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**Guidelines**

**The Scottish Government**

*Caring for people in the last days and hours of life - Guidance*
19 Dec 2014

The Scottish Government has published new guidance to support clinical and care staff who are planning and providing care during the last days and hours of life.

*Caring for people in the last days and hours of life* is based on four principles designed to ensure that patients and relatives are given the best support possible.

**New and Updated Cochrane Systematic Reviews**

**Updated Reviews – October 2014**

*Interventions for dysphagia in oesophageal cancer*

**New Reviews – November 2014**

*Droperidol for treatment of nausea and vomiting in palliative care patients*

**New Reviews – January 2015**

*Palliative pharmacological sedation for terminally ill adults*

**Updated Reviews – January 2015**

*Palliative radiotherapy regimens for patients with thoracic symptoms from non-small cell lung cancer*

*Repositioning for treating pressure ulcers*
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1. Title: A Case Study of Moral Distress
   Citation: Journal of Hospice and Palliative Nursing, Dec 2014, vol. 16, no. 8, p. 457-463, 1522-2179 (December 1, 2014)
   Author(s): Hamric, Ann B.
   Abstract: Moral distress occurs when an individual's moral integrity is seriously compromised, either because one
feels unable to act in accordance with core values and obligations, or attempted actions fail to achieve the desired outcome. Recurrent situations of moral distress can lead to the 'crescendo effect', with buildup of moral distress and moral residue in care providers. This article analyzes a case that led to moral distress in a health care team. Themes of moral distress are identified, and strategies are offered to help clinicians manage such cases. Institutional resources such as ethics committees and palliative care teams can be helpful in dealing with moral distress if they are knowledgeable about the phenomenon. [PUBLICATION] 15 references

Source: BNI

2.Title: Advance directives.
Citation: Nurse Practitioner, 01 November 2014, vol./is. 39/11(34-41), 03611817
Author(s): Nelson, Joan M., Nelson, Tessa C.
Language: English
Abstract: Advance directives were conceived as a prospective means of empowering patients to direct their own end-of-life care. Unfortunately, these directives have been inadequately incorporated into healthcare decisions due to less-than-optimal execution and implementation. The authors explore challenges to implementing advance directives and propose potential solutions.
Publication type: journal article
Source: CINAHL

3.Title: Anticipatory prescribing at the end of life in Lothian care homes.
Citation: British Journal of Community Nursing, 01 November 2014, vol./is. 19/11(544-547), 14624753
Author(s): Finucane, Anne M., McArthur, Dorothy, Stevenson, Barbara, Gardner, Hilary, Murray, Scott A.
Language: English
Abstract: Common symptoms at the end of life include pain, breathlessness, anxiety, respiratory secretions and nausea. National end-of-life care strategies advocate anticipatory prescribing for timely management of these symptoms to enhance patient care by preventing unnecessary distress. This study investigated the extent to which residents in eight Lothian care homes had anticipatory medications prescribed prior to death. Data were collected as part of a service development project to improve palliative care in nursing care homes in Edinburgh. Of the 77 residents who died in the care homes, 54% had anticipatory medicines prescribed. Only 15% had prescriptions for all four nationally recommended anticipatory medications. Many care home residents do not have the recommended anticipatory medications in place in the last days of life and thus may experience inadequate symptom control. Interventions that increase the availability of anticipatory medicines to manage common symptoms at the end of life for care home residents are required.
Publication type: journal article
Source: CINAHL
Full text: Available British Journal of Community Nursing at British Journal of Community Nursing

4.Title: Challenging situations when administering palliative chemotherapy – A nursing perspective.
Citation: European Journal of Oncology Nursing, 01 December 2014, vol./is. 18/6(591-597), 14623889
Author(s): Näppä, Ulla, Rasmussen, Birgit H., Axelsson, Bertil, Lindqvist, Olav
Language: English
Abstract: Palliative chemotherapy treatments (PCT) are becoming more common for patients with incurable cancer; a basic challenge is to optimize tumour response while minimizing side-effects and harm. As registered nurses most often administer PCT, they are most likely to be confronted with difficult situations during PCT administration. This study explores challenging situations experienced by nurses when administering PCT to patients with incurable cancer. Methods Registered nurses experienced in administering PCT were asked in interviews to recall PCT situations they found challenging. Inspired by the narrative tradition, stories were elicited and analysed using a structural and thematic narrative analysis. Results A total of twenty-eight stories were narrated by seventeen nurses. Twenty of these were dilemmas that could be sorted into three storylines containing one to three dilemmatic situations each. The six dilemmatic situations broadly related to three interwoven areas: the uncertainty of the outcome when giving potent drugs to vulnerable patients; the difficulty of resisting giving PCT to patients who want it; and insufficient communication between nurses and physician. Conclusion Nurses who administer PCT are engaged in a complex task that can give rise to a number of dilemmatic situations. The findings may be interpreted as meaning that at least some situations might be preventable if the knowledge and insight of all team members – nurses, physicians, patients, and relatives – are jointly communicated and taken into account when deciding whether or not to give PCT. Forming palliative care teams early in the PCT trajectory, could be beneficial for staff and patients.
Publication type: journal article
Source: CINAHL

5. Title: Conceptualizations of dignity at the end of life: exploring theoretical and cultural congruence with dignity therapy
Citation: Journal of Advanced Nursing, Dec 2014, vol. 70, no. 12, p. 2920-2931, 0309-2402 (December 2014)
Author(s): Li, Hui-Ching, Richardson, Alison, Speck, Peter, Armes, Jo
Abstract: Aim. To explore the conceptualization of patients' dignity in the context of end-of-life care in Taiwan.
Background. Dignity therapy - a novel nurse-delivered psychotherapeutic intervention - has been demonstrated to have potential to alleviate terminal patients' psycho-existential distress in western countries. In Taiwan, over half of end-of-life patients experience psychological-spiritual suffering and dignity therapy might be helpful in improving this situation. Hence, a preliminary study to clarify Taiwanese conceptualizations of 'dignity' was conducted prior to planning a feasibility study to gauge the potential cultural fit of an intervention of this type. Design. Qualitative exploration. Methods. Nine people with terminal cancer and ten health professionals were recruited from palliative care services in 2008. In-depth interviews were audiorecorded and transcribed verbatim. A hermeneutic approach was employed to analyse and interpret data. Findings. Being a valuable person is the core meaning of patients' dignity and this comprised intrinsic characteristics and extrinsic factors. Intrinsic characteristics of dignity encompassed living a moral life, having peace of mind and a sense of existence involving the perception of resignation to God's will. Extrinsic factors that influenced patients' dignity included illness-related distress, care delivery and the perception of being loved. A dynamic relationship between these elements determined the state of patients' dignity. Conclusion. The concept of dignity is culturally bound and understood differently in the Chinese and Western context; such differences should be considered when planning and delivering care. Modifications should be made to dignity therapy to ensure it is culturally congruent with Taiwanese patients' beliefs. [PUBLICATION] 57 references
Source: BNI
Full text: Available EBSCOhost EJS at Journal of Advanced Nursing

6. Title: Do place-of-death preferences for patients receiving specialist palliative care change over time?
Citation: International Journal of Palliative Nursing, Dec 2014, vol. 21, no. 12, p. 579-583, 1357-6321 (December 2014)
Author(s): Evans, Rebecca, Finucane, Anne, Vanhegan, Lynsey, Arnold, Elizabeth, Oxenham, David
Abstract: Background: Discussing preferred place of death (PPD) with patients approaching end of life is an important part of anticipatory care planning. Preferences at a specific point in time have been described; however the extent to which preferences may change is unclear. This study examines changes in PPD. Methods: A retrospective case note review of all patients who died under the care of a specialist palliative care service during a 6-month period in 2012 was undertaken. Notes relating to 299 patients were examined by a member of the clinical team. Results: Of the 204 patients who had more than one PPD assessment, 57% showed a change in preference status between the first and last assessment. The majority changed from an unclarified preference to identifying a preferred place. Only 15% of patients with two or more assessments switched from one location to another. Conclusions: Most patients under the care of a specialist palliative care service identify a preference for place of death as end of life approaches. Only a minority change their preference once a preferred place has been elicited. We recommend that patients are supported to explore their preferences for PPD as part of specialist palliative care, and that preferences are reviewed as end of life approaches. [PUBLICATION] 14 references
Source: BNI
Full text: Available EBSCOhost at International Journal of Palliative Nursing

7. Title: Existential encounters: Nurses' descriptions of critical incidents in end-of-life cancer care.
Citation: European Journal of Oncology Nursing, 01 December 2014, vol./is. 18/6(636-644), 14623889
Author(s): Browall, Maria, Henoch, Ingela, Melin-Johansson, Christina, Strang, Susann, Danielson, Ella
Language: English
Abstract: Nurses working with cancer patients in end of life care need to be prepared to encounter patients' psychosocial and spiritual distress. Aim The aim of this study was to describe nurses' experiences of existential situations when caring for patients severely affected by cancer. Methods and sample Nurses (registered and enrolled) from three urban in-patient hospices, an oncology clinic and a surgery clinic and a palliative homecare team were, prior to the start of a training program, invited to write down their experiences of a critical incident (CI), in which existential issues were featured. Results Eighty-eight CIs were written by 83 nurses. The CIs were analyzed with qualitative content analysis. Two main themes were found: Encounters with existential pain experiences, which concerned facing death and facing losses; and Encountering experiences of hope, which concerned balancing honesty, and desire to live. Conclusions This study points out that health care professionals need to be aware of
patients' feelings of abandonment in exposed situations such as patients' feelings of existential loneliness. That there are some patients that express a desire to die and this makes the nurses feel uncomfortable and difficult to confront these occurrences and its therefore important to listen to patients' stories, regardless of care organization, in order to gain access to patients' inner existential needs.

Publication type: journal article
Source: CINAHL

8.Title: Families and the transition to specialist palliative care.
Citation: Mortality, 01 November 2014, vol./is. 19/4(323-341), 13576275
Author(s): Kirby, Emma, Broom, Alex, Good, Phillip, Wootton, Julia, Adams, Jon
Language: English
Abstract: Families play important roles in transitions to end-of-life care, yet we know little about the social relations between doctors and families at the point of referral to specialist palliative care. In this study, we explore how medical specialists negotiated the transition to specialist palliative care with families. Drawing on data from 20 qualitative interviews, we examine data accounts about the roles of family members in discussions with clinical specialists about palliative care, and how families shape interpersonal dynamics. Our results indicate that families fulfil important ‘functions’ and ‘roles’ in these delicate and emotionally laden conversations. Specialists’ accounts articulated referral processes as distinctly relational moments, with families viewed as potential ‘resources’ but also as ‘complications’, in attempts to encourage the ‘smooth’ transition to end-of-life care. On the basis of these results, we argue that further attention should be paid to the centrality of families in key moments in care (and communication therein) and how they may be utilised, managed and experienced by a range of health professionals.
Publication type: journal article
Source: CINAHL

9.Title: High-Dose Neuroleptics and Neuroleptic Rotation for Agitated Delirium Near the End of Life
Citation: American Journal of Hospice and Palliative Medicine, Dec 2014, vol. 31, no. 8, p. 808-811, 1049-9091 (December 2014)
Author(s): Bascom, Paul B., Bordley, Jessica L., Lawton, Andrew J.
Abstract: Reason for the study: Agitated delirium presents unique challenges for hospice and palliative care clinicians. Haloperidol, the recommended neuroleptic, may be ineffective at low dose, or poorly tolerated at higher doses. Main Findings: This article reports on two patients with refractory agitated delirium. Both developed extrapyramidal symptoms from haloperidol and required rotation to an alternate neuroleptic. Patient #1 received 2000 mg/day oral chlorpromazine. Patient #2 received greater than 200 mg/day sublingual olanzapine. Control of agitation was achieved, though the doses were substantially higher than has previously reported in the literature. Each patient experienced considerable sedation, though this was an acceptable side effect for the family. Each patient was transferred from the acute care hospital to a location of family preference. There they died within a week of transfer. Conclusions: Agitated delirium is a palliative care emergency. High doses of neuroleptic medications, with rotation to an alternate neuroleptic when side effects occur with standard haloperidol, may effectively palliate agitated delirium. This remedy can provide the patient with a peaceful dying in a place of their choosing. [PUBLICATION] 21 references
Source: BNI

10.Title: Improving family carers' experiences of support at the end of life by enhancing communication: an action research study
Citation: International Journal of Palliative Nursing, Dec 2014, vol. 21, no. 12, p. 608-616, 1357-6321 (December 2014)
Author(s): Dosser, Isabel, Kennedy, Catriona
Abstract: Background: This paper builds on findings from phase one of a participatory action research study, which investigated support for family carers at the end of life in an acute hospital setting in Scotland, UK (Dosser and Kennedy, 2012). The research presented here is the second phase of the participatory action research study, in which nursing staff from an acute hospital ward are involved in ongoing analysis of data and ideas guided by action cycles and reflection. Methods: Two key change initiatives are reported; improving nurses' communication skills and improving the environment for family carers of loved ones at the end of life within the acute hospital setting. To address these points, nurses were enrolled on a communications skills course, and a new room for family carers was integrated into the hospital. Results: Data were analysed from interviews and questionnaires with the nurses, and from insights gathered in a reflective diary taken by the researcher. The changes implemented improved the confidence of participants in communicating with carers as well as patients and colleagues. Conclusion: The findings
highlight practical strategies and communication issues that can potentially impact on the grief experience of family carers, such as having a safe space nearby to rest in private, away from the bedside. [PUBLICATION] 43 references

Source: BNI

Full text: Available EBSCOhost at International Journal of Palliative Nursing

11. Title: Improving Quality of Life in Chronic Obstructive Pulmonary Disease by Integrating Palliative Approaches to Dyspnea, Anxiety, and Depression

Citation: Journal of Hospice and Palliative Nursing, Dec 2014, vol. 16, no. 8, p. 514-520, 1522-2179 (December 1, 2014)

Author(s): Long, Mary Bronwyn, Bekelman, David B., Make, Barry

Abstract: Chronic obstructive pulmonary disease (COPD), the third leading cause of death in the United States, is associated with persistent burdensome symptoms including dyspnea, anxiety, and depression. Few studies have examined treating these symptoms concurrently using palliative care. The goal of this study was to evaluate the feasibility and usefulness of an advance practice nurse-delivered palliative care intervention in patients with symptomatic COPD. We conducted a 3-month prospective, single-arm, mixed-method pilot study. A convenience sample of outpatients with Global Initiative for Chronic Obstructive Lung Disease stage III or IV COPD was enrolled from a single center. The advance practice nurse provided pharmacologic and nonpharmacologic palliative management of dyspnea, anxiety, and depression. Feasibility was measured by recruitment and retention rates and completion of survey measures. Usefulness was measured by changes in survey measures and an end-of-study semistructured participant interview. Sixty people were invited to participate in the study, and 15 enrolled (25%). Thirteen of 15 (87%) completed the study. Twelve of 15 (80%) used opioids for dyspnea, whereas 7 (47%) enrolled in pulmonary rehabilitation or another exercise program. All patients reported decreased anxiety and depression with improvement in dyspnea, so they opted not to treat either separately. Qualitative interviews revealed 3 themes: (1) improved quality of life, (2) issues around study participation, and (3) managing expectations. Participants reported subjective benefit from palliative care, and the intervention was feasible. [PUBLICATION] 34 references

Source: BNI

12. Title: Intensive care nurses’ experiences of providing end-of-life care after treatment withdrawal: a qualitative study

Citation: Journal of Clinical Nursing, Nov 2014, vol. 23, no. 21-22, p. 3188-3196, 0962-1067 (November 2014)

Author(s): Efstathiou, Nikolaos, Walker, Wendy

Abstract: To explore the experiences of intensive care nurses who provided end-of-life care to adult patients and their families after a decision had been taken to withdraw treatment. End-of-life care following treatment withdrawal is a common phenomenon in intensive care. Less is known about nurses’ experiences of providing care for the dying patient and their family in this context, when compared to specialist palliative care. Descriptive exploratory qualitative study. A purposive sample of 13 intensive care nurses participated in a semistructured face-to-face interview. Transcribed data were analysed using the principles of interpretative phenomenological analysis. The essence of nurses’ experiences of providing end-of-life care after the withdrawal of treatment was interpreted as ‘doing the best to facilitate a comfortable and dignified death’. Four master themes included the following: caring for the dying patient and their family; providing and encouraging presence; reconnecting the patient and family; and dealing with emotions and ambiguity. Uncertainties were evident on processes and actions involved in treatment withdrawal, how to reconnect patients and their family effectively and how to reduce the technological environment. Providing end-of-life care after a decision has been taken to withdraw treatment was a common aspect of intensive care. It was evident that nurses were doing their utmost to support patients and families at the end of life, despite the multiple challenges they faced. The interpretive findings from this study should assist intensive care unit nurses to better understand and develop their role in providing high-quality end-of-life care after treatment withdrawal. Practice guidelines should be developed to reduce ambiguity and support the delivery of high-quality care for adults as they approach the final stages of life in intensive care units. [PUBLICATION] 39 references

Source: BNI

13. Title: Managing cholestatic pruritus in palliative care

Citation: European Journal of Palliative Care, Nov 2014, vol. 21, no. 6, p. 266-269, 1352-2779 (Nov-Dec 2014)

Author(s): Magee, Claire

Abstract: How much do we know about pruritus and how is it best managed in palliative care? Claire Magee sums up current knowledge and evidence, outlining key treatment recommendations for healthcare practitioners. [PUBLICATION] 19 references
14. Title: Palliative cancer patients in the acute hospital setting - physiotherapists attitudes and beliefs towards this patient group
Citation: Progress in Palliative Care, December 2014, vol./is. 22/6(334-341), 0969-9260;1743-291X (01 Dec 2014)
Author(s): Taylor H.N., Bryan K.
Language: English
Abstract: Background: With advances in medical technology, increasing numbers of patients are 'living with' a terminal cancer diagnosis for longer periods; this coupled with changes in government policy is resulting in patients being treated closer to home rather than in specialist centres, bringing acute hospital physiotherapists into increasing contact with this patient group.Aim: To describe the experience of acute hospital physiotherapists with palliative cancer patients.Design: Semi-structured interviews analysed utilizing Colaizzi’s method of analysis, reported using the COREQ guidelines.Setting: Acute Hospital in the UK.Participants: The first 12 physiotherapists who volunteered for the study who met the inclusion criteria.Results: Two main themes were identified, attitudes and issues, with four sub-themes in attitudes (terminology, physiotherapists perceptions, other professionals perceived attitudes towards physiotherapists, and patients and families perceived attitudes towards physiotherapists); there were six sub-themes in issues (communication, education, emotions, boundaries, referring onward from the acute setting, and time).Conclusions and implications for practice: Some physiotherapists understand and apply their skills to improve the quality of life of palliative cancer patients. However, it is suggested that the majority of physiotherapists regard these patients as ‘dying from’ rather than ‘living with’ a terminal cancer diagnosis. Referral protocols and service pathways are lacking. There is an opportunity to improve how the profession promotes itself to other professionals, the public and physiotherapists of the future, to facilitate palliative cancer patients' access to rehabilitation when and where they need it, and to deliver services in line with government policy.
Publication type: Journal: Article
Source: EMBASE
Full text: Available EBSHOST EJS at Progress in Palliative Care

15. Title: Planning for the future: developing an advance care plan for patients with end-stage renal disease
Citation: European Journal of Palliative Care, Nov 2014, vol. 21, no. 6, p. 286-289, 1352-2779 (Nov-Dec 2014)
Author(s): Clipsham, Laura, Cooke, Caroline, Warwick, Graham
Abstract: Advance care planning can greatly benefit patients with end-stage renal disease, argue Laura Clipsham, Caroline Cooke, Graham Warwick and Coral Graham, who describe how a patient-held advance care plan was created at the Leicester General Hospital renal unit. [PUBLICATION] 14 references
Source: BNI

16. Title: Relationship With God, Loneliness, Anger, and Symptom Distress in Patients With Cancer Who Are Near the End of Life
Citation: Journal of Hospice and Palliative Nursing, Dec 2014, vol. 16, no. 8, p. 482-488, 1522-2179 (December 1, 2014)
Author(s): Scott, Linda Olson, Law, Johnathon M., Brodeur, Daniel P., Salerno, Christopher A., Thomas, Anzette, McMillan, Susan C.
Abstract: The study purpose was to explore relationship with God, symptom distress, and feelings of anger and loneliness in hospice patients with cancer. Three hundred fifty-four hospice patients completed the Memorial Symptom Assessment Scale and Hospice Quality of Life Index. Data were analyzed using descriptive statistics and correlations. Scores on satisfaction with relationship with God were very high (mean, 9.2 on a 0- to 10-point scale). We found weak, significant relationships between relationship with God and anger (r = 0.28; P = .000), loneliness (r = 0.25; p = .000), and symptom distress (r = 0.23, P = .000). If patients felt that they did not have a good relationship with God, they were more likely to feel angry. Patients who had a better relationship with God felt less lonely, which might suggest that religion was more than a set of beliefs but was a source of comfort, care, and support. Patients who perceived a satisfactory relationship with God reported less symptom distress. Patients appeared to be able to maintain their relationships with God. However, they still had other problems such as anger, loneliness, and symptom distress that are associated with their God relationship and that deserve attention. Thus, the interdisciplinary team, which includes chaplains, is critical and should remain the standard. [PUBLICATION] 35 references
Source: BNI

17. Title: Role of the community matron in advance care planning and 'do not attempt CPR' decision-making: a
qualitative study

Citation: British Journal of Community Nursing, Jan 2015, vol. 20, no. 1, p. 19-24, 1462-4753 (January 2015)
Author(s): Kazmierski, Mandy, King, Nigel
Abstract: The community matron (CM) is often the key worker caring for patients with chronic, life-limiting, long-term conditions, but these patients are not always recognised as palliative cases. This study explored the experiences of CMs with regard to advance care planning (ACP) and 'do not attempt cardiopulmonary resuscitation' (DNACPR) decision-making to understand whether or not they felt adequately prepared for this aspect of their role, and why. Qualitative data were generated from six CMs using a broad interpretive phenomenological approach. Face-to-face recorded interviews were analysed using template analysis. The study found that although participants faced complex ethical situations around ACP and DNACPR almost on a daily basis, none had received any formal training despite the emphasis on training in national and local guidelines. Participants often struggled to get their patients accepted on to the Gold Standards Framework. The research found variability and complexity of cases to be the main barriers to clear identification of the palliative phase. [PUBLICATION] 35 references
Source: BNI
Full text: Available British Journal of Community Nursing at British Journal of Community Nursing

18. Title: The changing role of palliative care in the ICU.
Citation: Critical Care Medicine, 01 November 2014, vol./is. 42/11(2418-2428), 00903493
Author(s): Aslakson, Rebecca A, Curtis, J Randall, Nelson, Judith E
Language: English
Abstract: OBJECTIVES: Palliative care is an interprofessional specialty as well as an approach to care by all clinicians caring for patients with serious and complex illness. Unlike hospice, palliative care is based not on prognosis but on need and is an essential component of comprehensive care for critically ill patients from the time of ICU admission. In this clinically focused article, we review evidence of opportunities to improve palliative care for critically ill adults, summarize strategies for ICU palliative care improvement, and identify resources to support implementation. DATA SOURCES: We searched the MEDLINE database from inception through January 2014. We also searched the Reference Library of The Improving Palliative Care in the ICU Project website sponsored by the National Institutes of Health and the Center to Advance Palliative Care, which is updated monthly. We hand-searched reference lists and author files. STUDY SELECTION: Selected studies included all English-language articles concerning adult patients using the search terms 'intensive care' or 'critical care' with 'palliative care,' 'supportive care,' 'end-of-life care,' or 'ethics.' DATA EXTRACTION: After examination of peer-reviewed original scientific articles, consensus statements, guidelines, and reviews resulting from our literature search, we made final selections based on author consensus. DATA SYNTHESIS: Existing evidence is organized to address: 1) opportunities to alleviate physical and emotional symptoms, improve communication, and provide support for patients and families; 2) models and specific interventions for improving ICU palliative care; 3) available resources for ICU palliative care improvement; and 4) ongoing challenges and targets for future research. Key domains of ICU palliative care have been defined and operationalized as measures of quality. There is increasing recognition that effective integration of palliative care during acute and chronic critical illness may help patients and families face challenges after discharge from intensive care. CONCLUSIONS: Palliative care is increasingly accepted as an essential component of comprehensive care for critically ill patients, regardless of diagnosis or prognosis. A variety of strategies to improve ICU palliative care appear to be effective, and resources including technical assistance and tools are available to support improvement efforts. As the longer-term impact of intensive care on those surviving acute critical illness is increasingly documented, palliative care can help prepare and support patients and families for challenges after ICU discharge. Further research is needed to inform efforts to integrate palliative care with intensive care more effectively and efficiently in and after the ICU and to document improvement using valid and responsive outcome measures. Publication type: journal article
Source: CINAHL
Full text: Available Critical care medicine at Critical Care Medicine

19. Title: The Death Rattle Dilemma
Citation: Journal of Hospice and Palliative Nursing, Dec 2014, vol. 16, no. 8, p. 466-471, 1522-2179 (December 1, 2014)
Author(s): Fielding, Flannery, Long, Carol O.
Abstract: Death rattle, defined as the noise created by the flow of air through secretions in the upper respiratory tract, is a well-known phenomenon associated with the dying process. The use of anticholinergics is standard practice in hospice and palliative care, yet despite a growing number of quality clinical trials, there is still no compelling scientific evidence that our interventions for death rattle are effective. Studies to date have focused on
antisecretory agents, primarily anticholinergics, with mixed results and variable interpretations. Recent placebo-controlled data suggest that death rattle may tend to diminish over time without medication. Objective measurements of patient distress indicate that dying patients experience very low levels of respiratory distress with or without death rattle. While treatment is often initiated based on the perceived distress of family members, emerging qualitative data suggest that death rattle is not always distressing to family and caregivers. Our current approach to death rattle presents a clinical and ethical dilemma; a better understanding of the range of responses and interpretations will allow nurses to frame the discussion of death rattle more effectively and help to guide care. More research is needed into nonpharmacologic, particularly communication-based, interventions for death rattle.

Source: BNI

20.Title: The experiences of patients and carers in the daily management of care at the end of life
Citation: International Journal of Palliative Nursing, Dec 2014, vol. 21, no. 12, p. 591-598, 1357-6321 (December 2014)
Author(s): Hardy, Beth, King, Nigel, Rodriguez, Alison
Abstract: Background: Home is the preferred location for most people with an advanced disease and at the end of life. A variety of care professionals work in community settings to provide support to this population. Patients and their spouses, who also care for them (spouse-carers), are rarely accompanied by these sources of support at all times, and have to manage independently between their contact with care professionals. Aim: To explore how patients and spouse-carers manage their involvement with care professionals in the community setting. Method: Interpretive phenomenology informs the design of the research, whereby 16 interviews were conducted with the patients and spouse-carers. Interviews were recorded and transcribed verbatim. Data were analysed using phenomenological techniques including template analysis. Findings: Patients and spouse-carers were interdependent and both parties played a role in co-ordinating care and managing relationships with professional care providers. The patients and spouse-carers actively made choices about how to manage their situation, and develop and modify managing strategies based on their experiences. Conclusions: When daily management is effective and care professionals acknowledge the dyadic nature of the patient and spouse-carer relationship, people have confidence in living with advanced disease.

Source: BNI
Full text: Available EBSCOhost at International Journal of Palliative Nursing

21.Title: The provision of care for residents dying in UK nursing care homes
Citation: Age and Ageing, 2014, vol./is. 43(375-379), 0002-0729;1468-2834 (2014)
Language: English
Abstract: Objectives: to identify the care currently provided to residents dying in UK nursing care homes. Method: study participants were residents who had died within 38 nursing care homes in southeast England over a 3-year period. The nursing care homes had been recruited to take part in a cluster randomised controlled trial looking at different models of facilitation while implementing the Gold Standards Framework in Care Homes (GSFCH) programme. Two researchers examined the notes and daily records of all residents who died in each of these homes between the 1 June 2008 and the 31 May 2011. Results: a total of 2,444 residents died during the 3-year period. Fifty-six percent of these residents died within a year of admission. The support from specialist healthcare services to residents during their last 6 months of life was variable. Conclusions: nursing care homes have established links with some external healthcare providers. These links included the GP, palliative care nurses and physiotherapy. As dependency of resident increase with 56% residents dying within a year of admission these links need to be expanded. The provision of health care that meets the needs of future nursing care home residents needs to be 'proactively' obtained rather than left to chance.
Publication type: Journal: Article
Source: EMBASE
Full text: Available AGE AND AGEING at Age and Ageing
Full text: Available AGE AND AGEING at Age and Ageing
Full text: Available AGE AND AGEING at Salisbury District Hospital Healthcare Library

22.Title: Using continuous sedation until death for cancer patients: A qualitative interview study of physicians' and nurses' practice in three European countries
Citation: Palliative Medicine, January 2015, vol./is. 29/1(48-59), 0269-2163;1477-030X (19 Jan 2015)
Author(s): Seymour J., Rietjens J., Bruinsma S., Deliens L., Sterckx S., Mortier F., Brown J., Mathers N., Van Der Heide
Abstract: Background: Extensive debate surrounds the practice of continuous sedation until death to control refractory symptoms in terminal cancer care. We examined reported practice of United Kingdom, Belgian and Dutch physicians and nurses. Methods: Qualitative case studies using interviews. Setting: Hospitals, the domestic home and hospices or palliative care units. Participants: In all, 57 Physicians and 73 nurses involved in the care of 84 cancer patients. Results: UK respondents reported a continuum of practice from the provision of low doses of sedatives to control terminal restlessness to rarely encountered deep sedation. In contrast, Belgian respondents predominantly described the use of deep sedation, emphasizing the importance of responding to the patient’s request. Dutch respondents emphasized making an official medical decision informed by the patient’s wish and establishing that a refractory symptom was present. Respondents employed rationales that showed different stances towards four key issues: the preservation of consciousness, concerns about the potential hastening of death, whether they perceived continuous sedation until death as an 'alternative' to euthanasia and whether they sought to follow guidelines or frameworks for practice. Conclusion: This qualitative analysis suggests that there is systematic variation in end-of-life care sedation practice and its conceptualization in the United Kingdom, Belgium and the Netherlands.

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

23.Title: Using Skype to Facilitate Presence at the End of Life
Citation: Journal of Hospice and Palliative Nursing, Dec 2014, vol. 16, no. 8, p. 489-494, 1522-2179 (December 1, 2014)
Author(s): Flanagan, Jane, DeSanto-Madeya, Susan, Simms, Benjamin
Abstract: Family presence at the end of life can be challenging in that not all people who wish to be physically present can always be there with the dying person. Social media, specifically Skype, are technology that allows persons who wish to be present to be available via videophone technology. Although this technology is widely used in business and social interactions, its use with dying persons, their families, and loved ones is poorly understood. Case studies are used to report the experience of 2 different families who used social media, specifically Skype, during the dying experience. In each case, family members who would not have otherwise been able to be present at the bedside during the dying process reported being able to actively participate in the experience. For these 2 families, the utilization of Skype at the bedside facilitated a sense of closure around the dying experience. [PUBLICATION] 24 references
Source: BNI

Publications

End of Life Care Horizon Scanning
http://palliativecarenwpctl.wordpress.com/

Social Care Institute for Excellence (SCIE) and National Council for Palliative Care (NCPC)
End of Life and palliative care: Thinking about the words we use
10 December 2014
New film from SCIE and NCPC

News

National Council for Palliative Care (NCPC)
http://www.ncpc.org.uk/news

Dying Matters
http://www.dyingmatters.org/news

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