

# End of Life Care Current Awareness Bulletin

June 2019

A number of other bulletins are also available – please contact the Academy Library for further details

If you would like to receive these bulletins on a regular basis please contact the library.

If you would like any of the full references we will source them for you.

Contact us: **Academy Library 824897/98**

Email: [ruh-tr.library@nhs.net](mailto:ruh-tr.library@nhs.net)

**TITLE: The effectiveness of end-of-life care simulation in undergraduate nursing education: A randomized controlled trial**

**Citation:** Nurse Education Today; May 2019; vol. 76 ; p. 1

**Author(s):** Tamaki, Tomoko; Inumaru, Anri; Yokoi, Yumie; Fujii, Makoto; Tomita, Mayu; Inoue, Yuta; Kido, Michiko; Ohno, Yuko; Tsujikawa, Mayumi

**Background:** Nursing students have limited opportunities to experience end-of-life care, so it is difficult for them to learn how to deliver it empirically. The use of simulations with standardized patients may be a way to provide realistic experience of end-of-life care for nursing students.

**Objectives:** The aim of this study was to evaluate the effectiveness of end-of-life care simulations with standardized patients in improving the knowledge, skill performance and self-confidence of undergraduate nursing students.

**Design:** Randomized controlled study. Setting: Japanese university nursing school. Participants: Thirty-eight students in the third year of the Bachelor's degree in nursing (simulation group = 20, control group = 18).

**Methods:** After randomization to a simulation or control group, participants in the simulation group participated in an end-of-life care simulation with standardized patients. The primary outcome of a change in the knowledge score was assessed using a knowledge questionnaire, skill performance by completing Objective Structured Clinical Evaluations, and self-confidence related to end-of-life care by self-reported questionnaires.

**Results:** The simulation group improved significantly in knowledge, skill performance in physical assessment and psychological care, and self-confidence related to end-of-life care. The results of the two-way analysis of variance showed a significant interaction between groups and time ( $p = 0.000$ ). Analysis of the simple main effect showed a significant difference ( $p = 0.000$ ) between groups after the end-of-life care simulation and a significant difference ( $p = 0.000$ ) over time in the simulation group. There were large effects on knowledge improvement ( $\eta^2 = 0.372$ ), physical assessment ( $\eta^2 = 0.619$ ), psychological care skill performance ( $\eta^2 = 0.588$ ), and self-confidence in both physical assessment ( $\eta^2 = 0.410$ ) and psychological care ( $\eta^2 = 0.722$ ).

**Conclusions:** End-of-life care simulation with standardized patients would be an effective strategy to train nursing students, who have limited opportunities to experience end-of-life care.

---

**TITLE: What role do Death Doulas play in end-of-life care? A systematic review**

**Citation:** Health & Social Care in the Community; May 2019; vol. 27 (no. 3); p. e82

**Author(s):** Rawlings, Deb; Tieman, Jennifer; Lauren Miller-Lewis; Swetenham, Kate

**Abstract:**

Current health and social care systems do not always meet the needs of the dying in our communities. As a result, patients and families are choosing to place their trust in those who can advocate for them or fill the gaps in care. Birth Doulas have been working with women during pregnancy and after birth for many years, and we are now seeing a new role, that of a Death Doula emerging in the end-of-life care space. How Death Doulas work within health and social care systems is not understood and we conducted a systematic review to explore the published literature to explore the role and potential implications for models of care delivery. Following the PRISMA recommendations, we searched the literature in January

2018 via bibliographic databases and the grey literature without search date parameters to capture all published literature. We looked for articles that describe the role/work of a death doula or a death midwife in the context of end-of-life care, or death and dying. Our search retrieved 162 unique records of which five papers were included. We analysed the papers in relation to relationship to health service, funding source, number and demand for services, training, licensing and ongoing support, and tasks undertaken. Death Doulas are working with people at the end of life in varied roles that are still little understood, and can be described as similar to that of "an eldest daughter" or to a role that has similarities to specialist palliative care nurses. Death doulas may represent a new direction for personalised care directly controlled by the dying person, an adjunct to existing services, or an unregulated form of care provision without governing oversight.

---

**TITLE: Nurses' perceptions of intensive care unit palliative care at end of life**

**Citation:** Nursing in Critical Care; May 2019; vol. 24 (no. 3); p. 141

**Author(s):** Freda DeKeyser Ganz; Sapir, Batel

**Background:** Significant barriers can block the provision of palliative care at the end of life in the intensive care unit (ICU). However, the relationship between perceptions of ICU quality palliative care and barriers to palliative care at the end of life is not well documented.

**Aims and objectives:** To describe ICU nurses' perceptions of quality palliative end-of-life care, barrier intensity and frequency to palliative care and their association with one another.

**Design:** This was a descriptive, correlational, cross-sectional design. Methods A convenience sample of 126 ICU nurses from two hospitals in Israel was recruited for the study. Participants completed three pencil-and-paper questionnaires (a personal characteristics questionnaire, the Quality of Palliative Care in the ICU and a revised Survey of Oncology Nurses' Perceptions of End-of-Life Care). Respondents were recruited during staff meetings or while on duty in the ICU. Ethical approval was obtained for the study from participating hospitals. Results The item mean score of the quality of palliative end-of-life care was 7.5/10 (SD = 1.23). The item mean barrier intensity and frequency scores were 3.05/5 (SD = 0.76) and 3.30/5 (SD = 0.61), respectively. A correlation of  $r = 0.46$ ,  $p < 0.001$  was found between barrier frequency and intensity and  $r = -0.19$ ,  $p = 0.04$  between barrier frequency and quality palliative end-of-life care. Conclusions ICU nurses perceived the quality of palliative care at the end of life as moderate despite reports of moderate barrier levels. The frequency of barriers was weakly associated with quality palliative end-of-life care. However, barrier intensity did not correlate with quality palliative end-of-life care at a statistically significant level. Further research that investigates other factors associated with quality ICU palliative care is recommended. Relevance to clinical practice Barriers to palliative care are still common in the ICU. Increased training and education are recommended to decrease barriers and improve the quality of ICU palliative care.

---

**TITLE: Emergency Nurses' Department Design Recommendations for Improved End-of-Life Care**

**Citation:** Journal of Emergency Nursing; May 2019; vol. 45 (no. 3); p. 286

**Author(s):**

**Introduction:** Although death is common in emergency departments, there is limited research regarding ED design as an obstacle to end-of-life care. This study identifies

emergency nurses' recommendations regarding ways designs have negative or positive impact on care for dying patients and their families.

**Methods:** A 25-item questionnaire was sent to a national random sample of 500 emergency nurses. Inclusion criteria were nurses who could read English, worked in emergency departments, and had cared for at least 1 patient at the end of life (EOL). Responses were individually reviewed and coded.

**Results:** Major obstacles included (1) issues related to limited space, (2) poor department layout and design, and (3) lack of privacy. Despite emergency departments being a challenging place to provide EOL care, positive ED design characteristics had impact on EOL care.

**Discussion:** Emergency nurses understand the need for family presence during resuscitation, for secure body stowage areas, and for more resuscitation rooms so that families have time to grieve before being removed because of the immediate needs of a second trauma patient. Nurses can evaluate existing facilities to identify areas in which potential change and remodeling could improve care, increase patient privacy, or further utilize space. Understanding ED design's impact on EOL care is crucial. Modifications to ED layout and design may be challenging; however, improvements to space, layout, and privacy need to be considered when planning new emergency departments or remodeling existing departments. Further research is required to determine the impact of ED design on EOL care.

---

**TITLE: Patient Dignity: Exploring oncology nurses' perceptions during end-of-life care.**

**Citation:** Clinical Journal of Oncology Nursing; Jun 2019; vol. 23 (no. 3)

**Author(s):** Crump, Barbara

**Background:** Research on nurses' perceptions of dignity is limited, with much work instead focusing on patients' experiences. Maintaining the dignity of patients is considered to be an important element of nursing care; however, it is often diminished by the acts and omissions of healthcare providers.

**Objectives:** The purposes of this study were to understand oncology nurses' perceptions of care that supports patients' dignity during end-of-life hospitalization and to propose a theoretical foundation consistent with these perceptions as a guide to practice.

**Methods:** A qualitative study using grounded theory was employed. Semistructured interviews with 11 experienced female oncology nurses generated insights into their perceptions of dignity in caring for terminally ill patients. Data were analyzed using the constant comparative method until data saturation was reached.

**Findings:** This study revealed an emerging model for dignity care that uses communication, support, and facilitation in the education of nurses during end-of-life care. The proposed model could enhance the facilitation of nursing education and aid in the design of nursing course curricula and practical experiences that may improve nurses' ability to provide care supporting dignity.

---

**TITLE: Improving Knowledge, Comfort, and Confidence of Nurses Providing End-of-Life Care in the Hospital Setting Through Use of the CARES Tools.**

**Citation:** Journal of Hospice & Palliative Nursing; Jun 2019; vol. 21 (no. 3); p. 200-206

**Author(s):** Stacy, Alison; Magdic, Kathy; Rosenzweig, Margaret; Freeman, Bonnie; Verosky, Denise

**Abstract:** Although most individuals prefer to die at home, approximately 60% of Americans die in the hospital setting. Nurses are inadequately prepared to provide end-of-life (EOL) care because of cure-focused education. Friends and family of dying patients report poor quality of death largely as a result of inadequate communication from health care professionals about the dying process. The purpose of this project was to improve nursing knowledge and comfort related to EOL care through use of the CARES tool and to improve the EOL experience of families of dying patients in the hospital setting through use of Final Journey. These acronym organized tools were developed based upon the common symptom management needs of the dying including Comfort, Airway, Restlessness and delirium, Emotional and spiritual support, and Self-care. The CARES tool for nurses improved nursing knowledge and comfort related to EOL care and common symptom management needs of the dying and also enhanced nurses' confidence in communicating about the dying process with friends and family. Final Journey, the friends and family version of the CARES tool, reinforced EOL information for friends and family, helped nurses answer difficult questions, and promoted and enhanced communication between health care professionals and friends and family of the dying.

---

**TITLE: A Pilot to Improve the Pain Medication Education Experience in Hospice.**

**Citation:** Journal of Hospice & Palliative Nursing; Jun 2019; vol. 21 (no. 3); p. 207-214

**Author(s):** Hay, Brittany B.; Marcelin, Jackie N.; Buck, Harleah G.

**Abstract:** Pain is one of the most feared symptoms experienced by patients at the end of life and one of the most difficult to manage. Families identify patient comfort as a priority in hospice, yet many have concerns regarding pain management and medication side effects. Timely, open, and ongoing communication with hospice teams can assuage concerns to improve care and outcomes relevant to pain medication use in hospice. A pilot project was undertaken to improve the patient and family/caregiver experience in end-of-life care relevant to communication regarding pain medication side effects and management within an inpatient hospice. A 5% improvement in the Consumer Assessment of Healthcare Providers & Services (CAHPS) Hospice quality indicator 18 (Understanding Side Effects) was sought. An evidence-based, interprofessional educational protocol and tool were designed and implemented to guide pertinent conversations. A 6.6% increase in favorable responses to the CAHPS Hospice target indicator occurred over the course of the pilot. Feedback from staff revealed positive responses to the tool with recommended expansion of use across hospice settings. Educational programming holds promise to support communication with hospice patients and families regarding pain medication side effects and management to improve experiential care quality as reflected in CAHPS Hospice surveys.

---

**TITLE: Interdisciplinary Communication: Documentation of Advance Care Planning and End-of-Life Care in Adolescents and Young Adults With Cancer.**

**Citation:** Journal of Hospice & Palliative Nursing; Jun 2019; vol. 21 (no. 3); p. 215-222

**Author(s):** Watson, Anne; Weaver, Meaghann; Jacobs, Shana; Lyon, Maureen E.

**Abstract:** Advance care planning is being increasingly recognized as a component of quality in end-of-life care, but standardized documentation in the electronic health record has not

yet been achieved, undermining interdisciplinary communication about care needs and limiting research opportunities. We examined the electronic health records of nine adolescent and young adults with cancer who died after participation in an advance care planning clinical trial (N = 30). In this secondary analysis of this subgroup, disease trajectory and end-of-life information were abstracted from the electronic health record, and treatment preferences from the original study were obtained. All deceased participants older than 18 years had a surrogate decision maker identified in the electronic health record, and all deceased participants had limitations placed on their care, varying from 1.5 hours up to 2 months before death. However, assessment of relations between treatment preferences and end-of-life care was difficult and revealed the presence of circumstances that advance care planning is designed to avoid, such as family conflict. Lack of an integrated health care record regarding advance care planning and end-of-life care makes both care coordination and examination of the association between planning and goal concordant care more difficult.

---

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

**Citation:** Age & Ageing; May 2019; vol. 48 (no. 3); p. 433-439

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

**Background:** 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.

**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: Hospice Care: Nurses' Experience and Perception of Older Adult Patients' Experience.**

**Citation:** Clinical Gerontologist; May 2019; vol. 42 (no. 3); p. 314-322

**Author(s):** Aeling, Jennifer Annette; Chavez, Ernest

**Objectives:** The current study sought to understand the differences hospice nurses perceived in caring for older adult patients who utilize hospice for longer and shorter periods, older adult patients' experience of hospice services, and if length of hospice stays influenced the patients' end-of-life experience.

**Methods:** Interpretative Phenomenological Analysis was used to extract themes and subthemes from 10 interviews conducted with hospice nursing staff.

**Results:** Four major themes were identified pertaining to nurses perspective on older adults' views of hospice and how length of hospice use impacts end-of-life care.

**Conclusion:** These themes suggest hospice nursing staff believe longer hospice stays are more positive and that older adults identify more positive aspects of hospice when using it for longer periods of time. Results suggest that nurses believe length of use directly impacts patient care and the experience of hospice services. Clinical Implications: Participating nurses reported that older adults have a lack of information on hospice services. It was suggested that more information is needed and that providing such education may lead to longer hospice stays.

---

**TITLE: The earlier the better: the role of palliative care consultation on aggressive end of life care, hospice utilization, and advance care planning documentation among gynecologic oncology patients.**

**Citation:** Supportive Care in Cancer; May 2019; vol. 27 (no. 5); p. 1927-1934

**Author(s):** Schneider, Mali K.; Karlekar, Mohana B.; Crispens, Marta A.; Prescott, Lauren S.; Brown, Alaina J.

**Purpose:** To evaluate the role of specialty palliative care consultation (PCC) on end of life care outcomes among terminally ill gynecologic oncology patients.

**Methods:** Retrospective chart review of currently deceased gynecologic oncology patients seen at a single, academic institution between October 2006 and October 2016. Clinical characteristics and outcomes were examined using descriptive statistics and logistic regression.

**Results:** Two hundred and four patients were eligible. Forty-one percent underwent at least one marker of aggressive care at the end of life. Most (53%) had a PCC prior to death, and of these most were inpatient (89%). Patients with a PCC had higher odds of hospice enrollment before death (OR 2.55,  $p = 0.016$ ) and higher odds of advance care planning documentation before death (OR 6.79,  $p < 0.001$ ). Among patients with an inpatient PCC, 44% underwent a marker of aggressive medical care at the end of life and 82% enrolled in hospice before death. Among patients with an outpatient PCC, 25% underwent a marker of aggressive medical care at the end of life and 92% enrolled in hospice before death. Patients with outpatient PCC were engaged in palliative care longer than patients with inpatient PCC (median 106 days vs. 33 days prior to death).

**Conclusions:** PCC increased hospice enrollment and advance care planning documentation. Patients with outpatient PCC had lower rates of aggressive medical care and higher rates of hospice enrollment when compared to inpatient PCC. Location of initial PCC plays an important role in end of life care outcomes.

**TITLE: Parents' acceptance and regret about end of life care for children who died due to malignancy.**

**Citation:** Supportive Care in Cancer; May 2019; vol. 27 (no. 5)

**Author(s):** Das, Kunal; Khanna, Tanvi; Arora, Anshika; Agrawal, Nitika

**Purpose:** To analyse the preference of end of life care place in paediatric oncology patients, and to understand the end of life care needs and regrets among the care givers.

**Method:** This was an observational qualitative study. Parents of in-curable paediatric malignancy patients who died during the years 2016-2018 were interviewed using a pre-formed open-ended questionnaire. Fears during the last phase of child's life, most disturbing symptoms, choice of end of life care plan, regret of care givers and reasons for such choices were noted and analysed.

**Result:** Twenty six families were interviewed. A median of 3 months of discordance was noted between declaration of in-curability and acceptance of the same by the family. During terminal months, pain (84.62%) was described as the most bothersome symptom followed by respiratory distress (73.08%). Eighteen families (69%) opted for home-based terminal care, 8 (31%) for hospital-based terminal care. Regret of choice was noted in 62.5% families of the hospital-based care group (separation from home environment being the main reason) and 38.89% of the home-based care group (lack of access to health care personnel and pain medication being the main reasons).

**Conclusion:** Home-based care is the preferred option for end of life care by the care givers. Lack of community-based terminal care support system and availability of analgesics are the main areas to work on in India.

---

**TITLE: End-of-life care research on people with intellectual disabilities: Challenges for proactive inclusion in an Irish context.**

**Citation:** British Journal of Learning Disabilities; Jun 2019; vol. 47 (no. 2); p. 70-76

**Author(s):** Cithambaram, Kumaresan; Duffy, Mel; Courtney, Eileen

**Accessible Summary:** People with intellectual disabilities are living longer than ever before. Although people with intellectual disabilities are living longer, they still suffer from many illnesses. This may reduce their lifespan, and they may die earlier than other people and therefore require good end-of-life care whatever age they die. Views and opinions of people with intellectual disabilities are important in determining what is good care at the end of life. Ethical and practical guidelines in relation to recruitment, obtaining consent, and having conversation around sensitive issues are clearly discussed in this paper.

**Background:** In recent times, people with intellectual disabilities are increasingly included in research studies; however, their participation in sensitive research such as palliative and end-of-life care is less frequent. The reasons for not including people with intellectual disabilities in these kinds of research studies are issues in relation to obtaining consent, difficulty of recruiting, and engaging and collecting relevant information. This paper aimed to provide insight into how people with intellectual disabilities could be proactively included in research which is sensitive to their unique needs.

**Method:** This study included 13 people with mild and moderate intellectual disabilities and explored their end-of-life care needs from their perspectives. After obtaining appropriate ethical approval, the research process was commenced. Applying the constructive grounded theory approach, data were collected and analysed by using the constant comparative



method. A story from the book *Am I Going to Die* was used to enhance the understanding of the concepts of death and dying while collecting data.

**Findings:** Participants with intellectual disabilities were recruited by establishing a close relationship with service providers. Capacity to consent and informed consent were fostered by carefully explaining the research process through easy-to-read information, and the data collection process was successfully completed by having a person-centred approach.

**Conclusion:** People with intellectual disabilities can be successfully included in research. This is possible when their diverse needs are carefully considered, and appropriately developed protocols which meet their needs in relation to their capacities and abilities are utilised. This approach requires a flexible and inclusive research process.

---

**TITLE: Disparities in Inpatient Intensity of End-of-Life Care for Complex Chronic Conditions.**

**Citation:** *Pediatrics*; May 2019; vol. 143 (no. 5); p. 1-10

**Author(s):** Johnston, Emily E.; Bogetz, Jori; Saynina, Olga; Chamberlain, Lisa J.; Bhatia, Smita; Sanders, Lee

**Background:** Children with complex chronic conditions (CCCs) require a disproportionate share of health care services and have high mortality rates, but little is known about their end-of-life care.

**Methods:** We performed a retrospective population-based analysis using a California State administrative database of children aged 1 to 21 years with a CCC who died of disease-related causes between 2000 and 2013. Rates of and sociodemographic and clinical factors associated with previously defined inpatient end-of-life intensity indicators were determined. The intensity indicators included the following: (1) hospital death, (2) receipt of a medically intense intervention within 30 days of death (ICU admission, cardiopulmonary resuscitation, hemodialysis, and/or intubation), and (3) having  $\geq 2$  intensity markers (including hospital death).

**Results:** There were 8654 children in the study population with a mean death age of 11.8 years (SD 6.8). The 3 most common CCC categories were neuromuscular (47%), malignancy (43%), and cardiovascular (42%). Sixty-six percent of the children died in the hospital, 36% had a medically intense intervention in the last 30 days of life, and 35% had  $\geq 2$  intensity markers. Living in a low-income neighborhood was associated with increased odds of hospital death, a medically intense intervention, and  $\geq 2$  intensity markers. Hispanic and "other" race and/or ethnicity were associated with hospital death and  $\geq 2$  intensity markers. Age 15 to 21 years was associated with hospital death, a medically intense intervention, and  $\geq 2$  intensity markers.

**Conclusions:** Sociodemographic disparities in the intensity of end-of-life care for children with CCCs raise concerns about whether all children are receiving high-quality and goal-concordant end-of-life care.

---

**TITLE: Compassionate leadership in palliative and end-of-life care: a focus group study.**

**Citation:** *Leadership in health services (Bradford, England)*; May 2019; vol. 32 (no. 2); p. 264-279

**Author(s):** Hewison, Alistair; Sawbridge, Yvonne; Tooley, Laura

**Purpose:** The purpose of this study was to explore compassionate leadership with those involved in leading system-wide end-of-life care. Its purpose was to: define compassionate leadership in the context of palliative and end-of-life care; collect accounts of compassionate leadership activity from key stakeholders in end-of-life and palliative care; and identify examples of compassionate leadership in practice.

**Design/Methodology/Approach:** Four focus groups involving staff from a range of healthcare organisations including hospitals, hospices and community teams were conducted to access the accounts of staff leading palliative and end-of-life care. The data were analysed thematically.

**Findings:** The themes that emerged from the data included: the importance of leadership as role modelling and nurturing; how stories were used to explain approaches to leading end-of-life care; the nature of leadership as challenging existing practice; and a requirement for leaders to manage boundaries effectively. Rich and detailed examples of leadership in action were shared.

**Research Limitations/Implications:** The findings indicate that a relational approach to leadership was enacted in a range of palliative and end-of-life care settings.

**Practical Implications:** Context-specific action learning may be a means of further developing compassionate leadership capability in palliative and end-of-life care and more widely in healthcare settings.

**Originality/Value:** This paper presents data indicating how compassionate leadership, as a form of activity, is envisaged and enacted by staff in healthcare.

---

**TITLE: Healthcare Providers' Attitudes, Knowledge, and Practice Behaviors for Educating Patients About Advance Directives: A National Survey.**

**Citation:** The American journal of hospice & palliative care; May 2019; vol. 36 (no. 5); p. 387-395

**Author(s):** Nedjat-Haiem, Frances R; Cadet, Tamara J; Amatya, Anup; Mishra, Shiraz I

**Background:** Advance care planning for end-of-life care emerged in the mid-1970's to address the need for tools, such as the advance directive (AD) legal document, to guide medical decision-making among seriously ill patients, their families, and healthcare providers.

**Objective:** Study aims examine providers' perspectives on AD education that involve examining (1) a range of attitudes about educating patients, (2) whether prior knowledge was associated with practice behaviors in educating patients, and (3) specific factors among healthcare providers such as characteristics of work setting, knowledge, attitudes, and behaviors that may influence AD education and documentation.

**Design:** To examine providers' views, we conducted a cross-sectional, online survey questionnaire of healthcare providers using social media outreach methods for recruitment.

**Methods:** This study used a cross-sectional survey design to examine the proposed aims. Healthcare providers, recruited through a broad approach using snowball methods, were invited to participate in an online survey. Logistic regression analyses were used to examine providers' views toward AD education.

**Results:** Of 520 participants, findings indicate that most healthcare providers said that they were knowledgeable about AD education. They also viewed providing education as beneficial to their practice. These findings suggest that having a positive attitude toward AD education and experiencing less organizational barriers indicate a higher likelihood that providers will educate patients regarding ADs.

**Conclusion:** Various disciplines are represented in this study, which indicates that attitudes and knowledge influence AD discussions. The importance of AD discussions initiated by healthcare providers is critical to providing optimal patient-centered care.

---

**TITLE: Do Health-Care Professionals Really Understand the Role of Occupational Therapy in Hospice Care?**

**Citation:** The American journal of hospice & palliative care; May 2019; vol. 36 (no. 5); p. 379-386

**Author(s):** Knecht-Sabres, Lisa Jean; Weppner, Ashley; Powers, Cassandra; Siesel, Brooke

**Background:** The distinct value of occupational therapy (OT) in end-of-life care is to facilitate quality of life for clients and their caregivers through engagement in occupations during the clients' remaining days. The purpose of this study was to explore health-care professionals' perceptions and knowledge regarding the role of OT in hospice care and to better understand why OT may be underutilized in this setting.

**Participants:** A total of 104 professionals working in hospice care from 31 different states participated in this study.

**Methods:** Electronic surveys were distributed to hospice agencies throughout the United States.

**Data Analysis:** Descriptive statistics was used to analyze quantitative data, and content analysis was used to identify patterns with qualitative data. Rigor was enhanced through peer-review, multiple coders, and triangulation.

**Results:** The results of this study revealed that OT's role in hospice care is misunderstood, and OT services are underutilized. Five themes were identified regarding the underutilization of OT services: (1) lack of reimbursement, (2) timing of referral, (3) knowledge of the role of OT, (4) refusal of services by family members, and (5) lack of OT presence in this setting.

**Conclusion:** This study revealed that health-care professionals do believe that OTs are vital members of the hospice care team. However, many recipients of hospice care are not receiving OT. More consistent referrals to OT may better ensure that the terminally ill are able to attain end-of-life goals and live their lives to the fullest, regardless of life expectancy.

---

**TITLE: Sitting with silence: hospital social work interventions for dying patients and their Families.**

**Citation:** Social work in health care; 2019; vol. 58 (no. 5); p. 444-458

**Author(s):** Moon, Felicity; Fraser, Lucinda; McDermott, Fiona

**Abstract:** The recent controversy around the hospital end of life care has highlighted the vulnerability of dying patients and their families. However, little is known about how social workers provide support and intervention around the end of life in the hospital. Eight hospital social workers provided qualitative descriptions of their clinical practice for adult patients and their families. Highlighting a theoretical orientation towards a person-in-environment approach, social workers develop unique interventions to contribute to multidisciplinary care. Findings emphasize the need to prepare social work students and clinicians for the reality of working with end of life issues.

**TITLE: End-of-Life Health Care Utilization Between Chronic Obstructive Pulmonary Disease and Lung Cancer Patients.**

**Citation:** Journal of pain and symptom management; May 2019; vol. 57 (no. 5); p. 933-943

**Author(s):** Kuo, Lou-Ching; Chen, Jin-Hua; Lee, Chih-Hsin; Tsai, Ching-Wen; Lin, Chia-Chin

**Context:** At the end of life, chronic obstructive pulmonary disease (COPD) and lung cancer (LC) patients exhibit similar symptoms; however, a large-scale study comparing end-of-life health care utilization between these two groups has not been conducted in East Asia.

**Objectives:** To explore and compare end-of-life resource use during the last six months before death between COPD and LC patients.

**Methods:** Using data from the Taiwan National Health Insurance Research Database, we conducted a nationwide retrospective cohort study in COPD (n = 8640) and LC (n = 3377) patients who died between 1997 and 2013.

**Results:** The COPD decedents were more likely to be admitted to intensive care units (57.59% vs 29.82%), to have longer intensive care unit stays (17.59 vs 9.93 days), and to undergo intensive procedures than the LC decedents during their last six months; they were less likely to receive inpatient (3.32% vs 18.24%) or home-based palliative care (0.84% vs 8.17%) and supportive procedures than the LC decedents during their last six months. The average total medical cost during the last six months was approximately 18.42% higher for the COPD decedents than for the LC decedents.

**Conclusion:** Higher intensive health care resource use, including intensive procedure use, at the end of life suggests a focus on prolonging life in COPD patients; it also indicates an unmet demand for palliative care in these patients. Avoiding potentially inappropriate care and improving end-of-life care quality by providing palliative care to COPD patients are necessary.

---

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

**Citation:** Journal of hospital medicine; May 2019; vol. 14 (no. 5); p. 303-310

**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: Disturbing and distressing: a mixed methods study on the psychological impact of end of life care on junior doctors.**

**Citation:** Irish journal of medical science; May 2019; vol. 188 (no. 2); p. 633-639

**Author(s):** Linane, Hannah; Connolly, Fergal; McVicker, Lyle; Beatty, Sharon; Mongan, Orla; Mannion, Eileen; Waldron, Dympna; Byrne, Dara

**Background:** The Irish Medical Council has identified gaps in knowledge and communications skills of new-entrant doctors in legal, ethical and practical aspects of end of life care.

**Aims:** To determine the frequency with which junior doctors deal with end of life care and patient death and to evaluate the impact this has on their psychological wellbeing.

**Design:** A questionnaire was distributed to junior doctors to determine the frequency with which the participants had managed a patient at end of life. An abbreviated Posttraumatic Stress Disorder Checklist-Civilian version was used to evaluate psychological distress. Critical incident technique interviews explored the challenges of caring for patients at end of life.

**Setting/Participants:** A total of 110 junior doctors in two teaching hospitals in Ireland completed the questionnaire: 39 (35.5%) interns and 71 (64.5%) senior house officers. In addition, 31 interviews were carried out with interns, senior house officers and registrars.

**Results:** The majority (81.8%) had pronounced a death with 39.4% of senior house officers doing so more than 10 times. Three quarters (75.5%) had discussed end of life with a patient's family. Of the 110 respondents that completed the posttraumatic stress disorder checklist, 11.8% screened positively for posttraumatic stress disorder. Challenges identified at interview included lack of knowledge and preparedness, difficulty communicating with family members, a lack of support and a feeling of failure.

**Conclusions:** Junior doctors are regularly carrying out tasks related to end of life care, resulting in high levels of psychological distress. Further training and a change in culture are required.

---

**TITLE: The role of specialist nurses for organ donation: A solution for maximising organ donation rates?**

**Citation:** Journal of Clinical Nursing; May 2019; vol. 28 (no. 9-10); p. 2020

**Author(s):** Tocher, Jennifer; Neades, Barbara; Smith, Graeme D; Kelly, Daniel

**Aims and objectives:** To explore the role that Donor Transplant Co-ordinators have played and the future potential of Specialist Nurses for Organ Donation (SN-ODs), within organ donation strategies in the UK and other countries.

**Background:** Organ donation and transplantation rates vary extensively around the world. However, there is a universal shortage of deceased donors, prompting different approaches to increase transplantation rates. Within the UK, the Clinical Lead for Organ Donation and Specialist Nurse in Organ Donation undertake a key role in the implementation of the Organ

Donation Strategy. The Human Transplantation (Wales) Act 2015 is a recent development which facilitates a deemed (presumed) consent approach to organ donation, the Specialist Nurse in Organ Donation undertakes a major role identifying the potential donor in this situation by confirming the deemed consent status of the donor and supporting bereaved relatives. UK governments in England and Scotland are currently seeking legislative changes to an opt-out system of organ donation, in line with the Wales change.

**Design:** This discursive paper explores the role from Donor Transplant Co-ordinator to Specialist Nurse in Organ Donation (SN-OD) within organ donation policy in different settings, but with a specific focus on the UK. The paper clarifies the current and future potential of nurses working with bereaved families when requesting authorisation for donation. Implications for nursing The current scope and future potential of Donor Transplant Co-ordinator and Specialist Nurse in Organ Donation roles need better recognition. Little empirical data exist about the key role that these nurses play in the organ donation process, especially in relation to gaining authorisation to proceed to donation.

**Conclusion:** There is a need to clarify the role of the Specialist Nurse in Organ Donation and their impact on improving rates of organ donation.

---

**TITLE: Donation Starts With a Decision: The Role of the Individual and Family in Organ Donation.**

**Citation:** Transplantation; May 2019; vol. 103 (no. 5); p. 864-865

**Author(s):** Gunderson, Susan

---

**TITLE: Understanding ambivalence toward organ donation and transplantation: An exploratory study of nursing students.**

**Citation:** Nurse education today; May 2019; vol. 76 ; p. 191-195

**Author(s):** Contiero, Paloma Peroni; Wilson, Donna M

**Background:** There is a continuing shortage of organs for transplantation purposes worldwide. Determining why this is a recurring problem is necessary as organ transplantation is a highly successful life saving measure. It is possible that ambivalence is key to this shortage.

**Objectives:** To explore the possible existence of ambivalence toward organ donation and transplantation among Canadian nursing students, and gaining insights into this ambivalence when present.

**Design:** An exploratory study using a structured questionnaire to explore the existence of ambivalence in relation to donating and receiving an organ for transplantation purposes.

**Methods:** A total of 170 undergraduate nursing students at a Canadian university participated in this study by completing a brief questionnaire distributed to all five classes of nursing students who were taking a mandatory research course during the 2017-18 university calendar year. The survey tool was designed to collect quantitative and qualitative data in relation to their ambivalence toward organ donation and transplantation.

**Results:** Nursing students are more willing to receive an organ than to donate. The willingness to donate or receive an organ was related to their personal beliefs and moral codes, religion, level of knowledge, and the existence of ambivalence.

**Conclusions:** This study reveals important insights into ambivalence about donating and receiving organs. The study found it was very easy to introduce ambivalence among nursing students, with this information highly relevant for student education and other applications.

---

**TITLE:** Is presumed consent an ethically acceptable way of obtaining organs for transplant?

**Citation:** Journal of the Intensive Care Society; May 2019; vol. 20 (no. 2); p. 92-97

**Author(s):** Prabhu, Pradeep Kumar

**Abstract:** The near-universal acceptance of cadaveric organ donation has been based on the provision of explicit consent by the donor while alive, either in the form of a formal opt-in or informal discussion of wishes with next of kin. Despite the success of transplantation programmes based on explicit consent, the ongoing imbalance between demand and supply of organs for transplantation has prompted calls for more widespread introduction of laws validating presumed consent with facility for opt-out as a means of increasing organ availability. The Department of Health (UK) has recently concluded a consultation on the introduction of such a law for England. This article explores the debate on presumed consent from an ethical point of view and summarises the key arguments on both sides of the ethical divide.

#### **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

#### **Disclaimer:**

The results of your literature search are based on the request that you made, and consist of a list of references, some with abstracts. Royal United Hospital Bath Healthcare Library will endeavour to use the best, most appropriate and most recent sources available to it, but accepts no liability for the information retrieved, which is subject to the content and accuracy of databases, and the limitations of the search process. The library assumes no liability for the interpretation or application of these results, which are not intended to provide advice or recommendations on patient care.