

**Setting:** 112 adults from 13 palliative care centers.

**Measurements:** Reasons for ceasing medication and the harms and benefits that followed this 24 and 72 hours later. Symptom burdens were summarised by the National Cancer Institute Common Terminology Criteria for Adverse Events Toxicity Gratings.

**Results:** Combination medication was most commonly ceased because of poor pain control or impaired hepatic function. The last median oral morphine equivalent oxycodone dose before the switch was 45 mg (range 7.5–240 mg) with 76 switched to an alternative long-acting opioid (initial median oral morphine equivalent dose being 45 mg [range 5–210 mg]). Subgroup analysis of those switched because of clinicians' concerns about hepatic dysfunction demonstrated this group were receiving significantly lower opioid doses pre-cessation compared to those switched because of other reasons ( $p = 0.007$ ). Regardless of why the medication was changed, improvements in pain and constipation scores were seen, the latter associated with an attendant increase in laxatives.

**Conclusions:** This preliminary work suggests that despite theoretical concerns regarding the effect of the naloxone on opioid doses, most people were switched safely to very similar opioid doses with attendant improvements in pain control.

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**Title: Palliative Care in a Community-Based Serious-Illness Care Program.**

**Citation:** Journal of Palliative Medicine; May 2020; vol. 23 (no. 5); p. 692-697

**Author(s):** Ernecoff, Natalie C.; Hanson, Laura C.; Fox, Alexandra L.; Daaleman, Timothy P.; Kistler, Christine E.

**Background:** Although community-based serious-illness care (CBSC) is an innovative care model, it is unclear to what extent CBSC addresses palliative care needs, particularly for those patients near death.

**Objectives:** To evaluate palliative care services of a CBSC program.

**Design:** Retrospective chart reviews.

**Setting/Subjects:** Patients enrolled in a CBSC program in central North Carolina.

**Measurement:** Descriptive statistics of palliative care needs and services, such as symptom management, psychosocial support, and advance care planning (ACP), for survivors and decedents.

**Results:** Patients were seen in an 18-month time frame ( $n = 159$ ). Mean enrollment in the program was 261.1 days (standard deviation 180.6). Patients' average age was 70 years, 56% were female, and 33% were black. Patients' most frequent comorbidities were dementia (32%), heart failure (32%), and diabetes (28%). Fifty patients (31%) died during the study period. Clinicians most frequently screened for pain (70%), constipation (57%), and dyspnea (57%). Of those screened positive, clinicians most frequently treated pain (92%), anxiety (84%), and constipation (83%). Among the 54% who screened positive for psychosocial distress, 82% received support. Clinicians screened 22% for spiritual needs; 4% received spiritual care. Among decedents, 66% were enrolled in hospice; 14% died in in-hospital. Decedents were more likely than survivors to have ACP (34% vs. 18%,  $p = 0.03$ ) and a primary goal of comfort (40% vs. 12%,  $p < 0.01$ ).

**Conclusions:** A CBSC program provided palliative care services comparable with other home-based palliative care programs. Although the CBSC program does not address all domains of palliative care, it provided most with symptom management, psychosocial support, and ACP.

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**Title: Palliative Care in Dysphagia and Dementia.**

**Citation:** Perspectives of the ASHA Special Interest Groups; Apr 2020; vol. 5 (no. 2); p. 506-510

**Author(s):** Smith, Pamela A.

**Purpose:** The purpose of this clinical focus article is to discuss palliative care for patients with dysphagia who also have a comorbid condition of dementia. It reviews the nature of palliative care as encompassing important aspects of patient/resident choice and comfort, which are important regardless of the cognitive status of the patient or the terminal nature of the diagnosis. It provides a comparison of palliative care, hospice care, and rehabilitative care. It then discusses issues that are specific to dementia and dysphagia for patients who are approaching the end of life.

**Conclusion:** The philosophy of palliative care need not be limited to end-of-life cases in dysphagia management as considerations for comfort, and patient's wishes should always be part of care planning. Clinicians working with cognitively impaired patients at the end of life must be particularly sensitive to their communication efforts and be willing to work cooperatively with family members and other stakeholders in developing plans of care using shared decision making

**Title: Building trust and facilitating goals of care conversations: A qualitative study in people with heart failure receiving home hospice care.**

**Citation:** Palliative medicine; May 2020 ; p. 269216320917873

**Author(s):** Baik, Dawon; Russell, David; Jordan, Lizeyka; Matlock, Daniel D; Dooley, Frances; Masterson Creber, Ruth

**Background:** Despite a majority of persons receiving hospice care in their homes, there are gaps in understanding how to facilitate goals of care conversations between persons with heart failure and healthcare providers.

**Aim:** To identify barriers and facilitators which shape goals of care conversations for persons with heart failure in the context of home hospice.

**Design:** A qualitative descriptive study design was used with semi-structured interviews.

**Setting/Participants:** We conducted qualitative interviews with persons with heart failure, family caregivers, and interprofessional healthcare team members at a large not-for-profit hospice agency in New York City between March 2018 and February 2019.

**Results:** A total of 39 qualitative interviews were conducted, including with healthcare team members (e.g. nurses, physicians, social workers, spiritual counselors), persons with heart failure, and family caregivers. Three themes emerged from the qualitative interviews regarding facilitators and barriers in goals of care conversations for better decision-making: (1) trust is key to building and maintaining goals of care conversations; (2) lack of understanding and acceptance of hospice inhibits goals of care conversations; and (3) family support and engagement promote goals of care conversations.

**Conclusion:** Findings from this study suggest that interventions designed to improve goals of care conversations in the home hospice setting should focus on promoting understanding and acceptance of hospice, family support and engagement, and building trusting relationships with interprofessional healthcare teams.

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**Title: Role of nurses in medication management at the end of life: a qualitative interview study.**

**Citation:** BMC palliative care; May 2020; vol. 19 (no. 1); p. 68

**Author(s):** Huisman, Bregje A A; Geijteman, Eric C T; Dees, Marianne K; Schonewille, Noralie N; Wieles, Margriet; van Zuylen, Lia; Szadek, Karolina M; van der Heide, Agnes

**Background:** Patients in the last phase of their lives often use many medications. Physicians tend to lack awareness that reviewing the usefulness of medication at the end of patients' lives is important. The aim of this study is to gain insight into the perspectives of patients, informal caregivers, nurses and physicians on the role of nurses in medication management at the end of life.

**Methods:** Semi-structured interviews were conducted with patients in the last phase of their lives, in hospitals, hospices and at home; and with their informal caregivers, nurses and physicians. Data were qualitatively analyzed using the constant comparative method.

**Results:** Seventy-six interviews were conducted, with 17 patients, 12 informal caregivers, 15 nurses, 20 (trainee) medical specialists and 12 family physicians. Participants agreed that the role of the nurse in medication management includes: 1) informing, 2) supporting, 3) representing and 4) involving the patient, their informal caregivers and physicians in medication management. Nurses have a particular role in continuity of care and proximity to

the patient. They are expected to contribute to a multidimensional assessment and approach, which is important for promoting patients' interest in medication management at the end of life.

**Conclusions:** We found that nurses can and should play an important role in medication management at the end of life by informing, supporting, representing and involving all relevant parties. Physicians should appreciate nurses' input to optimize medication management in patients at the end of life. Health care professionals should recognize the role the nurses can have in promoting patients' interest in medication management at the end of life. Nurses should be reinforced by education and training to take up this role.

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**Title: Preferred and actual place of death in haematological malignancies: a report from the UK haematological malignancy research network.**

**Citation:** BMJ supportive & palliative care; May 2020

**Author(s):** Sheridan, Rebecca; Roman, Eve; Smith, Alex G; Turner, Andrew; Garry, Anne C; Patmore, Russell; Howard, Martin R; Howell, Debra A

**Objectives:** Hospital death is comparatively common in people with haematological cancers, but little is known about patient preferences. This study investigated actual and preferred place of death, concurrence between these and characteristics of preferred place discussions.

**Methods:** Set within a population-based haematological malignancy patient cohort, adults ( $\geq 18$  years) diagnosed 2004-2012 who died 2011-2012 were included ( $n=963$ ). Data were obtained via routine linkages (date, place and cause of death) and abstraction of hospital records (diagnosis, demographics, preferred place discussions). Logistic regression investigated associations between patient and clinical factors and place of death, and factors associated with the likelihood of having a preferred place discussion.

**Results:** Of 892 patients (92.6%) alive 2 weeks after diagnosis, 58.0% subsequently died in hospital (home, 20.0%; care home, 11.9%; hospice, 10.2%). A preferred place discussion was documented for 453 patients (50.8%). Discussions were more likely in women ( $p=0.003$ ), those referred to specialist palliative care ( $p<0.001$ ), and where cause of death was haematological cancer ( $p<0.001$ ); and less likely in those living in deprived areas ( $p=0.005$ ). Patients with a discussion were significantly ( $p<0.05$ ) less likely to die in hospital. Last recorded preferences were: home (40.6%), hospice (18.1%), hospital (17.7%) and care home (14.1%); two-thirds died in their final preferred place. Multiple discussions occurred for 58.3% of the 453, with preferences varying by proximity to death and participants in the discussion.

**Conclusion:** Challenges remain in ensuring that patients are supported to have meaningful end-of-life discussions, with healthcare services that are able to respond to changing decisions over time.

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**Title: Medical Ethics Issues in Dementia and End of Life.**

**Citation:** Current psychiatry reports; May 2020; vol. 22 (no. 6); p. 31

**Author(s):** Allen, William

**Purpose of review:** I review ethical and legal challenges for end of life (EOL) care in dementia. Is access to hospice care for dementia patients impacted by Medicare's terminal prognosis requirement? Are dementia-specific advance directives warranted? How does state legislation affect dementia patients' EOL options? Should dementia patients' be able to refuse orally ingested food and fluids by advance directive?

**Recent Findings:** The difficulty of predicting time to death in dementia inhibits access to Medicare hospice benefits. Efforts have been made to create dementia-specific advance directives. Advance refusal of artificial nutrition and hydration are common, but the issue of oral ingestion of food and fluids by dementia patients remains controversial. Medicare's hospice benefit should be made more accessible to dementia patients. State advance directive threshold definitions should be broadened to include dementia, and capacitated persons who refuse in advance orally ingested food and fluids should have their choices honored.

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**Title: Redefining Palliative Care - a New Consensus-based Definition.**

**Citation:** Journal of pain and symptom management; May 2020

**Author(s):** Radbruch, Lukas; De Lima, Liliana; Knauth, Felicia; Wenk, Roberto; Ali, Zipporah; Bhatnagar, Sushma; Blanchard, Charmaine; Bruera, Eduardo; Buitrago, Rosa; Burla, Claudia; Callaway, Mary; Munyoro, Esther Cege; Centeno, Carlos; Cleary, Jim; Connor, Stephen; Davaasuren, Odontuya; Downing, Julia; Foley, Kathy; Goh, Cynthia; Gomez-Garcia, Wendy; Harding, Richard; Khanh, Quach T; Larkin, Phillippe; Leng, Mhoira; Luyirika, Emmanuel; Marston, Joan; Moine, Sebastien; Osman, Hibah; Pettus, Katherine; Puchalski, Christina; Rajagopal, M R; Spence, Dingle; Spruijt, Odette; Venkateswaran, Chitra; Wee, Bee; Woodruff, Roger; Yong, Jinsun; Pastrana, Tania

**Background:** The International Association for Hospice and Palliative Care (IAHPC) developed a consensus-based definition of palliative care (PC) that focuses on the relief of serious health related suffering, a concept put forward by the Lancet Commission Global Access to Palliative Care and Pain Relief.

**Aim:** The objective of this paper is to present the research behind the new definition.

**Methods:** The three-phased consensus process involved health care workers from countries in all income levels. In phase one, 38 PC experts evaluated the components of the World Health Organization (WHO) definition and suggested new/revised ones. In phase two, 412 IAHPC members in 88 countries expressed their level of agreement with the suggested components. In phase three, using results from phase two, the expert panel developed the definition.

**Results:** The consensus-based definition is "Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers." The definition includes a number of bullet points with additional details as well as recommendations for governments to reduce barriers to palliative care.

**Conclusions:** Participants had significantly different perceptions and interpretations of PC. The greatest challenge faced by the core group was trying to find a middle ground between those who think that PC is the relief of all suffering, and those who believe that PC describes the care of those with a very limited remaining life span.

**Title: Nasal fentanyl alone plus buccal midazolam: an open-label, randomised, controlled feasibility study in the dying.**

**Citation:** BMJ supportive & palliative care; May 2020

**Author(s):** Perkins, Paul; Parkinson, Anne; Akyea, Ralph Kwame; Husbands, Emma

**Introduction:** Many patients want to stay at home to die. They invariably become unable to take oral medication during their terminal phase. Symptoms are usually controlled by subcutaneous medications. There have been no studies on nasal fentanyl (NF) or buccal midazolam (BM) to control symptoms in the dying.

**Objective:** To establish how best to conduct a definitive, randomised controlled trial (RCT) to determine whether NF and BM administered by families, for patients dying at home, lead to faster and better symptom control and fewer community nursing visits than standard breakthrough medication by healthcare professionals.

**Method:** This open-label mixed-method feasibility RCT compared the efficacy of NF and BM by family members to standard breakthrough medication by nurses for the terminally ill in a specialist palliative care unit. Partway through the study, a third observational arm was introduced where BM alone was used. The primary outcomes were whether recruitment and randomisation were possible, assessment of withdrawal and drop-out, and whether the methods were acceptable and appropriate.

**Results:** Administration of NF and BM was acceptable to patients and families. Both were well tolerated. We were unable to obtain quality of life data consistently but did get time period data for dose-controlled symptoms.

**Conclusions:** Study participation in a hospice population of the dying was acceptable. The results will help guide future community study planning.

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**Title: Exploring Patients' Experience with Clinicians Who Recognize Their Unmet Palliative Needs: An Inpatient Study.**

**Citation:** Journal of palliative medicine; May 2020

**Author(s):** Gace, Denisa; Sommer, Robert K; Daubman, Bethany-Rose; Greer, Joseph A; Jacobsen, Juliet; LaSala, Cynthia; Rosenberg, Leah B; Greenwald, Jeffrey L

**Background:** Given the national shortage of palliative care specialists relative to the need for their services, engaging nonspecialists is important to ensure patients with serious illness have an opportunity to share their goals and values with their providers. Hospital medicine clinicians are well positioned to conduct these conversations given they care for many medically complex patients. Yet, little is known about the patient experience of inpatient goals and values conversations led by hospitalist teams.

**Objective:** To assess patients' experience and perception of the quality of goals and values conversations.

**Design/Setting/Participation:** Single center, tertiary care, nonrandomized, two group cohort trial of patients hospitalized on general medical inpatient units staffed by hospital medicine clinicians previously trained to conduct serious illness conversations.

**Intervention:** An automated screening tool was used to identify patients at increased risk for unmet palliative needs. The multidisciplinary team was informed of the screen's results on the intervention units but not on the control units. Intervention unit clinicians were asked to consider talking with patients about their goals and values.



**Results:** One hundred thirty patients participated in the study. The intervention patients reported improved quality of communication and fewer anxiety and depression symptoms compared with the control patients. Hospice utilization in addition to emergency department visits and hospital readmissions did not differ between the two groups.

**Conclusion:** This study suggests that informing the care team regarding their patients' potential unmet palliative care needs is associated with patients reporting improved experience of their care without adverse effects on their mood.

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**Title: Palliative care in the time of COVID-19.**

**Citation:** Journal of pain and symptom management; May 2020

**Author(s):** Mercadante, Sebastiano; Adile, Claudio; Ferrera, Patrizia; Giuliana, Fausto; Terruso, Lidia; Piccione, Tania

**Abstract:** After covid-19 crisis in Italy, serious restrictions have been introduced for relatives, with limitations or prohibitions on hospital visits. To partially overcome these issues "WhatsApp" has been adopted to get family members to participate in clinical rounds. Family members of patients admitted to the acute palliative care unit and hospice were screened for a period of 2 weeks. Four formal questions were posed: 1) Are you happy to virtually attend the clinical round? 2) Are you happy with the information gained in this occasion? 3) Do you think that your loved one was happy to see you during the clinical rounds? 4) This technology may substitute your presence during the clinical rounds? The scores were 0 = no, 1 = a little bit, 2 = much, 3 = very much. Relatives were free to comment about these points. Sixteen of 25 screened family members were interviewed. Most family members had a good impression, providing scores of 2 or 3 for the first three items. However, the real presence bedside (forth question) was considered irreplaceable. They perceived that their loved one, when admitted to hospice, had to say good-bye before dying.

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**Title: The Development and Implementation of a Cardiac Home Hospice Program: Results of a RE-AIM Analysis.**

**Citation:** The American journal of hospice & palliative care; May 2020 ; p. 1049909120925432

**Author(s):** Jordan, Lizeyka; Russell, David; Baik, Dawon; Dooley, Frances; Masterson Creber, Ruth M

**Background:** Use of hospice has grown among patients with heart failure; however, gaps remain in the ability of agencies to tailor services to meet their needs.

**Aim:** This study describes the implementation of a cardiac home hospice program and insights for dissemination to other hospice programs.

**Design:** We conducted a multimethod analysis structured around the Reach Effectiveness Adoption Implementation and Maintenance (RE-AIM) framework.

**Setting/Participants:** We used electronic medical records for our quantitative data source and interviews with hospice clinicians from a not-for-profit hospice agency (N = 32) for our qualitative data source.

**Results:** Reach-A total of 1273 participants were enrolled in the cardiac home hospice program, of which 57% were female and 42% were black or Hispanic with a mean age was

86 years. Effectiveness-The cardiac home hospice program increased hospice enrollment among patients with heart failure from 7.9% to 9.5% over 1 year (2016-2017). Adoption-Institutional factors that supported the program included the acute need to support medically complex patients at the end of life and an engaged clinical champion. Implementation-Program implementation was supported by interdisciplinary teams who engaged in care coordination. Maintenance-The program has been maintained for over 3 years.

**Conclusion:** The cardiac home hospice program strengthened hospice clinicians' ability to confidently provide care for patients with heart failure, expanded awareness of their symptoms among clinicians, and was associated with increased enrollment of patients with heart failure over the study period. This RE-AIM evaluation provides lessons learned and strategies for future adoption, implementation, and maintenance of a cardiac home hospice program.

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**Title: Dignity in end-of-life care at hospice: An Action Research Study.**

**Citation:** Scandinavian journal of caring sciences; May 2020

**Author(s):** Viftrup, Dorte Toudal; Hvidt, Niels Christian; Prinds, Christina

**Background:** Safeguarding the dignity of patients at the end of life is a key objective in palliative care practice in Denmark. The concept of dignity and how it influences a dying persons' quality of life is thus influential in end-of-life care at hospices. However, what is meant by dignity, how dignity is understood and practiced by healthcare professionals in Danish hospices, and whether this relates to the patients' understandings and needs concerning dignity remains unanswered.

**Aim:** The aim of this study was to explore and improve dignity in care through an action research study with patients and hospice staff at two different hospices in Denmark. This was done by exploring how patients and healthcare professionals expressed their understandings and needs concerning dignity and involving participants in the research process with the goal of improving dignity in care.

**Methods:** An action research method with reflection-of-praxis and action-in-praxis was applied. It was combined with methods of semi-structured individual interviews with twelve patients, five staff and nine focus-group interviews with staff.

**Results:** Three themes emerged from the analysis of data. The themes were as follows: (1) being understood, (2) contributing and (3) holistic care. Deeper analysis indicated that staff understandings of dignity mostly focused on preserving patients' autonomy, whereas patients expressed needs for relational and spiritual aspects of dignity. Staff were mostly concerned about preserving patients' autonomy when providing dignity in care, however, through the action-in-praxis they increased their awareness on their own praxis and patients' needs and understanding concerning dignity. The theoretical model on dignity presented in the study also worked as a map to guide staffs' reflections on dignity in praxis and facilitated a broader focus on supporting and caring for patients' dignity in care. We believe this study has improved dignity in care at the two hospices involved in the study.

**Title: Nursing competencies across different levels of palliative care provision: A systematic integrative review with thematic synthesis.**

**Citation:** Palliative medicine; May 2020 ; p. 269216320918798

**Author(s):** Hökkä, Minna; Martins Pereira, Sandra; Pölkki, Tarja; Kyngäs, Helvi; Hernández-Marrero, Pablo

**Background:** Palliative care exists in diverse healthcare settings. Nurses play a crucial role in its provision. Different levels of palliative care provision and education have been recognized in the literature. Therefore, nurses need a set of various competencies to provide high-quality palliative care.

**Aims:** To systematically synthesize the empirical evidence of (1) nursing competencies needed in palliative care and (2) whether these competencies differ across the level of palliative care.

**Design:** Systematic integrative review with thematic synthesis. Prospero: CRD42018114869. DATA SOURCE SCINAHL, PubMed, Academic Search Premier, Scopus and Medica databases. Studies on nursing competencies linked to palliative care reported in English, Swedish, Finnish, Spanish, Portuguese or German were considered. Search terms: 'palliative care or hospice care or end-of-life care', 'competency or professional competence or skills' and 'nursing'. Articles were independently screened and reviewed by two researchers. Quality appraisal was conducted following Hawker's criteria.

**Results:** A total of 7454 articles were retrieved, 21 articles were included in the analysis. Six diverse nursing competencies dimensions, namely leadership, communication, collaboration, clinical, ethico-legal and psycho-social and spiritual were identified. The reports rarely defined the level of palliative care and covered a wide array of healthcare settings.

**Conclusion:** Nurses need a wide range of competencies to provide quality palliative care. Few studies focused on which competencies are relevant to a specific level of palliative care. Further research is needed to systematize the nursing competencies and define which nursing competencies are central for different levels of palliative care to enhance palliative care development, education and practice.

### **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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