Healthcare Library
Current Awareness Bulletin – End of Life Care
November-December 2014

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Guidelines

National Institute for Health and Care Excellence (NICE)

Parafricta Bootees and Undergarments to reduce skin breakdown in people with or at risk of pressure ulcers
NICE medical technologies guidance [MTG20] Published date: November 2014

NHS England

NHS England has published ‘Actions for End of Life Care: 2014-16’ which sets out what the organisation intends to do over the next two years to improve end-of-life care for adults and children.

Royal College of Nursing (RCN), BMA, and Resuscitation Council (UK)

Decisions relating to cardiopulmonary resuscitation
Publication date: 7 Oct 2014
New guidance published jointly by the British Medical Association (BMA), the Resuscitation Council (UK), and the Royal College of Nursing (RCN)

UpToDate

What's new in palliative care
Additions to UpToDate considered by the editors and authors to be of particular interest.
You may need an Athens username and password. To register for an Athens account click here.

Journal Articles

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1. Title: 'Conditional candour' and 'knowing me': an interpretive description study on patient preferences for physician behaviours during end-of-life communication.
   Citation: BMJ Open, 2014, vol./is. 4/10(e005653), 2044-6055 (2014)
   Author(s): Abdul-Razzak A, You J, Sherifali D, Simon J, Brazil K
   Language: English
   Abstract: OBJECTIVE: To understand patients' preferences for physician behaviours during end-of-life communication.METHODS: We used interpretive description methods to analyse data from semistructured, one-on-one interviews with patients admitted to general medical wards at three Canadian tertiary care hospitals. Study recruitment took place from October 2012 to August 2013. We used a purposive, maximum variation sampling approach to recruit hospitalised patients aged >55 years with a high risk of mortality within 6-12 months, and with different combinations of the following demographic variables: race (Caucasian vs non-Caucasian), gender and diagnosis (cancer vs non-cancer).RESULTS: A total of 16 participants were recruited, most of whom (69%) were women and 70% had a non-cancer diagnosis. Two major concepts regarding helpful physician behaviour during end-of-life conversations emerged: (1) 'knowing me', which reflects the importance of acknowledging the influence of family roles and life history on values and priorities expressed during end-of-life communication, and (2) 'conditional candour', which describes a process of information exchange that includes an assessment of patients' readiness, being invited to the conversation, and sensitive delivery of information.CONCLUSIONS: Our findings suggest that patients prefer a nuanced approach to truth telling when having end-of-life discussions with their physician. This may have important implications for clinical practice and end-of-life communication training initiatives. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to http://group.bmj.com/group/rights-licensing/permissions.
   Publication type: Journal Article, Research Support, Non-U.S. Gov't
   Source: MEDLINE
   Full text: Available Highwire Press at BMJ Open

2. Title: A pragmatic approach to palliative sedation
   Citation: Journal of Palliative Care, Sep 2014, vol. 30, no. 3, p. 173-178, 0825-8597 (September 2014)
   Author(s): Cellarius, Victor
   Abstract: Palliative sedation refers to the use of medications to reduce suffering by lowering consciousness. overall, it has become an accepted part of palliative practice, but it remains contentious in certain manifestations. Many guidelines and frameworks have been created to help practitioners provide effective and ethical palliative sedation. These guidelines give much-needed direction where legal and professional frameworks offer only general rules, but the guidelines themselves can be further distilled into practical bedside approaches. The aim of this paper is to incorporate the directions of published guidelines into a pragmatic approach to palliative sedation. [Publication] 16 references
   Source: BNI
   Full text: Available ProQuest at Journal of Palliative Care

3. Title: A summary of the EAPC White Paper on core competencies for education in paediatric palliative care
   Citation: European Journal of Palliative Care, Sep 2014, vol. 21, no. 5, p. 245-249, 1352-2779 (Sep-Oct 2014)
   Author(s): Downing, Julia, Ling, Julie, Benini, Franca
   Source: BNI

4. Title: Advance Care Planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008-2012
   Citation: Palliative Medicine, Sep 2014, vol. 28, no. 8, p. 1026-1035, 0269-2163 (September 2014)
   Author(s): Lovell, Allison, Yates, Patsy
   Abstract: Background: Advance Care Planning is an iterative process of discussion, decision-making and documentation about end-of-life care. Advance Care Planning is highly relevant in palliative care due to intersecting clinical needs. To
enhance the implementation of Advance Care Planning, the contextual factors influencing its uptake need to be better understood. Aim: To identify the contextual factors influencing the uptake of Advance Care Planning in palliative care as published between January 2008 and December 2012. Methods: Databases were systematically searched for studies about Advance Care Planning in palliative care published between January 2008 and December 2012. This yielded 27 eligible studies, which were appraised using National Institute of Health and Care Excellence Quality Appraisal Checklists. Iterative thematic synthesis was used to group results. Results: Factors associated with greater uptake included older age, a college degree, a diagnosis of cancer, greater functional impairment, being white, greater understanding of poor prognosis and receiving or working in specialist palliative care. Barriers included having non-malignant diagnoses, having dependent children, being African American, and uncertainty about Advance Care Planning and its legal status. Individuals' previous illness experiences, preferences and attitudes also influenced their participation. Conclusion: Factors influencing the uptake of Advance Care Planning in palliative care are complex and multifaceted reflecting the diverse and often competing needs of patients, health professionals, legislature and health systems. Large population-based studies of palliative care patients are required to develop the sound theoretical and empirical foundation needed to improve uptake of Advance Care Planning in this setting. [PUBLICATION] 61 references

Source: BNI

Full text: Available Palliative medicine at Palliative Medicine

5. Title: Advance care planning for people living with dementia
Citation: British Journal of Community Nursing, Oct 2014, vol. 19, no. 10, p. 490-495, 1462-4753 (October 2014)
Author(s): Brooke, Joanne, Kirk, Mary
Abstract: The prevalence of dementia is increasing, however it is only recently that dementia has been recognised as a terminal disease where end-of-life care needs to be discussed and planned with the patient and their family. Early diagnosis of dementia enables the person with dementia and their family to discuss the future, including plans for end-of-life care such as Advance Care Planning (ACP). However, discussions regarding end-of-life care are not routine practice for people with dementia and their families. This article reviews the literature regarding barriers that impact on healthcare professionals' engagement with ACP for people with dementia and their families. [PUBLICATION] 35 references

Source: BNI

Full text: Available British Journal of Community Nursing at British Journal of Community Nursing

6. Title: An ethical defence of the Liverpool Care Pathway
Citation: Nursing Times, Oct 2014, vol. 110, no. 40, p. 20-21, 0954-7762 (October 1, 2014)
Author(s): Wrigley, Anthony
Abstract: Palliative care in the UK has been ranked as the best in the world. However, the Liverpool Care Pathway was criticised and phased out. This article looks at the LCP's aims, assesses the problems and how these should be tackled. Many of these problems stemmed not from the LCP itself, but its improper use. Better training on the pathway and on communication with patients and relatives could ensure it is used correctly. [Publication] 7 references

Source: BNI

Full text: Available ProQuest at Nursing Times
Full text: Available ProQuest at Salisbury District Hospital Healthcare Library
Full text: Available ProQuest at Nursing Times; NT

7. Title: Approaches to patients and families with strong religious beliefs regarding end-of-life care.
Citation: Current Opinion in Critical Care, December 2014, vol./is. 20(6(668-72), 1070-5295;1531-7072 (2014 Dec)
Author(s): Romain M, Sprung CL
Language: English
Abstract: PURPOSE OF REVIEW: End-of-life (EOL) decisions with limitations are made daily in ICUs around the world and may involve between 2 and 22% of patients admitted to an ICU. EOL decisions may be affected by numerous factors, including location and religion. This review aims to determine an approach to patients and families with strong religious views.RECENT FINDINGS: Different religions have different approaches and beliefs regarding EOL care. Religious people choose more active life-sustaining measures than would nonreligious people. The patient's views on EOL care should be understood, although this is often not possible and the family members' or surrogates' understanding of the patient's wishes is relied upon. This is problematic as the family's wishes may differ from those of the patient. Family members may also have different religious beliefs or have different expressions of their beliefs. Through an open communication with the patient and/or family members, an understanding of the patient's views can be obtained and decisions regarding their involvement in decision making can be taken. Conflicts can be resolved by an interdisciplinary team approach including religious leaders.SUMMARY: Through proper open communication and understanding of the patient's and/or family's views on EOL care and involvement of religious leaders, decisions can be made regarding how to further care for the patient.
Publication type: Journal Article
Source: MEDLINE
8. Title: Breathing is not an option; dyspnea is
Citation: Journal of Palliative Care, Sep 2014, vol. 30, no. 3, p. 188-191, 0825-8597 (September 2014)
Author(s): Kalluri, Meena, Richman-Eisenstat, Janice
Abstract: Idiopathic pulmonary fibrosis (IPF) is the most common idiopathic interstitial pneumonia. It is a progressive, fibrotic, incurable disease with a survival time of two to three years. The current guidelines place emphasis on early integrated palliative care and a symptom-based approach. Dyspnea is the most debilitating symptom of all advanced lung diseases, including IPF. Patients frequently end up using emergency services as a point of care. There is an urgent need for a comprehensive, integrated care delivery program that includes: physician support; detailed dyspnea action plans, including self-managed, home-based crisis action plans; and reassessment of goals of care. There is a significant knowledge gap in dyspnea management that leads to inadequate and inappropriate treatment in advanced cases. Most end-stage patients are not referred to palliative care, and most clinicians are not well versed in symptom based management. Opioids are used orally, subcutaneously, or intravenously to treat refractory dyspnea. To our knowledge, there are no published reports describing the use of sublingual fentanyl in dyspneic patients with IPF in conjunction with optimization of supplemental oxygen therapy and individualized home pulmonary rehabilitation programming. We report our approach to assessment and management of dyspnea using a collaborative, rehabilitative, and palliative approach.
[Publication] 22 references
Source: BNI
Full text: Available ProQuest at Journal of Palliative Care

9. Title: Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting
Citation: Palliative Medicine, Sep 2014, vol. 28, no. 8, p. 1046-1052, 0269-2163 (September 2014)
Author(s): O'Callaghan, Anne, Laking, George, Frey, Rosemary, Robinson, Jackie, Gott, Merryn
Abstract: Background: Screening to identify hospital inpatients with a short life expectancy may be a way to improve care towards the end of life. The Gold Standards Framework Prognostic Indicator Guidance is a screening tool that has recently been advocated for use in the hospital setting. Aim: To assess the clinical utility of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in an acute hospital setting. Main outcome measures: Mortality at 6 and 12 months and sensitivity, specificity and predictive value of the Gold Standards Framework Prognostic Indicator Guidance at 1 year. Design, setting and participants: Prospective cross-sectional study of 501 adult inpatients in a tertiary New Zealand teaching hospital screened utilising the Gold Standards Framework Prognostic Indicator Guidance. Results: A total of 99 patients were identified as meeting at least one of the Gold Standards Framework Prognostic Indicator Guidance triggers. In this group, 6-month mortality was 56.6% and 12-month mortality was 67.7% compared with 5.2% and 10%, respectively, for those not identified as meeting the criteria. The sensitivity and specificity of the Gold Standards Framework Prognostic Indicator Guidance at 1 year were 62.6% and 91.9%, respectively, with a positive predictive value of 67.7% and a negative predictive value of 90.0%. Conclusion: The sensitivity, specificity and predictive values of the Gold Standards Framework Prognostic Indicator Guidance in this study are comparable to, or better than, results of studies identifying patients with a limited life expectancy in particular disease states (e.g. heart failure and renal failure). Screening utilising the Gold Standards Framework Prognostic Indicator Guidance in the acute setting could be the first step towards implementing a more systematic way of addressing patient need &x96; both current unrecognised and future anticipated - thereby improving outcomes for this population. [PUBLICATION] 34 references
Source: BNI
Full text: Available Palliative medicine at Palliative Medicine

10. Title: Caring for the Infant With Trisomy 18: The Bioethical Implications of Treatment Decisions on Nurses
Citation: Journal of Hospice and Palliative Nursing, Oct 2014, vol. 16, no. 7, p. 388-393, 1522-2179 (October 1, 2014)
Author(s): Santucci, Gina, Battista, Vanessa, Kang, Tammy L.
Abstract: Infants born with trisomy 18 have multiple congenital abnormalities and shortened life spans. Advances in medical and surgical technology have provided some families with choices to optimize care. Given the differing outcomes that exist for infants born with trisomy 18, several questions are raised that carry weighty ethical implications. A case study will be discussed to illustrate the ethical dilemmas that nurses encounter when caring for infants with Trisomy 18. These dilemmas include the following: (1) When is it ethical to limit options offered for medical interventions? (2) Who makes decisions when options for medical interventions are considered futile? (3) What principles guide decisions about care? (4) What options are available to nurses when they do not agree with family members about suffering?
[PUBLICATION] 19 references
Source: BNI

11. Title: Clinical staff perceptions of palliative care-related quality of care, service access, education and training needs and delivery confidence in an acute hospital setting.
Citation: BMJ supportive & palliative care, December 2014, vol./is. 4/4(381-9), 2045-435X;2045-4368 (2014 Dec)
13. Title: Contributions of palliative care to pediatric patient care.

Citation: Seminars in Oncology Nursing, 2014, vol./is. 30/4(212-26), 0749-2081;1878-3449 (2014)

Author(s): Mandac C, Battista V

Language: English

Abstract: OBJECTIVES: To provide an overview of pediatric palliative care (PPC) as it relates to children and families living with oncologic disease. DATA SOURCES: Journal articles, clinical research reports, clinical guidelines, and national statistics. CONCLUSION: As new treatment protocols become available, the need for simultaneous supportive PPC, including adequate pain and symptom management, is evident. Further research and PPC program development is necessary for adherence to the current recommendation that PPC should be initiated at the time of diagnosis and continue throughout the course of a child’s disease. IMPLICATIONS FOR NURSING PRACTICE: Palliative care nursing holds a specific role in the pediatric oncology setting. Registered nurses and advanced practice nurses should be adequately trained in PPC because they are in an optimal role to contribute to interdisciplinary PPC for pediatric oncology patients and their families.

Publication type: Journal Article

Source: MEDLINE

14. Title: Developing a best practice model for partnership practice between specialist palliative care and intellectual
disability services: A mixed methods study.
Citation: Palliative Medicine, December 2014, vol./is. 28/10(1213-21), 0269-2163;1477-030X (2014 Dec)
Author(s): McLaughlin D, Barr O, Mcllfatrick S, McConkey R
Language: English
Abstract: BACKGROUND: The lack of access to good quality palliative care for people with intellectual disabilities is highlighted in the international literature. In response, more partnership practice in end-of-life care is proposed.AIM: This study aimed to develop a best practice model to guide and promote partnership practice between specialist palliative care and intellectual disability services.DESIGN: A mixed methods research design involving two phases was used, underpinned by a conceptual model for partnership practice.SETTING/PARTICIPANTS: Phase 1 involved scoping end-of-life care to people with intellectual disability, based on self-completed questionnaires. In all, 47 of 66 (71.2%) services responded. In Phase 2, semi-structured interviews were undertaken with a purposive sample recruited of 30 health and social care professionals working in intellectual disability and palliative care services, who had provided palliative care to someone with intellectual disability. For both phases, data were collected from primary and secondary care in one region of the United Kingdom.RESULTS: In Phase 1, examples of good practice were apparent. However, partnership practice was infrequent and unmet educational needs were identified. Four themes emerged from the interviews in Phase 2: challenges and issues in end-of-life care, sharing and learning, supporting and empowering and partnership in practice.CONCLUSION: Joint working and learning between intellectual disability and specialist palliative care were seen as key and fundamental. A framework for partnership practice between both services has been developed which could have international applicability and should be explored with other services in end-of-life care. The Author(s) 2014.
Publication type: Journal Article
Source: MEDLINE
Full text: Available Palliative medicine at Palliative Medicine

15. Title: District nurse consultations with vulnerable patients over wishes for end-of-life care
Citation: British Journal of Community Nursing, Sep 2014, vol. 19, no. 9, p. 458-460, 1462-4753 (September 2014)
Author(s): Griffith, Richard
Abstract: As part of an enhanced service under NHS England's Transforming Primary Care initiative, GP practices will begin to proactively case manage patients at risk of unplanned hospital admissions. At the centre of this service is a case management register and personalised care plan that indicates the patient's wishes for future care. The initiative, and particularly the asking of questions about 'do not attempt resuscitation' orders and end-of-life care, has drawn the criticism of district nurses who are frequently asked to complete the personalised care plans with patients - many of whom they have not previously met. This article considers whether the template for personal care plans is reflective of the law on consent and, in particular, the Mental Capacity Act 2005. [PUBLICATION] 11 references
Source: BNI
Full text: Available British Journal of Community Nursing at British Journal of Community Nursing

16. Title: Enabling ICU patients to die at home
Citation: Nursing Standard, Oct 2014, vol. 29, no. 5, p. 46-49, 0029-6570 (October 1, 2014)
Author(s): Battle, Emma, Bates, Lucy, Liderth, Emma
Abstract: There is often an overlap between intensive care medicine and palliative medicine. When all curative treatment options have been explored, keeping the patient comfortable and free from pain is the main concern for healthcare practitioners. Patient autonomy in end of life decisions has not been encouraged in the intensive care unit (ICU), until now, because of its specialised and technical nature. Staff at the Royal Bolton Hospital have broken down the barriers to enabling ICU patients to die in their own homes, and have developed a system of collaborative working that can help to fulfil a patient's final wish to go home. This article describes how ICU staff developed a process that enabled two ventilated patients to be transferred home for end of life care. [PUBLICATION] 11 references
Source: BNI
Full text: Available Nursing Standard at Nursing Standard

17. Title: End of life care services for patients with heart failure.
Citation: Nursing Standard, August 2014, vol./is. 28/51(35-41), 0029-6570;0029-6570 (2014 Aug 26)
Author(s): Charnock LA
Language: English
Abstract: Heart failure has high incidence and prevalence in the UK. However, access to palliative care services for patients with heart failure is inequitable. Patients with heart failure often do not receive specialist palliative care at the end of life, or referral is made only in the last days of life. This results in lost opportunities for advance care planning, psychological support for patients and families and symptom management. Prognostic tools are useful in ensuring appropriate referral. However, the controversy regarding the Liverpool Care Pathway has created uncertainty for healthcare professionals, patients and families. This article examines palliative care and end of life care services for patients with heart failure. It presents the case for service development and examines the benefits for patients who
18. Title: End-of-life care in advanced dementia.
Citation: Postgraduate Medicine, October 2014, vol./is. 126/6(119-28), 0032-5481;1941-9260 (2014 Oct)
Author(s): Heron CR, Simmons BB
Language: English
Abstract: In the next 30 years, the average age of the population will continue to increase, as will the prevalence of dementia. The management of advanced dementia requires the careful orchestration of communication, prognostication, patient care, and caregiver education. Understanding the specific tools available to establish prognosis and guide medical management in these complicated medical patients greatly improves patient and caregiver satisfaction at the end of the patient’s life. In caring for patients with advanced-stage dementia, providers should be knowledgeable regarding the terminal nature of the condition and its common comorbid diseases, and should be prepared to educate the patients’ caregivers, building a structure of support for the patient’s benefit and navigating the complexities of end-of-life care.
Publication type: Journal Article
Source: MEDLINE

19. Title: End-of-life decision making: withdrawing from dialysis: a 12-year retrospective single centre experience from the UK.
Citation: BMJ supportive & palliative care, December 2014, vol./is. 4/4(368-76), 2045-435X;2045-4368 (2014 Dec)
Author(s): Aggarwal Y, Baharani J
Language: English
Abstract: AIM: Withdrawal from dialysis is a common mode of death in patients undergoing dialysis. Anecdotally most patients have a physician-directed dialysis withdrawal (DW) following an acute medical precipitant, rather than a patient-narrated planned withdrawal as part of a collaborative end-of-life care plan. We report a 12-year retrospective experience of patients undergoing dialysis who died following DW, and suggest clinical parameters which can be used to identify patients who are able to direct their end-of-life care process.METHODS: Retrospective 12-year review of inhouse electronic and paper records.RESULTS: 867 patients undergoing dialysis died during the study period. 93 patients died from DW. 9 (10%) patients electively withdrew in the absence of an acute medical precipitant and 84(90%) withdrew from dialysis for medical reasons. Patients who chose to withdraw were 10 years younger at dialysis initiation and withdrawal, had greater reported sessional difficulties/intolerances (p<0.05), greater general deterioration in terms of comorbidity and physical dependency during the course of dialysis (p<0.05), were more likely to rehabilitate following an acute medical precipitant, and were more likely to reside in their own home on DW (p<0.05). All had decision-making capacity compared with 35(42%) patients who had dialysis withdrawn for medical reasons (p<0.05).CONCLUSIONS: Comorbidity, physical dependence, dialysis tolerance, cognitive decline, rehabilitation post an acute medical precipitant and, place of residence are parameters which differentiate between patients who choose to withdraw from dialysis and those who have dialysis withdrawn for medical reasons. These parameters can be used to identify terminal patients on dialysis who are able to be directive in their end-of-life advanced care planning. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to http://group.bmj.com/group/rights-licensing/permissions.
Publication type: Journal Article
Source: MEDLINE

20. Title: Establishing a nurse practitioner collaborative: evolution, development, and outcomes
Citation: International Journal of Palliative Nursing, Sep 2014, vol. 20, no. 9, p. 457-461, 1357-6321 (September 2014)
Author(s): Hudson, Karen Quinn*; Peter
Abstract: The first Australian palliative care nurse practitioner (NP) was endorsed in 2003. In 2009 the Victoria Department of Health funded the development of the Victorian Palliative Care Nurse Practitioner Collaborative (VPCNPC). Its aim was to promote the NP role, develop resources, and provide education and mentorship to NPs, nurse practitioner candidates (NPCs), and health service managers. Four key objectives were developed: identify the demographic profile of palliative care NPCs in Victoria; develop an education curriculum and practical resources to support the training and education of palliative care NPCs and NPs; provide mentorship to NPs, NPCs, and service managers; and ensure effective communication with all key stakeholders. An NPC survey was also conducted to explore NPC demographics, models of care, the hours of study required for the role, the mentoring process, and education needs. This paper reports on the establishment of the VPCNPC, the steps taken to achieve its objectives, and the results of the survey. The NP role in palliative care in Australia continues to evolve, and the VPCNPC provides a structure and resources to clearly articulate the benefits of the role to nursing and clinical services. [PUBLICATION] 12 references
Source: BNI
Full text: Available EBSCOhost at International Journal of Palliative Nursing
21. Title: Ethical and legal issues in palliative care.
Citation: Seminars in Oncology Nursing, 2014, vol./is. 30/4(287-95), 0749-2081;1878-3449 (2014)
Author(s): McCabe MS, Coyle N
Language: English
Abstract: OBJECTIVES: To provide foundational knowledge about approaches to ethical decision-making that arise as part of palliative care of cancer patients and their families.DATA SOURCE: Journal articles, research reports, state and federal regulations, professional codes of ethics and state of the science papers.CONCLUSION: More and more, cancer deaths occur after a long progressive illness, requiring ongoing goals of care discussion and a focus on joint decision-making. No matter how diverse the community or how advanced the healthcare setting, the needs, preferences, and values of the patient and family will continue to be at the core of palliative care.IMPLICATIONS FOR NURSING PRACTICE: The increasingly complex healthcare environment makes it essential that nurses have an understanding of medical ethics and relevant federal and state laws so that this knowledge can be applied to the many issues arising in palliative and end-of-life care.
Publication type: Journal Article
Source: MEDLINE

22. Title: Gastrostomy tube placement in patients with advanced dementia or near end of life.
Citation: Nutrition in Clinical Practice, December 2014, vol./is. 29/6(829-40), 0884-5336;1941-2452 (2014 Dec)
Language: English
Abstract: Based on current scientific literature, gastrostomy tube (G-tube) placement or other long-term enteral access devices should be withheld in patients with advanced dementia or other near end-of-life conditions. In many instances healthcare providers are not optimally equipped to implement this recommendation at the bedside. Autonomy of the patient or surrogate decision maker should be respected, as should the patient's cultural, religious, social, and emotional value system. Clinical practice needs to address risks, burdens, benefits, and expected short-term and long-term outcomes in order to clarify practice changes. This paper recommends a change in clinical practice and care strategy based on the results of a thorough literature review and provides tools for healthcare clinicians, particularly in the hospital setting, including an algorithm for decision making and a checklist to use prior to the placement of G-tubes or other long-term enteral access devices. Integrating concepts of patient-centered care, shared decision making, health literacy, and the teach-back method of education enhances the desired outcome of ethical dilemma prevention. The goal is advance care planning and a timely consensus among health team members, family members, and significant others regarding end-of-life care for patients who do not have an advance directive and lack the capacity to advocate for themselves. Achieving this goal requires interdisciplinary collaboration and proactive planning within a supportive healthcare institution environment. 2014 American Society for Parenteral and Enteral Nutrition.
Publication type: Journal Article
Source: MEDLINE

23. Title: Glycaemic control in end-of-life care.
Citation: Current Opinion in Supportive & Palliative Care, December 2014, vol./is. 8/4(378-82), 1751-4258;1751-4266 (2014 Dec)
Author(s): Lindskog M, Karvestedt L, Furst CJ
Language: English
Abstract: PURPOSE OF REVIEW: Diabetes mellitus is one of the most common comorbidities in palliative care. Yet, the optimal handling of diabetes mellitus in dying patients is debated. This review aims to discuss comprehensively the scientific basis as of today for diabetes mellitus management decisions in end-of-life (EOL) care.RECENT FINDINGS: Glycaemic control provides prognostic information in EOL care of diabetes mellitus patients. Original data on how to manage dying patients with type 2 diabetes mellitus are scarce. Findings in elderly type 2 diabetes mellitus patients and expert opinions support that glycaemic control should be relaxed in dying patients with type 2 diabetes mellitus, in the absence of risk factors for true insulin dependence, to avoid symptomatic hypoglycaemia. For terminal but conscious type 1 diabetes mellitus patients, regular blood glucose measurements and continued insulin therapy is the mainstay, with some discrepancy in preferred management between palliative care physicians and diabetes consultants. No randomized controlled trials are available. Improvement is clearly needed with regard to communication about diabetes mellitus in EOL and documentation of decisions. Corticosteroid-induced diabetes mellitus is a significant problem in palliative care, but predictors exist.SUMMARY: In the absence of large observational studies or randomized controlled trials, the current body of knowledge is based on expert opinions, surveys and retrospective studies. Nevertheless, some clinically meaningful recommendations can be made. Prospective studies need to be performed in order to improve our understanding about diabetes mellitus management in EOL. The palliative care community has a joint responsibility to address these questions.
Publication type: Journal Article
24. Title: How does involvement of a hospice nurse specialist impact on the experience on informal caring in palliative care? Perspectives of middle-aged partners bereaved through cancer  
Citation: European Journal of Cancer Care, Sep 2014, vol. 23, no. 5, p. 701-711, 0961-5423 (September 2014)  
Author(s): Borland, R., Glackin, M., Jordan, J.  
Abstract: The aim of this study was to retrospectively explore partners' understandings and experiences in relation to caring for a loved one with a terminal illness, with a particular focus on the role of the hospice nurse specialist (HNS). Participants were purposively sampled and recruited through HNS gatekeepers. Seven middle-aged, bereaved partners participated in semi-structured, qualitative interviews. The interviews were audio recorded and transcribed verbatim and data were analysed using thematic content analysis. Five main themes emerged regarding the impact of the HNS on informal caring: 'the ambivalence of caring', 'the HNS as a "confidante" in caring', 'the HNS as a "champion" in support', 'the work of the HNS - an unseen benefit' and 'being prepared for death and bereavement'. Findings from this study offer new insights into how involvement of a HNS impacts on the ability of carers to perform their role as an informal caregiver. Results highlight a crucial need for carers to have a clear understanding of all aspects of the HNS role so that full benefit is derived from their input. Recruitment of experienced and knowledgeable nurses is paramount, but equally important for carers is the supportive aspect of the role for which nurses need to demonstrate excellent communication skills and an intuitive, caring approach. [PUBLICATION] 36 references  
Source: BNI  
Full text: Available EBSCOhost EJS at European Journal of Cancer Care

25. Title: Integrating palliative care in the ICU.  
Citation: Current Opinion in Critical Care, December 2014, vol./is. 20/6(673-80), 1070-5295;1531-7072 (2014 Dec)  
Author(s): Hua M, Wunsch H  
Language: English  
Abstract: PURPOSE OF REVIEW: Although providing palliative care in the ICU has become a priority, the success of different methods to integrate palliative care into the ICU has varied. This review examines the current evidence supporting the different models of palliative care delivery and highlights areas for future study.RECENT FINDINGS: The need for palliative care for ICU patients is substantial. A large percentage of patients meet criteria for palliative care consultation and there is frequent use of intensive care and other nonbeneficial care at the end of life. Overall, the consultative model of palliative care appears to have more of an impact on patient care. However, given the current workforce shortage of palliative care providers, a sustainable model of delivering palliative care requires both an effective integrative model, in which palliative care is delivered by ICU clinicians, and appropriate use of the consultative model, in which palliative care consultation is reserved for patients at highest risk of having unmet or long-term palliative care needs.SUMMARY: Developing a mixed model of palliative care delivery is necessary to meet the palliative care needs of critically ill patients. Efforts focused on improving integrative models and appropriately targeting the use of palliative care consultants are needed.  
Publication type: Journal Article  
Source: MEDLINE

Citation: Seminars in Oncology Nursing, 2014, vol./is. 30/4(203-11), 0749-2081;1878-3449 (2014)  
Author(s): Mazanec P, Prince-Paul M  
Language: English  
Abstract: OBJECTIVES: To describe the evidence that palliative care, provided concurrently with disease-modifying treatment early in the course of a cancer diagnosis, can improve quality of life, length of survival, symptom burden, mood, and utilization of health services.DATA SOURCES: Current research, the National Consensus Guidelines for Quality Palliative Care, and the American Society of Clinical Oncology Provisional Opinion on Integrating Palliative Care into Standard Oncology Care.CONCLUSION: Despite recommendations and evidence, only a subset of cancer centers and community-based oncology clinics currently implement palliative care into ambulatory disease-focused cancer care.IMPLICATIONS FOR NURSING PRACTICE: Oncology nurses can improve access by becoming knowledgeable about generalist palliative care and by advocating for local and national practice change.  
Publication type: Journal Article  
Source: MEDLINE

27. Title: Integrating palliative care into the PICU: a report from the Improving Palliative Care in the ICU Advisory Board.  
Citation: Pediatric Critical Care Medicine, October 2014, vol./is. 15/8(762-7), 1529-7535;1529-7535 (2014 Oct)  
Language: English
Abstract: OBJECTIVE: This review highlights benefits that patients, families and clinicians can expect to realize when palliative care is intentionally incorporated into the PICU. DATA SOURCES: We searched the MEDLINE database from inception to January 2014 for English-language articles using the terms "palliative care" or "end of life care" or "supportive care" and "pediatric intensive care." We also hand-searched reference lists and author files and relevant tools on the Center to Advance Palliative Care website. STUDY SELECTION: Two authors (physicians with experience in pediatric intensive care and palliative care) made final selections. DATA EXTRACTION: We critically reviewed the existing data and tools to identify strategies for incorporating palliative care into the PICU. DATA SYNTHESIS: The Improving Palliative Care in the ICU Advisory Board used data and experience to address key questions relating to: pain and symptom management, enhancing quality of life, communication and decision-making, length of stay, sites of care, and grief and bereavement. CONCLUSIONS: Palliative care should begin at the time of a potentially life-limiting diagnosis and continue throughout the disease trajectory, regardless of the expected outcome. Although the PICU is often used for short term postoperative stabilization, PICU clinicians also care for many chronically ill children with complex underlying conditions and others receiving intensive care for prolonged periods. Integrating palliative care delivery into the PICU is rapidly becoming the standard for high quality care of critically ill children. Interdisciplinary ICU staff can take advantage of the growing resources for continuing education in pediatric palliative care principles and interventions.

Publication type: Journal Article
Source: MEDLINE

28. Title: Integration of palliative care in end-stage liver disease and liver transplantation.
Citation: Journal of Palliative Medicine, November 2014, vol./is. 17/11(1271-7), 1557-7740; 1557-7740 (2014 Nov)
Author(s): Potosek J, Curry M, Buss M, Chittenden E
Language: English
Abstract: UNLABELLED: Abstract Background: Patients with end-stage liver disease (ESLD) have a life-limiting illness that causes multiple distressing symptoms and negatively affects quality of life (QOL). This population traditionally has not had much attention within the palliative care community. DISCUSSION: This article provides an evidence-based review of palliative care issues that patients with ESLD and those awaiting liver transplant face, including approaches to prognosis, symptom management, advance care planning, and end-of-life care. CONCLUSION: Tremendous opportunity exists to integrate palliative medicine into the care of these patients.

Publication type: Journal Article
Source: MEDLINE

29. Title: Learning, development, and support needs of community palliative care clinical nurse specialists
Citation: International Journal of Palliative Nursing, Sep 2014, vol. 20, no. 9, p. 425-433, 1357-6321 (September 2014)
Author(s): Whittaker, Evelyn, Kernohan, W George, McLaughlin, Dorry
Abstract: Background: The palliative care clinical nurse specialist (PC-CNS) is a core member of the specialist palliative care team. According to professional policy, the role has four specific components: clinical practice, education, research, and leadership and management. Little is known about how to support staff in this role. Aim: The aim of this study was to explore what learning, development, and support PC-CNSs in one hospice need to enable them to fulfil all components of their role. Design: Using a descriptive exploratory approach, semi-structured interviews were undertaken with a purposive sample of community PC-CNSs from a hospice in Northern Ireland. Interviews were audio-recorded, transcribed verbatim, and thematically analysed. Findings: Seventeen interviews were analysed and three themes identified: influence of organisational culture, influence of the individual, and learning and development solutions. Conclusions: Participants reported that the PC-CNS role was stressful. They identified that the organisational culture and indeed individuals themselves influenced the learning and development support available to help them fulfil the four components of the role. Working relationships and stability within teams affected how supported individuals felt and had implications for managers in meeting the needs of staff while balancing the needs of the service. [PUBLICATION] 30 references
Source: BNI
Full text: Available EBSCOhost at International Journal of Palliative Nursing

30. Title: Making sense of continuous sedation in end-of-life care for cancer patients: an interview study with bereaved relatives in three European countries.
Citation: Supportive Care in Cancer, December 2014, vol./is. 22/12(3243-52), 0941-4355; 1433-7339 (2014 Dec)
Language: English
Abstract: PURPOSE: The purpose of the study was to explore relatives’ descriptions and experiences of continuous sedation in end-of-life care for cancer patients and to identify and explain differences between respondents from the Netherlands, Belgium, and the UK. METHODS: In-depth interviews were held between January 2011 and May 2012 with 38 relatives of 32 cancer patients who received continuous sedation until death in hospitals, the community, and hospices/palliative care units. RESULTS: Relatives’ descriptions of the practice referred to the outcome, to practical aspects, and to the goals of sedation. While most relatives believed sedation had contributed to a ‘good death’ for the
patient, yet many expressed concerns. These related to anxieties about the patient's wellbeing, their own wellbeing, and questions about whether continuous sedation had shortened the patient's life (mostly UK), or whether an alternative approach would have been better. Such concerns seemed to have been prompted by relatives witnessing unexpected events such as the patient coming to awareness during sedation. In the Netherlands and in Belgium, several relatives reported that the start of the sedation allowed for a planned moment of 'saying goodbye'. In contrast, UK relatives discerned neither an explicit point at which sedation was started nor a specific moment of farewell. CONCLUSIONS: Relatives believed that sedation contributed to the patient having a good death. Nevertheless, they also expressed concerns that may have been provoked by unexpected events for which they were unprepared. There seems to exist differences in the process of saying goodbye between the NL/BE and the UK.

**Publication type:** Journal Article  
**Source:** MEDLINE

31. **Title:** Managing palliation in the neonatal unit  
**Citation:** Archives of Disease in Childhood. Fetal and Neonatal Edition, Sep 2014, vol. 99, no. 5, p. F349, 1359-2998 (September 2014)  
**Author(s):** Uthaya, Sabita, Mancini, Alex, Beardsley, Christina, Wood, Daniel, Ranmal, Rita, Modi, Neena  
**Abstract:** Professionals working in neonatology have a duty to act in the best interests of the infant. Normally, the goal of care is to sustain life and restore health. However, there are circumstances in which treatments that sustain life are not considered to be in the infant's best interests. The Royal College of Paediatrics and Child Health (RCPCH) guidance, Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice, focuses on the decision making process. The British Association of Perinatal Medicine guidance, Palliative Care (Supportive and End of Life Care) A Framework for Clinical Practice in Perinatal Medicine, sets out the principles of palliative care for infants. Following a systematic review of the literature we have developed evidence-based guidance for the practical aspects of caring for an infant receiving palliative and end of life care. We define palliative care as the 'the active, total care of infants whose disease is not responsive to curative treatment; the goal of palliative care is achievement of the best possible quality of life for infants and their families'. Here we summarise the Guidance, a publication from Chelsea and Westminster NHS Foundation Trust developed in collaboration with the RCPCH. [PUBLICATION] 5 references  
**Source:** BNI  
**Full text:** Available Highwire Press at Salisbury District Hospital Healthcare Library  
**Full text:** Available Highwire Press at Fetal and Neonatal

32. **Title:** Neuropathic pain in people with cancer (part 1): incidence, manifestation, and assessment  
**Citation:** International Journal of Palliative Nursing, Sep 2014, vol. 20, no. 9, p. 442-447, 1357-6321 (September 2014)  
**Author(s):** Taverner, Tarnia  
**Abstract:** Many patients with cancer are at risk of experiencing neuropathic pain. This type of pain is complex and therefore requires complex assessment with a focus on impact on quality-of-life issues such as sleep and depression. Nurses are well placed to identify patients with possible signs and symptoms of neuropathic pain and so it is important for nurses to understand neuropathic pain and its manifestation, impact on quality of life, and management. Part 1 of this paper provides an overview of neuropathic cancer pain incidence, manifestation, and assessment; part 2 will address management. [PUBLICATION] 46 references  
**Source:** BNI  
**Full text:** Available EBSCOhost at International Journal of Palliative Nursing

33. **Title:** Nurses supporting life-partners conversations about end-of-life care wishes: a literature review for guidelines  
**Citation:** Australian Journal of Advanced Nursing, Sep 2014, vol. 32, no. 1, p. 23-29, 1447-4328 (Sep-Nov 2014)  
**Author(s):** Rabbetts, Lyn  
**Abstract:** Objective: A literature review was conducted to establish what guidelines are available for nurses to encourage discussions between life partners about end-of-life care wishes. Subjects: Life partners and nurses Primary argument: This literature review located articles that addressed the impact terminal illness, culture and established communication patterns have on end-of-life discussions for the broad group of family members and carers. Articles generally presented the challenges doctors, nurses and other health care professionals face in speaking about end-of-life care wishes with patients, carers and family members. However, articles relating to conversations specifically between life partners about end-of-life care wishes were not evident. This is surprising because frequently the life partner is the primary care giver during the end-of-life care phase of a life limiting illness. Furthermore, literature indicates life partners who are able to speak freely about most life issues adjust better to the challenges that events such as illness, may present to them as a couple. Conclusion: By using the main themes identified within the literature review from discussions held by family members, nurses and health professionals it may be possible to develop guidelines for life partners. The use of a guideline may assist nurses in encouraging life partners to have conversations about end-of-life care wishes. This will not only acknowledge the uniqueness of the relationship between life partners, but also contribute to providing holistic patient centred care for each couple. [Publication] 32 references
34. Title: Nursing strategies to support family members of ICU patients at high risk of dying
Citation: Heart & Lung, Sep 2014, vol. 43, no. 5, p. 406-415, 0147-9563 (Sep-Oct 2014)
Author(s): Adams, Judith A, Anderson, Ruth A, Docherty, Sharron L, Tulsky, James A, Steinhauser, Karen E, Bailey, Donald E
Abstract: To explore how family members of ICU patients at high risk of dying respond to nursing communication strategies. Family members of ICU patients may face difficult decisions. Nurses are in a position to provide support. Evidence of specific strategies that nurses use to support decision-making and how family members respond to these strategies is lacking. This is a prospective, qualitative descriptive study involving the family members of ICU patients identified as being at high risk of dying. Family members described five nursing approaches: demonstrating concern, building rapport, demonstrating professionalism, providing factual information, and supporting decision-making. This study provides evidence that when using these approaches, nurses helped family members to cope; to have hope, confidence, and trust; to prepare for and accept impending death; and to make decisions. Knowledge lays a foundation for interventions targeting the areas important to family members and most likely to improve their ability to make decisions and their well-being. [PUBLICATION] 43 references
Source: BNI

35. Title: Nutrition and hydration in dying patients: the perceptions of acute care nurses
Citation: Journal of Clinical Nursing, Sep 2014, vol. 23, no. 17-18, p. 2609-2617, 0962-1067 (September 2014)
Author(s): Higgins, Isabel, van der Riet, Pamela, Sneesby, Ludmilla, Good, Phillip
Abstract: To explore the perceptions of nurses regarding the provision and nonprovision of medical nutrition and hydration during the end stage of life when death is imminent in the acute care setting. When people are dying, they often experience a loss of appetite and desire for drinking which are natural processes at this time. The cessation of eating and drinking challenges both family members and clinical staff. This article builds on previous studies that describe the perceptions of medical doctors and palliative care nurses regarding medical nutrition and hydration during the end stage of life when death is imminent. Qualitative descriptive design. This study included three focus group meetings with ten nurses in an acute care setting in medical, oncology and haematology units. An interview schedule was used to guide the discussions. The main theme to emerge from this study was ‘finding a comfort space/ambiguous spaces of unrest’ that included four subthemes: (1) limited involvement in decision-making, (2) comfort vs. discomfort, (3) uncertainty and (4) the comfort of withdrawing treatment. Finding a comfort space captures the challenges nurses faced when speaking about the concerns of patients and family. In this space, there were ambiguities that created unease and unrest: a reluctance to talk about death; a reluctance to engage with the patient and the family. Acute care nurses need to be more cognisant of the palliative approach to care and become more engaged with decision-making during the end stage of life when death is imminent. Nurses in acute care settings need to be involved in decision-making and advocate for patients and family during the dying phase. Nurses in acute care need better understanding about the palliative approach to care and nutrition and hydration for people who are dying. [PUBLICATION] 39 references
Source: BNI

36. Title: Palliative and end of life care for people with dementia: lessons for clinical commissioners
Citation: Primary Health Care Research and Development, Oct 2014, vol. 15, no. 4, p. 406-417, 1463-4236 (October 2014)
Author(s): Raymond, Mareeni, Warner, Alex, Davies, Nathan, Nicholas, Nirusha, Manthorpe, Jill, Iliffe, Steve
Abstract: Aim: To synthesize information about management of end of life care in people with dementia using review papers. Background: There are increasing numbers of people being diagnosed with dementia worldwide, and the needs of people with dementia and their carers at the end of life may be different from those with other chronic diseases. By highlighting the challenges of palliative care in persons with dementia and the ways they are best managed, practitioners in primary care may be able to improve services for this group of people at the end of life. Methods: A search of electronic databases of English language papers published in peer-reviewed journals, 2000-2011 inclusive was undertaken using broad terms related to palliative care and dementia. 6167 papers were identified. Titles and abstracts were read. Papers were included if they were literature reviews of palliative or end of life care for people with dementia/Parkinson’s disease/Lewy body dementia/cognitive impairment/Alzheimer’s disease or any other cognitive impairment, in any setting (hospital, care home, community) and covering people of all ages. Papers were excluded if they covered palliative care focusing on other conditions, or were about an aspect of dementia care and treatment not related to palliative care. Findings: Our critical synthesis generated five main themes from this review of the reviews: (1) carers’ (family caregivers’) experiences; (2) person-centred care; (3) practice (including advance care planning, pain and comfort, nutrition, medical complications and minimizing the distress of behavioural symptoms); (4) system factors, including ethical dilemmas, decision making, information, and training; and (5) research priorities. There appears to be good evidence on the care and management of patients with dementia at the end of life which can be used to influence policy development and emerging specificity about research priorities in palliative care practice for people with dementia. [PUBLICATION] 44 references
Source: BNI
37. Title: Palliative care at the end of life.
Citation: Seminars in Oncology Nursing, 2014, vol./is. 30/4(268-79), 0749-2081;1878-3449 (2014)
Author(s): Lynch MT
Language: English
Abstract: OBJECTIVES: To describe the process of symptom management in the care of oncology patients with advanced cancer. DATA SOURCES: Journal articles, evidence-based reviews, textbooks, and clinical guidelines. CONCLUSION: Symptom management is an essential component of oncology nursing practice that improves quality of life for patients and families throughout the cancer trajectory. IMPLICATIONS FOR NURSING PRACTICE: Effective symptom management requires that oncology nurses holistically assess the patient’s symptom experience and goals of care, formulate specific symptom diagnoses, and develop, implement, and evaluate the outcomes of an evidence-based plan of care that is individualized and acceptable to the patient.
Publication type: Journal Article
Source: MEDLINE

38. Title: Palliative care communication.
Citation: Seminars in Oncology Nursing, 2014, vol./is. 30/4(280-6), 0749-2081;1878-3449 (2014)
Author(s): Wittenberg-Lyles E, Goldsmith J, Platt CS
Language: English
Abstract: OBJECTIVES: To summarize the challenges of teaching, practicing, and learning palliative care communication and offer resources for improving skills and educating others. DATA SOURCES: A theoretically grounded, evidence-based communication curriculum called COMFORT (Communication, Orientation and opportunity, Mindful presence, Family, Openings, Relating, and Team). CONCLUSION: The COMFORT curriculum is available for free through a Web site, a smartphone/iPad application, and online for continuing education units. IMPLICATIONS FOR NURSING PRACTICE: The COMFORT curriculum provides resources to support the expansion and inclusion of palliative care practice not only in oncology, but also in a wide variety of disease contexts.
Publication type: Journal Article
Source: MEDLINE

39. Title: Palliative care delivery models.
Citation: Seminars in Oncology Nursing, 2014, vol./is. 30/4(227-33), 0749-2081;1878-3449 (2014)
Author(s): Wiencek C, Coyne P
Language: English
Abstract: OBJECTIVES: To provide an overview of the four major palliative care delivery models: ambulatory clinics, home-based programs, inpatient palliative care units, and inpatient consultation services. The advantages and disadvantages of each model and the generalist and specialist roles in palliative care will be discussed. DATA SOURCES: Literature review. CONCLUSION: The discipline of palliative care continues to experience growth in the number of programs and in types of delivery models. Ambulatory and home-based models are the newest on the scene. IMPLICATIONS FOR NURSING PRACTICE: Nurses caring for oncology patients with life-limiting disease should be informed about these models for optimal impact on patient care outcomes. Oncology nurses should demonstrate generalist skills in the care of the seriously ill and access specialist palliative care providers as warranted by the patient's condition.
Publication type: Journal Article
Source: MEDLINE

40. Title: Palliative care for patients with advanced chronic kidney disease.
Citation: Journal of the Royal College of Physicians of Edinburgh, September 2014, vol./is. 44/3(224-31), 1478-2715;2042-8189 (2014 Sep)
Author(s): Douglas AA
Language: English
Abstract: Over the past three decades there has been a dramatic rise in the number of patients with advanced chronic kidney disease. The fastest expanding group receiving dialysis has been the elderly. However, for those patients who are very elderly with co-morbidity, dialysis may not offer a survival advantage. Therefore, active conservative management is a growing service offered by many renal units in the UK and focuses on non-dialytic correction of fluid and electrolytes, management of renal anaemia, and assessment and management of symptoms. The five-year survival of a patient over 75 years of age starting dialysis is 20% and if a patient is over 75 years, has co-morbidity, or a poor performance status, dialysis may not offer any survival advantage. Whether a patient is managed by dialysis or by conservative management the symptom burden suffered is high. These symptoms are under-recognised and often managed poorly because of increased drug toxicity in renal failure. This complex group of patients require close working between renal, palliative care,
medicine for the elderly, and community teams, to allow best quality of life and end of life care. This review describes some of the challenges in providing Advanced Care Planning for dialysis and conservatively managed patients, highlights the symptom burden of patients with advanced chronic kidney disease, and offers guidance in how to manage the symptoms effectively.

**Publication type:** Journal Article  
**Source:** MEDLINE

41. Title: Palliative care needs of cancer survivors.  
**Citation:** Seminars in Oncology Nursing, 2014, vol./is. 30/4(262-7), 0749-2081;1878-3449 (2014)  
**Author(s):** Economou D  
**Language:** English  
**Abstract:** OBJECTIVES: To describe the importance of early integration of palliative care into cancer survivor care. To discuss common symptoms experienced by cancer survivors and how integration of palliative care can improve management.

DATA SOURCES: Peer-reviewed literature, Clinical Practice Guidelines for Quality Palliative Care, Institute of Medicine report: From Cancer Patient to Cancer Survivor-Lost in Transition.

CONCLUSION: Primary symptoms may vary depending on disease, age, treatment, and other comorbidities. A multidisciplinary palliative care team can help manage the primary late effects for cancer survivors including fatigue, depressive symptoms, anxiety and distress, pain, and sleep disturbance.

IMPLICATIONS FOR NURSING PRACTICE: The long-term and late effects of cancer survivors will best be provided for by knowledgeable nurses who can anticipate and integrate palliative care into survivorship care early in their treatment plan.

**Publication type:** Journal Article  
**Source:** MEDLINE

42. Title: Palliative radiotherapy and oncology nursing.  
**Citation:** Seminars in Oncology Nursing, 2014, vol./is. 30/4(242-52), 0749-2081;1878-3449 (2014)  
**Author(s):** McMenamin E, Ross N, Jones J  
**Language:** English  
**Abstract:** OBJECTIVES: To describe indications and expected outcomes for palliative radiotherapy and to highlight opportunities for nurse involvement in palliative radiotherapy.

DATA SOURCE: Journal articles, clinical guidelines, case studies.

CONCLUSION: Palliative radiotherapy is a safe, effective treatment modality for many symptoms of advanced cancer. Opportunities exist to help patients and families opt for shorter palliative radiotherapy courses when quality of life is the goal.

IMPLICATIONS FOR NURSING PRACTICE: Nurses involved in the care of patients receiving palliative radiotherapy must be aware of the indications and expected outcomes associated with therapy. Nurses can play an important role in the management of symptoms, education, and communication between the team and the patient and family.

**Publication type:** Journal Article  
**Source:** MEDLINE

43. Title: Palliative surgery: incidence and outcomes.  
**Citation:** Seminars in Oncology Nursing, 2014, vol./is. 30/4(234-41), 0749-2081;1878-3449 (2014)  
**Author(s):** Sun V, Krouse RS  
**Language:** English  
**Abstract:** OBJECTIVES: To describe the goals of treatment, decision-making, incidence, and outcomes of surgical palliation in advanced cancer.

DATA SOURCES: Journal articles, research reports, state of the science papers, and clinical guidelines.

CONCLUSION: Surgical palliation is common in advanced cancer settings, and is indicated primarily in settings where the goals of treatment are focused on quality of life, symptom control, and symptom prevention. More research is needed to guide evidence-based best practices in palliative surgery.

IMPLICATIONS FOR NURSING PRACTICE: Oncology nurses practicing in clinical and research settings have a responsibility to arm themselves with knowledge related to the indications and options of palliative procedures, and the impact of surgery on quality of life for patients and families facing advanced cancer.

**Publication type:** Journal Article  
**Source:** MEDLINE

44. Title: Patients', family caregivers', and professionals' perspectives on quality of palliative care: A qualitative study  
**Citation:** Palliative Medicine, Oct 2014, vol. 28, no. 9, p. 1128-1138, 0269-2163 (October 2014)  
**Author(s):** Vedel, Isabelle, Ghadi, Véronique, Lapointe, Liette, Routelous, Christelle, Aegerter, Philippe, Guirimand, Frédéric  
**Abstract:** Background: The quality of palliative care is the foremost preoccupation of clinicians, decision-makers, and managers as well as patients and families. Major input from healthcare professionals is required to develop indicators for the quality of palliative care, but the involvement of patients and families is also recognized as essential, even though this is rarely achieved in practice. Aim: The objectives of this study were to identify (1) convergences and divergences in the
points of view of different stakeholders (patients, families, healthcare professionals) relative to key elements of the quality of palliative care and (2) avenues for refining existing indicators of quality of palliative care. Design: Cross-sectional qualitative study. Setting/participants: There were six settings: two hospital-based palliative care units, one hospice, and three other medical units where a mobile palliative care team intervene. Semi-structured interviews were conducted among 61 patients, families, healthcare professionals, and managers. Results: Four major dimensions of quality of care are deemed critical by patients, their families, and professionals: comprehensive support for the patients themselves, clinical management, involvement of families, and care for the imminently dying person and death. Differences exist between various stakeholders regarding perceptions of some dimensions of quality of care. Avenues for improving current quality of care indicators are identified. Conclusion: Our study results can be used to refine or develop quality indicators that truly mirror the points of view of patients and their families and of healthcare professionals. [PUBLICATION] 21 references

Source: BNI
Full text: Available Palliative medicine at Palliative Medicine

45. Title: Patterns of dignity-related distress at the end of life: A cross-sectional study of patients with advanced cancer and care home residents
Citation: Palliative Medicine, Oct 2014, vol. 28, no. 9, p. 1118-1127, 0269-2163 (October 2014)
Author(s): Hall, Sue, Davies, Joanna M, Gao, Wei, Higginson, Irene J
Abstract: Background: To provide effective palliative care in different settings, it is important to understand and identify the sources of dignity-related distress experienced by people nearing the end of life. Aim: To describe and compare the sources of dignity-related distress reported by cancer patients and care home residents. Design: Secondary analysis of merged data. Participants completed the Patient Dignity Inventory (assessing 25 sources of dignity-related distress) and measures of quality of life and depression. Setting/participants: A total of 45 adult patients with advanced cancer referred to hospital-based palliative care teams in London, United Kingdom, and 60 residents living in one of 15 care homes in London. Results: Care home residents were older and had poorer functioning. Both groups reported a wide range of dignity-related problems. Although the number or problems reported on the Patient Dignity Inventory was similar for the two groups (mean [standard deviation]: 5.9 (5.5) for cancer patients and 4.1 (4.3) for care home residents, p = 0.07), there was a tendency for more cancer patients to report some existential problems. Experiencing physically distressing symptoms and functional limitations were prevalent problems for both groups. Patient Dignity Inventory problems were associated with poorer performance status and functioning for residents, with age and cognitive impairment for cancer patients and with poorer quality of life and depression for both groups. Conclusion: Although characteristics of the samples differed, similarities in the dignity-related problems reported by cancer patients and care home residents support research suggesting a common pathway towards death for malignant and non-malignant disease. A wider understanding of the sources of dignity-related distress would help clinicians provide more effective end-of-life care. [PUBLICATION] 28 references
Source: BNI
Full text: Available Palliative medicine at Palliative Medicine

46. Title: Persistent Hiccups in Advanced Neuro-oncology Patients: Findings From a Descriptive Phenomenological Study
Citation: Journal of Hospice and Palliative Nursing, Oct 2014, vol. 16, no. 7, p. 396-401, 1522-2179 (October 2014)
Author(s): Palese, Alvisa, Condolo, Giulio, Dobrina, Raffaella, Skrap, Miran
Abstract: There is insufficient evidence to guide the treatment of persistent or intractable hiccups; to date, no studies have involved advanced neuro-oncological patients who have experienced persistent hiccups with the aim of understanding their experience, gaining insights, and contributing to knowledge in the field. A purposeful sample of 5 consecutive patients suffering from more than 1 persistent hiccups experience lasting more than 48 hours and persisting for less than 1 month, aged at least 18 years, able to answer open-ended questions, and who had given informed consent were invited to participate. Recruitment ended when data saturation was achieved. According to the patients' experience, living with persistent hiccups was characterized by 3 main themes: (a) resignation to its unpredictable nature; (b) despair that there is nothing worse than hiccups; and (c) learning to control the pauses. Persistent hiccups have a negative impact on patients' and families' quality of life, leading to extreme anguish and to a feeling of powerlessness when it becomes clear that there is no useful pharmacological therapy. In trying to interrupt hiccups, patients learn to control their pauses, lengthening the interval between 1 spasm and the next. Adopting this palliative effort, patients might reach 4 hiccups/min, with 1 every 15 seconds, achieving an acceptable level of symptom discomfort. [PUBLICATION] 22 references
Source: BNI

47. Title: Sedation at the end of life: a hospice's decision-making practices in the UK.
Citation: International Journal of Palliative Nursing, October 2014, vol./is. 20/10(474-81), 1357-6321;1357-6321 (2014 Oct)
Author(s): Dean A, Miller B, Woodwork C
Language: English
Abstract: The administration of sedative drugs at the end of life raises both clinical and ethical challenges. This article
details the evolution of sedation decision-making practices at a 14-bedded UK hospice over the course of 5 years through an initial review and two follow-up audits. Key areas, such as documented consideration of hydration status and discussion with family members, have been improved following the implementation of a checklist of decision-making prompts, demonstrating how practice can be improved and sustained over time.

**Publication type:** Journal Article  
**Source:** MEDLINE  
**Full text:** Available EBSCOhost at International Journal of Palliative Nursing
The effects of advance care planning published in 2000-2012. Results: The search yielded 3571 papers, of which 113 were relevant for this review. For each study, the level of evidence was graded. Most studies were observational (95%), originated from the United States (81%) and were performed in hospitals (49%) or nursing homes (32%). Do-not-resuscitate orders (39%) and written advance directives (34%) were most often studied. Advance care planning was often found to decrease life-sustaining treatment, increase use of hospice and palliative care and prevent hospitalisation. Complex advance care planning interventions seem to increase compliance with patients’ end-of-life wishes. Conclusion: The effects of different types of advance care planning have been studied in various settings and populations using different outcome measures. There is evidence that advance care planning positively impacts the quality of end-of-life care. Complex advance care planning interventions may be more effective in meeting patients’ preferences than written documents alone. More studies are needed with an experimental design, in different settings, including the community.

Source: BNI
Full text: Available Palliative medicine at Palliative Medicine

51. Title: The role and organisation of community palliative specialist nursing teams in rural England.
Citation: British Journal of Community Nursing, November 2014, vol./is. 19/11(551-5), 1462-4753;1462-4753 (2014 Nov)
Author(s): Leadbeater M, Staton W
Language: English
Abstract: This article describes a study that used a qualitative approach, purposive sampling and semi-structured telephone interviews conducted with specialist palliative care nurses from six rural community teams in England. The study investigated how services were organised and the issues of delivering specialist palliative nursing care in a rural area. Qualitative content analysis was used to analyse the data. The findings showed many similarities in that the majority of patients in rural areas were not accessing hospice services and there was a greater reliance on care at home. However, the challenges in delivering care ranged from managing patient expectations, geographical distance, lack of technology to support remote working and education for the specialist palliative care teams. The study makes specific recommendations for rural community specialist palliative care teams.
Publication type: Journal Article
Source: MEDLINE
Full text: Available British Journal of Community Nursing at British Journal of Community Nursing

52. Title: Using subcutaneous fluids in end-of-life care
Citation: Nursing Times, Oct 2014, vol. 110, no. 40, p. 12-14, 0954-7762 (October 1, 2014)
Author(s): Bowen, Patricia, Mansfield, Alison, King, Helen
Abstract: There are currently no universally accepted medical or nursing guidelines for the administration of subcutaneous fluids at the end of life. Each case must be considered individually as it is unclear whether giving parenteral fluids to people who are dying causes, rather than alleviates, symptoms. This article discusses how to give fluids safely and suggests that relatives, who often feel very strongly about giving parenteral fluids, should be supported and involved in the decision making and care of their family member at the end of life. [Publication] 22 references
Source: BNI
Full text: Available ProQuest at Nursing Times
Full text: Available ProQuest at Salisbury District Hospital Healthcare Library
Full text: Available ProQuest at Nursing Times; NT

53. Title: Water immersion in neonatal bereavement photography.
Citation: Nursing for Women’s Health, October 2014, vol./is. 18/5(429-33), 1751-4851;1751-486X (2014 Oct)
Author(s): Duffey H
Language: English
Abstract: Water immersion in neonatal bereavement photography is a new technique intended to enhance the quality of the photographs provided to families following their loss. Water immersion appears to be most helpful following a second trimester fetal demise. This technique can be used by nurses, professional photographers and others in addition to more traditional neonatal bereavement photography. It does not require special skills or equipment and can be implemented in virtually any perinatal setting. The enhanced quality of photographs produced with this method can potentially provide a source of comfort to grieving families. 2014 AWHONN.
Publication type: Journal Article
Source: MEDLINE

54. Title: What do bereaved parents want from professionals after the sudden death of their child: a systematic review of the literature.
Citation: BMC Pediatrics, 2014, vol./is. 14/(269), 1471-2431;1471-2431 (2014)
Author(s): Garstang J, Griffiths F, Sidebotham P
BACKGROUND: The death of a child is a devastating event for parents. In many high income countries, following an unexpected death, there are formal investigations to find the cause of death as part of wider integrated child death review processes. These processes have a clear aim of establishing the cause of death but it is less clear how bereaved families are supported. In order to inform better practice, a literature review was undertaken to identify what is known about what bereaved parents want from professionals following an unexpected child death.

METHODS: This was a mixed studies systematic review with a thematic analysis to synthesis findings. The review included papers from Europe, North America or Australasia; papers had to detail parents' experiences rather than professional practices.

RESULTS: The review includes data from 52 papers, concerning 4000 bereaved parents. After a child has died, parents wish to be able to say goodbye to them at the hospital or Emergency Department, they would like time and privacy to see and hold their child; parents may bitterly regret not being able to do so. Parents need to know the full details about their child's death and may feel that they are being deliberately evaded when not given this information. Parents often struggle to obtain and understand the autopsy results even in the cases where they consented for the procedure. Parents would like follow-up appointments from health care professionals after the death; this is to enable them to obtain further information as they may have been too distraught at the time of the death to ask appropriate questions or comprehend the answers. Parents also value the emotional support provided by continuing contact with health-care professionals.

CONCLUSION: All professionals involved with child deaths should ensure that procedures are in place to support parents; to allow them to say goodbye to their child, to be able to understand why their child died and to offer the parents follow-up appointments with appropriate health-care professionals.
Practical plans for difficult conversations in medicine: strategies that work in breaking bad news.
Shelfmark: WA270

End of life care in neurological disease
Shelfmark: WL300

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