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**Palliative Care related topics**

**What’s new in Palliative Care**

**Journal Articles**

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**Journal Articles:**

1. A Qualitative Analysis of Patient and Family Perspectives of Palliative Care.
   
   **Citation:** Journal of Palliative Medicine, 01 March 2015, vol./is. 18/3(282-285), 10966218
   
   **Author(s):** Ciemins, Elizabeth L., Brant, Jeannine, Kersten, Diane, Mullette, Elizabeth, Dickerson, Dustin
   
   **Language:** English
   
   **Abstract:** Background: To provide truly patient-centered palliative care services, there is a need to better understand the perspectives and experiences of patients and families. Increased understanding will provide insight into the development of health care team competencies and organizational changes necessary to improve patient care. Objective: Our aim was to explore patient and family perceptions of palliative care services at the end of life or during serious illness and to identify facilitators and barriers to receipt of palliative care services. Methods: In-depth, semi-structured patient and family interviews were conducted, transcribed, and independently reviewed using grounded theory methodology and preliminary interpretations. A combined deductive and inductive iterative qualitative approach was used to identify recurring themes. The study was conducted in a physician-led, not-for-profit, multispecialty integrated health system serving three large, western, rural states. A purposive sample of 14 individuals who received palliative care services were interviewed alone or with their families for a total of 12 interviews. Results: Presence, Reassurance, and Honoring Choices emerged as central themes linked to satisfaction with palliative care services. Themes were defined as including health care professional attributes of respect, approachability, genuineness, empathy, connectedness, compassion, sensitivity, an ability to listen, good communication, provision of information, empowerment, and timeliness. Honoring Choices included those pertaining to treatment, spirituality, and family needs. Conclusions: At end of life or during times of serious illness, patients and families identified behaviors of Presence, Reassurance, and Honoring Choices as important. According to patients/families, health care providers must be compassionate and empathetic and possess skills in listening, connecting, and interacting with patients and families.
   
   **Publication type:** journal article
   
   **Source:** CINAHL

2. A qualitative exploration of perceived key knowledge and skills in end-of-life care in dementia patients among medical, nursing, and pharmacy students
   
   **Citation:** Journal of Palliative Medicine, January 2015, vol./is. 18/1(56-61), 1096-6218;1557-7740 (01 Jan 2015)
   
   **Author(s):** Nguyen C.M., Jansen B.D.W., Hughes C.M., Rasmussen W., Weckmann M.T.
   
   **Language:** English
   
   **Abstract:** Background: The steady increase in the number of people living and dying with dementia, coupled with the recent focus on quality of care, has highlighted the importance of dementia training for health care professionals. This exploratory study aimed to discover which skills health care students felt were important in providing quality end-of-life care to dementia patients. Methods: Ninety-four medicine, nursing, and pharmacy students participated in a larger study using open-ended and closed questions to explore attitudes related to caring for dementia patients at the end of life. This study looks at the student responses to an open-ended question regarding the skills and knowledge they believe are needed to provide end-of-life care to dementia patients. Individual responses were reviewed by the researchers, coded into key issues, and tabulated for frequency of occurrences and group differences. Results: Several common issues emerged: knowledge, patience, empathy, understanding,
family involvement, compassion, medication knowledge, respect/patient autonomy, communication, quality of life, and patient education. Significant differences were observed among the participant groups on the following issues: Patience and understanding (pharmacy students mentioned these issues less frequently than medical and nursing students), compassion (medical students mentioned this issue more frequently than pharmacy students), and medication knowledge (pharmacy students mentioned this issue more frequently than medical and nursing students). Conclusions: Different health care disciplines (in-training) value different skill sets for the provision of dementia care at the end-of-life. As health care education for dementia patients at the end of life is expanded, it will be important to understand which skills both patients and health care students value.

Publication type: Journal: Article
Source: EMBASE

3. A review of clinical practice guidelines for palliative nursing
Citation: Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(375), 0885-3924 (February 2015)
Author(s): Kehl K.
Language: English
Abstract: Objectives * Recognize and locate at least three clinical guidelines that are relevant to palliative nursing. * Identify domains of quality palliative care that are in need of nursing clinical practice guidelines. Systemic Review Background. Clinical practice guidelines are meant to provide evidence-based recommendations that can optimize care. While the National Consensus Guidelines for Quality Palliative Care have provided an excellent foundation of understanding for the interdisciplinary practice of palliative care, clear practice guidelines for nurses can improve patient and family outcomes and guide nursing education. Practice guidelines concerning palliative care have been developed by various organizations and groups, but it has not been clear which of these are relevant to the clinical practice of palliative nursing. Aims. The aims of this review were to (1) Identify existing clinical practice guidelines with relevance to the practice of palliative nursing and (2) Identify gaps in the existing guidelines that require additional research or guideline development. Methods/Session Descriptions. Searches were conducted in the National Guidelines Clearinghouse, Pub Med, and websites of professional nursing organizations using terms including palliative, nursing, symptoms, end-of-life, and hospice. Inclusion criteria included guidelines that were (a) specifically directed at nursing practice or that included nursing as one of multiple disciplines, (b) published, (c) evidence based, and (d) included references. There were 25 appropriate guidelines, including the Oncology Nursing Society's Putting Evidence Into Practice, which includes 20 topics. The National Consensus Guidelines for Quality Palliative Care were used as an organizing framework. The quality of the guidelines was assessed using AGREE II. Conclusion. Some excellent, evidence-based guidelines are available that give clear direction for nurses' clinical practice. The domains best represented include physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, and structure and processes of care. There is a need for guidelines concerning spiritual, religious, and existential aspects of care; cultural aspects of care; care of the patient at the end of life; and ethical and legal aspects of care. Additional guidelines are also needed on specific aspects of some domains, including some common symptoms that are not represented and anticipatory grief.
Publication type: Journal: Conference Abstract
Source: EMBASE

4. A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure
Citation: Palliative Medicine, March 2015, vol./is. 29/3(260-267), 0269-2163;1477-030X (26 Mar 2015)
Language: English
Abstract: Background: As heart failure often follows an unpredictable clinical trajectory, there has been
an impetus to promote iterative patient-provider discussions regarding prognosis and preferences for end-of-life care. Aim: To examine clinicians practices, expectations, and personal level of confidence in discussing goals of care and providing end-of-life care to their patients with heart failure. Design: Multi-site clinician survey. Setting and Participants: Physicians, nurse practitioners, and physician assistants at Mayo Clinic (Rochester, Minnesota, USA) and its surrounding health system were asked to participate in an electronic survey in October 2013. Tertiary Care Cardiology, Community Cardiology, and Primary Care clinicians were surveyed. Results: A total of 95 clinicians participated (52.5% response rate). Only 12% of clinicians reported having annual end-of-life discussions as advocated by the American Heart Association. In total, 52% of clinicians hesitated to discuss end-of-life care citing provider discomfort (11%), perception of patient (21%) or family (12%) unreadiness, fear of destroying hope (9%), or lack of time (8%). Tertiary and Community Cardiology clinicians (66%) attributed responsibility for end-of-life discussions to the heart failure cardiologist, while 66% of Primary Care clinicians felt it was their responsibility. Overall, 30% of clinicians reported a low or very low level of confidence in one or more of the following: initiating prognosis or end-of-life discussions as advocated by the American Heart Association. Most clinicians expressed interest in further skills acquisition. Conclusion: Clinicians vary in their views and approaches to end-of-life discussions and care. Some lack confidence and most are interested in further skills acquisition.

Publication type: Journal: Article
Source: EMBASE
Full text: Available Palliative medicine at Palliative Medicine

5. Actions of Hospice Nurses to Alleviate Guilt in Family Caregivers During Residential Care Transitions.
Citation: Journal of Hospice & Palliative Nursing, 01 February 2015, vol./is. 17/1(48-55), 15222179
Author(s): Martz, Kim
Language: English
Abstract: Transitioning elderly family members enrolled in hospice care to and between home, assisted-living facilities, and nursing home facilities at the end-of-life may induce a reciprocal type of suffering for both the elderly dying persons and their families. Glaserian grounded theory was used to examine how hospice nurses experienced and perceived caring for patients and their family caregivers during care transitions. A sample of 16 participants included 13 hospice nurses, 1 hospice social worker, 1 skilled nursing facility social worker, and 1 assisted-living facility nurse. In addition, 4 nurses received follow-up interviews, and 2 theoretical interviews were conducted after the model was developed and totaled 22 interviews. Findings described the actions of the nurses utilizing the situation-specific model of the basic social psychological process that families experience as a scaffold. Results revealed the specific therapeutic actions of the hospice nurses as actions of hospice nurses to alleviate guilt in family caregivers: supporting the transition. Actions in alleviating guilt included advocating, navigating the complexities of both facility systems and families, and especially coaching during the dying process. The results have educational implications for hospice nurses and interdisciplinary teams supporting family caregivers through these difficult transitions.
Publication type: journal article
Source: CINAHL

6. Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer
Citation: Pediatric Blood and Cancer, April 2015, vol./is. 62/4(710-714), 1545-5009;1545-5017 (01 Apr 2015)
Author(s): Jacobs S., Perez J., Cheng Y.I., Sill A., Wang J., Lyon M.E.
Language: English
Abstract: Background: Little is known about how well family members accurately represent adolescents when making EOL decisions on their behalf. This study reports on surveys given to adolescents with
cancer and their parents as part of a larger study facilitating advanced care discussions, as well as the results of a survey for health care providers. Procedure: Trained facilitators administered surveys orally to adolescents and families in the intervention arm of the FAmily CEntered Advance Care Planning (ACP) for Teens with Cancer (FACE-TC) study. In addition, a post-hoc survey was sent to oncology providers. Results: Seventeen adolescent/family dyads completed this survey. Seventy five percent of adolescents believed it was appropriate to discuss EOL decisions early and only 12% were not comfortable discussing death. Most preferred to be at home if dying. There were substantial areas of congruence between adolescents and their surrogates, but lower agreement on the importance of dying a natural death, dying at home and "wanting to know if I were dying." Among providers, 83% felt their patients' participation in the study was helpful to the patients and 78% felt it was helpful to them as providers. Conclusions: Adolescents with cancer were comfortable discussing EOL, and the majority preferred to talk about EOL issues before they are facing EOL. There were substantive areas of agreement between adolescents and their surrogates, but important facets of adolescents' EOL wishes were not known by their families, reinforcing the importance of eliciting individual preferences and engaging dyads so parents can understand their children's wishes. Pediatr Blood Cancer 2015;62:710-714.

Publication type: Journal: Article
Source: EMBASE

7. Are nurse prescribers issuing prescriptions in palliative care?
Citation: Nurse Prescribing, Feb 2015, vol. 13, no. 2, p. 98-102, 1479-9189 (February 2015)
Author(s): Cole, Tracey, Gillett, Karen
Abstract: Prescribing in palliative care was an 'early candidate' area for the extension of nurse prescribing authority, but has failed to meet expectations. The low number of nurse prescribers working in palliative care, and the impact of the lack of this kind of professional, has received little attention. This paper gives details of an 'in-depth service evaluation project' relating to the prescribing activity of specialist palliative care nurse independent prescribers (SPCNIPs) in one community palliative care team to ascertain the volume of their prescribing activity as well identifications of the outcomes and influences to their prescribing activity. [PUBLICATION] 25 references
Source: BNI
Full text: Available Nurse Prescribing at Nurse Prescribing

Citation: International Journal of Palliative Nursing, 01 February 2015, vol./is. 21/2(66-70), 13576321
Author(s): Fragala, Guy
Language: English
Abstract: Ensuring patients are comfortable in bed is key to effective palliative care, but when moving and positioning patients in bed, health professionals face an occupational risk of injury. The turning and positioning (TAP) system is a new method of moving patients in bed, that evidence has shown to reduce the risk of injury to caregivers. Providing the correct bed surface is another aspect of bed care essential to the comfort of the palliative patient, and to aid wound prevention and treatment. It is important to take a patient-centred approach when considering the most appropriate bed surface patients. This article provides an overview and discussion of these two aspects of bed care for palliative patients.
Publication type: journal article
Source: CINAHL
Full text: Available EBSCOhost at International Journal of Palliative Nursing

9. Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK.
Citation: European Journal of Cancer Care, 01 March 2015, vol./is. 24/2(253-266), 09615423
The Midhurst Macmillan Specialist Palliative Care Service (MMSPCS) is a UK, medical consultant-led, multidisciplinary team aiming to provide round-the-clock advice and care, including specialist interventions, in the home, community hospitals and care homes. Of 389 referrals in 2010/11, about 85% were for cancer, from a population of about 155,000. Using a mixed method approach, the evaluation comprised: a retrospective analysis of secondary-care use in the last year of life; financial evaluation of the MMSPCS using an Activity Based Costing approach; qualitative interviews with patients, carers, health and social care staff and MMSPCS staff and volunteers; a postal survey of General Practices; and a postal survey of bereaved caregivers using the MMSPCS. The mean cost is about 3000 GBP (3461 EUR) per patient with mean cost of interventions for cancer patients in the last year of life 1900 GBP (2192 EUR). Post-referral, overall costs to the system are similar for MMSPCS and hospice-led models; however, earlier referral avoided around 20% of total costs in the last year of life. Patients and carers reported positive experiences of support, linked to the flexible way the service worked. Seventy-one per cent of patients died at home. This model may have application elsewhere.

Publication type: journal article
Source: CINAHL

Caring for people who are dying: priorities at the end of life
Citation: Nursing Standard, Feb 2015, vol. 29, no. 24, p. 51-58, 0029-6570 (February 11, 2015)
Author(s): Regan, Ann, Colling, Jane
Abstract: Care of people who are dying is an emotive topic, and there is only one chance to get it right for each individual approaching death. Failure to do so can hinder and complicate the grieving process of those left behind. Embedding core nursing values is integral to improving the quality of care given to all patients and those close to them. The Leadership Alliance for the Care of Dying People examined criticism of the Liverpool Care Pathway and formulated a new proposal, introducing five priorities for end of life care. Organisations, teams and individuals should consider how they can use these priorities to achieve high quality end of life care for all, at the time and in the way that each individual needs it.

Source: BNI

Creation and validation of a computerized algorithm to identify breast and lung cancer patients at the end of life
Citation: Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(450-451), 0885-3924 (February 2015)
Author(s): Rhodes R.
Language: English
Abstract: Objectives * Examine the use of the electronic health record in palliative and end-of-life care. * Examine the characteristics of patients identified by the algorithm described above. Original Research Background. Physicians often have difficulty with prognostication and identification of patients who are in need of counseling about options for care at the end of life. Research Objectives. To create and validate a computerized algorithm that will identify breast and lung cancer patients most in need of counseling about end-of-life care options, including advance care planning, palliative care, and hospice. Methods. Clinical and non-clinical data were extracted from the electronic medical record of breast and lung cancer patients admitted to a large, urban hospital from January 2010 to December 2010. These data were used to create an electronic (e-EOL) algorithm designed to identify advanced breast and lung cancer patients that could benefit from in-depth discussion about end-of-life care options using national guidelines. Results. We identified 387 patients who had ICD-9 Codes indicative of breast or lung cancer for the year 2010. Of those identified, 39% had breast cancer and 58% had lung cancer. Only 3% of those identified by the algorithm were found to have an error in ICD9 coding, and were determined on chart review not to have a diagnosis of breast or lung cancer. The e-EOL algorithm identified 54 (14%) patients that met assigned criteria (presence of metastatic disease and albumin <2.5 g/dl), while physician chart
abstractors felt that 64% of patients met criteria indicating a need for in-depth discussion about EOL care options. The sensitivity, specificity, and positive predictive value of the first generation algorithm were as follows: 20%, 96%, and 90% respectively. Conclusions. Initial testing of the e-EOL algorithm appears to be promising. Other markers of advanced illness will be added to refine the algorithm and improve its test operating characteristics. Implications for Research, Policy, or Practice. The electronic health record and health information technology can and should be used to advance the cause of providing quality palliative and end-of-life care.

**Publication type:** Journal: Conference Abstract  
**Source:** EMBASE

12. **Crisis at the end of life: How prehospital providers respond**  
**Citation:** Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(458-459), 0885-3924 (February 2015)  
**Author(s):** Waldrop D., Clemency B., Lindstrom H.  
**Language:** English  
**Abstract:** Objectives * Describe the distinct elements of prehospital providers’ assessment of a person who is dying from an advanced illness and his or her family. * Identify the nature of crisis responses that families experience when someone is actively dying. * Describe how the sources of conflict in emergency end-of-life calls influence decision making. Original Research Background. Emergency calls to 911 are often made when the end stage of an advanced illness is accompanied by alarming symptoms and substantial anxiety for family caregivers, particularly when an approaching death has not been anticipated. Prehospital providers (Paramedics and Emergency Medical Technicians [EMTs]) are often the first responders to medical or caregiving crises that immediately precede death, yet how they manage end-of-life crises is largely unknown. Research Objectives. The purpose of the study was to describe: (1) the decision-making process that occurs during emergency end-of-life calls and (2) how prehospital providers respond to families in crisis. Methods. The study design was exploratory and cross-sectional. In-depth interviews were conducted with 43 prehospital providers. Interviews were audiotaped, transcribed, and submitted to iterative qualitative data analysis which involved systematic coding, collapsing conceptually overlapping codes, and axial coding to identify the distinct properties of each theme. Rigor or the trustworthiness of the qualitative data analysis was upheld by the use of co-coding, interdisciplinary triangulation, and an audit trail of analytic decisions. Results. Four themes illuminated the unique nature of emergency end-of-life calls: (1) Rapid comprehensive assessment, (2) Family responses, (3) Conflicts, and (4) Management. Family caregivers who are providing care in the advanced stages of a life-limiting illness often do not understand the dying process and need validation. Prehospital providers provide support, validation, and assistance in decision-making about resuscitation and transport. Conclusions. Witnessing the dying process is common for healthcare providers, while losing a loved one is a once in a life time experience for families with little preparation. Implications for Research, Policy, or Practice. Hospice and Palliative care practitioners can prepare families for end-of-life crises and decision-making through advance care planning. Policies about the documentation of patient wishes (or its absence) dictate emergency decisions in the field and can result in unwanted aggressive treatment and hospitalization at life’s end.

**Publication type:** Journal: Conference Abstract  
**Source:** EMBASE

13. **Death cafes: A tool for teaching about end of life in both academic and community settings**  
**Citation:** Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(386-387), 0885-3924 (February 2015)  
**Author(s):** Adler S., Zen R.R., Coulter Y.Z., Miller B.J.  
**Language:** English  
**Abstract:** Objectives * Increase awareness of death with a view to helping people make the most of their (finite) lives. * Create a safe and informal forum for health professions learners (medical and nursing
students, residents, fellows) and community members to discuss EOL issues openly and authentically. * Build a foundation for subsequent training in relationship-centered EOL care, contemplative care, and cross-cultural approaches to dying and death. Background. Since 2011 over 1,000 Death Cafes have been held around the world. A Death Cafe is a casual group discussion of dying and death, typically hosted in someone's home. Participants, usually strangers, gather to eat cake, drink tea, and discuss death. The Death Cafe model was developed by Jon Underwood and Sue Barsky Reid (Great Britain), based on the ideas of sociologist Bernard Crettaz (Switzerland). We hosted the first Death Cafe in San Francisco as part of the UCSF 80-hour interprofessional course "Integrative Approaches to End-of-Life Care." Over the past 2 years, UCSF and Zen Hospice Project have hosted regular Death Cafes in both academic and community settings as part of our end-of-life (EOL) educational partnership. Methods. Each Death Cafe consists of a 2-hour meeting with 15-25 participants (typically talking in small groups of four to six people). One or two facilitators loosely structure the session through prepared discussion prompts or short exercises designed to encourage conversation. Results. In written evaluations (responses to open-ended prompts regarding the nature and impact of the Death Cafe experience), participants note that discussing difficult or taboo subjects in a safe, informal context has helped to transform their attitudes toward death. People report being surprised at the ease with which they are able to discuss end-of-life issues in these settings; they emphasize that sharing personal concerns in a group of strangers is not only comforting, but also serves to normalize the death-related topics. Discussion. Because Death Cafes provide a secure and casual context in which to explore one of the most challenging and fear-inducing topics, the discussions can be used strategically as points of entry for much-needed societal reappraisal of how we approach and how we want to approach the end of life. Conclusion. We have found Death Cafes to be an extremely effective educational tool. We will share practical guidelines and suggestions for the use of Death Cafes in both academic and community settings.

Publication type: Journal: Conference Abstract
Source: EMBASE

Citation: International Journal of Nursing Studies, 01 March 2015, vol./is. 52/3(756-768), 00207489
Author(s): Candy, Bridget, France, Rachel, Low, Joe, Sampson, Liz
Language: English
Abstract: Context: Despite the extent of volunteers' contribution to palliative care, and their role in direct patient care, there has been no systematic evaluation of the evidence-base on volunteers in relation to patient and family wellbeing. Objective: To critically review research, on the impact of volunteers involved in the direct care of palliative patients and their families. Methods: We searched for studies, reporting patient and family data on the impact of volunteer services in palliative care in thirteen citation databases up to May 2013. We included quantitative comparative studies. We also noted any non-comparative studies, enabling us to give a comprehensive review of the existing research. We also included qualitative studies that explored the experiences of patients and families who received volunteer support, potentially illustrating which aspects of volunteer activities patients and families value. We applied quality appraisal criteria to all studies meeting inclusion criteria. Two researchers undertook key review processes. Results: We found eight studies. Only two studies were undertaken outside of North America; one in the Netherlands and the other in Uganda. All studies were in adult palliative care services. All evaluated volunteers were in home care settings, three of the studies included other settings such as hospitals and nursing homes. All of the studies fulfilled our quality appraisal criteria. Six of them were quantitative studies and two were comparative: one found that those families who experienced greater (as opposed to lesser) volunteer involvement were significantly more satisfied with care; the other found that patients survived significantly longer if they had received home visits from a volunteer. Four cross-sectional studies focused on satisfaction ratings. No study considered possible disadvantages or adverse effects of volunteer involvement. Two qualitative studies were identified; both highlighted the uniqueness of the role volunteers may fulfil in care support, from the
viewpoint of patients and their families. Conclusions: Further research is needed to ensure the resource of volunteers in palliative care is used appropriately and effectively. Evaluation in well-designed comparative studies is recommended including economic analyses, as are further qualitative studies to explore the roles, benefits and possible adverse effects of volunteers. Evaluation is particularly needed outside of North America and in dedicated hospice facilities.

Publication type: journal article
Source: CINAHL

15. Dying in the Hospital: What Happens and What Matters, According to Bereaved Relatives
Citation: Journal of Pain and Symptom Management, Feb 2015, vol. 49, no. 2, p. 203-213, 0885-3924 (February 2015)
Author(s): Witkamp, Frederika E., Van Zuylen, Lia, Borsboom, Gerard, van der Rijt, Carin C.D., Heide, Agnes van der
Abstract: Context: Most deaths in Western countries occur in hospital, but little is known about factors determining the quality of dying (QOD). Objectives: The aim was to assess the QOD in hospital as experienced by relatives and identify factors related to QOD. Methods: A cross-sectional study on 18 wards of a university hospital in The Netherlands was conducted, including relatives of patients who died after an admission of more than six hours, from June 2009 to March 2011. Relatives' perceptions of QOD and quality of care and the relation between dimensions of QOD and overall QOD scores were assessed. Results: Two hundred forty-nine relatives participated (51%) and rated overall QOD at 6.3 (SD 2.7; range 0-10). According to relatives, patients suffered from 7.0 (SD 5.8) of 22 symptoms and were at peace with imminent death in 37%. Patients had been aware of imminent death in 26%, and relatives were aware in 49%. Furthermore, 39% of patients and 50% of relatives had said good-bye, and 77% of patients died in the presence of a relative. Symptom alleviation was sufficient in 53%, and in 75%, sufficient efforts had been made to relieve symptoms. Characteristics of QOD and quality of care could be summarized in nine domains, explaining 34% of the variation of QOD scores. Medical, personalized, and supportive care were most strongly related to QOD. Conclusion: Relatives rated QOD as sufficient. A majority of patients and relatives were not sufficiently prepared for imminent death, and relatives experienced many problems. QOD appears to be a multidimensional construct, strongly affected by medical care and staff attentiveness. [PUBLICATION] 54 references
Source: BNI

16. Ethical Issues Experienced by Hospice and Palliative Nurses
Citation: Journal of Hospice and Palliative Nursing, Feb 2015, vol. 17, no. 1, p. 7-13, 1522-2179 (February 1, 2015)
Author(s): Cheon, Jooyoung, Coyle, Nessa, Wiegand, Debra L., Welsh, Sally
Abstract: Nurses encounter ethical dilemmas in their clinical practice especially those associated with palliative and end-of-life care. The Hospice and Palliative Nurses Association (HPNA) members were asked to participate in an ethics survey. The survey aimed to identify ethical issues experienced by hospice and palliative nurses, identify resources available to them and barriers if any to their use, and to identify how HPNA can be of support to hospice and palliative nurses. One hundred twenty-nine (n = 129) HPNA members completed the online survey. The information from each of the surveys was carefully reviewed, and responses were collapsed into 6 themes. The ethical dilemmas included inadequate communication, provision of nonbeneficial care, patient autonomy usurped/threatened, issues with symptom management and the use of opioids, issues related to decision making, and issues related to discontinuing life-prolonging therapies. Approximately two-thirds of the nurses used resources in an attempt to resolve the ethical issues, including a formal ethics consultation, involvement of the palliative/hospice team, consulting with other professionals, and use of educational resources. One-third of the nurses said there were institutional or personal barriers that prevented the ethical dilemma from being resolved. Participants suggested ways that HPNA could help them to effectively manage ethical dilemmas. [PUBLICATION] 20 references
17. Evolving role of palliative care and hospice for patients with advanced cardiac disease

**Citation:** Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(324), 0885-3924 (February 2015)

**Author(s):** Dave J., Lewis E., Gafford E.F., Matlock D., Swetz K., Wordingham S., Hollenbach S.

**Language:** English

**Abstract:** Objectives * Assess workshop participants’ needs, using an audience response system, regarding attitudes, knowledge, and skills on common issues in palliative and hospice care of patients with advanced cardiac diseases and tailor discussion based on audience needs. * Define a model for high-quality, patient-centered care across the continuum for patients with cardiac diseases from the time of diagnosis to death. * Describe the role of palliative care and hospice in cardiac disease, with special emphasis on barriers and strategies to overcome them. Advances in cardiovascular medicine have led to remarkable success in life extension, which in turn has increased the prevalence of people living with heart failure and other chronic cardiac diseases. Many patients with advanced cardiac diseases require coordinated symptom management and decision support as the illness progresses, which offers an opportunity for synergism between HPM providers, primary care physicians, cardiologists, and cardiothoracic surgery teams. The opportunity for palliative care clinicians to partner in the care of cardiac patients will continue to grow in the future. Despite heart disease being the leading cause of death and evidence supporting palliative care as an obvious strategy to address the needs of patients with cardiac disease, numerous studies have documented underutilization of palliative care and hospice. Patients with cardiac disease are often not receiving palliative care interventions, even at the end of life. For example, less than 10% of heart failure patients receive palliative care services, and heart disease is the primary diagnosis in less than 12% of hospice patients. Numerous studies have documented unmet needs, such as symptom management, difficulties performing daily activities, and psychosocial concerns in patients with cardiac disease. With increasing recognition of the effectiveness of palliative care, a growing number of cardiologists and cardiothoracic teams are developing innovative programs to deliver timely palliative care interventions for patients and their caregiving families across the continuum of this complicated illness trajectory. Recent financial and delivery model reform has led to growing support for the palliative care and hospice model to improve outcomes such as readmissions. An interdisciplinary team representing cardiology, palliative care, nursing, and primary care will lead this comprehensive, coordinated, and evidence-based workshop. They will share practical tools for decision support, prognostication, and program development. They will conduct a panel discussion on policy implications and discuss practical implications during the last 30 minutes.

**Publication type:** Journal: Conference Abstract

**Source:** EMBASE

18. Factors influencing the provision of end-of-life care in critical care settings: development and testing of a survey instrument.

**Citation:** Journal of Advanced Nursing, 01 March 2015, vol./is. 71/3(697-709), 03092402

**Author(s):** Ranse, Kristen, Yates, Patsy, Coyer, Fiona

**Language:** English

**Abstract:** Aim To develop and psychometrically test a survey instrument to identify the factors influencing the provision of end-of-life care by critical care nurses. Background Following a decision to withdraw life-sustaining treatment, critical care nurses remain with the patient and their family providing end-of-life care. Identification of factors influencing the provision of this care can give evidence to inform practice development and support nurses. Design A cross-sectional survey of critical care nurses. Method An online survey was developed, reviewed by an expert panel and pilot tested to obtain preliminary evidence of its reliability and validity. In May 2011, a convenience sample of critical care nurses (n = 392, response rate 25%) completed the survey. The analytical approach to data obtained from the 58 items measured on a Likert scale included exploratory factor analysis and descriptive statistics. Results
Exploratory factor analysis identified eight factors influencing the provision of end-of-life care: emotional support for nurses, palliative values, patient and family preferences, resources, organizational support, care planning, knowledge and preparedness. Internal consistency of each latent construct was deemed satisfactory. The results of descriptive statistics revealed a strong commitment to the inclusion of families in end-of-life care and the value of this care in the critical care setting. Conclusion This paper reports preliminary evidence of the psychometric properties of a new survey instrument. The findings may inform practice development opportunities to support critical care nurses in the provision of end-of-life care and improve the care that patients and their families receive.

**Publication type:** journal article  
**Source:** CINAHL

19. From "NPO, needs feeding tube" to palliative dysphagia management: how to collaborate with speech-language pathologists  
**Citation:** Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(398-399), 0885-3924 (February 2015)  
**Author(s):** Stranberg S., Childers J., Leslie P., Wasserman-Wincko T.  
**Language:** English  
**Abstract:** Objectives * Describe a quality improvement initiative to maximize collaboration between speech-language pathology and palliative care. * Describe three complex cases in which speech-language pathology and palliative care collaboration improved care. * Create ideas for how speech-language pathology and palliative care could collaborate at your institution. Clinical decision-making about dysphagia management is challenging when caring for complex and end-of-life patients. Palliative care and speech-language pathology are often the primary services that address these issues. As with many disciplines, speech-language pathologists’ academic training regarding the assessment and management of dysphagia in end-of-life cases is limited. This results in recommendations that may not be consistent with a patient’s goals of care, as well as an element of clinician distress. Speech pathologists’ training is targeted at "preventing aspiration" rather than how to address feeding/swallowing issues in complex cases. Mixed messages regarding perceived risks can result in primary services receiving conflicting information from speech-language pathology and palliative care consultations. We developed a quality improvement initiative involving collaboration between speech-language pathology and palliative care services with the goals of providing clear, consistent recommendations to patients and their families regarding swallowing status as it relates to oral intake options, aspiration risks, and eating for quality of life. Discussion will include the joint development of written guidelines and standards of documentation that provide structure and a consistent means of communication between numerous palliative care and speech-language pathology staff across the continuum of inpatient care. This session will provide examples of typical speech-language pathology consults of clinically challenging situations that were occurring prior to this project and present case examples that demonstrate the enhanced patient care provided with implementation of this protocol. In conclusion, the session will detail means that were used to objectively measure staff opinions of and usage of these guidelines and goals for sustaining and improving this multidisciplinary collaboration. We will include small and large group discussions of ways that you could develop similar interventions at your institution, including identifying speech-language pathology and palliative care champions, education of both the speech-language pathology and palliative care teams, and methods for optimizing communication regarding shared cases.  
**Publication type:** Journal: Conference Abstract  
**Source:** EMBASE

20. Historical Review in Understanding Burnout, Professional Compassion Fatigue, and Secondary Traumatic Stress Disorder From a Hospice and Palliative Nursing Perspective.  
**Citation:** Journal of Hospice & Palliative Nursing, 01 February 2015, vol./is. 17/1(66-72), 15222179  
**Author(s):** Melvin, Christina S.  
**Language:** English
Abstract: This article compares and contrasts the terms burnout, professional compassion fatigue, and secondary traumatic stress disorder as they relate to hospice and palliative care nurses. Burnout describes distress experienced by employees related to job expectations and working conditions. In the 1990s, the term professional compassion fatigue emerged to describe the weariness experienced by health care providers repeatedly exposed to seriously ill, traumatized, suffering, and dying patients. More recently, the term secondary traumatic stress disorder has been used to describe the reactions of health care providers who experience a traumatic event vicariously by caring for seriously ill and dying patients. Recommendations include early detection of burnout, professional compassion fatigue, and secondary traumatic stress disorder. Strategies to preserve the nurse’s ability to cope include developing supports, personal awareness, and refinement of resiliency skills, self-care strategies, assertiveness skills, debriefing sessions, spirituality, and the ability of the nurse to say no. The symptoms, recommendations, and intervention strategies for nurses are described.

Publication type: journal article
Source: CINAHL

21. Impact of a clinical pathway on end-of-life care following stroke: A mixed methods study
Citation: Palliative Medicine, March 2015, vol./is. 29/3(249-259), 0269-2163;1477-030X (26 Mar 2015)
Author(s): Cowey E., Smith L.N., Stott D.J., McAlpine C.H., Mead G.E., Barber M., Walters M.
Language: English
Abstract: Background: Death after stroke is common, but little is known about end-of-life care processes in acute stroke units. Aim: (1) To identify family and health-care worker perceptions of an end-of-life care pathway for patients who die after acute stroke. (2) To determine whether patients with fatal stroke judged to require an end-of-life care pathway differ from patients with fatal stroke who die without introduction of such a pathway. Design: Mixed methods study integrating qualitative semi-structured interviews with quantitative casenote review. Setting/participants: In four Scottish acute stroke units, 17 relatives of deceased stroke patients and 23 health-care professionals were interviewed. Thematic analysis used a modified grounded theory approach. Multivariate analysis was performed on casenote data, identified prospectively from 100 consecutive stroke deaths. Results: Deciding pathway use was a consultative process, occurring within normal working hours. Families were commonly involved and could veto or trigger aspects of end-of-life care. Families sometimes felt responsible for decisions such as pathway use, resuscitation or hydration. Families were often led to expect their relatives death early in the post-stroke period. Prolonged dying processes, particularly where patients had severe dysphagia, added to distress for families. Preferences for place of care were discussed infrequently. No link was found between demographic or clinical characteristics and care pathway use. Conclusion: Distressing stroke-related clinical problems dominated relatives concerns rather than use of the end-of-life care pathway. At times, relatives felt primarily responsible for key aspects of decision-making. Relatives often felt unprepared for a prolonged dying process after stroke, particularly where patients had persistent major swallowing difficulties.
Publication type: Journal: Article
Source: EMBASE
Full text: Available Palliative medicine at Palliative Medicine

22. Interdisciplinary team care for home hospice patients and their families during the last week of life
Citation: Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(422-423), 0885-3924 (February 2015)
Author(s): Ellington L., Casarett D., Reblin M., Clayton M., Cloyes K.
Language: English
Abstract: Objectives * Demonstrate knowledge of hospice interdisciplinary team care patterns during the final week of a patient’s life. * Distinguish different hospice interdisciplinary care patterns during the final week of a patient’s life based on patient characteristics. Background. Hospice is designed to provide
intensive, interdisciplinary care to patients near the end of life and their families. However, it is not known how patients nearing the end of life utilize members of the hospice team, nor is it known whether utilization of some disciplines increases more rapidly than that of others. Objective. To describe the trajectory of hospice team member visits in the last week of life. Methods. Retrospective cohort study of electronic medical record data from twelve not-for-profit U.S. hospices. Hospice team member visits were calculated as the number of in-person contacts recorded for each day of home hospice care. Linear regression models clustered by hospice were used to define the change in visit frequency per team member during the last week of life. Results. Of 164,032 patients admitted to hospice over 5 years, 138,893 (84.7%) were in hospice for at least a week. For these patients, at 7 days prior to death, the average number of total home visits was 0.41 (SD=0.15). The frequency of home visits increased over the last 7 days of life (b=0.35; p<0.001). The most dramatic increase was for nurses (b=0.39; p<0.001), followed by social workers (b=0.30; p<0.001), hospice aides (b=0.29; p<0.001), and chaplains (b=0.24; p<0.001). A larger increase in visit frequency during the last week of life was seen in cancer patients (b=0.42; p<0.001) compared to other diagnoses (b=0.18; p<0.001). Conclusions. Patients nearing the end of life and their families seem to draw increasingly on hospice resources. Predicting needs of hospice patients and their families, based on these findings, could guide use of interdisciplinary team care for patients and families during their final days.

Publication type: Journal: Conference Abstract
Source: EMBASE

23. "It's about the conversation": A multidisciplinary intervention to support advance care planning
Citation: Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(464), 0885-3924 (February 2015)
Author(s): Zachariah F., Klein L., Clifton-Hawkins N., Andrews M., Gross D.
Language: English
Abstract: Objectives * Understand how the "Go Wish" card game is played. * Describe how various forms of media can be used to advertise and effectively engage patients, caregivers, and staff. Original Research Background. A recent California Healthcare Foundation study found 60% of Californians highly valued "making sure their families are not burdened by tough decisions about their care." However, less than 50% have communicated end-of-life (EOL) wishes to their surrogate decision maker. 82% say it is important to have EOL wishes in writing, but only 23% say they have done so. At City of Hope (COH), the advance directive (AD) completion rate is less than 15%. Research Objectives. The event should engage patients and staff in advance care planning (ACP) conversations and increase AD completion. Methods. A multi-disciplinary team designed a social media advertised 4-hour interactive event. Over 40 staff and volunteers facilitated individualized ACP conversations, private consultations with social workers, showed novel COH ACP videos, provided multilingual ACP literature and AD documents available for completion with complimentary notary support on-site. Results. Over 300 people attended. 47 ADs were completed (24 by patient/caregivers, 23 by COH staff). 29 Go Wish games were facilitated (2 in Spanish). Of 52 attendees who completed exit evaluations, 44% were patients, 31% staff, and 11% were caregivers. Respondents reported the event increased their comfort and likelihood of having ACP conversations with others. Importantly, 38 of the 52 surveyed did not have an AD prior to attending the event. Of those 38 attendees, 18 of them completed an AD at the event (or 47%). Conclusions. ACP is an all too often avoided conversation that results in increased distress of patients, families, and providers. By proactively designing opportunities for facilitated conversations in dynamic and public arenas, fear and stigmas are diffused and the true focus and intent of discovering what people wish so the medical team, surrogates, and family can ensure their values are honored and met. Implications for Research, Policy, or Practice. Further research is needed to effectively engage patients, caregivers, and staff in ACP.
Publication type: Journal: Conference Abstract
Source: EMBASE

**Citation:** International Journal of Nursing Studies, 01 April 2015, vol./is. 52/4(794-803), 00207489

**Author(s):** Gallagher, Ann, Bouss, Regina Syllt, McCarthy, Joan, Kohlen, Helen, Andrews, Tom, Paganini, Maria Cristina, Abu-El-Noor, Nasser Ibrahim, Cox, Anna, Haas, Margit, Arber, Anne, Abu-El-Noor, Mysoon Khalil, Baliza, Michelle Freire, Padilha, Katia Grillo

**Language:** English

**Abstract:** Background: Intensive care units (ICUs) focus on treatment for those who are critically ill and interventions to prolong life. Ethical issues arise when decisions have to be made regarding the withdrawal and withholding of life-sustaining treatment and the shift to comfort and palliative care. These issues are particularly challenging for nurses when there are varying degrees of uncertainty regarding prognosis. Little is known about nurses’ end-of-life (EoL) decision-making practices across cultures. Objectives: To understand nurses’ EoL decision-making practices in ICUs in different cultural contexts. Design: We collected and analysed qualitative data using Grounded Theory. Settings: Interviews were conducted with experienced ICU nurses in university or hospital premises in five countries: Brazil, England, Germany, Ireland and Palestine. Participants: Semi-structured interviews were conducted with 51 nurses (10 in Brazil, 9 in England, 10 in Germany, 10 in Ireland and 12 nurses in Palestine). They were purposefully and theoretically selected to include nurses having a variety of characteristics and experiences concerning end-of-life (EoL) decision-making. Methods: The study used grounded theory to inform data collection and analysis. Interviews were facilitated by using key questions. The comparative analysis of the data within and across data generated by the different research teams enabled researchers to develop a deeper understanding of EoL decision-making practices in the ICU. Ethical approval was granted in each of the participating countries and voluntary informed consent obtained from each participant. Results: The core category that emerged was ‘negotiated reorienting’. Whilst nurses do not make the ‘ultimate’ EoL decisions, they engage in two core practices: consensus seeking (involving coaxing, information cuing and voice enabling); and emotional holding (creating time-space and comfort giving). Conclusions: There was consensus regarding the core concept and core practices employed by nurses in the ICUs in the five countries. However, there were some discernible differences regarding the power dynamics in nurse–doctor relationships, particularly in relation to the cultural perspectives on death and dying and in the development of palliative care. The research suggests the need for culturally sensitive ethics education and bereavement support in different cultural contexts.

**Publication type:** journal article

**Source:** CINAHL

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25. No easy task: A mixed methods study of barriers to conducting effective end-of-life conversations reported by multi-specialty doctors

**Citation:** Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(446-447), 0885-3924 (February 2015)

**Author(s):** Periyakoil V., Neri E., Kraemer H.

**Language:** English

**Abstract:** Objectives * Gain an initial understanding of the current state and the gap between patients’ desire to discuss end-of-life issues with their doctors who are often reluctant to do so. * Identify the top six barriers to conducting effective end-of-life conversations with diverse patients and families. * Gain an initial understanding of the how the clinician’s age, ethnicity, gender and sub-specialty may impact the care they provide. Original Research Background. Though most patients wish to discuss end-of-life (EOL) issues, doctors are reluctant to conduct EOL conversations. Research Objectives. To identify barriers doctors face (if any) in conducting EOL conversations with diverse patients and to determine if the doctors’ age, gender, ethnicity and sub-specialty influenced the barriers reported. Methods. Mixed methods study of doctors caring for diverse, seriously ill patients in two large academic medical centers at the end of the training. Results. 1,040 of 1,234 potential subjects (84.3%) participated. 29 participants were designated as the development cohort for qualitative analyses using grounded theory methods to
identify primary barriers. Codes were validated by analyzing responses from 50 randomly drawn subjects from the validation cohort (n=996 doctors). Only 0.01% doctors denied barriers to conducting EOL conversations with patients. 99.99% doctors reported barriers with 85.7% finding it very challenging to conduct EOL conversations, especially with patients whose ethnicity was different from their own. Asian-American doctors reported the most struggles (91.3%), followed by African-Americans (85.3%), Caucasians (83.5%) and Hispanic-Americans (79.3%). Barriers included language/medical interpretation issues, patient/family religious/spiritual beliefs, doctors’ ignorance of patients’ cultural values, patient/family’s cultural differences in truth handling and decision making, limited health literacy, patients’ mistrust of doctors. Doctors’ ethnicity (Chi-Square=12.77, DF=4, p=0.0125) and medical subspecialty (Chi-Square=19.33, DF=10, p=0.036) influenced their reported barriers. Friedman’s test used to examine ranking of the barriers across sub-groups identified significant differences by age (F statistic=303.5, DF=5, p<0.0001) and medical sub-specialty (F statistic=163.7, DF=5, p<0.0001).

Conclusions. Doctors struggle with conducting effective EOL conversations, especially with patients whose ethnicity is different from theirs. Implications for Research, Policy, or Practice. Culturally competent care is imperative if we want to better serve diverse patients/families. Cultural competence training is vital for all clinicians caring for diverse patients.

Publication type: Journal: Conference Abstract
Source: EMBASE

26. Novel tool reveals varied life priorities of advanced cancer patients: "living as long as possible" generally not a top priority
Citation: Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(411), 0885-3924 (February 2015)
Author(s): Bernacki R., Paladino J., Neville B., Gawande A., Block S.
Language: English
Abstract: Objectives * Understand the importance of identifying the key life priorities of patients with serious illness. * Explain the development of the Life Priorities Survey as a novel instrument to measure patient outcomes related to goals of care at the end of life. * Describe the priorities that patients identify in the top three as elucidated in our study, and how the life priorities scale correlates with patient choice of care plan. Original Research Background. Many oncology patients do not receive goal-consistent care at the end of life. Identifying patients’ priorities allows better tailoring of care plans to meet patient goals. Research Objectives. To identify life priorities important to advanced cancer patients; to determine if ranking of "live as long as possible, no matter what" correlates with choice of comfort-focused versus life-extending care. Methods. As part of a single institution study, cancer patients at risk of death within a year were systematically enrolled and surveyed about their life priorities. Results. 174 advanced cancer patients (median age=60) completed at least one life priorities survey. Almost all patients (97.5%) rated the following as important: being at home, physically comfortable, mentally aware, spiritually/emotionally at peace, independent, having medical decisions respected, not being a burden, supporting family. One-fifth (22%) rated "living as long as possible, no matter what" as not important at all; 23% of patients ranked "living as long as possible" among their top three goals. The goals most frequently ranked among top three were mental awareness (46%), comfort (41%), and being at home (32%). Patients who ranked the goal of "living as long as possible" in the top three were highly likely (95%) to choose a care plan focused on extending life, even if that meant more discomfort; patients who did not rank "live as long as possible" in top three were highly likely (74%) to choose a plan focused on relieving discomfort, even if that meant not living as long (tetrachoric correlation for two rating scales = 0.89 (95% CI 0.78-0.99)). Conclusions. Patients have multiple and variable priorities besides living longer. The life priorities scale is a novel tool to identify patient goals. Implications for Research, Policy, or Practice. Clinicians cannot assume living as long as possible is a top patient priority, and should ask patients directly about priorities in formulating a treatment plan.
Publication type: Journal: Conference Abstract
27. Nurses' Assessment of Delirium With Underlying Dementia in End-of-Life Care  
**Citation:** Journal of Hospice and Palliative Nursing, Feb 2015, vol. 17, no. 1, p. 16-21, 1522-2179  
(February 1, 2015)  
**Author(s):** Oligario, Grace Cullen, Buch, Carrie, Piscotty, Ronald  
**Abstract:** Because of physical and metabolic changes during end of life, patients with dementia are very susceptible to develop delirium. The recognition of delirium with underlying dementia can be difficult because of their overlapping behavioral manifestations. Previous studies conducted among nurses caring for patients with delirium have shown that nurses are often not able to detect the presence of delirium using their subjective assessments. This study evaluated the nurses' ability to subjectively assess for delirium in patients with underlying dementia in end of life. Their findings were compared with the results of objective assessments performed by the researcher using Confusion Assessment Method. In 30 paired assessments, the objective and subjective assessments had the same findings. The remaining 20 paired assessments showed disagreement between the subjective and objective findings. A 0 measure of agreement was performed with a result of 0.074 and a significance of P < 0.05. This finding indicates no statistically significant agreement between the subjective nursing assessment for delirium and the objective assessment using Confusion Assessment Method. Accurate nursing assessment yields appropriate nursing interventions. The findings of this study support the need for improved subjective nursing assessment for delirium in patients with dementia at the end of life. [PUBLICATION] 18 references  
**Source:** BNI

28. Nutritional considerations for the palliative care patient  
**Citation:** International Journal of Palliative Nursing, Jan 2015, vol. 21, no. 1, p. 7-15, 1357-6321 (January 2015)  
**Author(s):** Shaw, Clare, Eldridge, Lucy  
**Abstract:** Many palliative care patients experience nutritional problems as their conditions progress. This includes those with progressive neurological conditions, chronic obstructive pulmonary disease (COPD) as well as advanced cancer. Nutritional issues not only impact patients physically but also psychologically and can also have an effect on those caring for them. It is important that patients are screened appropriately and that one identifies what symptoms are potentially affecting their intake. Decisions should always be patient-centred. Nutritional interventions range from food modification and nutritional supplements, to more intense methods such as enteral or parenteral nutrition, and these may have ethical and legal considerations. This article explores the nutritional issues faced by palliative patients, the ethical issues supporting decision-making and the methods of nutritional support available. [PUBLICATION] 40 references  
**Source:** BNI  
**Full text:** Available EBSCOhost at [International Journal of Palliative Nursing](https://www.ncbi.nlm.nih.gov/pubmed/25611604)  

29. Palliative needs of kidney health professionals, barriers to provision of quality palliative care, and recommendations from survey participants  
**Citation:** Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(409), 0885-3924  
(February 2015)  
**Author(s):** Arnella C., Lupu D.  
**Language:** English  
**Abstract:** Objectives * Identify at least 3 unmet palliative care needs identified in the survey. * Name at least 3 barriers to the provision of patient-centered palliative care to dialysis patients identified in the survey. * Name at least 2 currently available resources that could be helpful to kidney and palliative professionals in meeting palliative needs of their patients with chronic kidney disease. Original Research Background. In the summer of 2013, the Coalition for the Supportive Care of Kidney Patients (CSCPK)
conducted an online survey of the needs and priorities of kidney health professionals and dialysis staff in regards to their ability to manage the palliative care needs of patients with advanced kidney disease. These surveys were part of data-gathering on the part of the CSCKP which helped to inform the development of the CSCKP strategic plan. Research Objectives. Identify palliative care needs of kidney dialysis health professionals, the barriers to high quality palliative care delivery, the awareness of currently available kidney palliative resources on the part of kidney health professionals, and the proposed recommendations to address unmet palliative care needs. Methods. Online survey of dialysis staff and members of the Renal Physicians Association (n=540). Results. On a scale from 1 (needs not met) to 5 (needs met exceptionally well), respondents scored their dialysis center as less than 3 for spiritual support and bereavement support. The only need rated higher than 4 was care coordination within the renal team. The top three barriers to high quality palliative and end of life care -ratings above 3.25 on scale of 1 (not a barrier) to 5 (very significant barrier)-were: * No formal mechanism (such as a predictive algorithm) for identifying patient at high risk of dying within 6 months. * Patient reluctance to discuss. * No specific policy to follow for providing end-of-life care. Conclusions. There are many unmet palliative needs of kidney patients and kidney healthcare professionals, numerous barriers to provision of patientcentered care, and a gap between available resources and awareness and use of resources. Many useful recommendations were offered from frontline providers. Implications for Research, Policy, or Practice. This and other data informed the CSCKP Strategic Plan, which has already resulted in initiatives to address identified needs, and planned initiatives in the future to address gaps.

Publication type: Journal: Conference Abstract
Source: EMBASE

Citation: Health Communication, 01 March 2015, vol./is. 30(3)(241-250), 10410236
Author(s): Amati, Rebecca, Hannawa, Annegret F.
Language: English
Abstract: Communication is undoubtedly a critical element of competent end-of-life care. However, physicians commonly lack communication skills in this particular care context. Theoretically grounded, evidence-based guidelines are needed to enhance physicians’ communication with patients and their families in this important time of their lives. To address this need, this study tests and validates a Contradictions in End-of-Life Communication (CEOLC) scale, which disentangles the relational contradictions physicians commonly experience when communicating with end-of-life patients. Exploratory factors analysis confirmed the presence of eight physician-perceived dialectical tensions, reflecting three latent factors of (1) integration, (2) expression, and (3) dominance. Furthermore, a number of significant intercultural differences were found in cross-cultural comparisons of the scale in U.S., Swiss, and Italian physician samples. Thus, this investigation introduces a heuristic assessment tool that aids a better understanding of the dialectical contradictions physicians experience in their interactions with end-of-life patients. The CEOLC scale can be used to gather empirical evidence that may eventually support the development of evidence-based guidelines and skills training toward improved end-of-life care.
Publication type: journal article
Source: CINAHL

31. Place of death and the differences in patient quality of death and dying and caregiver burden.
Citation: Journal of Clinical Oncology, 01 February 2015, vol./is. 33/4(357-363), 0732183X
Author(s): Kinoshita, Hiroya, Maeda, Isseki, Morita, Tatsuya, Miyashita, Mitsunori, Yamagishi, Akemi, Shirahige, Yutaka, Takebayashi, Toru, Yamaguchi, Takuhiro, Igarashi, Ayumi, Eguchi, Kenji
Language: English
Abstract: PURPOSE: To explore the associations between place of death and quality of death and dying
and caregiver burden in terminally ill patients with cancer and their families. METHODS: Two bereavement surveys were conducted in October 2008 and October 2011. A total of 2,247 family caregivers of patients with cancer who were deceased responded to the mail surveys (response rate, 67%). Family members reported patient quality of death and dying and caregiver burden by using the Good Death Inventory and Caregiving Consequences Inventory. RESULTS: Patient quality of death and dying was significantly higher at home relative to other places of dying after adjustment for patient and/or family characteristics (adjusted means): 5.0 (95% CI, 4.9 to 5.2) for home, 4.6 (95% CI, 4.5 to 4.7) for palliative care units, and 4.3 (95% CI, 4.2 to 4.4) for hospitals. For all combinations, pairwise P < .001; the size of the difference between home and hospital was moderate (Hedges' g, 0.45). Home was superior to palliative care units or hospitals with respect to "dying in a favorite place," "good relationships with medical staff," "good relationships with family," and "maintaining hope and pleasure" (P < .001 for all combinations of home v palliative care units and home v hospitals). Home death was significantly associated with a lower overall (P = .03) and financial caregiver burden (P = .004) relative to hospital death. CONCLUSION: Dying at home may contribute to achieving good death in terminally ill patients with cancer without causing remarkably increased caregiver burden. Place of death should be regarded as an essential goal in end-of-life care.

Publication type: journal article
Source: CINAHL
Full text: Available American Society of Clinical Oncology at Journal of Clinical Oncology

32. The last 8 weeks of life: Family caregiver distress and patient symptoms
Citation: Journal of Pain and Symptom Management, February 2015, vol./is. 49/2(443-444), 0885-3924 (February 2015)
Author(s): Mooney K., Berry P., Wong B., Donaldson G.
Language: English
Abstract: Objectives * Describe the objective of the study and methods used. * Describe two results of the study and the implications for practice of each. Original Research Background. Family caregivers manage patient symptoms while simultaneously experiencing their own distress and symptoms. Research Objectives. To describe family caregiver (FC) perception of patient symptoms during the last 8 weeks of life in home hospice care and the relationship of PT symptom severity to FC distress. Methods. Cancer family caregivers (FC) (n=109) and patients (PT) were monitored using an automated telephone symptom monitoring system as controls in a larger clinical trial. FCs called the monitoring system daily reporting by proxy past 24 hour presence, severity and FC distress on 11 common PT EOL symptoms using a 0-10 scale. FCs also reported their own fatigue, sleep, mood, and anxiety symptom severity (0-10 scale). Eight weeks pre-death to death call data from the 1503 calls were analyzed. The call compliance was 60% of expected days. Results. Most of the PTs were White (94%), mean age of 72 with 52% males. Most of the FCs were White (95%), mean age of 60 and 66% were female. The majority of FCs were Spouses (59%), 32% were Adult Children and 9% were another relationship. The most frequently reported PT symptoms were Fatigue (70%), Pain (64%), Appetite Change (54%), Anxiety (39%), and Change in Thinking (38%). While symptom trajectories varied over the 8 weeks, all symptoms escalated in the last week of life. Mixed modeling was used to examine the relationship of patient symptom severity with caregiver's perceived distress. All patient symptoms were highly related to caregiver distress (all p-values <.001). Mood of the FCs was predictive of PT symptom severity. Conclusions. In addition to monitoring patient symptoms at end of life, managing family caregiver distress and symptoms could improve wellbeing for both patients and caregivers. Implications for Research, Policy, or Practice. Future research should examine the dyad of patient and caregiver physical and emotional symptom trajectories. Treating caregiver symptoms may improve the Hospice experience.
Publication type: Journal: Conference Abstract
Source: EMBASE
33. The person behind the patient: a feasibility study using the Patient Dignity Question for patients with palliative care needs in hospital.

**Citation:** International Journal of Palliative Nursing, 01 February 2015, vol./is. 21/2(71-77), 13576321

**Author(s):** Johnston, Bridget, Gaffney, Marion, Pringle, Jan, Buchanan, Deans

**Language:** English

**Abstract:** Objective: The purpose of this study was to assess the feasibility and acceptability of the Patient Dignity Question (PDQ) ‘what do I need to know about you as a person to take the best care of you that I can?’, as a person-centred intervention for patients with palliative needs in the acute hospital setting in Scotland, UK. Method: To test the feasibility of the research design, a purposive sample of nine patients and five health-care professionals (HCPs) were recruited from acute wards in the east of Scotland. Responses to the PDQ were assessed using a PDQ feedback questionnaire to gauge participant reaction to its use. A person-centred climate questionnaire (PCQ-P) was used to assess responses to the environment in relation to the person-centred approach. Results: The results from responses to the PDQ feedback questionnaire indicate that it is feasible to carry out this type of study for people with palliative care needs in the acute care setting, and that participants found the PDQ acceptable. The PCQ-P was effective in determining the person-centred nature of the hospital climate. However, it was not possible to determine if the PDQ had a direct influence on this, without pre- and post-intervention data. Conclusions: The PDQ was feasible and acceptable for this group of participants as a means by which HCPs may enhance person-centred care for people with palliative needs in an acute hospital. Testing the implementation of the PDQ in a before-and-after study would be beneficial.

**Publication type:** journal article

**Source:** CINAHL

**Full text:** Available EBSCOhost at International Journal of Palliative Nursing

34. The role of chaplains in end-of-life decision making: Results of a pilot survey.

**Citation:** Palliative & Supportive Care, 01 February 2015, vol./is. 13/1(45-51), 14789515

**Author(s):** Clemm, Stephanie, Jox, Ralf J, Borasio, Gian Domenico, Roser, Traugott

**Language:** English

**Abstract:** OBJECTIVE: The overall aim of this study was to discover how chaplains assess their role within ethically complex end-of-life decisions. METHODS: A questionnaire was sent to 256 chaplains working for German health care institutions. Questions about their role and satisfaction as well as demographic data were collected, which included information about the chaplains' integration within multi-professional teams. RESULTS: The response rate was 59%, 141 questionnaires were analyzed. Respondents reported being confronted with decisions concerning the limitation of life-sustaining treatment on average two to three times per month. Nearly 74% were satisfied with the decisions made within these situations. However, only 48% were satisfied with the communication process. Whenever chaplains were integrated within a multi-professional team there was a significantly higher satisfaction with both: the decisions made (p = 0.000) and the communication process (p = 0.000). Significance of the results: Although the results of this study show a relatively high satisfaction among surveyed chaplains with regard to the outcome of decisions, one of the major problems seems to reside in the communication process. A clear integration of chaplains within multi-professional teams (such as palliative care teams) appears to increase the satisfaction with the communication in ethically critical situations.

**Publication type:** journal article

**Source:** CINAHL

35. The Use of Very-Low-Dose Methadone and Haloperidol for Pain Control in the Hospital Setting: A Preliminary Report.

**Citation:** Journal of Palliative Medicine, 01 February 2015, vol./is. 18/2(114-119), 10966218

**Author(s):** Salpeter, Shelley R., Buckley, Jacob S., Buckley, Nicholas S., Bruera, Eduardo

**Language:** English

**Abstract:** Objective: Our aim was to evaluate the use of very-low-dose methadone with haloperidol in
the acute-care setting. Methods: We reviewed the records of 735 hospitalized patients receiving a palliative care consultation between 2011 and 2014. All patients with pain on opiates were offered conversion to methadone, 2.5 mg/day to 15 mg/day, in conjunction with scheduled haloperidol. Additional doses of haloperidol or short-acting opiates were given as needed for pain. Patients receiving an opiate at a morphine-equivalent daily dose (MEDD) of ≥40 mg had pain scores assessed daily, before and after conversion. Descriptive statistics were used to summarize the results. Results: Forty-three patients underwent conversion from another opiate (median MEDD, 78.5 mg) to methadone (median daily dose, 5 mg) and haloperidol (median daily dose, 1.5 mg). The median pain score was 5 in the week prior to conversion, 1 in week 1 after conversion (p<0.001 for difference), and zero in week 2. Similar results were seen for patients with cancer and noncancer diagnoses and for those with the highest and lowest initial opiate doses. Conclusion: The use of very-low-dose methadone in conjunction with haloperidol in the acute-care setting resulted in improved pain control after conversion from typical opiates.

Publication type: journal article
Source: CINAHL

36. 'To move or not to move': a national survey among professionals on beliefs and considerations about the place of end-of-life care for people with intellectual disabilities.

Citation: Journal of Intellectual Disability Research, 01 March 2015, vol./is. 59/3(226-237), 09642633

Language: English

Abstract: Background The aim of this article was to investigate the beliefs and considerations of professionals concerning an appropriate environment for end-of-life care for people with intellectual disabilities (ID). Method A survey questionnaire was composed based on a scan of relevant literature and the results of group interviews with professionals, family members and people with ID. The questionnaire focused on the respondents' general beliefs about an appropriate environment for end-of-life care and their specific considerations regarding the place of care of the last client for whom the respondent provided end-of-life care. The questionnaire was sent to 294 care staff members recruited from a nationally representative panel of nurses and social workers, 273 ID physicians recruited from the members list of the Dutch professional association of ID physicians, and 1000 general practitioners (GPs) recruited from a nationally representative sample from a national registration of GPs. Results The overall response was 46%. Professionals predominantly believe that all efforts should be made to ensure that a person with ID receives end-of-life care in their own home environment, and that 24/7 care is available. Respondents indicated that most of the clients (79%) who had last received end-of-life care from an ID care service were able to stay in their own home environment. Decisions to keep the client in their own home environment were primarily based on the familiarity of the environment and the expertise of the team in end-of-life care. Insufficient expertise and a lack of adequate equipment were the main considerations in decisions to move a client. Despite the belief of care staff in particular that the wishes of the person with ID should always be leading when deciding on the place of end-of-life care, only 8% of the care staff and ID physicians explicitly mentioned that the client's wishes were taken into account in actual decision-making. Conclusions Professionals agree that end-of-life care for people with ID should preferably take place in the client's home environment, even when nursing expertise, experience and adequate equipment are not (yet) in place. Nonetheless, a lack of expertise in end-of-life care is the foremost consideration in decisions to move a client. If ID care services want to promote end-of-life care in the client's own home, we recommend formulating a policy on how to realise end-of-life care in the client's own home environment and provide sufficient training and support for staff. To involve people with ID as much as possible, we recommend that professionals integrate more collaborative principles in decision-making about the place of end-of-life care.

Publication type: journal article
Source: CINAHL
37. Translating Evidence Into Practice at the End of Life: Information Needs, Access, and Usage by Hospice and Palliative Nurses

Citation: Journal of Hospice and Palliative Nursing, Feb 2015, vol. 17, no. 1, p. 24-30, 1522-2179

Author(s): Klein-Fedyshin, Michele

Abstract: Information literacy is important for evidence-based nursing and quality patient care. Hospice/palliative nurses are often unaffiliated with academic institutions and may experience barriers accessing information. The project’s goals were to identify nurses’ (1) access to evidence-based resources, (2) information literacy skills, and (3) training needs. The research design was a descriptive assessment. Members of the Hospice and Palliative Nurses Association in 4 states received the assessment in collaboration with the University of Pittsburgh. The methodology yielded data on information needs, access, and literacy skills. Data analysis included frequency distributions, cross tabulations, and a #2 test. Of the respondents, 69% worked clinically. The need for drug or disease information occurred in 89% to 100% of respondents across sites. Respondents knew of PubMed in 28% to 70% of sites. Evidence databases were unavailable in 7% to 39% of settings. The most frequent source of information was colleagues (74%), followed by Internet searches (70%). About 43% of respondents felt confident using health literacy strategies. The greatest training needs were finding quality nursing information (79%), reliable patient education (65%), and evidence for practice/quality improvement (64%). There is a large need for quality nursing, patient, and evidence-based information in hospice environments. Hospice nurses access the Internet, although evidence/database access is often lacking or unknown, making it suboptimal. [PUBLICATION] 18 references

Source: BNI

38. Transnationals’ experience of dying in their adopted country: A systematic review

Citation: Journal of Palliative Medicine, January 2015, vol./is. 18/1(76-81), 1096-6218;1557-7740 (01 Jan 2015)

Author(s): Bray Y., Goodyear-Smith F., Gott M.

Language: English

Abstract: Background: Social and emotional challenges of migration and integration include managing memories and perceptions of country of birth, leaving loved relatives behind, and the challenges of maintaining traditions, such as cultural food and practices. For many migrants, the strong connection with their birth country is never completely severed, which may become pertinent at particular events and stages in life with inherent emotional impact. This may be particularly the case for end-of-life experience. Objective: We undertook a systematic review of published evidence of research to identify the lived experience of migrants dying in a country different from their country of birth. Design: The search terms [transnationals OR migran* OR immigran*] AND [emotions OR belonging OR acculturation OR national identity] AND [dying OR end-of-life OR contemplation of dying] AND [palliative care OR terminal care] were used on the following electronic databases: MEDLINE, Embase, CINAHL, EBSCO, Geobase, PsychINFO, and Scopus to the end date of January 2014. No date limit was imposed. All research methodologies were included. The search was restricted to human subjects and English language. Results: Seven qualitative studies met the criteria. Thematic analysis of these studies identified three main themes: sense of dual identity, importance of traditions from their country of origin, and dying preferences. Conclusion: Findings have implications for the provision of palliative end-of-life care for dying transnationals, particularly in relation to providing support for migrants who are dying to resolve social and emotional issues.

Publication type: Journal: Review

Source: EMBASE

39. Views and experiences of nurses and health-care assistants in nursing care homes about the Gold Standards Framework

Citation: International Journal of Palliative Nursing, Jan 2015, vol. 21, no. 1, p. 35-41, 1357-6321 (January
2015)

**Author(s):** Nash, Anne, Fitzpatrick, Joanne M

**Abstract:** Aim: To explore the views and experiences of nurses and health-care support staff about the use of the Gold Standards Framework (GSF) for end-of-life care (EoLC) for older people in nursing care homes (NCHs) with GSF accreditation. Methods: A qualitative descriptive study was conducted with three purposively selected NCHs in London. Individual interviews were conducted with NCH managers (n=3) and in each NCH, a focus group was conducted with registered nurses (RNs) and health-care assistants (HCAs): focus group 1, n=2 RN, n=2 HCA; focus group 2, n=2 RN, n=3 HCA; focus group 3, n=3 RN, n=3 HCA. Interviews were audio-recorded, transcribed and analysed using framework analysis. Findings: Three core themes were identified: (i) a positive regard for the GSF for care homes (GSFCH); (ii) challenges around EoLC for older people; and (iii) difficulties in using the GSFCH. Conclusions: RNs, HCAs and managers regarded the training and support afforded by the GSFCH programme to inform EoLC for older residents positively. The framework has the potential to promote a coordinated approach to EoLC for older people. In the post accreditation period, there is a need for ongoing support and development to help embed the key tenets of the GSFCH in the culture of caring. [PUBLICATION] 28 references

**Source:** BNI

**Full text:** Available EBSCOhost at [International Journal of Palliative Nursing](http://www.ncbi.nlm.nih.gov/pubmed/)

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**40. Who will speak for me? Identifying decision-makers in family-centered palliative care research**

**Citation:** Journal of Adolescent Health, February 2015, vol./is. 56/2 SUPPL. 1(S52-S53), 1054-139X

**Author(s):** Lee B.C., Kimmel A.L., Lyon M.E.

**Language:** English

**Abstract:** Purpose: Providing a structured interaction that facilitates conversations between teens and families about end-of-life may achieve the Healthy People 2020 goal of increasing the proportion of adolescents who are connected to a trusted adult with whom they can talk about serious problems. FACE seeks to help adolescents identify a healthcare agent or surrogate and to facilitate conversations to achieve the adolescents’ medical care goals through patient and family-centered decision-making in a period of medical decision-making transition. Methods: Adolescents (>14 and <21 years) and their families were recruited into a longitudinal multi-site two-arm randomized controlled clinical trial. Adolescents <18 years of age participated with a parent or legal guardian; however, adolescents > 18 years had the opportunity to choose a surrogate decision-maker >18 years old. We designed a five-pronged recruitment strategy: 1) Who: involvement of the multidisciplinary care team and trained research staff in identifying and recruiting eligible patients; 2) What: delivery of a comprehensive orientation of study to patients and their families; 3) Where: location of recruitment (in hospital in-patient and out-patient clinics and over the phone); 4) When: timing of the recruitment (7 am-7 pm, seven days a week); 5) Why: adolescents' motivation for a voice in their own care. Results: A total of 366 potentially eligible adolescents were approached either over the phone or in-person between July 2011 and June 2014. Benchmark of greater than 50% of eligible dyads enrolled was met at 53.5%: 107 dyads were enrolled; 93 dyads declined participation; 40 adolescents were interested but did not enroll before enrollment ended; 126 adolescents were ineligible. Of those who were ineligible, 29 were screening failures (i.e. cognitive disability), 35 were interested but not ready to participate, and 62 (49.2%) were ineligible due to failure to identify surrogate decision-maker whom they trusted enough to make medical decisions for them, if they could not make decisions for themselves. Conclusions: More than half of the adolescents approached who agreed to participate had a parent/caregiver whom also agreed to participate. Nevertheless, nearly half of ineligible adolescents were unable to identify a surrogate/caregiver; that is, a trusted person who will be called on to make healthcare choices for them if unable to speak for himself or herself in a medical crisis. Ethical concerns for justice are raised as adolescents who most need support in future medical decision making, because of lack of status disclosure or social isolation, are least likely to have this support. There is a gap in services for this unique
population. To achieve the Healthy People 2020 goal, further research and programming should shift focus to resilience-building, particularly in ways that strengthen adult support systems or treatment buddies who are actively engaged in adolescents' medical care.

Publication type: Journal: Conference Abstract
Source: EMBASE

41. Withdrawal of Life-Sustaining Treatment: Patient and Proxy Agreement: A Secondary Analysis of "Contracts, Covenants, and Advance Care Planning"

Citation: Dimensions of Critical Care Nursing, Mar 2015, vol. 34, no. 2, p. 91-99, 0730-4625 (March 2015)

Author(s): Hinderer, Katherine A., Friedmann, Erika, Fins, Joseph J.

Abstract: Background: Families of critically ill patients often make difficult decisions related to end-of-life (EOL) care including the withdrawal of life-sustaining therapies. Objectives: This study explored patient and proxy decisions related to mechanical ventilator withdrawal in scenarios characterizing 3 distinct disease trajectories (cancer, stroke, and heart failure [HF]) with different prognoses. The relationship between patient directives, modification of directives, prognosis, trust, and EOL decisions were examined. Methods: This secondary analysis of data obtained in the "Contracts, Covenants, and Advance Care Planning" study included a sample of 110 subjects with 50 patient-proxy pairs. Patient and proxy agreement was assessed in response to questions regarding mechanical ventilator withdrawal while considering directives or modification of directives in 3 different scenarios. Results: Patient and proxy agreement ranged from 48% (n = 24 pairs) to 94% (n = 47 pairs). Agreement was lowest in HF (uncertain prognosis) when the directive indicated "do nothing" or "did not indicate any preference." Modified directives yielded 48% (n = 24 pairs) to 84% (n = 42 pairs) agreement. Changing directives from "do nothing" to "more hopeful" in HF (uncertain prognosis) had the highest agreement among modified scenarios. Despite wide variability in agreement, patients reported a high level of trust in their proxies' decisions. Discussion: This study highlighted differences in patient and proxy agreement about withdrawal of mechanical ventilation. Critical care nurses provide a key role in supporting EOL decisions. Encouraging ongoing communication about preferences and understanding the role of disease process and prognosis in decision making are paramount. Future research needs to explore factors that may improve patient and proxy agreement in EOL decisions and ways critical care nurses can support patients and proxies in these decisions, ultimately improving EOL care. [PUBLICATION] 61 references

Source: BNI

News

Commons Health Select Committee
End of Life Report
Sunday 15th March 2015
The care that people receive at the end of their lives has a profound impact not only upon them but also upon their families and carers. At the most difficult of times, their experience will be made worse if they encounter poor communication and planning or inadequate professional expertise. The Health Committee has looked at the state of end of life care since the independent Review of the Liverpool Care Pathway, chaired by Baroness Neuberger, and found great variation in quality and practice across both acute and community settings.

Department of Health
Choice in end of life care report
Thursday 26th February 2015
This report identifies the issues people approaching the end of life are currently facing and offers a blueprint for how greater choice in end of life care can be achieved. Our advice is focused around a ‘national choice offer’ – a simple expression of what should be offered to each individual who needs end of life care.
NHS England

Developing a new approach to palliative care funding
Thursday 5th March 2015

Based on a two year data collection from sites covering both adults’ and children’s services, NHS England has produced a development currency for palliative care which focuses on patient need. The aim of the work is to provide a transparent basis for palliative care commissioning.

Public Health England

End of life care coordination: national information standard
Monday 2nd March 2015

Public Health England’s National End of Life Care Intelligence Network (NEoLCIN) has opened a consultation this week. The consultation asks questions on proposed changes to the national information standard for end of life care coordination (ISB1580).

Improving palliative care: national data collection
Monday 2nd March 2015

Public Health England’s National End of Life Care Intelligence Network (NEoLCIN) has opened a consultation this week. This consultation asks for feedback on proposals to introduce a national individual-level data collection from specialist palliative care services.

Resources for Professionals

End of Life Care Horizon Scanning
Bulletin Volum7 Issue 2

National Council for Palliative Care (NCPC)

Dying Matters campaign

News stories

Resources for Professionals

National End of Life Care Intelligence Network (NEoLCIN)

Events

Resources

Social Care Institute for Excellence (SCIE)

End of Life Care Resources, Advice and Guidance

End of Life and palliative care: Thinking about the words we use
10 December 2014
New film from SCIE and NCPC
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