Royal United Hospitals Bath
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End of Life Care
Current Awareness Bulletin

March 2019

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The Daffodil Standards

GP surgeries will now be able to display a 'daffodil mark' as a sign of commitment to improving end-of-life care, as part of a new partnership between the Royal College of GPs and the terminal illness charity Marie Curie. The mark, synonymous with the charity, is based on a new set of criteria called the Daffodil Standards – a set of eight quality improvement statements designed to support primary care teams in delivering care to patients living with an advanced, serious illness or at the end of their lives, and their loved ones.

Journal Articles

Title: The Role of Primary Care Physicians in Providing End-of-Life Care.

Citation: American Journal of Hospice & Palliative Medicine; Mar 2019; vol. 36 (no. 3); p. 249-254

Author(s): Liu, Jan Tse; Kovar-Gough, Iris; Farabi, Nabila; Animikwam, Frank; Weers, Sarah Beth; Phillips, Julie

Objective: Primary care physicians (PCPs) frequently have long-term relationships with patients as well as their families. As such they are well positioned to care for their patients at the end of their lives. As the number of patients in need of end-of-life care continues to grow, it is critical to understand how PCPs can fulfill that need. The purpose of our study is to perform a narrative review of the literature and develop a theoretical model delineating the overarching roles played by PCPs in caring for patients at the end of life.

Methods: For this narrative review, the authors searched Medline (PubMed), Embase, Cochrane Library, and Scopus up to March 22, 2017. Articles were not limited by geography.

Results: Review of existing literature generally supports 4 broad categories as the primary roles for PCP involvement in end of life: pain and symptom management; information management, including transmitting and clarifying information, setting care priorities, and assisting patients with treatment decisions; coordinating care and collaborating with other providers; and addressing patients' social, emotional, and spiritual needs.

Conclusions: Based on the results of this review, PCPs provide a wide range of services to patients at the end of life. Promoting the provision of the full scope of services by PCPs will help ensure improved continuity of care while providing the highest quality of care for patients, both in the United States and around the world.

Title: Advanced care planning 5 years on: An observational study of multi-centred service development for children with life-limiting conditions.

Citation: Child: Care, Health & Development; Mar 2019; vol. 45 (no. 2); p. 234-240

Author(s): Martin, Alice E.; Beringer, Antonia J.

Objective: The purpose of this study was to compare how planning has developed over the 5 years across a range of children's health care services in a single U.K. city. **Background:** Advanced planning for end of life care (EOLC) is an essential component of care for children with life-limiting and life-threatening (LLLT) conditions. We report the findings of a follow-up study (R2) completed 5 years after the initial review (R1). Documented advanced care planning (ACP) was measured against published children's palliative care standards.

Method: We used a manual retrospective review of health care records, using focused data collection. Inclusion criteria were children who died before the age of 18 years, as a consequence of an LLLT condition, over an 18-month period and had lived locally to a regional children's hospital.

Results: The first review (R1) included 48 patients with 114 health care records: median age at death 0 years (range 0 to 18 years). The follow-up review (R2) included 47 patients, with 80 health care records: median age at death 2 years (range 0 to 17 years). The proportion of records containing evidence of a prognostic discussion had risen from 73% (R1) to 91% (R2), $p < 0.005$. The proportion of health care records with ACP was consistent between R1 and R2 (75% and 72%, respectively). An ACP tool was found to be in regular use in R2 compared with no examples in R1. The acute hospital trust plans were more detailed in R2 than R1. The proportion of cases where preferred location of death matched actual location was stable, around half.

Conclusions: EOLC conversations increased over the 5 years studied. In the acute hospital trust, there is evidence of a better quality ACP although quantity is stable: enabled by the implementation of an ACP tool and education programme. Challenges remain in engaging children and young people in advanced planning.

Title: "Remembrance": A Self-Care Tool for Clinicians.

Citation: Journal of Palliative Medicine; Mar 2019; vol. 22 (no. 3); p. 316-319

Author(s): Morris, Sue E.; Kearns, John P.; Moment, Amanda; Lee, Kathleen A.; deLima Thomas, Jane

Abstract: Despite increasing attention in the medical and nursing literature about the importance of self-care for clinicians and the prevention of burnout, coping with the deaths of patients is an often-neglected component of clinical training. In this article, we describe the development of "Remembrance," an interdisciplinary approach to acknowledge and process the deaths of patients on our inpatient palliative care service, paying particular attention to how patients and their families affect us as clinicians. We believe that such a practice is an important component of both quality end-of-life care and clinician self-care, which should be routinely taught and incorporated into clinical services. We provide a template that summarizes our approach, which can be easily adapted by other hospitals to use.

Title: Dying in hospital: what are the priorities for care?

Citation: British Journal of Hospital Medicine (17508460); Feb 2019; vol. 80 (no. 2); p. 66-67

Author(s): Kite, Suzanne

Abstract: The article discusses the five priorities for care of people dying in hospital. Specialist palliative care teams are said to be accessible to support ward teams in caring for dying people. Physicians have a role in enhancing the initiation and development of end-of-life care communication with people who they recognize may die soon. Fatigue and delirium are often felt at the very end of life that limits the capacity of the dying person to directly participate.

Title: Focus on the family: A case example of end-of-life care for an older LGBT veteran.

Citation: Clinical Gerontologist; Mar 2019; vol. 42 (no. 2); p. 204-211

Author(s): Hinrichs, Kate LM; Christie, Kysa M.

Abstract: The Department of Veterans Affairs (VA) is likely the largest provider of health care for LGBT persons in US. However, histories of homophobia, stigma, discrimination, and past military policies have all had a lasting impact on the health of LGBT veterans. Effects can be seen across healthcare needs, disparities, access, and utilization for or by LGBT veterans. A case from a VA hospice unit is used to illustrate some challenges and opportunities when providing end-of-life care for an older, lesbian veteran. This veteran had been cared for by her wife who was struggling to meet care needs at home. Over time, it became clear that the wife was emotionally and financially dependent on the veteran, and would be facing many psychosocial and financial challenges when the veteran died. However the wife was reticent to accept referrals for help or services due to past negative experiences with social service agencies related to her sexual orientation. The interdisciplinary team collaborated to care for the veteran's medical needs, and the wife's emotional and psychosocial needs, until after the veteran's death. This case highlights many of the unique needs and challenges that may arise in caring for LGBT veterans and their families at end-of-life.

Title: Undergraduate nursing students' knowledge about palliative care and attitudes towards end-of-life care: A three-cohort, cross-sectional survey.

Citation: Nurse Education Today; Mar 2019; vol. 74; p. 7-14

Author(s): Dimoula, Maria; Kotronoulas, Grigorios; Katsaragakis, Stylianos; Christou, Maria; Sgourou, Stavroula; Patiraki, Elisabeth

Objective: Ensuring adequate knowledge about palliative care and positive attitudes towards death and dying are crucial educational aspects when preparing undergraduate nursing students to respond effectively to the complexities of care for people affected by a progressive, life-limiting illness. In undergraduate nursing education in Greece, the level of students' attained knowledge and developed attitudes towards palliative and end-of-life care remain unknown. The aim of this study was to investigate undergraduate nursing students' knowledge about palliative care and attitudes towards death and end-of-life care, and explore demographic and academic factors as potential moderators of student knowledge and attitudes.

Methods: We conducted a descriptive, cross-sectional, questionnaire-based survey. We recruited 2nd, 3rd and 4th year undergraduate nursing students from the country's two University Faculties. Participants completed a demographic form, the Palliative Care Quiz for Nursing (PCQN), and the Frommelt Attitudes Towards Care of the Dying (FATCOD) questionnaire.

Results: The final sample was 529 students (response rate = 87.6%). Mean total PCQN scores revealed low levels of knowledge. Knowledge about pain/symptom management and psychosocial/spiritual care was insufficient. Mean total FATCOD scores indicated positive, liberal and supportive attitudes towards end-of-life care, with 60% of respondents keen to care for a dying person and their family. We noted less positive attitudes mainly in relation to student comfort with the care of a dying person and his/her imminent death. Academic parameters (year of study) and student demographic characteristics (older age) were the most significant moderators of both knowledge and attitudes. Greater knowledge about palliative care was a relatively weak, yet significant, predictor of more liberal attitudes towards care of the dying.

Conclusion: Our findings suggest that structured courses in palliative care can be a core part of undergraduate nursing education. Specific attention could be given to such areas patient-health professional communication, misconceptions and biases towards death and dying, and comfort in caring for the dying in order to prepare student nurses to psychologically deal with the sensitive and challenging process of death and dying.

Title: Nursing Care at the End of Life: Optimizing care of the family in the hospital setting.

Citation: Clinical Journal of Oncology Nursing; Feb 2019; vol. 23 (no. 1); p. 13-17

Author(s): Boyle, Deborah A.

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

Title: "Song of Life (SOL)" study protocol: a multicenter, randomized trial on the emotional, spiritual, and psychobiological effects of music therapy in palliative care.

Citation: BMC Palliative Care; Jan 2019; vol. 18 (no. 1)

Author(s): Warth, Marco; Koehler, Friederike; Weber, Martin; Bardenheuer, Hubert J.; Ditzen, Beate; Kessler, Jens

Objective: Although patients in palliative care commonly report high emotional and spiritual needs, effective psychosocial treatments based on high quality studies are rare. First research provides evidence for benefits of psychosocial interventions in advanced cancer care. To specifically address end-of-life care requirements, life review techniques and creative-arts based therapies offer a promising potential. Therefore, the present study protocol presents a randomized controlled trial on the effectiveness of a newly developed music therapy technique that is based on a biographically meaningful song ("Song of Life"; SOL).

Methods: In a design with two parallel arms, 104 patients at two palliative care units will be randomly assigned to three sessions of either SOL (experimental group) or relaxation exercises (control group). Improvements in the psychological domain of quality of life will be the primary endpoint, while secondary outcomes encompass spiritual well-being, ego-integrity, overall quality of life, and distress. Additionally, caregivers will be asked to provide feedback about the treatment. Assessment of biopsychological stress markers and qualitative analysis of perceived strengths and weaknesses will complement data collection.

Discussion: Based on the results of a previous pilot study, we dedicated considerable efforts to optimizing the intervention and selecting appropriate outcomes for the present trial. We are confident to have designed a methodologically rigorous study that will contribute to the evidence-base and help to develop the potential of psychosocial interventions in palliative care.

Title: The extended palliative phase of dementia – An integrative literature review.

Citation: Dementia (14713012); Jan 2019; vol. 18 (no. 1); p. 108-134

Author(s): Hanson, Elizabeth; Hellström, Amanda; Sandvide, Åsa; Jackson, Graham A.; MacRae, Rhoda; Waugh, Anna; Abreu, Wilson; Tolson, Debbie

Abstract: This article presents an integrative literature review of the experience of dementia care associated with the extended palliative phase of dementia. The aim was to highlight how dementia is defined in the literature and describe what is known about the symptomatology and management of advanced dementia regarding the needs and preferences of the person with dementia and their family carer/s. There was no consistent definition of advanced dementia. The extended palliative phase was generally synonymous with end-of-life care. Advanced care planning is purported to enable professionals to work together with people with dementia and their families. A lack of understanding of palliative care among frontline practitioners was related to a dearth of educational opportunities in advanced dementia care. There are few robust concepts and theories that embrace living the best life possible during the later stages of dementia. These findings informed our subsequent work around the concept, 'Dementia Palliare'.

Title: Understanding the factors associated with patients with dementia achieving their preferred place of death: a retrospective cohort study.

Citation: Age and ageing; Feb 2019

Author(s): Wiggins, Natasha; Droney, Joanne; Mohammed, Kabir; Riley, Julia; Sleeman, Katherine E

Objective: Dying in one's preferred place is a quality marker for end-of-life care. Little is known about preferred place of death, or the factors associated with achieving this, for people with dementia. This study aims to understand preferences for place of death among people with dementia; to identify factors associated with achieving these preferences.

Population: Adults with a diagnosis of dementia who died between December 2015 and March 2017 and who were registered on Coordinate My Care, an Electronic Palliative Care Coordination System.

Design: Retrospective cohort study.

Analysis: Multivariable logistic regression investigated factors associated with achieving preferred place of death.

Results: We identified 1,047 people who died with dementia; information on preferred and actual place of death was available for 803. Preferred place of death was most commonly care home (58.8%, n = 472) or home (39.0%, n = 313). Overall 83.7% (n = 672) died in their preferred place. Dying in the preferred place was more likely for those most functionally impaired (OR 1.82 95% CI 1.06-3.13), and with a ceiling of treatment of 'symptomatic relief only' (OR 2.65, 95% CI 1.37-5.14). It was less likely for people with a primary diagnosis of cancer (OR 0.52, 95% CI 0.28-0.97), those who were 'for' cardio-pulmonary resuscitation (OR 0.32, 95% CI 0.16-0.62) and those whose record was created longer before death (51-250 days (ref <50 days) OR 0.60, 95% CI 0.38-0.94).

Conclusions: Most people with dementia want to die in a care home or at home. Achieving this is more likely where goals of treatment are symptomatic relief only, indicating the importance of advance care planning.

Title: Social Work Practice with Medical Assistance in Dying: A Case Study.

Citation: Health & social work; Feb 2019

Author(s): Antifaeff, Kelsey

Abstract: Medical assistance in dying (MAiD) recently became legal in Canada, and social workers have an integral role providing psychosocial care to those considering this end-of-life care option. Research has found that most requests for assisted dying have a psychosocial dimension. Social workers are uniquely equipped to understand the personal and contextual factors informing the choice for MAiD and offer supports. A case example highlights practice opportunities for social workers throughout the MAiD process.

Title: Limitation of Life-Sustaining Care in the Critically Ill: A Systematic Review of the Literature.

Citation: Journal of hospital medicine; Feb 2019; vol. 14; p. E1

Author(s): Mcpherson, Katie; Carlos, W Graham; Emmett, Thomas W; Slaven, James E; Torke, Alexia M

Abstract: When life-sustaining treatments (LST) are no longer effective or consistent with patient preferences, limitations may be set so that LSTs are withdrawn or withheld from the patient. Many studies have examined the frequency of limitations of LST in intensive care unit (ICU) settings in the past 30 years. This systematic review describes variation and patient characteristics associated with limitations of LST in critically ill patients in all types of ICUs in the United States. A comprehensive search of the literature was performed by a medical librarian between December 2014 and April 2017. A total of 1,882 unique titles and abstracts were reviewed, 113 were selected for article review, and 36 studies were fully reviewed. Patient factors associated with an increased likelihood of limiting LST included white race, older age, female sex, poor preadmission functional status, multiple comorbidities, and worse illness severity score. Based on several large, multicenter studies, there was a trend toward a higher frequency of limitation of LST over time. However, there is large variability between ICUs in the proportion of patients with limitations and on the proportion of deaths preceded by a limitation. Increases in the frequency of limitations of LST over time suggests changing attitudes about aggressive end-of-life-care. Limitations are more common for patients with worse premorbid health and greater ICU illness severity. While some differences in the frequency of limitations of LST may be explained by personal factors such as race, there is unexplained wide variability between units.

Title: What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis.

Citation: Palliative medicine; Feb 2019; p. 269216319828650

Author(s): Stow, Daniel; Spiers, Gemma; Matthews, Fiona E; Hanratty, Barbara

Objective: The number of older people living and dying with frailty is rising, but our understanding of their end-of-life care needs is limited. This study aims to synthesise evidence on the end-of-life care needs of people with frailty.

Design: Systematic review of literature and narrative synthesis.

Data sources: Fourteen electronic databases (CINAHL, Cochrane, Embase, EThOS, Google, Medline, NDLTD, NHS Evidence, NICE, Open grey, Psychinfo, SCIE, SCOPUS and Web of Science) searched from inception to October 2017 and supplemented with bibliographic screening and reference chaining. Studies were included if they used an explicit definition or measure of frailty. Quality was assessed using the National Institute for Health tool for observational studies.

Results: A total of 4998 articles were retrieved. Twenty met the inclusion criteria, providing evidence from 92,448 individuals (18,698 with frailty) across seven countries. Thirteen different measures or definitions of frailty were used. People with frailty experience pain and emotional distress at levels similar to people with cancer and also report a range of physical and psychosocial needs, including weakness and anxiety. Functional support needs were high and were highest where people with frailty were cognitively impaired. Individuals with frailty often expressed a preference for reduced intervention, but these preferences were not always observed at critical phases of care.

Conclusion: People with frailty have varied physical and psychosocial needs at the end of life that may benefit from palliative care. Frailty services should be tailored to patient and family needs and preferences at the end of life.

Title: Advance Care Planning in Community: An Evaluation of a Pilot 2-Session, Nurse-Led Workshop.

Citation: The American journal of hospice & palliative care; Feb 2019; vol. 36 (no. 2); p. 143-146

Author(s): Rabow, Michael W; McGowan, Marilyn; Small, Rebecca; Keyssar, Redwing; Rugo, Hope S

Objective: Engaging patients in advance care planning (ACP) is challenging but crucial to improving the quality of end-of-life care. Group visits and multiple patient-clinician interactions may promote advance directive (AD) completion. This study aims to facilitate ACP discussions with patients and caregivers and the creation of notarized AD's at a comprehensive cancer center.

Design: Two-session, nurse-led ACP workshops for patients and their family caregivers.

Setting/participants: The workshop was offered to patients with cancer at a comprehensive cancer center and their family caregivers.

Measurements: Validated 4-question ACP engagement survey, creation of a notarized AD by end of the workshop, and semistructured interviews.

Results: Thirty-five patients participated in 10 workshops held March 2017 to February 2018. Median age was 52. Of 35, 24 (68.5%) patients completed pre- and postworkshop evaluation surveys. Mean preworkshop ACP readiness was 3.64 of 5; postworkshop readiness increased to 4.26 of 5 (P = .001). Of 26, 17 (65.4%) of the patients who attended both workshop sessions had a new notarized AD scanned into the electronic medical record at the completion of the workshop series. Three family caregivers completed and had their own ADs notarized. Patient and family member response was overwhelmingly positive, with participants citing opportunities for group discussion and inclusion of family caregivers as important.

Conclusions: The ACP workshop was well received by participants and increased ACP readiness, discussion, and completion. Attendance at the workshop was low and barriers to attending workshops must be explored.

Title: Compassion Fatigue in Palliative Care Nursing: A Concept Analysis.

Citation: Journal of hospice and palliative nursing: JHPN: the official journal of the Hospice and Palliative Nurses Association; Feb 2019; vol. 21 (no. 1); p. 21-28

Author(s): Cross, Lisa A

Abstract: The purpose of this review was to define compassion fatigue in the context of palliative care nursing. Compassion fatigue was first introduced as a description for nursing burnout; however, it was not fully described. An initial concept analysis within nursing placed it in terms of a psychological model for secondary traumatic stress disorder, with continual revisions of this application. Palliative care nurses are routinely exposed to pain, trauma, and the suffering they witness by nature of ongoing symptom management and end-of-life care delivery; however, the focus of care is on healthy end-of-life management rather than preservation of life. The literature was reviewed to provide clarification of compassion fatigue for palliative care nurses to assist in future identification and direction in the profession. CINAHL, EBSCO, Journals@Ovid, MEDLINE, PsycINFO, PubMed, and ScienceDirect databases were queried for peer-reviewed literature, and dictionaries were examined for subject-specific definitions. The method that was used was a concept analysis in the tradition of Walker and Avant. A concept definition was proposed for the discipline of palliative care nursing. Identification of compassion fatigue for this profession helps facilitate the recognition of symptoms for a group that deals with patient suffering on a regular basis.

Title: Is an opt-out system likely to increase organ donation?

Citation: BMJ: British Medical Journal (Online); Mar 2019; vol. 364

Author(s): English, Veronica; Johnson, Emma; Sadler, Blair L; Sadler, Alfred M, Jr

Abstract: As England’s presumed consent law for 2020 clears parliament, Veronica English and Emma Johnson say that evidence from Wales and other countries shows that it could increase transplantation rates. But Blair L Sadler and Alfred M Sadler Jr consider such legal changes a distraction lacking strong evidence: they say that public education and trained staff would have a proven impact

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Title: A narrative review of family members' experience of organ donation request after brain death in the critical care setting.

Citation: Intensive care medicine; Mar 2019

Author(s): Kentish-Barnes, Nancy; Siminoff, L A; Walker, W; Urbanski, M; Charpentier, J; Thuong, M; Sarti, A; Shemie, S D; Azoulay, E

Introduction: Family members of critically ill patients suffer from high levels of anxiety and depression in the ICU, and are at risk of developing post-ICU syndrome following ICU discharge. In the case of brain death, and potential organ donation, the family is at the center of the decision process: within a limited time frame, the family will be informed that the patient is brain-dead and will be approached about potential organ donation.

Materials and methods: Family experience with organ donation has been the topic of several research papers allowing one to gain knowledge about family members' experience of organ donation, emphasizing specific needs, adequate support, and pointing out gaps in current delivery of family-centered care. In this narrative review, experts, clinicians, and researchers present the various legal systems regarding family implication in organ donation decisions; describe factors that influence the decision-making process; highlight family perspectives of care and respect for potential donors in the ICU environment; describe the impact of organ donation discussions and decisions on post-ICU syndrome; and suggest communication skills and support to be developed in the future. A research agenda for the next decade is also encouraged.

Conclusion: Overall, challenges remain and concern all persons involved in the process, ICU doctors and nurses, the organ procurement organization, family members, and, in some cases, the patients themselves. Looking at the big picture will provide opportunities for further improvements.

Title: Ensuring appropriate assessment of deemed consent in Wales.

Citation: Journal of medical ethics; Mar 2019; vol. 45 (no. 3); p. 210

Author(s): Parsons, Jordan Alexander

Abstract: Albertsen, in his recent article, offers an assessment of the recently introduced opt-out system for organ donation in Wales. However, he focuses on whether concerns raised prior to the enactment of the new system have been realised, rather than any positive impact on the number of actual donors. This side-lining of the main issue has resulted in a strangely positive portrayal of a system that has not yet yielded the results hoped for. Further, his failure to examine data over a number of years-instead opting for just 2, fails to even provide a fair assessment of the concerns he acknowledges.

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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