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**Literature search results**

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**Search details**

Preferred priorities for end of life care/preferred place of end of life care. Reasons for choices and why choices can or cannot be met.

**Resources searched**

NHS Evidence; TRIP Database; Cochrane Library; AMED; BNI; CINAHL; EMBASE; MEDLINE; PsychINFO; Google Scholar

**Database search terms**: "end of life" adj2 car*; palliative* adj2 car*; terminal* adj2 car*; PALLIATIVE CARE; hospice* adj2 car*; supportive adj2 car*; comfort adj2 car*; dying adj2 car*; HOSPICE CARE; TERMINAL CARE; preference*; choice*; priorit*; dying; "terminally ill"; carer*; patient*; barrier*

**Google search string**: (~"end of life care" OR "care of the dying") (patient OR patients) (choice OR choices OR priority OR priorities OR preference OR preferences OR barrier OR barriers)

**Summary**

There is a great deal of research into patient preferences for end-of-life care and the problems in meeting them. As the request was for a broad search, I am not able to summarise further.

**Guidelines**

**British Association of Perinatal Medicine**

Palliative Care (supportive and end of life care) 2010

**Clinical Practice Guidelines Portal (Australia)**
Evidence-based reviews

Best Evidence Statements - Cincinnati Children’s Hospital
Sibling Support in End of Life Care 2011

Cochrane Database of Systematic Reviews
End-of-life care pathways for improving outcomes in caring for the dying 2011
End-of-life pathways are used for people who are in the last days of their life to guide care; aid decision making; and provide efficient care. This review examined whether using end-of-life care pathways in caring for the dying was effective. No studies meeting the inclusion criteria were found that used an end-of-life care pathway in caring for the dying. Therefore, there is insufficient data at present to make recommendations regarding the use of such end-of-life care pathways for the dying.

Hospital at home: home-based end of life care 2011
The evidence included in this review supports the use of end of life home-care programmes for increasing the number of patients who will die at home, although the numbers of patients being admitted to hospital while receiving end of life care should be monitored. Future research should also systematically assess the impact of end of life home care on care givers.

Clinical Practice Guidelines and Protocols in British Columbia
Palliative Care for the Patient with Incurable Cancer or Advanced Disease - Part 1: Approach to Care 2010

Database of Abstracts of Review of Effects
Impact on patients and carers: Based on one study (self-report audit), those who used the Gold Standards Framework indicated improved end-of-life care for patients (and to a
lesser degree carers). Improvements included increased equity of care, greater access to specialist support and more responsive care, and potential improvements in patient choice.

Working with Evidence about Learning Disabilities
Carers’ perspectives on end of life care for people with learning disabilities 2011

Published research

Results from CINAHL and EMBASE

1. End-of-life care pathways as tools to promote and support a good death: a critical commentary.

Author(s): Watts, T.

Citation: European Journal of Cancer Care, 01 January 2012, vol./is. 21/1(20-30), 09615423

Publication Date: 01 January 2012

Abstract: WATTS T. (2012) European Journal of Cancer Care 21, 20-30, End-of-life care pathways as tools to promote and support a good death: a critical commentary This paper calls into question whether and how end-of-life care pathways facilitate the accomplishment of a 'good death'. Achieving a 'good death' is a prominent social and political priority and an ideal which underpins the philosophy of hospice and palliative care. End-of-life care pathways have been devised to enhance the care of imminently dying patients and their families across care settings and thereby facilitate the accomplishment of a 'good death'. These pathways have been enthusiastically adopted and are now recommended by governments in the UK as 'best practice' templates for end-of-life care. However, the literature reveals that the 'good death' is a nebulous, fluid concept. Moreover, concerns have been articulated regarding the efficacy of care pathways in terms of their impact on patient care and close analysis of two prominent end-of-life pathways reveals how biomedical aspects of care are privileged. Nonetheless drawing on a diverse range of evidence the literature indicates that end-of-life care pathways may facilitate a certain type of 'good death' and one which is associated with the dying process and framed within biomedicine.

Source: CINAHL


Author(s): Neergaard, Mette Asbjoern, Jensen, Anders Bonde, Sondergaard, Jens, Sokolowski, Ineta, Olesen, Frede, Vedsted, Peter

Citation: Scandinavian Journal of Caring Sciences, 01 December 2011, vol./is. 25/4(627-636), 02839318

Publication Date: 01 December 2011

Abstract: Scand J Caring Sci; 2011; 25; 627-636 Preference for place-of-death among terminally ill cancer patients in Denmark Achieving home death is often seen as an important endpoint in palliative care, but no studies of the preferred place-of-death have yet been conducted in Scandinavia. Furthermore, we do not know if professionals' report on deceased patients' preference of place-of-death is a valid information. The aim of this study was to describe where terminally ill Danish cancer patients prefer to die and to determine if their preference changed during the palliative period, as reported retrospectively by bereaved relatives, general practitioners (GPs) and community nurses (CNs) and to assess the agreement of their accounts. The study was a population-based, cross-sectional combined register and questionnaire study in Aarhus County, Denmark. The population comprised 599 deceased adult cancer patients who had died from 1 March to 30 November 2006 and were identified through merging of health registers. Relatives returned 198 questionnaires about patients’ preferred place-of-death, GPs 333 and CNs 201. The study showed that most terminally ill cancer patients preferred home death (up to
The reported preference for home death weakened as death approached (down to 64.4%). A better congruence was seen between relatives' and GPs' accounts of preference for place of death at the end of the palliative period (0.71) than between relatives' and CNs' accounts (0.37). In conclusion, bereaved relatives (and GPs and CNs) report retrospectively that most terminally ill cancer patients wish to die at home. The preference weakened significantly as death approached. The agreement between relatives' and GPs' accounts on patients' preferences at the end of the palliative period was 'substantial', whereas the agreement between relatives' and CNs' accounts at the same time was significantly less outspoken. This indicates that CNs may be facing a problem in assessing their patients' wishes retrospectively.

Source: CINAHL


Author(s): Turan B., Goldstein M.K., Garber A.M., Carstensen L.L.

Citation: Health Psychology, 01 November 2011, vol./is. 30/6(814-818), 02786133

Abstract: Objective: At times, caregivers make life-and-death decisions for loved ones. Yet very little is known about the factors that make caregivers more or less accurate as surrogate decision makers for their loved ones. Previous research suggests that in low stress situations, individuals with high attachment-related anxiety are attentive to their relationship partners' wishes and concerns, but get overwhelmed by stressful situations. Individuals with high attachment-related avoidance are likely to avoid intimacy and stressful situations altogether. We hypothesized that both of these insecure attachment patterns limit surrogates' ability to process distressing information and should therefore be associated with lower accuracy in the stressful task of predicting their loved ones' end-of-life health care wishes. Method: Older patients visiting a medical clinic stated their preferences toward end-of-life health care in different health contexts, and surrogate decision makers independently predicted those preferences. For comparison purposes, surrogates also predicted patients' perceptions of everyday living conditions so that surrogates' accuracy of their loved ones' perceptions in nonstressful situations could be assessed. Results: Surrogates high on either type of insecure attachment dimension were less accurate in predicting their loved ones' end-of-life health care wishes. It is interesting to note that even though surrogates' attachment-related anxiety was associated with lower accuracy of end-of-life health care wishes of their loved ones, it was associated with higher accuracy in the nonstressful task of predicting their loved ones' everyday living conditions. Conclusions: Attachment orientation plays an important role in accuracy about loved ones' end-of-life health care wishes. Interventions may target emotion regulation strategies associated with insecure attachment orientations.

Source: CINAHL

4. New service gives dying patients choice of going home.

Citation: Primary Health Care, 01 November 2011, vol./is. 21/9(5-5), 02645033

Source: CINAHL

Full Text: Available in fulltext at EBSCOhost

5. Knowing Loved Ones' End-of-Life Health Care Wishes: Attachment Security Predicts Caregivers' Accuracy

Author(s): Turan B., Goldstein M.K., Garber A.M., Carstensen L.L.

Citation: Health Psychology, November 2011, vol./is. 30/6(814-818), 0278-6133;1930-7810 (November 2011)

Abstract: Objective: At times, caregivers make life-and-death decisions for loved ones.
Yet very little is known about the factors that make caregivers more or less accurate as surrogate decision makers for their loved ones. Previous research suggests that in low stress situations, individuals with high attachment-related anxiety are attentive to their relationship partners' wishes and concerns, but get overwhelmed by stressful situations. Individuals with high attachment-related avoidance are likely to avoid intimacy and stressful situations altogether. We hypothesized that both of these insecure attachment patterns limit surrogates' ability to process distressing information and should therefore be associated with lower accuracy in the stressful task of predicting their loved ones' end-of-life health care wishes. Method: Older patients visiting a medical clinic stated their preferences toward end-of-life health care in different health contexts, and surrogate decision makers independently predicted those preferences. For comparison purposes, surrogates also predicted patients' perceptions of everyday living conditions so that surrogates' accuracy of their loved ones' perceptions in nonstressful situations could be assessed. Results: Surrogates high on either type of insecure attachment dimension were less accurate in predicting their loved ones' end-of-life health care wishes. It is interesting to note that even though surrogates' attachment-related anxiety was associated with lower accuracy of end-of-life health care wishes of their loved ones, it was associated with higher accuracy in the nonstressful task of predicting their loved ones' everyday living conditions. Conclusions: Attachment orientation plays an important role in accuracy about loved ones' end-of-life health care wishes. Interventions may target emotion regulation strategies associated with insecure attachment orientations. 2011 American Psychological Association.

Source: EMBASE

6. Do interventions designed for 'home alone' people dying from cancer improve their end of life experience?

Author(s): Aoun S.M., O'Connor M., Skett K., Smith J.M., Deas K.

Citation: Asia-Pacific Journal of Clinical Oncology, November 2011, vol./is. 7/(172), 1743-7555 (November 2011)

Publication Date: November 2011

Abstract: Objectives: This project implemented and evaluated two models of palliative care service delivery for terminally ill people with cancer and living alone at home, in collaboration with Silver Chain Hospice Care Service. The aim was to assess the impact of the models of care on the participants' quality of life, symptom distress, anxiety and depression, satisfaction with care and perceived benefits and barriers to using them, from patients' and service providers' perspectives. Methods: Two models of care were piloted and evaluated in collaboration with Silver Chain Hospice Care (SCHC): Installing CareLink Alarm systems and providing extra care aide support. Using a pilot randomised controlled trial design, a third of participants received extra Care-aide time, another third received CareLink alarms and the last third received standard care (20 in each group). The intervention period was between six to twelve weeks depending on prognosis. Results: Findings are discussed in light of two methodological considerations: The wide variation in the degrees of "home aloneness" and the RCT methodological challenges in palliative care. This research project has highlighted the difficulties experienced by clients who live home alone with a terminal illness. There were physical and psychological benefits for clients associated with provision of the two interventions and a service provision benefit for nursing staff. Conclusion: This pilot study provided essential information for the planning of a definitive multi-centred study. It assessed the feasibility and acceptability of the approach for this client group and in a community based setting. The outcomes of the project have prompted changes in practice when providing care to clients who are home alone.

Source: EMBASE

7. Needs, priorities, and concerns of terminally ill cancer patients: A literature review

Author(s): Lelorain S., Anne B., Dolbeault S., Sultan S.

Citation: Psycho-Oncology, October 2011, vol./is. 20/(181), 1057-9249 (October 2011)

Publication Date: October 2011
Abstract: BACKGROUND: Terminally ill cancer patients face many wearing issues such as the idea of a near death and the management of the disease and its symptoms. They also often have to adapt to the new environment of a palliative care unit. Our goal was to review the literature on these specific patient needs, priorities, and concerns in order to provide an overview of what is really important from the patient's perspective near the end of life. METHOD: Using PubMed and PsycInfo databases, we carried out the search on cancer patients with the 2 following entries in forced combination: index terms referring to terminally ill cancer patients (i.e. "terminally ill patients", "terminal cancer", "palliative care", "hospice") AND index or simple terms referring to the patient's point of view about what is important to them at this specific stage of their life (i.e. 'priorities', 'needs', 'concerns', 'values', 'satisfaction', 'well-being', 'quality of life', 'adjustment', 'person-environment fit', 'goals', 'motivation'). Only journal articles were searched. RESULTS: Twenty-seven returned hits were kept. Patient priorities and needs were: the management of pain, the maintenance of dignity, as much independence/autonomy as possible, involvement in everyday and social life, experiencing personal and emotional control, meaningful personal relationships, and an immediate convivial environment with the expectation of a helpful and human medical staff. The maintenance of hope and an optimistic outlook as well as a sense of spirituality and wisdom/acceptance were also reported as important components of the current quality of life. Patients were concerned for their family and did not want to become a burden to them. CONCLUSIONS: These results should be considered in a palliative setting which patients cannot leave. This is why the immediate palliative care environment seems to play a major role in this context. Indeed, pain relief, patient dignity, conveying hope, and social life all depend to a great extent on the palliative care setting, and thus are essential resources for patient well-being and coping with the difficulties of a terminal disease. RESEARCH IMPLICATIONS: Based on these first results as well as on further studies, questionnaires about the needs and priorities of terminally ill cancer patients could be created and tested. Such questionnaires could be a useful alternative to the current quality of life questionnaires since the latter have sometimes shown unexpected high scores in the palliative context, revealing the limited relevance of the quality of life concept in such a setting. CLINICAL IMPLICATIONS: This review suggests that, as far as their physical health allows, patients would welcome a livelier place for a palliative unit. Shared, multibedded rooms, and more contact with the outside environment could be implemented, and would probably be a basis for the actualization of positive mental coping and thus a more meaningful end of life. All mental and social activities that could help patients to gain control should be envisaged.

Source: EMBASE

8. Emergency department-initiated palliative care consults: A descriptive analysis

Author(s): Lamba S., Nagurka R., Saripalli S., Driscoll T., Walther S., Murphy P.

Citation: Annals of Emergency Medicine, October 2011, vol./is. 58/4 SUPPL. 1(S250-S251), 0196-0644 (October 2011)

Publication Date: October 2011

Abstract: Study Objectives: There has been a major interest in the fast-growing field of palliative medicine, to move such services upstream to the emergency department (ED). There is potential to enhance patient-centered ED care by providing earlier goals-of-care discussions in those suffering with end-stage life-limiting illnesses and aligning treatment with patient values/preferences. The needs for palliative care (PC) services are likely to be quite different in the ED setting, where care is focused on the acutely ill and those with ill-defined prognosis and disease trajectories as compared to the traditional in-patient PC consultations. We study the patterns of ED-Initiated PC consults (EDIPCC) and provision of PC services in this setting in order to characterize the needs of the ED patients/ED clinicians when they seek PC consults. Methods: Descriptive analyses of PC consults performed from March 3, 2008 to June 10, 2009. We further analyze EDIPCC in an urban, level-1 Trauma Center ED with 100,000 visits per year. The PC team comprises of; 2 advanced nurse practitioners, 2 masters trained specialists/bereavement support counselors with availability of social workers and volunteer clergy. Results: There were 71 EDIPCC requested in the time period and available for analyses. The majority of patients were African-American (48/71, 67%), with average age of 49 years, and equal sex distribution (48% females; 52% males). Mortality rate in those with EDIPCC was 65%
Disposition of EDPICC patients was death (46/71, 65%), discharge home or to home-hospice (18/71, 14%) and hospitalization (7/71, 11%) with an average length of stay; 2 days in hospital or 1.1 day in ICU. In comparison, mortality rate of in-patient requested PC was 37% (7/19) with average hospital length of stay of 6.1 days. EDIPCC provided the following major services; emotional support (69/71, 94%); goals-of-care discussions (39/71, 55%); bereavement support (39/71, 55%); EOL care (36/71, 51%); hospice-related discussions (22/71, 31%) and withdrawal of life-support (9/71, 13%). Communication comprised mainly around; advance directive/DNR (28/71, 40%); family meeting (63/71, 89%); communicating family needs with care providers (RN 90%, resident 58%, ED attending 68%); social work consult (25%), clergy (14%) and palliative care order sheet (6%). There were no significant differences in PC provision in the patients who died, but an expected increase in bereavement support (37/46, 80%). Conclusion: EDIPCC patients involve a young patient population, likely secondary to traumatic and critical, sudden life-altering events. In-hospital mortality rate for EDIPCC patients is very high (most dying in the ED setting); signifying a trend for ED to request PC consults in those who are imminently dying. PC consult teams who are called for an ED consult should therefore expect to provide time-sensitive services and anticipate a high level of bereavement/emotional support to distraught, unprepared families, with major discussions around goals-of-care, advance directives, and hospice.

Source: EMBASE

Full Text:
Available in fulltext at the ULHT Library and Knowledge Services' eJournal collection


Author(s): Whiteside, Kathy

Citation: Australian Nursing Journal, 01 October 2011, vol./is. 19/4(24-24), 13203185

Publication Date: 01 October 2011

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost

10. Evidence-Based Practice. The Going Home Initiative: Getting Critical Care Patients Home With Hospice.

Author(s): Lusardi, Paula, Jodka, Paul, Stambovsky, Mark, Stadnicki, Beth, Babb, Betty, Plouffe, Danielle, Doubleday, Nancy, Pizlak, Zophia, Walles, Katherine, Montonye, Martin

Citation: Critical Care Nurse, 01 October 2011, vol./is. 31/5(46-57), 02795442

Publication Date: 01 October 2011

Abstract: Although considerable effort is being directed at providing patients and their families with a "good death," most patients in intensive care units, if given the choice, would prefer to die at home. With little guidance from the literature, the palliative care committee of an intensive care unit developed guidelines to get patients home from the intensive care unit to die. In the past few years, the unit has transferred many patients home with hospice care, much to the delight of their families. Although several obstacles to achieving this goal exist, the unit has achieved success in a small-scale implementation of its Going Home Initiative.

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost


Author(s): Bakitas, Marie, Kryworuchko, Jennifer, Matlock, Dan D., Volandes, Angelo E.

Citation: Journal of Palliative Medicine, 01 October 2011, vol./is. 14/10(1109-1116),
Assisting patients and their families in complex decision making is a foundational skill in palliative care; however, palliative care clinicians and scientists have just begun to establish an evidence base for best practice in assisting patients and families in complex decision making. Decision scientists aim to understand and clarify the concepts and techniques of shared decision making (SDM), decision support, and informed patient choice in order to ensure that patient and family perspectives shape their health care experience. Patients with serious illness and their families are faced with myriad complex decisions over the course of illness and as death approaches. If patients lose capacity, then surrogate decision makers are cast into the decision-making role. The fields of palliative care and decision science have grown in parallel. There is much to be gained in advancing the practices of complex decision making in serious illness through increased collaboration. The purpose of this article is to use a case study to highlight the broad range of difficult decisions, issues, and opportunities imposed by a life-limiting illness in order to illustrate how collaboration and a joint research agenda between palliative care and decision science researchers, theorists, and clinicians might guide best practices for patients and their families.

Source: CINAHL

Available in fulltext at EBSCOhost

12. Influence of location on a good death.

Author(s): Paddy, Miranda

Citation: Nursing Standard, 07 September 2011, vol./is. 26/1(33-36), 00296570

Abstract: With the recent emphasis of the Department of Health on reducing unnecessary hospitalisation at the end of life and improving community care for people dying at home, it could be assumed that dying at home is the gold standard. However, healthcare professionals should be able to give a patient choice over where they die, whether that is at home, in hospital or in a hospice. This article asks the reader to consider whether location of death has influence on the quality of death.

Source: CINAHL

Available in fulltext at EBSCOhost

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

Available in print at South County Hospital Medical Library

Available in print at Pilgrim Hospital Staff Library

13. Influence of location on a good death

Author(s): Paddy M.

Citation: Nursing standard (Royal College of Nursing (Great Britain) : 1987), September 2011, vol./is. 26/1(33-36), 0029-6570 (2011 Sep 7-13)

Abstract: With the recent emphasis of the Department of Health on reducing unnecessary hospitalisation at the end of life and improving community care for people dying at home, it could be assumed that dying at home is the gold standard. However, healthcare professionals should be able to give a patient choice over where they die, whether that is at home, in hospital or in a hospice. This article asks the reader to consider whether location of death has an influence on the quality of death.

Source: EMBASE
14. Perceptions of terminally ill patients and family members regarding home and hospice as places of care at the end of life

Author(s): Luijkx K.G., Schols J.M.G.A.

Citation: European Journal of Cancer Care, September 2011, vol./is. 20/5(577-584), 0961-5423;1365-2354 (September 2011)

Publication Date: September 2011

Abstract: To enable demand-based palliative care, it is important to know the perceptions of terminally ill patients and their family members regarding home and hospice as places of care at the end of life. Eight women and five men suffering from cancer and with a life expectancy of 3 months or less were interviewed. In each case one of the family members was also interviewed. Four patients spent their last phase of life at home, nine in a hospice. This paper provides further insight in the patient perspective in palliative care. The results reveal that a cohabiting partner seems an important prerequisite for terminally ill patients to stay at home. For spouses it is an obvious choice to facilitate the patients' stay at home, even when it becomes too demanding, something not discussed between spouse and patient. When sufficient care at home seems impossible and the negotiation between patients and family members results in the opinion that living at home is no longer an option, it is decided that the patient moves to a hospice. The choice for the specific setting of the patients' new residence seems to be random; one possibility is pointed out to them and seems appropriate. 2010 Blackwell Publishing Ltd.

Source: EMBASE

15. Supportive care for women with recurrent miscarriage: Patients' preferences

Author(s): Musters A.M., Koot Y.E.M., Van Den Boogaard N.M., Van Kaaijk E., MacKlon N.S., Van Der Veen F., Nieuwkerk P.T., Goddijn M.

Citation: Journal of Reproductive Immunology, August 2011, vol./is. 90/2(157-158), 0165-0378 (August 2011)

Publication Date: August 2011

Abstract: Introduction: Supportive care is regularly offered to women with recurrent miscarriages (RM), reporting live birth rates up to 85%. What these women prefer as supportive care in their next pregnancy has recently been identified by qualitative research. The aim of this study was to quantify these supportive care options and identify women's characteristics that predict the need for supportive care in women with RM. Materials and methods: A questionnaire study was conducted in 266 women with recurrent miscarriages in three hospitals in the Netherlands. All women that received diagnostic work-up for recurrent miscarriages (>=2 miscarriages) between January 2010 and December 2010 were sent a questionnaire. The questionnaire consisted of three parts. In the first part, general data on the women was collected. This included age, education level, ethnicity, diagnosis (translocations, antiphospholipid syndrome, endocrine disorders, uterine abnormalities and unexplained), if they still had a wish to conceive and their obstetric history. The second part of the questionnaire contained 41 Likert scale item supportive care options that were identified in our previous qualitative study (Musters et al., 2011). The five point Likert scale items ranged from total disagreement to total agreement for a particular supportive care option that could be offered in their next pregnancy. To assess the overall preference for supportive care during their next pregnancy, we asked participants to state their need for supportive care on a one to ten scale, in the final part of the questionnaire. Ten reflected the highest and one reflected the lowest need for supportive care. All questionnaires were sent by post in January 2011. Two reminders were sent to non-respondents in a period of 10 weeks. In each questionnaire a prepaid
return envelope was added. Results: In total, 174 women responded (response rate 65%) and 171 questionnaires were analysed. In general, women with RM prefer the following supportive care options for their next pregnancy: to make a plan for the first trimester (80%) with one doctor (70%) preferably a gynaecologist or doctor specialized in RM (79%) that shows understanding (81%), takes you seriously (87%), listens to you (86%) and shows empathy (76%), informs how you are doing (74%), informs on your emotional needs (60%), has knowledge of the obstetric history (86%) and gives information about RM (84%). Also an ultrasound during symptoms (88%), directly after a positive pregnancy test (67%) and every two weeks a repeat ultrasound (66%) was preferred by the majority of women with RM. Finally 61% of women would prefer to talk to a medical or psychological professional after their next miscarriage. In general, the majority of the women did not prefer admittance to a hospital ward on the same gestational age as previous miscarriages (65%) nor bereavement therapy (66%). The mean preference for supportive care for women with RM on a one to ten scale was 8.0+/-2.2. Ethnicity, education level, parity, pregnancy during questionnaire and time passed since last miscarriage proved to be predictors in the preference of different supportive care options, female age did not. Conclusions: In conclusion, our study shows that women with RM want supportive care during their next pregnancy. Women with RM prefer medical supportive care from a gynaecologist or doctor specialized in RM that takes them seriously. Women from ethnic minorities and women who were not pregnant during the questionnaire are the two patient groups that prefer the most supportive care options. Tailor-made supportive care can now be offered to women with RM.

Source: EMBASE

16. Aligning patient preferences and patient care at the end of life

Author(s): Dunn A., Litrivis E.

Citation: Journal of General Internal Medicine, July 2011, vol./is. 26/7(681-682), 0884-8734;1525-1497 (July 2011)

Publication Date: July 2011

Source: EMBASE

17. England's approach to improving end-of-life care: a strategy for honoring patients' choices

Author(s): Gray B.H.

Citation: Issue brief (Commonwealth Fund), July 2011, vol./is. 15/(1-15), 1558-6847 (Jul 2011)

Publication Date: July 2011

Abstract: In the U.S. health care system, and in those of many other countries, the care of dying patients is generally not performed well, with pain and other distress frequently undertreated and patients' preferences not respected. England's evidence-based End of Life Care Strategy could prove instructive. This issue brief discusses the origins, content, and implementation of the Strategy, as well as its potential impact. Both England and the United States struggle with similar challenges, including looking beyond the province of hospice and palliative-care specialists and initiating palliative services before the patient's final days. Aspects of the English approach that may be useful in the United States include strategies to help physicians recognize when patients are entering a trajectory that may end in death, the use of "death at home" as a metric for measuring progress, improving the skills of clinical and caregiving personnel through Web-based training, and developing a national improvement pathway.

Source: EMBASE

18. What are patients’ priorities when facing the end of life? A critical review

Author(s): Black J.

Citation: International Journal of Palliative Nursing, June 2011, vol./is. 17/6(294-300), 1357-6321 (June 2011)
**Abstract:** This critical review aimed to investigate what patients’ priorities are when facing the end of life, in order to gain further understanding of this issue. Academic databases were searched using key terms, and through a method of elimination and deduction using specific inclusion/exclusion criteria, suitable research studies were found. These articles were then assessed for their quality, and specific data was extracted from the final selection using appropriate information-gathering tools. In these final four articles the methodological processes used to explore terminally ill patients’ needs were generally appropriate, although there was a lack of reflexivity (researcher reflection on the experience). Useful narrative themes were produced from all four papers for further discussion. The patients had similar priorities across all four articles, which were related to understanding and accepting their changing health status, the need to hold on to some normality in life, the need to feel supported by friends and family and to know they will be taken care of after the death, and the need to have good and trusting relationships with health professionals.

**Source:** EMBASE

**Full Text:** Available in fulltext at EBSCOhost

19. **Applying the preferred priorities for care document in practice.**

**Author(s):** Reynolds, Joanne, Croft, Sue

**Citation:** Nursing Standard, 11 May 2011, vol./is. 25/36(35-42), 00296570

**Publication Date:** 11 May 2011

**Abstract:** Patient choice and control should be central to the delivery of high-quality, end of life care. Advance care planning (ACP) is a process through which a patient’s choices and preferences for care can be discussed and documented. It also enables patients to express what they would want to happen to them in the event that they lose capacity to make decisions. This article focuses on the use of the patient-held Preferred Priorities for Care (PPC) document, an example of an ACP tool. This article aims to provide a greater understanding of the PPC document as an end of life care tool and increase practitioners’ knowledge, confidence and competence in undertaking ACP conversations with patients and their carers. Four case studies are provided to link theory to practice.

**Source:** CINAHL

**Full Text:** Available in fulltext at EBSCOhost

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

Available in print at Louth County Hospital Medical Library

Available in print at Pilgrim Hospital Staff Library

20. **Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: A systematic review.**

**Author(s):** Frost DW, Cook DJ, Heyland DK, Fowler RA

**Citation:** Critical Care Medicine, 01 May 2011, vol./is. 39/5(1174-1189), 00903493

**Publication Date:** 01 May 2011

**Abstract:** OBJECTIVES: The need for better understanding of end-of-life care has never been greater. Debate about recent U.S. healthcare system reforms has highlighted that end-of-life decision-making is contentious. Providing compassionate end-of-life care that is appropriate and in accordance with patient wishes is an essential component of critical care. Because discord can undermine optimal end-of-life care, knowledge of factors that influence decision-making is important. We performed a systematic review to determine which factors are known to influence end-of-life decision-making among patients and healthcare providers. DATA SOURCES, SELECTION, AND ABSTRACTION:: We...
conducted a structured search of Ovid Medline for interventional and observational research articles incorporating critical care and end-of-life decision-making terms. DATA SYNTHESIS: Of 6259 publications, 102 were relevant to our review question. Patient factors predicting less intensive end-of-life care include increasing age, comorbidity, and limited functional status; these factors appear to be influential for both clinicians and patients. Patient and clinician race, ethnicity, and nationality also appear to influence the technological intensity of end-of-life care. In general, white patients and those in North America and Northern Europe may be less likely to desire intensive end-of-life care than others. Physicians of similar geo-ethnic origin to patients appear less likely to prescribe such therapy. Physicians with more clinical experience and those routinely working in the intensive care unit are less likely than other physicians to recommend technologically intense care for critically ill patients at the end-of-life. CONCLUSIONS: Patients and clinicians may approach end-of-life discussions with different expectations and preferences, influenced by religion, race, culture, and geography. Appreciation of those factors associated with more and less technologically intense care may raise awareness, aid communication, and guide clinicians in end-of-life discussions.

Source: CINAHL

Full Text:
Available in full text at the ULHT Library and Knowledge Services' eJournal collection

21. Preferences for end of life: views of hospice patients, family carers, and community nurse specialists.
Author(s): Holdsworth, Laura, King, Annette
Citation: International Journal of Palliative Nursing, 01 May 2011, vol./is. 17/5(251-255), 13576321
Publication Date: 01 May 2011
Abstract: An exploratory qualitative study was undertaken with the aim of identifying issues around discussing and recording preferences on place of death from the perspective of hospice patients, carers, and hospice community nurses. A purposive sample was selected from three hospices in the south east of England of six community nurse specialists (CNSs), five patients, five carers, and five bereaved carers. The patients and carers said it was important to them to discuss their preferences, but they acknowledged that discussing dying was difficult. The CNSs stated that there were several barriers that inhibited end-of-life discussions and that discussing preferences was not always a primary goal of care planning. It was felt among the service users, particularly the bereaved carers, that having more knowledge about what to expect of the dying process, knowing their relative’s wishes, and understanding the role of hospice and palliative care could improve the experience of events leading up to death.

Source: CINAHL

Full Text:
Available in full text at EBSCOhost

22. Preferences for end of life: Views of hospice patients, family carers, and community nurse specialists
Author(s): Holdsworth L., King A.
Citation: International Journal of Palliative Nursing, May 2011, vol./is. 17/5(251-255), 1357-6321 (May 2011)
Publication Date: May 2011
Abstract: An exploratory qualitative study was undertaken with the aim of identifying issues around discussing and recording preferences on place of death from the perspective of hospice patients, carers, and hospice community nurses. A purposive sample was selected from three hospices in the south east of England of six community nurse specialists (CNSs), five patients, five carers, and five bereaved carers. The patients and carers said it was important to them to discuss their preferences, but they acknowledged that discussing dying was difficult. The CNSs stated that there were several barriers that
inhibited end-of-life discussions and that discussing preferences was not always a primary goal of care planning. It was felt among the service users, particularly the bereaved carers, that having more knowledge about what to expect of the dying process, knowing their relative's wishes, and understanding the role of hospice and palliative care could improve the experience of events leading up to death.

Source: EMBASE

Full Text:
Available in fulltext at EBSCOhost

23. Nurses' perceptions and experiences with end-of-life communication and care

Author(s): Boyd D., Merkh K., Rutledge D.N., Randall V.

Citation: Oncology Nursing Forum, May 2011, vol./is. 38/3(E229-E239), 0190-535X;1538-0688 (May 2011)

Publication Date: May 2011

Abstract: Purpose/Objectives: To characterize oncology nurses' attitudes toward care at the end of life (EOL) and their experiences in caring for terminally ill patients, hospice discussions with patients and families, and the use of palliative care practices. Design: Descriptive correlational survey study. Setting: A Magnet-designated hospital in southern California with more than 500 beds. Sample: 31 oncology nurses. Methods: Nurses completed the adapted version of the Caring for Terminally Ill Patients Nurse Survey. Main Research Variables: Attitudes toward care at EOL and care experiences with terminally ill patients. Findings: Despite having fairly positive attitudes toward hospice and having discussions about prognosis with terminally ill patients, nurses reported missed opportunities for discussions and patient referrals to hospice. On average, nurses cared for more than seven terminally ill patients during a three-month period while only discussing hospice care with a third of these patients and their family members. Most nurses acknowledged that patients would benefit from earlier initiation of hospice care. Specific palliative care practices used by nurses in the past three months varied, with active and passive listening and requesting increased pain medications used most frequently and aromatherapy and guided imagery used least. Conclusions: Missed opportunities may reflect nurses' attitudes. However, lack of patient and family member acceptance was the most important barrier to discussion of hospice. Implications for Nursing: Strategies to enable nurses to have a stronger voice during this critical time for their patients are needed and, when developed, supported in practice to ensure that they are used.

Source: EMBASE

24. What nurses need to know about Buddhist perspectives of end-of-life care and dying

Author(s): Chan T.W., Poon E., Hegney D.G.

Citation: Progress in Palliative Care, March 2011, vol./is. 19/2(61-65), 0969-9260;1743-291X (March 2011)

Publication Date: March 2011

Abstract: Palliative care professionals, particularly nurses, understand that it is crucial to deliver culturally and religiously appropriate care to the dying while attending to their physical needs. This article provides a brief overview of the different types of Buddhism and the major beliefs of Buddhists, particularly around suffering and death. It explores the impact of some of the current practices of end-of-life care from the Buddhist perspective, with an emphasis on Buddhist goals, beliefs, and practices at the time of death. It outlines the importance of advanced care planning, particularly with respect to the use of analgesia, palliative sedation, and any special dietary requirements. It notes that regardless of advanced care planning, nurses should continue to assess the needs of the patient, and in discussion with family, titrate medication and provide an environment that helps the Buddhist reach his/her spiritual goals. It outlines the importance of the environment in achieving this goal, particularly as the Buddhist practitioner will wish to use non-medication practices, such as meditation and chanting, to finish the last meditation before death. The
paper provides guidance on how nurses can ensure a good death for the dying Buddhist, and their family or loved ones, especially in the area of choice in terminal pain management and palliative sedation therapy. W.S. Maney & Son Ltd. 2011.

**Source:** EMBASE

25. **Dying with dignity -- the case for end of life choices.**

**Author(s):** Levett, Coral

**Citation:** Australian Nursing Journal, 01 March 2011, vol./is. 18/8(48-48), 13203185

**Publication Date:** 01 March 2011

**Source:** CINAHL

**Full Text:**
Available in fulltext at EBSCOhost

26. **The Supportive Care Needs of Men With Advanced Prostate Cancer.**

**Author(s):** Carter, Nancy, Bryant-Lukosius, Denise, DiCenso, Alba, Blythe, Jennifer, Neville, Alan J.

**Citation:** Oncology Nursing Forum, 01 March 2011, vol./is. 38/2(189-198), 0190535X

**Publication Date:** 01 March 2011

**Abstract:**
Purpose/Objectives: To better understand the priority supportive care needs of men with advanced prostate cancer.
Research Approach: Qualitative, descriptive study.
Setting: Outpatient cancer center and urology clinics in central western Ontario, Canada.
Participants: 12 men with hormone-sensitive prostate cancer and 17 men with hormone-refractory prostate cancer.
Methodologic Approach: Participants participated in focus groups and interviews that examined their supportive care needs, their priority needs, and suggestions for improvements to the delivery of care. Tape-recorded focus group discussions and interviews were organized using NVivo software.
Main Research Variables: Patients' supportive care needs.
Findings: Participants identified prostate cancer-specific information and support to maintain their ability "to do what they want to do" as priority needs. Both hormone-sensitive and hormone-refractory groups cited problems with urinary function, the side effects of treatment, fatigue, and sexual concerns as major functional issues. Participants experienced emotional distress related to diagnosis and treatment.
Conclusions: A priority health need for men with advanced prostate cancer is to improve or maintain functional abilities. In addition, men require support to meet their stage-specific information needs and to address concerns about the diagnosis and ambivalent feelings about past treatment decisions.
Interpretation: Nurses could play an important role in addressing men's information needs and providing emotional support. The complex care needs of men with advanced prostate cancer provide opportunity for the development of advanced practice nurse roles that would use the clinical and nonclinical aspects of the role.

**Source:** CINAHL

27. **Why is end-of-life care delivery sporadic?: A quantitative look at the barriers to and facilitators of providing end-of-life care in the neonatal intensive care unit**

**Author(s):** Wright V., Prasun M.A., Hilgenberg C.

**Citation:** Advances in Neonatal Care, February 2011, vol./is. 11/1(29-36), 1536-0903 (February 2011)

**Publication Date:** February 2011

**Abstract:**
PURPOSE: According to the Centers for Disease Control and Prevention Infant Mortality Statistics, 28 384 infants died in the United States in 2005. On examining the state of the science in providing end-of-life care for newborns, it is important to examine the practice of providing compassionate and dignified palliative care at the end of life. The purpose of this research study was to examine the barriers to and facilitators of providing a quality end-of-life care in one large Midwestern tertiary NICU. 

SUBJECTS: A convenience sample of 50 NICU registered nurses from a Level III Midwestern Facility participated.
METHODS: A quantitative, prospective, cross-sectional design was used. Data were collected with the Neonatal Palliative Care Attitude Scale questionnaire. RESULTS: Five barriers and 8 facilitators to end-of-life care practice in the NICU were identified. The 5 barriers were the nurses' inability to express opinions values and beliefs regarding palliative care (M = 2.98, SD = 1.30), less than ideal physical environment (M = 2.70, SD = 1.31), technological imperatives (M = 3.22, SD = 1.11), parental demands (M = 3.46, SD = 1.07), and, finally, lack of education (M = 2.86, SD = 1.44). The 8 facilitators were supportive medical staff (M = 3.60, SD = 1.29), parental involvement of decisions (M = 3.76, SD = 1.17), parents informed of options (M = 3.32, SD = 1.22), support from medical team when palliative care is implemented (M = 3.20, SD = 1.28), staffing (M = 3.60, SD = 1.29), time spent with dying baby (M = 3.52, SD = 1.31), policies/guidelines supporting palliative care (M = 3.76, SD = 1.19), and available counseling (M = 3.566, SD = 1.26).

CONCLUSIONS: Barriers and facilitators continue to exist within neonatal end-of-life care. There is significant importance for NICU nurses to recognize and understand the barriers to and facilitators of providing end-of-life care within their specific unit. Further research is warranted regarding implementation of end-of-life care education in the NICU to improve patient care.

Source: EMBASE


Author(s): Vogel L

Citation: CMAJ: Canadian Medical Association Journal, 11 January 2011, vol./is. 183/1(0- ), 08203946

Publication Date: 11 January 2011

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost
Available in fulltext at EBSCOhost
Available in fulltext at National Library of Medicine

29. The important role for nurses in supporting the Asian Hindu patient and family at end of life: providing culturally sensitive end-of-life care.

Author(s): Singh, Anuradha, Freeman, Michelle

Citation: Canadian Oncology Nursing Journal, 01 January 2011, vol./is. 21/1(46-47), 1181912X

Publication Date: 01 January 2011

Abstract: As cultural ecology of Canada evolves with daily arrival of new immigrants, Canadians welcome them and feel very proud of preserving their multicultural heritage. As minority groups, especially South Asian Hindus, continue to grow, there is a need to understand their cultural perspectives and accommodate their cultural preferences for end-of-life care. This article addresses end-of-life care from a point of view of Hindu culture and religion and provides a brief overview of their beliefs and rituals related to it. This article also guides nurses to understand diverse Hindu cultural practices and beliefs to help support their patients and families at this difficult time of life.

Source: CINAHL

30. Patients Who Make ‘Wrong’ Choices.

Author(s): Macauley, Robert

Citation: Journal of Palliative Medicine, 01 January 2011, vol./is. 14/1(13-16), 10966218

Publication Date: 01 January 2011

Source: CINAHL

Full Text:

Author(s): Gheorghe C, Vazquez R, Casanegra AI, Argento V, Dadu R, Feng Y, Amoateng-Adjepong Y, Manthous CA

Citation: Journal of the American Medical Directors Association, 01 January 2011, vol./is. 12/1(22-28), 15258610

Publication Date: 01 January 2011

Abstract: Hypothesis: Elders’ predilections regarding end-of-life interventions vary with their living environs. Methods: Patients in 3 settings—assisted living/outpatient, skilled nursing facility (SNF), and acute hospitalization—were asked to complete a brief questionnaire. Results: A total of 269 patients who averaged 80.0 ± (SD) 8.1 years, 44% male, 70% white were studied. Eighty-five patients were outpatient elderly, 101 were hospitalized for acute illnesses, and 83 were interviewed in SNFs. Outpatients (44/85; 52%) and acutely ill inpatients (40/101; 40%) were more likely than patients residing in SNFs (19/81; 23%) to choose comfort care only (P = .047) for acute pneumonia requiring endotracheal intubation (ETI). Overall, 32% changed their choice for ETI, opting for comfort care only if acute pneumonia was followed by disposition to an SNF. However, ambulatory and acutely ill elderly patients were 3 times as likely as SNF patients to change from aggressive to comfort care if the most likely outcome was disposition to an SNF (P < .001). In multivariate regression models, age (>80), gender, number of lost ADLs (>2), and self-described quality of life were not associated with choosing comfort care instead of ETI, whereas place of residence (SNF versus home) was independently associated with choosing ETI (odds ratio = 3.5; 95%CI = 1.9–6.4). Similarly, those already living in an SNF were more likely to opt for remaining there for advancing dementia (odds ratio = 7.7; 95%CI = 3.8–15.8). However, choices for ETI did not coincide with choosing an SNF for advancing dementia. Conclusions: Elders residing in nursing homes were more likely than ambulatory patients to request invasive end-of-life care, a difference that was more pronounced when outcome required disposition to an SNF. These preferences were not dependent on patients’ self-described disability or quality of life. This study suggests that qualitative outcomes matter to patients and their choices are associated with their place of residence.

Source: CINAHL

32. Polst complement advance directives to better honor patients’ preferences for end-of-life care... physician orders for life-sustaining treatment.

Author(s): Mitchell JK

Citation: ONS Connect, 01 January 2011, vol./is. 26/1(19-19), 19351623

Publication Date: 01 January 2011

Source: CINAHL

33. Dying at home: A literature review (741)

Author(s): Lysaght S., Ersek M.

Citation: Journal of Pain and Symptom Management, January 2011, vol./is. 41/1(297), 0885-3924 (January 2011)

Publication Date: January 2011

Abstract: Objectives: 1. Describe important empirically driven components of dying at home. 2. Discuss complicated meanings for patients, caregivers and providers of dying at home. Background. Dying at home may have initially been introduced as a response to misguided and poor care of dying patients in hospitals. However, the significant increase in place of death for hospice patients in inpatient settings versus private residences suggests that dying at home is a concept needing reclarification and evaluation. Research objectives. The purpose of this review was to develop a literature-based definition of the
concept dying at home that could be used as a conceptual framework to guide further research. Methods. Three electronic databases (ie, CI-NAHL, PubMed, and PsychINFO) were searched with restriction to English language, humans, and older adults (age greater than 65 years) for dying or death and home nursing or home care services or hospice care. Overall, 405 abstracts were collected; abstracts were reviewed for saliency and criteria for inclusion was a focus on location of care of the dying at home, explanation of the meaning of dying at home, and a data based publication. A total of 35 articles met the criteria. Content was analyzed and integrated into the final framework. Results. Major themes identified in these articles included predictors of place of death, multiple meanings of being at home, expressed end-of-life preferences, transitions, and caregiver involvement. A preliminary framework focused on dying at home was elucidated and included adequate resources, a physical location of care, patient preference, caregiver preference, awareness of prognosis, caregiver support, a time-limited course, access to symptom management and feeling at home. Conclusion. Dying at home is a multi-layered, complex concept for patients, caregivers, and providers influenced by many factors. A more cautious view of dying at home as a gold standard should be considered for future hospice policy discussions. Implications for research, policy, or practice. Clinically relevant research in this area calls for a better understanding of needs, appropriateness, and evaluation of the role of dying at home in patient and caregiver outcomes.

Source: EMBASE

34. The impact of a palliative care unit on location of death for medical intensive care unit patients (719)

Author(s): Digwood G., Lustbader D., Frankenthaler M., Smith F., Hussain E., Gorowski E., Walia R., Pekmezaris R.

Citation: Journal of Pain and Symptom Management, January 2011, vol./is. 41/1(283-284), 0885-3924 (January 2011)

Publication Date: January 2011

Abstract: Objectives: 1. Evaluate ability of a non monitored inpatient palliative care unit (PCU) to accommodate dying medical ICU (MICU) patients. 2. Evaluate the impact of an inpatient PCU on MICU mortality rate. Background. Intensive care unit (ICU) deaths are associated with higher costs, pain, and, often, burdensome interventions. Most US deaths occur in hospitals, often with failed ICU-level care. This study evaluated the developmental impact of an inpatient palliative care unit (PCU) on medical ICU (MICU) mortality rates over time. Research objectives. (1) Evaluate ability of a nonmonitored inpatient PCU to accommodate dying MICU patients. (2) Evaluate the impact of an inpatient PCU on MICU mortality rate. Methods. We performed a retrospective electronic database review examining MICU mortality of all MICU discharges (7,245 cases) from January 1, 2004 through December 31, 2009. We compared MICU mortality rates before and after the opening of the PCU (January 1, 2008) through the runs test to determine whether quarterly MICU mortality rates followed a random or non-random serial pattern. Results. Our data showed that MICU mortality was significantly lower than expected by chance (P < 0.05, 1-tailed exact test). Specifically, most of the mortality rates that were above the median (which forms the basis of the runs test) were prior to mid-2007 and most of the rates below the median were observed after the opening of the PCU. Conclusion. The creation of an inpatient PCU resulted in significant reduction in MICU mortality rate, as dying MICU patients were moved to the PCU. Our data show that a dedicated inpatient PCU with ventilator capacity can protect terminally ill patients from an ICU death, transitioning them to a more appropriate location for end-of-life care. Implications for research, policy, or practice. (1) PCUs can be non-monitored and staffed to accommodate dying ICU patients receiving mechanical ventilation, dialysis, hemodynamic support, and other life-sustaining treatments. (2) PCUs are well suited to align treatments with patient preferences through the use of time-limited trials of life-sustaining measures.

Source: EMBASE

35. Clinicians’ rankings of most important considerations in pediatric end-of-life decision making (413-A)

Author(s): Morrison W., Hexem K., Feudtner C.

Citation: Journal of Pain and Symptom Management, January 2011, vol./is. 41/1(230).
Abstract: Objectives: 1. Recognize ethical and values considerations that may be considered important in pediatric end-of-life care. 2. Discuss various factors clinicians may value at the bedside when conflicts arise between families and the healthcare team in pediatric end-of-life care. 3. Discuss that empirical data from this survey of clinicians support the primacy of the best interests standard in pediatric end-of-life care but suggests that there are subgroups of differing secondary preferences that may affect how clinicians make decisions. Background: In pediatric end-of-life care, the prior wishes of patients regarding the use of life-sustaining technologies are usually unknown and are not legally binding. The child's best interest has long been touted as the ideal decision-making standard. Research objectives: Collect empirical data regarding the importance that bedside clinicians place on the best interests standard versus other considerations. Methods: We surveyed physicians and nurses in pediatric intensive care units, pediatric cardiac intensive care units, and neonatal intensive care units and received 364 responses (54%). The factors respondents could consider were: the child's best interests, the child's comfort, prolonging life, the best interests of the entire family, religious requirements, the parents' preferences, maintaining harmony between the family and healthcare team, following the best medical evidence/team's judgment, or the responsible use of scarce resources. We employed maximum difference scaling, a market preference research technique, to estimate the importance afforded to each factor, and then with latent class analysis identified five groups of respondents with congruent sets of values ratings.

Results: All five groups rated the child's best interests and the child's comfort as most important, but differed regarding how they valued other considerations: Group 1 rated highly considerate of the entire family and medical judgment; Group 2, medical judgment and prolonging the child's life; Group 3, the entire family, parents' preferences, and religious beliefs; Group 4, responsible use of medical resources; and Group 5, maintaining harmony between parents and medical team. Gender and years of experience did not affect preferences. Physicians were slightly more likely than nurses to prioritize the interests of the entire family. Conclusion: Clinicians who care for dying children display recognizable and differing constellations of beliefs about what is most important when making medical decisions. Implications for research, policy, or practice: Pediatric palliative care and ethics consultative services should be aware of and prepared to address these differing concerns.

Source: EMBASE

36. Hospital at home: home-based end of life care

Author(s): Shepperd S., Wee B., Straus S.E.

Citation: Cochrane database of systematic reviews (Online), 2011, vol./is. /7(CD009231), 1469-493X (2011)

Publication Date: 2011

Abstract: The policy in a number of countries is to provide people with a terminal illness the choice of dying at home. This policy is supported by surveys indicating that the general public and patients with a terminal illness would prefer to receive end of life care at home. To determine if providing home-based end of life care reduces the likelihood of dying in hospital and what effect this has on patients' symptoms, quality of life, health service costs and care givers compared with inpatient hospital or hospice care. We searched the Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library) to October 2009, Ovid MEDLINE(R) 1950 to March 2011, EMBASE 1980 to October 2009, CINAHL 1982 to October 2009 and EconLit to October 2009. We checked the reference lists of articles identified for potentially relevant articles. Randomised controlled trials, interrupted time series or controlled before and after studies evaluating the effectiveness of home-based end of life care with inpatient hospital or hospice care for people aged 18 years and older. Two authors independently extracted data and assessed study quality. We combined the published data for dichotomous outcomes using fixed-effect Mantel-Haenszel meta-analysis. When combining outcome data was not possible we presented the data in narrative summary tables. We included four trials in this review. Those receiving home-based end of life care were statistically significantly more likely to die at home compared with those receiving usual care (RR 1.33, 95% CI 1.14 to 1.55, P = 0.0002; Chi
We detected no statistically significant differences for functional status (measured by the Barthel Index), psychological well-being or cognitive status, between patients receiving home-based end of life care compared with those receiving standard care (which included inpatient care). Admission to hospital while receiving home-based end of life care varied between trials and this was reflected by high levels of statistically significant heterogeneity in this analysis. There was some evidence of increased patient satisfaction with home-based end of life care, and little evidence of the impact this form of care has on care givers. The evidence included in this review supports the use of end of life home-care programmes for increasing the number of patients who will die at home, although the numbers of patients being admitted to hospital while receiving end of life care should be monitored. Future research should also systematically assess the impact of end of life home care on care givers.

Source: EMBASE

Full Text:
Available in fulltext at Wiley

37. Can 'end of life care' for patients dying of colorectal cancer (CRC) be improved by the trial of a community based palliative care register?

Author(s): Cruttenden-Wood D., PJohn S.K., Bradbury P., Pugh R., Fozard J.B.J.
Citation: Colorectal Disease, January 2011, vol./is. 13/1(118-119), 1462-8910 (January 2011)
Publication Date: January 2011
Abstract: Aim The government's 'End of life care strategy' emphasised that too many people are dying in hospital, often unnecessarily. Up to 74% of people wish to die at home., but only 18% manage to. Could a community based palliative care register (PCR) significantly change place of death? How would this affect palliative care (PC) services? Method A 3 year MDT audit was carried out of the treatment and care of each patient who died of CRC. A PCR was introduced in the final 18 months. The effect of this initiative and improved communication with the community PC teams on unnecessary admissions was studied? Results There were 134 patients in the study. 52% of patients died in hospital before the PCR was introduced compared with 21% afterwards (P = 0.005). 18% died at their place of residence before and 46% afterwards (P = 0.005). 27% died in a specialist PC unit before and 32% afterwards (P = 0.641). 48% were reviewed by the PC team before and 46% afterwards. Of patients known to the PC services, 29% died in hospital before and 8% afterwards. Conclusion The PCR enables more people to die at home without overloading specialist PC services. It has improved 'choice' and 'end of life care'.

Source: EMBASE

Full Text:
Available in fulltext at EBSCOhost

38. Is it recorded in the notes? Documentation of end-of-life care and preferred place to die discussions in the final weeks of life

Author(s): Cox K., Moghaddam N., Almack K., Pollock K., Seymour J.
Citation: BMC Palliative Care, 2011, vol./is. 10/, 1472-684X (2011)
Publication Date: 2011
Abstract: Background: Over the past ten years there has been an increasing focus on the need for improving the experience of end of life care. A number of policy initiatives have been introduced to develop approaches to discussing and documenting individual preferences for end of life care, in particular preferred place to die. Methods. The aim was to investigate practice in relation to discussing and documenting end of life care and preferred place to die in the last 4 weeks of life with patients and their families. The study utilised an audit of 65 case notes, alongside four group interviews with a mix of health care professionals involved in palliative care provision. Results: While there was evidence that discussions relating to end of life care and preferred place to die had taken place in around half of the audited case notes, there appeared to be a lack of a systematic approach to the
recording of discussions with patients or carers about these kind of issues. Health care staff subsequently highlighted that initiating discussions about end of life care and preferences in relation to place of death was challenging and that the recording and tracking of such preferences was problematic. Conclusions: Further work is required to establish how information may be adequately recorded, revised and transferred across services to ensure that patients' preferences in relation to end of life care and place of death are, as far as possible, achieved. 2011 Cox et al; licensee BioMed Central Ltd.

Source: EMBASE

Available in fulltext at BioMedCentral
Available in fulltext at National Library of Medicine

39. Determinants of place of death for recipients of home-based palliative care

Author(s): Masucci L., Guerriere D.N., Cheng R., Coyte P.C.

Citation: Journal of Palliative Care, December 2010, vol./is. 26/4(279-286), 0825-8597 (Winter 2010)

Publication Date: December 2010

Abstract: Introduction: Health system restructuring combined with the preferences of many terminally ill care recipients and their caregivers has led to an increase in home-based palliative care, yet many care recipients die within institutional settings such as hospitals. This study sought to determine the place of death and its predictors among palliative care patients with cancer. Methods: Study participants were recruited from the Temmy Latner Centre for Palliative Care, a regional palliative care program based in Toronto, Canada. A total of 137 patients and their family caregivers participated in the study; application of various exclusion criteria restricted analysis to a sub-sample of 110. Bivariate (chi-square) and multivariate (logistic regression) analyses were conducted. Results: 66 percent of participants died at home. Chisquare analysis indicated that women were more likely to die at home than men; multivariate analysis indicated that women and those living with others were significantly more likely to die at home than men or those who lived alone. Conclusion: Place of death is influenced by the socio-demographic characteristics of patients, the characteristics of their caregivers, and health service factors. Palliative care programs need to tailor services to men and those living alone in order to reduce institutional deaths. 2010 Institut universitaire de geriatri de Montreal.

Source: EMBASE

40. Determinants of place of death for recipients of home-based palliative care.

Author(s): Masucci, Lisa, Guerriere, Denise N., Cheng, Richard, Coyte, Peter C.

Citation: Journal of Palliative Care, 01 December 2010, vol./is. 26/4(279-286), 08258597

Publication Date: 01 December 2010

Abstract: Health system restructuring combined with the preferences of many terminally ill care recipients and their caregivers has led to an increase in home-based palliative care, yet many care recipients die within institutional settings such as hospitals. This study sought to determine the place of death and its predictors among palliative care patients with cancer.

Source: CINAHL

41. Nurse and Physician Preferences for End-of-Life Care for Trauma Patients.

Author(s): Jacobs LM, Burns KJ, Jacobs BB

Citation: Journal of Trauma, 01 December 2010, vol./is. 69/6(1567-1573), 00225282

Publication Date: 01 December 2010

Abstract: BACKGROUND: End-of-life care for trauma patients requires unique practice guidelines because it is fraught with difficulties not encountered in end-of-life care for terminally ill patients. The purpose of this project was to analyze survey information from
nurses and physicians regarding preferences for end-of-life care in trauma that would inform best-practice guidelines. METHODS: A survey was sent via the US Postal Service to a convenience sample of trauma professionals, including physicians, nurses, and emergency medical technicians. Questions were designed to provide information on difficult issues related to death and dying from trauma. The general public was also surveyed, and all results were used to develop a best-practice model for end-of-life care. RESULTS: Seven hundred seventy-four trauma professionals returned the survey for a response rate of 51%. This included 460 nurses and 181 physicians. Some salient findings include: (1) If a loved one required resuscitation in the emergency department, more nurses (78.4%) than physicians (38.7%) prefer to be in the treatment room rather than in the waiting room; (2) similar percentages of nurses (97.7%) and physicians (99.4%) agree that life-sustaining treatment should be withdrawn in cases in whom there is no hope of recovery; and (3) a larger percentage of nurses (58.8%) than physicians (20.6%) believe that patients have the right to demand care that physicians think is medically futile. CONCLUSIONS: Nurses and physicians agree on some issues about end-of-life care in trauma but disagree on others. Education and discourse among trauma professionals are needed to bring understanding to the issues.

Source: CINAHL

Full Text:
Available in fulltext at the ULHT Library and Knowledge Services’ eJournal collection

42. Advance care planning ensures patient choice on place of death.

Author(s): Sherwen E

Citation: Nursing Times, 12 October 2010, vol./is. 106/40(8-8), 09547762

Publication Date: 12 October 2010

Abstract: Trusts must embed Preferred Priorities of Care within everyday practice. This action will enable patients in all settings have a say over where they die, argues Eleanor Sherwen.

Source: CINAHL

Full Text:
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Author(s): Holmes, L, Addington-Hall, J, Grande, G, Payne, S, Seymour, J, Hanratty, B

Citation: Journal of Epidemiology & Community Health, 02 September 2010, vol./is. 64/(0-0), 0143005X

Publication Date: 02 September 2010

Abstract: Background Transitions between care settings have been associated with poor continuity and quality of care for older people. Movements between places of care occur frequently in the months before death, making them an important influence on well-being and health status. People with heart failure may be particularly likely to experience frequent, unplanned admissions to hospital. Objective To explore and understand experiences of care transitions for older adults with heart failure at the end-of-life. Design In-depth qualitative interviews with 35 people with heart failure, lung cancer or stroke. Framework methodology was used for data analysis. Participants Fifteen adults aged over 75 years with heart failure, whose hospital clinician answered “no” to the question, would you be surprised if this patient dies within the next 12 months? Half the participants were from socially disadvantaged backgrounds. Findings Participants described how they struggled to have control over many of their end of life experiences. Their ability to negotiate their role with professionals, family and the wider world was threatened by their
biographical experiences and physical helplessness. Long-standing relationships with family doctors were associated with low expectations and a perceived loss of control, particularly for the most disadvantaged people. A majority had lost all trust in their GPs, and the doctor was allowed to share in symptom management only when severe—preserving some autonomy for the older person, but threatening physical health and future choices. The rest had taken on the role of passive recipients of advice and treatment. Frequent admissions to hospital were tainted by the perception of being a burden to staff reluctant to help with basic care, and families obliged to visit. Conclusions Notions of choice and empowerment prevalent in current health policy discourses appeared to have little relevance to the lived experiences of the older adults in this study. Without an understanding of biographical and social context, analyses of how older people experience health and social care at the end-of-life risk promoting concepts of individual control that many older adults do not enjoy. If end-of-life care policies are to produce equitable outcomes, they must go beyond simple solutions to address the complexity of relationships older adults have developed with health services over their lifetimes.

Source: CINAHL

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☐ 44. Invasive palliative interventions: when are they worth it and when are they not?

Author(s): Strasser F, Blum D, Bueche D

Citation: Cancer Journal, 01 September 2010, vol./is. 16/5(483-487), 15289117

Publication Date: 01 September 2010

Abstract: In palliative cancer care situations, invasive palliative interventions are frequently considered. The perception of invasiveness has a wide range and is subjective. A structured palliative care approach can guide decisional processes. It may contain 6 key elements: (1) multidimensional and multiprofessional assessment patients current priorities, (2) quality of current symptom management for the potential target intervention, (3) documentation of potential reasons to reduce symptomatic medications, (4) cautious judgment if patients' potential clinical benefit can be extrapolated from published evidence, (5) a decisional process for the considered intervention (e.g., the 7 P's model: priority, price, probability, prognosis, progression, prevention, preferences), and (6) agreement on the goal of the intervention before the invasive intervention. The examples of pleural effusion and parenteral nutrition are briefly emphasized. Oncologists may be competent to foster patients' participation in decision making and to use available specialist palliative care competencies and those of other professions.

Source: CINAHL

☐ 45. Dying at home: community nurses' views on the impact of informal carers on cancer patients' place of death.

Author(s): JACK B, O'BRIEN M

Citation: European Journal of Cancer Care, 01 September 2010, vol./is. 19/5(636-642), 09615423

Publication Date: 01 September 2010


Dying at home: community nurses' views on the impact of informal carers on cancer patients' place of death Giving patients with cancer a choice in where they want to die including the choice to die at home if they so wish, underpin the recent UK government policies and is embedded in the End of Life Care Programme. However, this presents increasing challenges for the informal carers particularly with an increasingly aging population. Despite the policy initiatives, there remain a persistent number of patients with cancer who had chosen to die at home being admitted to hospital in the last days and hours of life. A qualitative study using two focus group interviews with community nurses (district nurses and community specialist palliative care nurses) was undertaken across two primary care trusts in the north-west of England. Data were analysed using a thematic
analysis approach. The results indicated that informal carer burden was a key reason for prompting hospital admission. Recommendations for the development of a carer assessment tool with appropriate supportive interventions are made.

Source: CINAHL

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46. 'A good death': how does this relate to the national End of Life Care Strategy?

Author(s): Raftery A, Willard C

Citation: European Journal of Palliative Care, 01 September 2010, vol./is. 17/5(228-231), 13522779

Publication Date: 01 September 2010

Abstract: There is more than one way of dying well, say Anne-Marie Raftery and Carole Willard. Here, they discuss the attributes of 'a good death' and how the UK end-of-life care agenda and palliative care must accommodate individual preferences.

Source: CINAHL

47. A retrospective analysis of preferred and actual place of death for hospice patients.

Author(s): Holdsworth L, Fisher S

Citation: International Journal of Palliative Nursing, 01 September 2010, vol./is. 16/9(424-430), 13576321

Publication Date: 01 September 2010

Abstract: The purpose of this study was to explore recording rates of preferences, and the preferred and actual place of death among hospice patients. Data was collected retrospectively from a group of three hospices over a 6-month period. Of 298 patients, 174 patients (58.4%) had no expressed preference for place of death. The congruence of preferred and actual place of death was: home 52.5%; hospice 86.2%; hospital 100%; and care home 50%. The overall congruence was 61.7% and kappa value was 0.38 (0.23--0.52, 95% confidence interval). The low rate of expressed preferences suggests that congruence of preferred and actual place of death was a suitable outcome measurement for less than half of hospice patients. A wider range of patient-focused indicators for identifying the quality of end-of-life services is needed as preferred place of death may not be the only suitable indicator for all patients.

Source: CINAHL

48. Improving integrated team working to support people to die in the place of their choice.

Author(s): Bowers B, Roderick S, Arnold S

Citation: Nursing Times, 17 August 2010, vol./is. 106/32(14-16), 09547762

Publication Date: 17 August 2010

Abstract: Dying in a place of one's choice is considered to be a quantifiable measure of the effectiveness of end of life services in primary care. Although most people say they would prefer to die in their own home, very few actually do so. This article looks at how a team of community nurses and GPs changed their practice by using recognised end of life care tools. These helped practitioners in supporting adults with terminal illnesses to die in a place of their choice. A subsequent audit of patients' actual place of death against their
preferred place demonstrates how working in more integrated ways has helped.

**Source:** CINAHL

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49. The high impact actions for nursing and midwifery 6: where to die when the time comes.

**Author(s):** Ward L, Fenton K, Maher L

**Citation:** Nursing Times, 17 August 2010, vol./is. 106/32(18-19), 09547762

**Publication Date:** 17 August 2010

**Abstract:** Around half of the 500,000 deaths in England each year occur in acute hospitals, while around half of all complaints made to acute trusts relate to an aspect of end of life care. However, research suggests that 4096 of people who the in hospital have no medical need to be there, and that 5596 of people with cancer would prefer to the at home while only around 25% do so. When people die in hospital despite having a preference to die at home and no medical reason to be in hospital, it causes unnecessary distress to patients and their families, and is costly to the NHS. This article, the seventh in our series on the high impact actions for nursing and midwifery, looks at how nurses can help to improve end of life care.

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50. How nurses working in acute care can help to ensure patients achieve a good death.

**Author(s):** Hayes A

**Citation:** Nursing Times, 13 July 2010, vol./is. 106/27(18-18), 09547762

**Publication Date:** 13 July 2010

**Abstract:** People should be able to die in the place of their choice. New guidance gives practical advice on how to ensure patients' preferred priorities are achieved.

**Source:** CINAHL

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51. Barriers to dying at home: the impact of poor co-ordination of community service provision for patients with cancer.

**Author(s):** O'Brien M, Jack B

**Citation:** Health & Social Care in the Community, 01 July 2010, vol./is. 18/4(337-345), 09660410
Abstract: For patients dying of cancer, there is an emphasis on giving choice regarding preferred location for care, with the option of dying at home, which is integral to UK government health initiatives such as the End of Life Care Programme. However, patients continue to be admitted to hospital in the terminal phase of their illness when they have expressed a desire to die at home. A qualitative study, using two audio tape-recorded focus group interviews, with a purposive sample of district nurses and community specialist palliative care nurses (19) was undertaken across two primary care trusts in the north west of England. Data were analysed using a thematic analysis approach. From a service provision perspective, the results reveal that poor discharge planning and co-ordination, difficulty in establishing additional equipment and services together with inadequate out of hours medical provision were all factors contributing to hospital admissions for patients with cancer in the last hours and days of life, and thus were barriers to dying at home.

Source: CINAHL

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52. Advanced care decision making: asking the right people the right questions.
Author(s): Mahon MM
Citation: Journal of Psychosocial Nursing & Mental Health Services, 01 July 2010, vol./is. 48/7(13-19), 02793695
Publication Date: 01 July 2010
Abstract: Aging often includes chronic disability and/or acute periods of illness. When seriously ill, people may be less able to participate in decision making. Decision making capacity, the ability to give informed consent or informed refusal, may not be accurately assessed or may not be assessed at all. Nurses are often ideally positioned to contribute to decision making by the clinical team and with the patient. Understanding how to assess capacity, and when and how to integrate surrogates into clinical decision making, can contribute to improved patient care. An example is used to explore the process of decision making based on medical indications, patient preferences, and the appropriate roles and responsibilities of the health care team and a surrogate decision maker.
Source: CINAHL
Full Text:
Available in fulltext at EBSCOhost

Citation: Nursing, 01 July 2010, vol./is. 40/7(21-21), 03604039
Publication Date: 01 July 2010
Source: CINAHL

54. A survey regarding physician preferences in end-of-life practices in intensive care across Scotland
Author(s): McAree S.J., Doherty P.A.
Citation: Journal of the Intensive Care Society, July 2010, vol./is. 11/3(182-186), 1751-1437 (July 2010)
Publication Date: July 2010
Abstract: Despite the large proportion of intensive care patients whose care is ultimately terminal, there is a lack of evidence to support best clinical practice caring for these patients. Ninety-seven consultants covering intensive care day sessions across Scotland
were invited to take part in a web-based questionnaire. Fifty-eight respondents (60%) completed the questionnaire. Non-escalation of therapy and abrupt withdrawal appear to be the preferred methods of limiting treatment at the end of life. This was achieved most commonly by a reduction in FiO₂ and cessation of inotropic support. Extubation was not favoured, with only four respondents claiming it as routine practice. Practical efforts made to determine futility appear to be made by at least two intensive care consultants. Of respondents, 24% consider non-escalation of treatment and active withdrawal to be ethically different and 15% held the view that there was moral equivalence between withdrawing treatment and the active shortening of the dying process. There are wide variations in clinician preferences for the methods used to limit treatment at the end of life. Consensus, therefore, may prove to be a challenge to achieve. The Intensive Care Society 2010.

Source: EMBASE

55. Ensuring patient choices about dignity and place of death are respected at the end of life.

Author(s): Bracegirdle L

Citation: Nursing Times, 08 June 2010, vol./is. 106/22(22-24), 09547762

Publication Date: 08 June 2010

Abstract: Patient choice and dignity are priorities in providing high quality end of life care. This article discusses the importance of psychosocial care when patients receive a terminal diagnosis, and district nurses' role in ensuring their choices about place of death are respected. It examines some of the dilemmas nurses may face in respecting patients' preferences about place of care and death, and looks at how services may need to change in the future to meet the needs of the increasing ageing population.

Source: CINAHL

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56. The influence of age on the likelihood of receiving end-of-life care consistent with patient treatment preferences.

Author(s): Parr JD, Zhang B, Nilsson ME, Wright A, Balboni T, Duthie E, Paulk E, Prigerson HG

Citation: Journal of Palliative Medicine, 01 June 2010, vol./is. 13/6(719-726), 10966218

Publication Date: 01 June 2010

Abstract: Background: Age differences may help to explain discrepancies in medical care received by cancer patients near death. Objectives: Understanding age differences in advanced cancer patients' end-of-life experiences. Design: NCI and NIMH funded multi-site prospective cohort study. Participants: 396 deceased cancer patients, mean age (58.6 ± 12.5), in the Coping with Cancer study. Measurements: Baseline interviews (Treatment Preference) and 1 week postmortem chart reviews (Treatment Received). Results: 14.1% of patients were 20-44 years old, 54.0% were 45-64 years old, and 31.8% were >=65 years old. Compared to younger patients, middle-aged patients wanted less life-prolonging care (OR 0.32; CI 0.16-0.64). In the last week of life, older patients were less likely to undergo ventilation (OR 0.27; CI 0.07-1.00) than younger patients. Middle-aged patients who preferred life-prolonging care were less likely to receive it than younger patients (OR 0.21; CI 0.08-0.54), but were more likely to avoid unwanted life-prolonging care (OR 2.38; CI 1.20-4.75) than younger patients. Older patients were less likely to receive desired life-prolonging care than younger patients (OR 0.23; CI 0.08-0.68), however, they were not more likely to avoid unwanted life-prolonging care than younger patients (OR 1.74; CI 0.87-3.47). Conclusions: Likelihood of a patient's treatment preference being consistent with care differ by age and treatment preferences. Older patients preferring life-prolonging
therapies are less likely to receive them than younger patients; middle-aged patients who want to avoid life-prolonging care are more likely to do so than younger patients. Both findings have implications for patients’ quality-of-death, indicating a need for further research.

Source: CINAHL

Available in fulltext at EBSCOhost

57. Maintaining integrity in the face of death

Author(s): Horne G., Seymour J., Payne S.

Citation: Palliative Medicine, June 2010, vol./is. 24/4 SUPPL. 1(S87), 0269-2163 (June 2010)

Abstract: Aim: To explore the experiences of patients with advanced lung cancer and their families in discussing preferences and wishes for end of life care. Methods: 25 patients aged 47 to 83 years (18 men and 7 women) with a diagnosis of lung cancer. Patients were mainly working class and lived in the UK. 14 family members and 8 bereaved family members were also recruited. A cross sectional qualitative interview study using a grounded theory approach was chosen to aid interpretation of the meanings people gave to their experiences in discussing wishes for end of life care. Interviews were conducted between 2006 and 2008. All interviews were audio-taped and transcribed verbatim. A comparative analysis was used and themes that emerged from earlier interviews were theoretically explored through later interviews. Results: Key findings were that patients preferred not to discuss the future but to carry on as normal, living in the present. A theory of maintaining integrity in the face of death is proposed. This theory purports that balancing living and dying is a process of attempting to manage the dilemma of living in the present and preparing for death. Acting and talking with integrity are ways of 'doing' this balancing work which requires huge psychological effort in addition to a focus on wellness. Knowing about death includes the internal and external sources of knowledge acquired about death and dying that influences people's ability to maintain theirs and their family's integrity. Family integrity explains how concern for family well-being causes patients to place importance on protecting family by exhibiting normative social behaviors. Conclusion: Current UK political rhetoric promotes choice and opportunities to state preferences and wishes for care and treatment at the end of life. This paper argues that patients with lung cancer facing the end of their life place little importance on choice. They focus on living in the present and maintaining integrity.

Source: EMBASE

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58. Meeting the needs of dying patients - Reality or ideal idea

Author(s): Schaefer I., Messerli E., Gasser R., Boothe B., Bkki J.

Citation: Palliative Medicine, June 2010, vol./is. 24/4 SUPPL. 1(S86), 0269-2163 (June 2010)

Abstract: Aim: Nurses consider fulfilling the needs of dying patients a pivotal part of their job. This work focuses on how nurses experience and consider the needs of dying patients. Therefore three independent studies, conducted in a Swiss university hospital, were evaluated to gain a deeper knowledge of nurses’ awareness of dying patients’ needs. Methods: A. Qualitative study: reductive content analysis of 16 semi-structured interviews about the perception of current end-of-life care practice (E. Messerli) B. Quantitative study: validated, semi-structured questionnaire (n=52): descriptive statistical analysis and content analysis according to Mayring (R. Gasser) C. Qualitative study: interpretive
phenomenological analysis according to Diekelmann of 29 open-ended episodic interviews about nurses' experience when involved in the care of dying patients (I. Schaefer) All studies used convenience sampling, informed consent was obtained. Results: Nurses emphasized the needs of dying patients being an important part of their profession. However, it was not always clear whose needs were met: while many nurses interpreted their own perceptions of a good death to be the same as the patients', others differentiated between the two. In doing so, nurses of the latter subgroup were able to disengage themselves from ideal perceptions of good death and to reflect the benefit of their interventions. For them, caring for patients who were not able to express their needs caused stress. Conclusion: Nurses are not always aware of conflicts between dying patients' and their own needs. Strong beliefs within the team are a barrier to reflection how dying patients' needs are best met; instead, emphasis is shifted to interprofessional problems. These findings challenge nurses to improve patient-oriented needs assessment and communication culture, but it is still unclear whether dying patients derive any benefit from existing good death concepts.

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59. Using population based methodologies to study crossnational differences in place of death and influencing factors

Author(s): Cohen J.

Citation: Palliative Medicine, June 2010, vol./is. 24/4 SUPPL. 1(S48), 0269-2163 (June 2010)

Publication Date: June 2010

Abstract: Most people prefer to die at home and there are indications that dying in familiar surroundings can improve the overall dying experience for the dying person and the next of kin. Hence, place of death is considered an important aspect of the quality of end-of-life care, and enabling the patient to die in their usual place of residence is an objective of palliative care. In order to optimise end-of-life care in all care settings and to facilitate death in the place of choice, knowledge of where people die, and why they die there, is essential. Cross-national comparisons are very useful in this context. From a health sociology perspective, they indicate how societies broadly approach death and dying and have, accordingly, organized their end-of-life care. From a health care policy perspective, they enable the identification of the national or regional factors and policies which facilitate death in the place of choice. A major problem with existing research is the diversity of study populations and research methods, which hinders valid cross-national comparison. The challenge is, therefore, to use adequate population-based methodologies to study cross-national differences in place of death, and their influencing factors. To address this challenge, a European collaborative research project has been conducted, collecting death certificate data of all deaths of the year 2003 for eight European countries, linking them with regional healthcare statistics and area characteristics, and integrating them into a common database. The study revealed large differences in place of death between countries. Of all deaths, between 62.8% in Wales and 33.9% in the Netherlands occurred in hospital. Country differences were particularly large for cancer patients and the very old (aged 80 and over): from 30.8% of all cancer patients in the Netherlands died in a hospital while 85.1% did in Sweden; in the Netherlands 45.4% died at home while 12.8% did in Norway. Compared to the Netherlands, the very old were about 5 times more likely to die in a hospital in Sweden, 3.5 times more likely in England, and 1.3 times more likely in Flanders, taking into account differences for sex, age at death, cause of death, hospital bed availability, and care home bed availability. Older age was associated with lower chances of dying at home, except in Italy where the opposite was the case. In conclusion, the study found some indication that the international variations in place of death have underlying organizational, policy, and cultural causes. As well as these findings and their implications, this plenary lecture will discuss the need to widen the cross-national approach to include other European and non-European countries and to develop more sophisticated epidemiological population-based methodologies in order to construct predictive models.
useful in clinical practice, and to evaluate the influence of palliative care service involvement on place of death across patient groups and care settings.

Source: EMBASE

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60. A "good death": perspectives of Muslim patients and health care providers.

Author(s): Tayeb MA, Al-Zamel E, Fareed MM, Abouellail HA

Citation: Annals of Saudi Medicine, 01 May 2010, vol./is. 30/3(215-221), 02564947

Publication Date: 01 May 2010

Abstract: BACKGROUND AND OBJECTIVES: Twelve "good death" principles have been identified that apply to Westerners. This study aimed to review the TFHCOP good death perception to determine its validity for Muslim patients and health care providers, and to identify and describe other components of the Muslim good death perspective. SUBJECTS AND METHODS: Participants included 284 Muslims of both genders with different nationalities and careers. We used a 12-question questionnaire based on the 12 principles of the TFHCOP good death definition, followed by face-to-face interviews. We used descriptive statistics to analyze questionnaire responses. However, for new themes, we used a grounded theory approach with a "constant comparisons" method. RESULT: On average, each participant agreed on eight principles of the questionnaire. Dignity, privacy, spiritual and emotional support, access to hospice care, ability to issue advance directives, and to have time to say goodbye were the top priorities. Participants identified three main domains. The first domain was related to faith and belief. The second domain included some principles related to self-esteem and person's image to friends and family. The third domain was related to satisfaction about family security after the death of the patient. Professional role distinctions were more pronounced than were gender or nationality differences. CONCLUSION: Several aspects of "good death," as perceived by Western communities, are not recognized as being important by many Muslim patients and health care providers. Furthermore, our study introduced three novel components of good death in Muslim society.

Source: CINAHL

Full Text: Available in fulltext at National Library of Medicine

61. Ask a different question, get a different answer: why living wills are poor guides to care preferences at the end of life.

Author(s): Winter L, Parks SM, Diamond JJ

Citation: Journal of Palliative Medicine, 01 May 2010, vol./is. 13/5(567-572), 10966218

Publication Date: 01 May 2010

Abstract: Context: Living wills have a poor record of directing care at the end of life, as a copious literature attests. Some speculation centers on the questionable correspondence between the scenario described in living wills versus the real-life circumstances that typically arise at the end of life. Objective: To assess the strength of association between responses to a standard living will question and preferences for treatments in six end-of-life scenarios. Design: Cross-sectional. Setting: Telephone interviews. Participants: Two hundred two community-dwelling men and women 70 years of age or older in the greater Philadelphia area. Main outcome measures: Strength of preferences for four life-sustaining treatments in each of six poor-health scenarios. Results: Associations between responses to the standard living will question and preferences for treatment (means across the four) in six specific scenarios were statistically significant but modest in size, accounting for 23% of variance at most. The association for the worse-case scenario (severe stroke with coma) was significantly stronger than for any other association. Conclusions: The modest correspondence between living will responses and wishes for life-sustaining treatment in
specific scenarios helps to elucidate the living will's poor performance. Presentation of more realistic end-of-life scenarios should improve the living will's ability to guide care, as well as preparing patients and families better for the end of life.

**Source:** CINAHL

**Full Text:**
Available in [fulltext](#) at EBSCOhost

62. **End-of-Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent With Preferences.**

**Author(s):** Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG

**Citation:** Journal of Clinical Oncology, 01 March 2010, vol./is. 28/7(1203-1208), 0732183X

**Publication Date:** 01 March 2010

**Abstract:** PURPOSE Physicians have an ethical obligation to honor patients' values for care, including at the end of life (EOL). We sought to evaluate factors that help patients to receive care consistent with their preferences. METHODS This was a longitudinal multi-institutional cohort study. We measured baseline preferences for life-extending versus symptom-directed care and actual EOL care received in 325 patients with advanced cancer. We also measured associated sociodemographic, health, and communication characteristics, including EOL discussions between patients and physicians. Results Preferences were assessed a median of 125 days before death. Overall, 68% of patients (220 of 325 patients) received EOL care consistent with baseline preferences. The proportion was slightly higher among patients who recognized they were terminally ill (74%, 90 of 121 patients; P = .05). Patients who recognized their terminal illness were more likely to prefer symptom-directed care (83%, 100 of 121 patients; v 66%, 127 of 191 patients; P = .003). However, some patients who were aware they were terminally ill wished to receive life-extending care (17%, 21 of 121 patients). Patients who reported having discussed their wishes for EOL care with a physician (39%, 125 of 322 patients) were more likely to receive care that was consistent with their preferences, both in the full sample (odds ratio [OR] = 2.26; P < .0001) and among patients who were aware they were terminally ill (OR = 3.94; P = .0005). Among patients who received no life-extending measures, physical distress was lower (mean score, 3.1 v 4.1; P = .03) among patients for whom such care was consistent with preferences. CONCLUSION Patients with cancer are more likely to receive EOL care that is consistent with their preferences when they have had the opportunity to discuss their wishes for EOL care with a physician.

**Source:** CINAHL

**Full Text:**
Available in [fulltext](#) at the ULHT Library and Knowledge Services' eJournal collection

63. **Factors associated with congruence between preferred and actual place of death.**

**Author(s):** Bell CL, Somogyi-Zalud E, Masaki KH

**Citation:** Journal of Pain & Symptom Management, 01 March 2010, vol./is. 39/3(591-604), 08853924

**Publication Date:** 01 March 2010

**Abstract:** Congruence between preferred and actual place of death may be an essential component in terminal care. Most patients prefer a home death, but many patients do not die in their preferred location. Specialized (physician, hospice, and palliative) home care visits may increase home deaths, but factors associated with congruence have not been systematically reviewed. This study sought to review the extent of congruence reported in the literature and examine factors that may influence congruence. In July 2009, a comprehensive literature search was performed using MEDLINE, PsychInfo, CINAHL, and Web of Science. Reference lists, related articles, and the past five years of six palliative care journals were also searched. Overall congruence rates (percentage of met preferences for all locations of death) were calculated for each study using reported data to allow cross-study comparison. Eighteen articles described 30%-91% congruence. Eight
specialized home care studies reported 59%-91% congruence. A physician-led home care program reported 91% congruence. Of the 10 studies without specialized home care for all patients, seven reported 56%-71% congruence and most reported unique care programs. Of the remaining three studies without specialized home care for all patients, two reported 43%-46% congruence among hospital inpatients, and one elicited patient preference “if everything were possible,” with 30% congruence. Physician support, hospice enrollment, and family support improved congruence in multiple studies. Research in this important area must consider potential sources of bias, the method of eliciting patient preference, and the absence of a single ideal place of death.

Source: CINAHL

64. End-of-life issues in acute stroke care: a qualitative study of the experiences and preferences of patients and families.
Author(s): Payne S, Burton C, Addington-Hall J, Jones A
Citation: Palliative Medicine, 01 March 2010, vol./is. 24/2(146-153), 02692163
Publication Date: 01 March 2010
Source: CINAHL

65. Determining & prioritising key factors of care needs for patients & carers known to Hospice@Home.
Author(s): Greene K, Evans T, Doherty T
Citation: Palliative Medicine, 01 March 2010, vol./is. 24/2(229-230), 02692163
Publication Date: 01 March 2010
Source: CINAHL

66. Palliative care: do all patients now have a choice about where they die?
Author(s): Slater L
Citation: Nursing Times, 23 February 2010, vol./is. 106/7(20-22), 09547762
Publication Date: 23 February 2010
Abstract: Modern day palliative care has developed over the past 40 years and many government policies have been produced to support development of services. Guidance sets out the aims and objectives for delivering palliative care, which are that every person with a life threatening illness has the right to receive appropriate palliative care wherever they are. This article explores whether people do have a real choice about the care they receive and where that care is delivered.
Source: CINAHL

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<th>67. Parental preference or child well-being: an ethical dilemma.</th>
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<td><strong>Author(s):</strong> Turner HN</td>
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<td><strong>Citation:</strong> Journal of Pediatric Nursing, 01 February 2010, vol./is. 25/1(58-63), 08825963</td>
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<td><strong>Abstract:</strong> An ethical dilemma that is not uncommon to encounter when caring for children occurs when parental preference does not appear to be in the child's best interest. Challenges facing the health care team are further amplified when the family's cultural background does not match that of the team. A case study will be used to illustrate the challenges of a pediatric palliative care ethical dilemma further complicated by cultural diversity. Review of the child's medical condition, patient/parent preferences, quality of life, and contextual features will be followed by an analysis and recommendations for resolution of this challenging situation.</td>
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<td><strong>Source:</strong> CINAHL</td>
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<th>68. Next-of-kin's perspectives of end-of-life care.</th>
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<tr>
<td><strong>Citation:</strong> Journal of Hospice &amp; Palliative Nursing, 01 January 2010, vol./is. 12/1(41-50), 15222179</td>
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<td><strong>Publication Date:</strong> 01 January 2010</td>
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<td><strong>Abstract:</strong> The purpose of this article was to describe the next-of-kin's perspective of the end-of-life (EOL) experiences associated with the death of a family member or close friend. The quality of EOL care from the next-of-kin's perspective given to their loved one needs further study in the context of a community setting focus. A secondary analysis of data from a survey of a random sample of dying experiences in the community setting included qualitative descriptive analysis of open-ended survey data and content analysis used to count the number of positive, negative, mixed, and not applicable responses. Qualitative content analysis of 186 next-of-kin responses revealed two themes: (1) communication and (2) family values and preferences including three subthemes of having a supportive environment to secure a peaceful death with dignity and respect, the desire to be present at the time of death, and attending to the needs and wishes of the dying individual and family. The need for palliative care services in institutionalized settings, continuity of provider care (physician and nurse), family presence, and support for caregiver and financial concerns with hospice services was identified. Communication remains an essential component in all aspects of EOL care with further examination involving the loved one's perspectives.</td>
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<td><strong>Source:</strong> CINAHL</td>
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<th>69. Decisions at the end of life: have we come of age?</th>
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<td><strong>Author(s):</strong> Emanuel L., Scandrett K.G.</td>
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<tr>
<td><strong>Citation:</strong> BMC medicine, 2010, vol./is. 8/(57), 1741-7015 (2010)</td>
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<td><strong>Publication Date:</strong> 2010</td>
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<td><strong>Abstract:</strong> Decision making is a complex process and it is particularly challenging to make decisions with, or for, patients who are near the end of their life. Some of those challenges will not be resolved - due to our human inability to foresee the future precisely and the human proclivity to change stated preferences when faced with reality. Other challenges of the decision-making process are manageable. This commentary offers a set of approaches which may lead to progress in this field. One clearly desirable approach can and should be used more often than it is: the routine inclusion of discussions about the goals of care and documentation with all patients who have a poor prognosis. The match between a patient's goals and the care received should be the gold standard for quality palliative care. Planning for future situations is necessary but hard. In order to achieve efficient elicitation and documentation of advance care planning, research is needed on each individual's thresholds for transitioning from curative to palliative intent and on the trajectory of changed preferences when illness occurs. Another clearly desirable approach is the</td>
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documentation and use of community preferences, so that proxies making decisions without guidance from the patient can at least know what the majority of people considering similar situations chose to do. Part of the challenge of achieving “quality dying” may have to do with the still current (mainly Western) tendency to a death-denying culture and the inability of dying people to enter into the dying role. Awareness of the tasks of the dying role and the provision of time and space for those tasks during the delivery of medical care is essential. Medicine needs to continue to enhance the existential maturity of our profession, our patients and the cultures in which we practice. This state of mind should provide for decisions made with a more settled acceptance of mortality and with more awareness of the necessary connection to our survivors and next generation that mortality creates. Specific interventions, such as Dignity Therapy and advance care planning, may aid this state of mind.

Source: EMBASE

Full Text:
Available in fulltext at EBSCOhost
Available in fulltext at BioMedCentral
Available in fulltext at National Library of Medicine

70. Caring for people dying at home: a research study into the needs of community nurses.

Author(s): Smith R, Poroc D

Citation: International Journal of Palliative Nursing, 01 December 2009, vol./is. 15/12(601-608), 13576321

Publication Date: 01 December 2009

Abstract: The majority of patients in the United Kingdom would choose to die at home, however, less than 20% of patients achieve this. Community nurses are central to care at the end of life, however, little attention has been given to the attitudes of community nurses to this role and how these may influence patient care, and ultimately facilitate patient preferences. This study aimed to identify the attitudes of community nurses to the care of the dying patient and discover the factors that influence these attitudes. Almost 40% of community nurses held negative attitudes to care of the dying. These attitudes improved with training and education but were not significantly influenced by experience alone. Attitudes were also influenced by levels of support, workload and time constraints. The study recommends the development of training and educational interventions to improve knowledge and practical competence, thus improving attitudes. Further study should also examine how the intensity of community nursing visits affects the number of home deaths.

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost

71. Seriously ill patients’ discussions of preparation and life completion: an intervention to assist with transition at the end of life.

Author(s): Steinhauser KE, Alexander SC, Byock IR, George LK, Tulsky JA

Citation: Palliative & Supportive Care, 01 December 2009, vol./is. 7/4(393-404), 14789515

Publication Date: 01 December 2009

Abstract: OBJECTIVE: Patients approaching the end of life not only face challenges to physical well-being but also threats to emotional and spiritual integrity. Yet, identifying appropriate, effective, and brief interventions to address those concerns has proven elusive. We developed an intervention based on life review and emotional disclosure literatures and conducted a pilot study to determine feasibility and acceptability. This article presents qualitative intervention responses. METHOD: We conducted a three-armed randomized control trial to evaluate the effects of preparation and life completion discussion on health outcomes in patients with advanced serious illness. Hospice-eligible subjects were randomly assigned to one of three groups: (1) intervention (life completion
Discussion intervention), (2) attention control (relaxation meditation), and control (no intervention). Subjects in the intervention arm met with a facilitator three times. Session 1 focused on life story, Session 2 on forgiveness, and Session 3, on heritage and legacy.

RESULTS: Eighteen subjects participated in the pilot intervention interviews. Subjects from a range of socioeconomic backgrounds completed the intervention with equal facility. Results from Session 1 demonstrate narrative responses participants gave as they reconnected with previous life roles, values, and accomplishments. The second session illustrated reflections of choices one might have made differently and exploration of forgiveness offered and sought. Content from the first and second sessions laid the foundation for discussing Session 3's lessons learned and heritage and legacy. Responses are summarized to assist clinicians in anticipating life review content that may improve overall quality of life at the end of life. SIGNIFICANCE OF RESULTS: Discussions of life completion may improve important health outcomes for patients at the end of life. This intervention may provide a brief, standardized, and transportable means for improving the quality of life of patients with advanced serious illness.

Source: CINAHL

72. The Marie Curie Delivering Choice Programme.

Author(s): Agelopoulos N, Tate T

Citation: European Journal of Palliative Care, 01 November 2009, vol./is. 16/6(290-294), 13522779

Publication Date: 01 November 2009

Abstract: Nicky Agelopoulos and Teresa Tate discuss the Marie Curie Delivering Choice Programme, designed to help improve services for palliative care patients so that they can chose their place of care and death, and stress the importance of a 'whole-system' approach.

Source: CINAHL

73. Dying old in the 21st century: a neglected issue for social work.

Author(s): Holloway M

Citation: International Social Work, 01 November 2009, vol./is. 52/6(713-725), 00208728

Publication Date: 01 November 2009

Abstract: Dying in old age has become the majority dying of the developed world, yet older people are routinely denied palliative care, their dying characterized by failure to facilitate choice and recognize their needs. Social workers in all settings should embrace their contribution to quality end-of-life care for older people.

Source: CINAHL

74. Responding to suffering: providing options and respecting choice.

Author(s): Berry ZS

Citation: Journal of Pain & Symptom Management, 01 November 2009, vol./is. 38/5(797-800), 08853924

Publication Date: 01 November 2009

Abstract: Voluntary stopping of eating and drinking (VSED) as a legal means to hasten death has been discussed by some as an option for persons who wish to end their lives. A case is presented of a woman who elected to forgo eating and drinking to end intractable suffering. The potential for benefit and harm in physicians discussing VSED is discussed. Physicians working with terminally ill patients need to consider the discussion of VSED as a therapeutic tool in their support and care of patients with intractable suffering.

Source: CINAHL

Full Text:

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.
75. 'A bed in the middle of nowhere': parents' meanings of place of death for adults with cystic fibrosis.

Author(s): Lowton K

Citation: Social Science & Medicine, 01 October 2009, vol./is. 69/7(1056-1062), 02779536

Publication Date: 01 October 2009

Abstract: As populations age and chronic conditions become more prevalent, an individual's ability to choose the location of their end-of-life care and death is increasingly considered important in the provision of good healthcare, with home implied as the 'best' place of death through UK government policy and specialist and voluntary palliative care services. However, considering meanings of place of end-of-life care and death is complex for young adults with life-limiting conditions where the disease course is variable and uncertain, and aggressive and palliative treatments are administered both at home and in hospital often until death. Although 'place' is a pivotal element in healthcare practice, research and policy, there has been little attempt to understand the meaning and importance of place in understanding experiences of care at end of life. Through analysis of in-depth interviews and letters received from parents of 27 young adults in England, Scotland and Wales who died from cystic fibrosis from 1999 to 2002 aged 17-36 years, key factors that influence families' meanings of place at end of life are presented. Both home and hospital deaths are reported, with no deaths in hospices. Preferences for possible locations of death are generally limited early in the disease course by choice of aggressive treatment, particularly lung transplantation. Rate of health decline, organisation and delivery of services, and relationships with specialist and general healthcare staff strongly influence parents' experience of death at home or in hospital, although no physical location was regarded a 'better' place of death. Meanings of, and attachment to place are mediated for families through these factors, questioning the appropriateness of a 'home is best' policy for those dying from life-limiting conditions.

Source: CINAHL

76. The dying patient: Choices, control, and communication

Author(s): Zagaria M.A.E.

Citation: U.S. Pharmacist, October 2009, vol./is. 34/10(32-34), 0148-4818 (21 Oct 2009)

Publication Date: October 2009

Source: EMBASE

77. End-of-life concerns and care preferences: congruence among terminally ill elders and their family caregivers.

Author(s): Gardner DS, Kramer BJ

Citation: Omega: Journal of Death & Dying, 01 September 2009, vol./is. 60/3(273-297), 00302228

Publication Date: 01 September 2009

Abstract: This study examined the end-of-life challenges, concerns, and care preferences of terminally ill elders and their family caregivers, with a focus on areas of congruence and incongruence. Ten elders and 10 family caregivers participated in separate, semi-structured, face-to-face interviews. Data analysis included team coding and thematic analysis, guided by an a priori set of categories based on the study questions. Shared challenges and concerns included experiencing decline, managing pain and discomfort, and living with uncertainty. There was also congruence regarding end-of-life care preferences, specifically the importance of quality care, treatment with dignity and respect, and avoiding unnecessary life-sustaining treatment. Areas of incongruence included the elders' difficulties in accepting dependence, their fears of becoming a burden, and desire to be prepared for death. Family caregivers were most concerned with providing adequate care to meet the elders' physical and spiritual care needs. Open family communication was associated with greater congruence. The authors discuss implications of these findings for research and intervention.
78. Methodological review: measured and reported congruence between preferred and actual place of death.

Author(s): Bell CL, Somogyi-Zalud E, Masaki KH

Citation: Palliative Medicine, 01 September 2009, vol./is. 23/6(482-490), 02692163

Publication Date: 01 September 2009

Abstract: Congruence between preferred and actual place of death is an important palliative care outcome reported in the literature. We examined methods of measuring and reporting congruence to highlight variations impairing cross-study comparisons. Medline, PsychInfo, CINAHL, and Web of Science were systematically searched for clinical research studies examining patient preference and congruence as an outcome. Data were extracted into a matrix, including purpose, reported congruence, and method for eliciting preference. Studies were graded for quality. Using tables of preferred versus actual places of death, an overall congruence (total met preferences out of total preferences) and a kappa statistic of agreement were determined for each study. Twelve studies were identified. Percentage of congruence was reported using four different definitions. Ten studies provided a table or partial table of preferred versus actual deaths for each place. Three studies provided kappa statistics. No study achieved better than moderate agreement when analyzed using kappa statistics. A study which elicited ideal preference reported the lowest agreement, while longitudinal studies reporting final preferred place of death yielded the highest agreement (moderate agreement). Two other studies of select populations also yielded moderate agreement. There is marked variation in methods of eliciting and reporting congruence, even among studies focused on congruence as an outcome. Cross-study comparison would be enhanced by the use of similar questions to elicit preference, tables of preferred versus actual places of death, and kappa statistics of agreement.
80. Do older adults know their spouses’ end-of-life treatment preferences?

**Author(s):** Moorman SM, Hauser RM, Carr D  
**Citation:** Research on Aging, 01 July 2009, vol./is. 31/4(463-491), 01640275  
**Publication Date:** 01 July 2009  
**Abstract:** When terminally ill patients become mentally incapacitated, their surrogates often make treatment decisions in collaboration with health care providers. The authors examined how surrogates’ errors in reporting their spouses’ preferences are affected by their gender, status as durable power of attorney for health care (DPAHC), whether they and their spouses discussed end-of-life preferences, and their spouses’ health status. Structural equation models were applied to data from married couples in their mid-60s from the 2004 wave of the Wisconsin Longitudinal Study. Surrogates reported their spouses’ preferences incorrectly 13% and 26% of the time in end-of-life scenarios involving cognitive impairment and physical pain, respectively. Surrogates projected their own preferences onto their spouses’. Similar patterns emerged regardless of surrogate gender and status as DPAHC, marital discussions about end-of-life preferences, or spousal health status. Implications for the process of surrogate decision making and for future research are discussed.  
**Source:** CINAHL

81. Oncology nurses’ perceptions of obstacles and supportive behaviors at the end of life

**Author(s):** Beckstrand R.L., Moore J., Callister L., Bond A.E.  
**Citation:** Oncology nursing forum, July 2009, vol./is. 36/4(446-453), 1538-0688 (Jul 2009)  
**Publication Date:** July 2009  
**Abstract:** PURPOSE/OBJECTIVES: To determine the magnitude of selected obstacles and supportive behaviors in providing end-of-life (EOL) care to patients with cancer as perceived by oncology nurses. DESIGN: Cross-sectional survey. SETTING: National survey sample. SAMPLE: A geographically dispersed national random sample of 1,000 Oncology Nursing Society members who had cared for inpatient patients with cancer, could read English, and had experience in EOL care. METHODS: Eligible respondents received a 68-item questionnaire in the mail adapted from previous studies and were asked to rate the size of obstacles and supportive behavior items in caring for patients with cancer at the EOL. MAIN RESEARCH VARIABLES: EOL, oncology, barriers, supportive behaviors, oncology nurses, and survey research. FINDINGS: Returns after three mailings yielded 375 usable questionnaires from 907 eligible respondents for a return rate of 41%. The items with the highest perceived obstacle magnitude were (a) dealing with angry family members, (b) families not accepting what they are told about patients’ poor prognosis, and (c) nurses being called away from dying patients to care for other patients. The three-highest scoring supportive behaviors were (a) allowing family members adequate time alone with patients after they died, (b) having social work or palliative care staff as part of the patient care team, and (c) having family members accept that patients are dying. CONCLUSIONS: EOL care can be improved by working to decrease the highest-rated barriers and by continuing to support the highest-rated supportive behaviors. IMPLICATIONS FOR NURSING: Oncology nurses are dedicated, experienced, and comfortable handling most issues in EOL care. Recommendations to support oncology nurses include strategies to interact effectively with angry, anxious, or overly optimistic family members as well as involving social work and palliative care staff on the oncology interdisciplinary team. In addition, the information regarding identified obstacles and supportive behaviors in oncology EOL care can be used to facilitate discussion and change within oncology interdisciplinary teams and improve EOL care for patients with cancer and their families.  
**Source:** EMBASE  
**Full Text:** Available in fulltext at EBSCOhost
82. Patients need to be provided with real choice in end-of-life care.

Author(s): Pooler J

Citation: Nursing Times, 30 June 2009, vol./is. 105/25(11-11), 09547762

Publication Date: 30 June 2009

Abstract: As the government publishes palliative care competences, Jacqueline Pooler highlights the importance of choice over place of death -- and the right kinds of bed to enable this.

Source: CINAHL

Full Text:
Available in fulltext at the ULHT Library and Knowledge Services' eJournal collection
Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.
Available in print at Pilgrim Hospital Staff Library

83. Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care.

Author(s): Black BS, Fogarty LA, Phillips H, Finucane T, Loreck DJ, Baker A, Blass DM, Rabins PV

Citation: Journal of Aging & Health, 01 June 2009, vol./is. 21/4(627-650), 08982643

Publication Date: 01 June 2009

Abstract: OBJECTIVE: This study examines how surrogate decision makers for dementia patients developed an understanding of patient preferences about end-of-life (EOL) care and patient wishes. METHODS: Semistructured interviews were conducted with 34 surrogate decision makers for hospice-eligible nursing home patients with dementia. The data were content analyzed. RESULTS: Most surrogates reported that patients had previously completed an advance directive (59%), discussed preferences for EOL care (56%), or done both (38%). Catalysts for and barriers to completing an advance directive or having EOL care discussions included factors that were both intrinsic and extrinsic to the patient. The most commonly reported wish for EOL care was to not be kept alive by "machines" or "extraordinary measures." DISCUSSION: Health care providers may be able to assist patients and families by normalizing discussions of dying, encouraging advance care planning, helping them identify goals for EOL care, and providing information to support treatment decisions consistent with patients' wishes.

Source: CINAHL

84. Patients' choice in their final resting place.

Author(s): Dawes J

Citation: British Journal of Community Nursing, 01 April 2009, vol./is. 14/4(141-141), 14624753

Publication Date: 01 April 2009

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost

85. POLST offers next stage in honoring patient preferences.

Author(s): Meier DE, Beresford L

Citation: Journal of Palliative Medicine, 01 April 2009, vol./is. 12/4(291-295), 10966218

Publication Date: 01 April 2009

Source: CINAHL
86. Young adults' opinions about hospice and home death.

Author(s): Webb NM, Tucker D

Citation: Journal of Palliative Medicine, 01 April 2009, vol./is. 12/4(337-342), 10966218

Abstract: BACKGROUND: Exploring preferences for and barriers to quality end-of-life care is essential to improving care for dying individuals. Young adults often are involved or will be involved in decisions about the care of a loved one, and little research has examined opinions about end-of-life care among this population. RESEARCH OBJECTIVES: The current study examined factors that may affect young adults' opinions about hospice care and home death. METHODS: Participants were 1035 introductory psychology students at a southeastern university. The sample was 66% female and 60% Caucasian. The study questionnaire assessed participants' knowledge about hospice, experience with the death of a loved one, and opinions about hospice care and home death. RESULTS: Approximately 44% of the sample reported experience with the death of a loved one from a terminal illness. Hospice knowledge was higher among females, and females were more likely to report a positive opinion about hospice care as well as a greater likelihood of recommending hospice services for a loved one. Caucasians had a more positive opinion of home death than African Americans. Individuals describing their prior experience with the death of a loved one as negative had a more positive opinion of home death than those with no prior experience or a non-negative experience. CONCLUSIONS: Young adults' opinions about hospice and home death vary significantly with respect to gender and race. Large percentages of neutral responses suggest that interventions targeted at young adults could significantly impact their views of and ultimate choices about of end-of-life care.

Source: CINAHL

Full Text: Available in fulltext at EBSCOhost

87. Informal carer bereavement outcome: relation to quality of end of life support and achievement of preferred place of death.

Author(s): Grande GE, Ewing G

Citation: Palliative Medicine, 01 April 2009, vol./is. 23/3(248-256), 02692163

Abstract: This study investigated (a) whether carer bereavement outcome is affected by the achievement of the patient's and/or carers' preferred place of death and (b) the relationship between carer satisfaction with end of life care and bereavement outcome. Participants were 216 carers of patients referred to hospice at home (H@H). Prospective recording of preferred and actual place of death were obtained from H@H records. Carers' level of grief and mental health and assessment of end of life care were obtained through postal survey three to four months post-bereavement. Fulfilment of carer preference for place of death only related to post-bereavement mental health at P < 0.1. Adequacy of psychological support showed the clearest relationship with bereavement outcome both in univariate and multivariate analyses. The level of support, particularly psychological, may be more important for carers' bereavement outcome than achievement of the preferred place of death for the patient.

Source: CINAHL

Full Text: Available in fulltext at EBSCOhost

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.
88. Place of death of adolescents and young adults with cancer: first study in a French population.

Author(s): Montel S, Laurence V, Copel L, Pacquement H, Flahault C

Citation: Palliative & Supportive Care, 01 March 2009, vol./is. 7/1(27-35), 14789515

Publication Date: 01 March 2009

Abstract: Objective: To improve the palliative care and more effectively meet the needs of young patients and their families at the end of life, the authors investigated the place of death of adolescents and young adults treated in their institution and identified some of the factors influencing the choice of place of death. Methods: The parents and/or partners of adolescents and young adults (15 to 25 years old) who died at Institut Curie (cancer center) between 2000 and 2003 were contacted. Twenty-one families agreed to participate in the interview between October 2005 and April 2006. Analysis of the interviews comprised a descriptive part and a thematic part. Results: Nineteen out of 21 (90%) families declared that they did not really choose their child's place of death due to lack of time. However, all families said that they preferred the hospital. No family attended a bereavement group after their child's death and only 3 families (14%) consulted a mental health care professional. Thematic analysis showed that representations and beliefs concerning life and death at least partly determined the family's capacity to discuss the place of death with their child. Significance of results: Although progress has been made over recent years in France, there is still considerable room for improvement of palliative care to more effectively meet the needs of young patients and their families at the end of life.

Source: CINAHL

89. Semiprivate: dying patients should be given the choice, whenever possible, of spending their last hours in a private room.

Author(s): Behuniak SM

Citation: American Journal of Nursing, 01 February 2009, vol./is. 109/2(11-11), 0002936X

Publication Date: 01 February 2009

Source: CINAHL

Full Text: Available in fulltext at Ovid

Available in fulltext at the ULHT Library and Knowledge Services' eJournal collection

90. Shared priorities for the end-of-life period.

Author(s): Downey L, Engelberg RA, Curtis JR, Lafferty WE, Patrick DL

Citation: Journal of Pain & Symptom Management, 01 February 2009, vol./is. 37/2(175-188), 08853924

Publication Date: 01 February 2009

Abstract: This study investigated end-of-life priorities of terminally ill patients and their intimate associates. A primary goal was to reduce the number of items in an existing instrument measuring survivors' evaluations of the quality of dying and death. Three Seattle-area patient samples (chronic obstructive pulmonary disease patients, hospice patients, and participants in an efficacy trial of complementary comfort care) and their significant others provided priority rankings of 26 experiences at end of life. Two items represented top priorities for all subgroups: time with family/friends and pain control. Clustered multivariate probit regression models suggested only a few significant differences between participant groups in priority rankings: higher education increased the priority placed on having available means to hasten death, cancer patients and persons in the hospice sample (likely those experiencing disproportionate pain) assigned pain control higher priority than other groups, persons in the clinical trial (which included massage as an intervention) assigned higher priority to human touch, and racial/ethnic minorities emphasized the importance of having funeral arrangements made. In the clinical trial sample (the most recently interviewed), the importance attributed to taking care of health
care costs increased over time. If researchers were to use a reduced set of the 17 items mentioned among the top five priorities by at least 10% of the sample, none of the items that varied significantly between subgroups or over time would be eliminated. This change would reduce respondent burden in future investigations, simplify analyses aimed at identifying domains underlying the dying-and-death experience, and exclude the top-priority item of fewer than 4% of respondents. Copyright © 2009 U.S. Cancer Pain Relief Committee.

Source: CINAHL

Full Text:
Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

91. Decision making near life’s end: a prescription for change.

Author(s): Gillick MR

Citation: Journal of Palliative Medicine, 01 February 2009, vol./is. 12/2(121-125), 10966218

Publication Date: 01 February 2009

Abstract: The publication of SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) in 1995 identified major problems with decision making near the end of life. Since that time, palliative care has developed as a specialty and end-of-life communication has evolved. However, five problems in decision-making remain today: the need to discuss underlying health status with patients; the overburdening of patients and families with too many choices; lack of appreciation of the importance of symbolism in end-of-life care; confusion between cultural beliefs and scientific facts; and difficulties with making decisions because of rapid shifts by the medical team from advocating cure to comfort. Each of these issues is described.

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost


Author(s): Murray MA, Fiset V, Young S, Kryworuchko J

Citation: Oncology Nursing Forum, 01 January 2009, vol./is. 36/1(69-77), 0190535X

Publication Date: 01 January 2009

Abstract: Purpose/Objectives: To describe the determinants of place of end-of-life (EOL) care for patients with cancer.Data Sources: A systematic literature review of primary research studies (1997-2007) was conducted. Studies that investigated place of EOL care or identified place of EOL care in relation to outcomes were examined, their critical quality was appraised, and references were mapped.Data Synthesis: Of the 735 articles identified, 39 (representing 33 studies) met inclusion criteria. Two main research designs emerged: large-scale epidemiologic reports and smaller descriptive studies. Findings suggest that factors related to the disease, the individual, and the care and social environment influence place of EOL care for patients with cancer. Social support, healthcare inputs (from services and programs and healthcare provider contact), and patient preferences were the most important factors.Conclusions: Most patients with terminal cancer prefer home palliation; however, most die in an institution. The reasons are complex, with various determinants influencing decisions regarding place of EOL care.Implications for Nursing: Findings may highlight evidence-based interventions to assist patients and families facing decisions regarding place of EOL care. A clearer understanding of factors that influence place of EOL care for patients with cancer could enhance healthcare policy and guide needs-based modifications of the healthcare system.

Source: CINAHL

Full Text:
93. Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England

Author(s): Munday D., Petrova M., Dale J.

Citation: BMJ (Clinical research ed.), 2009, vol./is. 339/(b2391), 1468-5833 (2009)

Publication Date: 2009

Abstract: OBJECTIVE: To explore the experiences and perceptions of general practitioners and community nurses in discussing preferences for place of death with terminally ill patients. DESIGN: Qualitative study using semi-structured interviews and thematic analysis. PARTICIPANTS: 17 general practitioners and 19 nurses (16 district nurses, three clinical nurse specialists). SETTING: 15 general practices participating in the Gold Standards Framework for palliative care from three areas in central England with differing socio-geography. Practices were selected on the basis of size and level of adoption of the standards framework. RESULTS: All interviewees bar one had experience of discussing preferred place of death with terminally ill patients. They reported that preferences for place of death frequently changed over time and were often ill defined or poorly formed in patients' minds. Preferences were often described as being co-created in discussion with the patient or, conversely, inferred by the health professional without direct questioning or receiving a definitive answer from the patient. This inherent uncertainty challenged the practicability, usefulness, and value of recording a definitive preference. The extent to which the assessment of enabling such preferences can be used as a proxy for the effectiveness of palliative care delivery is also limited by this uncertainty. Generally, interviewees did not find discussing preferred place of death an easy area of practice, unless the patient broached the subject or led the discussions. CONCLUSIONS: Further research is needed to enable development of appropriate training and support for primary care professionals. Better understanding of the importance of place of death to patients and their carers is also needed.

Source: EMBASE

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Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.
Available in print at Louth County Hospital Medical Library
Available in print at Pilgrim Hospital Staff Library

94. Barriers to home care for terminally ill Turkish and Moroccan migrants, perceived by GPs and nurses: A survey

Author(s): De Graaff F.M., Francke A.L.

Citation: BMC Palliative Care, 2009, vol./is. 8/1, 1472-684X (2009)

Publication Date: 2009

Abstract: Background. Previous qualitative research proved that relatives of elderly terminally ill Turkish and Moroccan immigrants experience several barriers to the use of Dutch professional home care. The aim of this study was to explore how general practitioners and home care nurses perceive the home care for terminally ill Turkish and Moroccan migrants and their families in the Netherlands. Methods: Questionnaires were sent to home care organizations and GPs working in areas where most of these migrants are living. 93 nurses and 78 GPs provided information about their experiences and
opinions regarding home care for this group of patients. The data were analyzed by descriptive statistics. Results. GPs refer relatively few patients from these migrant groups to home care. They often find it difficult to assess the needs of these patients and their families. In 40% of the GPs' cases in which terminally ill Turkish and Moroccan migrants were not referred to home care, the GP regretted this afterwards: the patients had not received sufficient qualified care, and their informal carers had often become overburdened. In addition, home care nurses often express dissatisfaction with the home care given to terminally ill Turkish or Moroccan patients, because of communication problems, the patients' lack of knowledge of the disease, or difficulties in making suitable appointments with the patient or with the family. Conclusion. Nurses and GPs cite chiefly similar factors influencing access to and use of home care as family members did in a previous study. However, according to GPs and nurses, the main barrier to the use of home care concerns communication problems, while relatives cited the preference for family care as the main reason for abstaining from the use of home care. 2009 de Graaff and Francke; licensee BioMed Central Ltd.

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95. Next-of-kin caregivers in palliative home care -- from control to loss of control.

Author(s): Munck B, Fridlund B, Mårtensson J

Citation: Journal of Advanced Nursing, 15 December 2008, vol./is. 64/6(578-586), 03092402

Publication Date: 15 December 2008

Abstract: Aim. This paper is a report of a study to describe situations influencing next-of-kin caregivers' ability to manage palliative care in the home. Background. Palliative home care often involves major resources from next-of-kin, municipal and county personnel. Next-of-kin caregivers' situation is depicted as so demanding and exhausting that it can affect their mental health and limit their ability to continue as a caregiver. Methods. A qualitative study using the Critical Incident Technique was conducted. Nine next-of-kin caregivers from palliative home care were strategically chosen and data were collected using audiotaped interviews in 2005. Findings. The analysis resulted in two main areas: 'Maintaining control' and 'Losing control'. Next-of-kin caregivers wanted to maintain control over their lives by being continuously available 24 hours a day and by supporting and taking complete responsibility for all of the patient's needs. They lost this control when professional assistance was lacking and they described feelings of inadequacy when their physical energy or time was insufficient. They felt incapable as the patient's physical or mental persona metamorphosed or as serious symptoms developed that they could not control. Conclusion. Next-of-kin caregivers and the patients must feel free to choose where palliative home care will be provided and that their choice at any time can be re-evaluated, due to insecurity or workload changes. When planning for palliative care, they should be informed that having only one caregiver reduces the chances of completing palliative care in the home.

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost

96. Eliciting individual preferences about death: development of the End-of-Life Preferences Interview.


Citation: Journal of Pain & Symptom Management, 01 October 2008, vol./is. 36/4(335-350), 08853924
Abstract: The capability to make decisions about one's own dying and death is commonly considered a necessary component of a good death, but difficulties in communicating about imminent death have been documented. This paper attempts to describe the process of constructing an instrument to elicit individual preferences concerning dying, while respecting the patient's awareness, and to verify its applicability in a palliative care setting. The development of the End-of-Life Preferences Interview (ELPI) was performed through (a) a literature search aimed at identifying relevant issues; (b) examination by a panel of experts in the field of palliative care of the items generated; and (c) pretesting of feasibility on all eligible consecutive patients referred to three centers of palliative care during a two-month period. The final version of the ELPI consisted of two parts: The first level explores preferences about issues regarding the caregiving process, and the second level focuses on preparation for death. Each of the two parts is introduced by key questions aimed at allowing the patient to decide whether and when to stop exploring such sensitive matters. Among the 49 eligible patients (41%), the interview was proposed to only 13 of them (27%), and only one of them refused. The reasons for such a low compliance of physicians in proposing the ELPI were evaluated by a semi-structured interview and are herein discussed. The use of the ELPI in clinical practice can favor the passage to a greater consideration of the self-determination of the patient at the end of life, with due consideration of his or her cultural and emotional needs. Copyright © 2008 U.S. Cancer Pain Relief Committee.

Source: CINAHL

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Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

97. Family discord and proxy decision makers’ end-of-life treatment decisions.

Author(s): Winter L, Parks SM

Citation: Journal of Palliative Medicine, 01 October 2008, vol./is. 11/8(1109-1114), 10966218

Abstract: Background: Because many Americans are decisionally incapacitated at the end of life, the last treatment decisions are often made by family proxies. Family discord concerning end-of-life (EOL) care may not only exacerbate a family crisis but also influence treatment decisions. We tested the extent to which family discord would be associated with preferences for types of end-of-life care, predicting that greater discord would be associated with weaker preferences for palliative care and stronger preferences for life-prolonging care. Setting/subjects: Sixty-eight proxy decision makers for elderly relatives were interviewed in their homes over the telephone. Measurements: The 35-minute telephone interview assessed preferences for four life-prolonging treatments and for palliative care and included a family discord measure, an EOL values scale, and questions about sociodemographic characteristics. Results: Repeated-measures analyses of covariance and regression analyses showed that greater family discord was associated with stronger preferences for life-prolonging treatments and weaker preferences for palliative care, independently of EOL values and sociodemographic characteristics. Conclusions: In counseling patients with life-limiting illnesses and their families, clinicians should explore possible family discord surroundings EOL care. Counseling protocols should be developed and clinicians should be trained in counseling to minimize family conflict.

Source: CINAHL

Full Text:
Available in fulltext at EBSCOhost

98. Preference for place of care and place of death in palliative care: are these different questions?

Author(s): Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy
Abstract: Place of death is at times suggested as an outcome for palliative care services. This study aimed to describe longitudinal preferences for place of care and place of death over time for patients and their caregivers. Longitudinal paired data of patient/caregiver dyads from a prospective unblinded cluster randomised control trial were used. Patients and caregivers were separately asked by the palliative care nurse their preference at that time for place of care and place of death. Longitudinal changes over time for both questions were mapped; patterns of agreement (patient and caregiver; and preference for place of death when last asked and actual place of death) were analysed with kappa statistics. Seventy-one patient/caregiver dyads were analysed. In longitudinal preferences, preferences for both the place of care (asked a mean of >6 times) and place of death (asked a mean of >4 times) changed for patients (28% and 30% respectively) and caregivers (31% and 30%, respectively). In agreement between patients and caregivers, agreement between preference of place of care and preferred place of death when asked contemporaneously for patients and caregivers was low [56% (kappa 0.33) and 36% (kappa 0.35) respectively]. Preference versus actual place of death, preferences were met for 37.5% of participants for home death; 62.5% for hospital; 76.9% for hospice and 63.6% for aged care facility. This study suggests that there are two conversations: preference for current place of care and preference for care at the time of death. Place of care is not a euphemism for place of death; and further research is needed to delineate these. Patient and caregiver preferences may not change simultaneously. Implications of any mismatch between actual events and preferences need to be explored.

Source: CINAHL

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Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.


Author(s): Schleinich MA, Warren S., Nekolaichuk C, Kaasa T, Watanabe S.

Citation: Palliative Medicine, 01 October 2008, vol./is. 22/7(822-830), 02692163

Publication Date: 01 October 2008

Abstract: Rehabilitation in palliative care is often overlooked. Settings that do consider occupational or physical therapy for palliative care patients often consult to therapists with competing caseloads. Few therapists specialise in palliative care, but nearly all ask, ‘What needs doing?’ and ‘How well am I doing that’? No existing instruments address their questions. The objective is to develop and test a questionnaire for identifying patient goals and priorities for rehabilitation in palliative care. A questionnaire representing 11 domains of the Canadian Model of Occupational Performance was designed and pilot tested at four palliative care sites. Each question reflected a typical rehabilitation intervention in palliative care. Patients were asked to rate how important each of these interventions was on a numerical rating scale (0, not important-10, extremely important). Open-ended questions captured verbatim comments regarding thoughts of rehabilitation. The questionnaire was tested for test-retest reliability with two interviews approximately 1 week apart. Forty patients participated in the first interview and 32 in the second. Eight of eleven domain subscores achieved an intra-class correlation coefficient of 0.6 or higher. The highest means were for the physical (8.2), institutional (7.8) and self-care (7.8) domains on the first interview and for the spiritual domain (7.9) on the second interview. Suggestions are provided to shorten the questionnaire and strengthen validity. This work furthers the understanding of the role of rehabilitation in palliative care. It also illustrates the feasibility of involving palliative care patients in research that contributes to setting standards and measuring quality of service.

Source: CINAHL
100. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences.

Author(s): Smith AK, McCarthy EP, Paulk E, Balboni TA, Maciejewski PK, Block SD, Prigerson HG

Citation: Journal of Clinical Oncology, 01 September 2008, vol./is. 26/25(4131-4137), 0732183X

Abstract: PURPOSE Despite well-documented racial and ethnic differences in advance care planning (ACP), we know little about why these differences exist. This study tested proposed mediators of racial/ethnic differences in ACP. PATIENTS AND METHODS We studied 312 non-Hispanic white, 83 non-Hispanic black, and 73 Hispanic patients with advanced cancer in the Coping with Cancer study, a federally funded multisite prospective cohort study designed to examine racial/ethnic disparities in ACP and end-of-life care. We assessed the impact of terminal illness acknowledgment, religiousness, and treatment preferences on racial/ethnic differences in ACP. Results Compared with white patients, black and Hispanic patients were less likely to have an ACP (white patients, 80%; black patients, 47%; Hispanic patients, 47%) and more likely to want life-prolonging care even if he or she had only a few days left to live (white patients, 14%; black patients, 45%; Hispanic patients, 34%) and to consider religion very important (white patients, 44%; black patients, 88%; Hispanic patients, 73%; all P < .001, comparison of black or Hispanic patients with white patients). Hispanic patients were less likely and black patients marginally less likely to acknowledge their terminally ill status (white patients, 39% v Hispanic patients, 11%; P < .001; white v black patients, 27%; P = .05). Racial/ethnic differences in ACP persisted after adjustment for clinical and demographic factors, terminal illness acknowledgment, religiousness, and treatment preferences (has ACP, black v white patients, adjusted relative risk, 0.64 [95% CI, 0.49 to 0.83]; Hispanic v white patients, 0.65 [95% CI, 0.47 to 0.89]). CONCLUSION Although black and Hispanic patients are less likely to consider themselves terminally ill and more likely to want intensive treatment, these factors did not explain observed disparities in ACP.

Source: CINAHL

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Available in fulltext at the ULHT Library and Knowledge Services’ eJournal collection

101. Respectful death: a model for end-of-life care

Author(s): Wasserman L.S.

Citation: Clinical journal of oncology nursing, August 2008, vol./is. 12/4(621-626), 1092-1095 (Aug 2008)

Abstract: The Respectful Death Model (RDM) is a research-based, holistic, and practical model developed to improve end-of-life care. A respectful death is one which supports dying patients, their families, and professionals in the completion of life cycles and can be used by all members of the healthcare team. The model is a process method commencing with the establishment of a therapeutic relationship with the dying patient and his or her family and, as a result, their stories are heard and incorporated into the care plan. This article demonstrates that hospice and palliative care nurses have been practicing this model since the origination of care of the dying. Other topics addressed are the current culture toward death in the United States, the roles of nurses in the RDM, and the barriers and benefits of the RDM. Recommendations for future research in end-of-life care also are addressed.
102. Determinants of home death in palliative home care: Using the interRAI palliative care to assess end-of-life care

Author(s): Brink P., Frise Smith T.
Citation: American Journal of Hospice and Palliative Medicine, August 2008, vol./is. 25/4(263-270), 1049-9091 (August-September 2008)
Publication Date: August 2008

Abstract: Many terminally ill patients are given the choice to die at home. This study identified determinants of home death among patients receiving palliative home care. Health information was collected using the interRAI palliative care assessment tool. The sample included health information from 536 patients receiving home health care from one community care access centre in Ontario, Canada. Patients who died at home were more likely to be functionally impaired and less likely to live alone. The patients' wish to die at home and the family's ability to cope were strong determinants of home death. This study suggests that the presence of a supportive family that is able to work with the health care team to implement a plan of care is important to the patients' ability to die at home. This study highlights the need to treat the patient and the caregiver(s) as a unit of care. 2008 Sage Publications.

Source: EMBASE

103. Managing a good death in critical care: can health policy help?

Author(s): Coombs M., Long T.
Citation: Nursing in critical care, July 2008, vol./is. 13/4(208-214), 1478-5153 (2008 Jul-Aug)
Publication Date: July 2008

Abstract: AIM: This paper discusses end-of-life care (EoLC) in critical care through exploration of what is known from the international literature and what is currently presented within UK policy. BACKGROUND AND CONTEXT: EoLC is an important international critical care issue, and currently provides a key focus for health care policy in the UK. While society holds that critical care is delivered in a highly technical area with a strong focus on cure and recovery, mortality rates in this speciality remain at approximately 20%. When patient recovery is not an outcome, discussions with patient, family and extended care teams turn towards futility of treatment and end-of-life management. However, there are specific barriers to overcome in EoLC for the critically ill. CONCLUSION: A key issue for EoLC in critical care is a lack of robust systems to prospectively identify individuals who are most at risk of dying. A further challenge is divergent perspectives within and across clinical teams on treatment withdrawal and limitation practices. To streamline patient management and underpin a hospice approach to care, EoLC policies are currently being used within the UK. While this provides a national framework to address some key critical care clinical issues in the UK, there is a need for further refinement of the tool to reflect the reality of EoLC for the critically ill. It is important that international best practice exemplars are examined and clinicians actively engage and contribute to ensure that any local EoLC frameworks are fit for purpose.

Source: EMBASE

104. Patient and surrogate disagreement in end-of-life decisions: can surrogates accurately predict patients' preferences?

Author(s): Marks MAZ, Arkes HR
BACKGROUND: When a patient is too incapacitated to make important end-of-life decisions, doctors may ask a preappointed surrogate to predict the patient's preferences and make decisions on the patient's behalf. The current study investigates whether surrogates project their own views onto what they predict the patients' preferences are.

METHODS: Using data from seriously ill patients and their surrogates, the authors created a "projection" variable that addresses the following question: When surrogates are asked to predict a patient's end-of-life preferences, do they mistakenly replace this prediction with what they would want the patient to do? The authors examined the 144 patient-surrogate pairs in which surrogates inaccurately predicted patients’ CPR (cardiopulmonary resuscitation) v. DNR (do not resuscitate) decisions and the 294 pairs in which surrogates inaccurately predicted patients' extend life v. relieve pain preferences. Among these patient-surrogate pairs, the authors determined the extent to which surrogates' wishes for the patient matched their incorrect predictions of what the patient wanted. RESULTS: Of the patient-surrogate pairs who disagreed on CPR v. DNR and extend life v. relieve pain preferences, 62.5% and 88.4% of surrogates demonstrated projection for CPR v. DNR decisions and extend life v. relieve pain preferences, respectively. Age-related and demographic variables did not predict cases in which projection did and did not occur. CONCLUSION: When surrogates inaccurately predict the CPR v. DNR and extend life v. relieve pain preferences of seriously ill, hospitalized loved ones, surrogates' prediction errors often represent surrogates' own wishes for the patient.
research relating to end-of-life preferences may need to focus on a patient education model incorporating the use of decision aids such as video to ensure informed decision-making.

Source: CINAHL

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Available in fulltext at EBSCOhost

106. A literature review of preferences for end-of-life care in developed countries by individuals with different cultural affiliations and ethnicity.

Author(s): Thomas R, Wilson DM, Justice C, Birch S, Sheps S

Citation: Journal of Hospice & Palliative Nursing, 01 May 2008, vol./is. 10/3(142-163), 15222179

Publication Date: 01 May 2008

Abstract: Anticipatory decision making about end-of-life care is predominantly a North American concept. Researchers investigated four themes: advance directives, life support, communication, and decision making. Substantial differences exist among cultural groups in the percentages with living wills/advance directives, and they are less frequent for those with family-centered decision making or with less trust in the healthcare system. African Americans prefer life support more than Asian Americans or European Americans. Cultural groups vary in their preferences about communicating terminal diagnoses. Non-English-speaking patients perceive communication as a barrier to care. Mexican Americans, Korean Americans, and Canadian First Nations emphasize family-based decision making at the end of life, and European Americans emphasize patient autonomy.

Source: CINAHL

107. The potential impact of decision role and patient age on end-of-life treatment decision making.

Author(s): Zikmund-Fisher BJ, Lacey HP, Fagerlin Å

Citation: Journal of Medical Ethics, 01 May 2008, vol./is. 34/5(327-331), 03066800

Publication Date: 01 May 2008

Abstract: BACKGROUND: Recent research demonstrates that people sometimes make different medical decisions for others than they would make for themselves. This finding is particularly relevant to end-of-life decisions, which are often made by surrogates and require a trade-off between prolonging life and maintaining quality of life. We examine the impact of decision role, patient age, decision maker age and multiple individual differences on these treatment decisions. METHODS: Participants read a scenario about a terminally ill cancer patient faced with a choice between an aggressive chemotherapy regimen that will extend life by two years and palliative treatments to control discomfort for one remaining month. Participants were randomly assigned to one of three decision roles (patient, physician, or an abstract other) and the scenario randomly varied whether the patient was described as 25 or 65-years old. RESULTS: When deciding for a 65-year old patient, approximately 60% of participants selected aggressive chemotherapy regardless of decision role. When deciding for a 25-year old patient, however, participants were more likely to select chemotherapy for a patient (physician role) or another person (abstract other) than for themselves (70%, 67%, and 59%, respectively). In addition, confidence that powerful others (eg, physicians) control one's health, as well as respondents' age and race, consistently predicted treatment choices. CONCLUSIONS: Patient age appears to influence medical decisions made for others but not those that we make for ourselves. These findings may help to explain the discord that often occurs when younger cancer patients refuse life-extending treatments.

Source: CINAHL

Full Text:
Available in fulltext at Highwire Press
Available in fulltext at National Library of Medicine
108. A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia

Author(s): Birch D., Draper J.

Citation: Journal of Clinical Nursing, May 2008, vol./is. 17/9(1144-1163), 0962-1067;1365-2702 (May 2008)

Publication Date: May 2008

Abstract: Aim. This paper considers the challenges of delivering effective palliative care to older people with dementia and the possible strategies to overcome barriers to end-of-life care in these patients. Background. In UK alone, approximately 100 000 people with dementia die each year and as the number of older people increases, dementia is set to become even more prevalent. Dementia is a progressive terminal illness for which there is currently no cure. Patients dying with dementia have significant health-care needs and in recent years it has been recognised that palliative care should be made available to everyone regardless of diagnosis, as this improves comfort and quality of life. Despite this, patients dying with dementia are often still not given access to palliative care services.

Method. A review of English language literature published after 1996 to the present day relating to older people with dementia during the terminal phase of their illness.

Results. Twenty-nine articles met inclusion criteria for the review. Most originated from North America and UK and were mostly quantitative in nature. Four key themes were identified: difficulties associated with diagnosing the terminal phase of the illness (prognostication); issues relating to communication; medical interventions; and the appropriateness of palliative care intervention.

Conclusions. This review reinforces the importance of providing appropriate palliative care to individuals suffering from end-stage dementia and identifies some of the barriers to extending such specialist palliative care provision. Relevance to practice. There is an urgent need to improve palliative care provision for older people with end-stage dementia and, in addition, more research is required on the needs of patients entering the terminal phase of dementia to assist the allocation of appropriate resources and training to ensure quality and equality in the provision of end-of-life care. 2008 Blackwell Publishing Ltd.

Source: EMBASE

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Available in fulltext at the ULHT Library and Knowledge Services' eJournal collection
Available in print at Pilgrim Hospital Staff Library

109. End of life issues

Author(s): Sykes N.

Citation: European Journal of Cancer, May 2008, vol./is. 44/8(1157-1162), 0959-8049 (May 2008)

Publication Date: May 2008

Abstract: Despite advances in cancer survival rates, end of life care remains a vital aspect of cancer management. The use of integrated care pathways can facilitate effective care of dying patients in a generalist setting. However, it remains important that staff are able to recognise the onset of the dying process, not only in order to make symptom control provision, but also that appropriate communication can occur with patients and those close to them. This allows the exercise of choice over place and style of care. The key symptoms at the end of life are restlessness, agitation, breathlessness, pain and noisy respiration from retained airway secretions. Ethical tensions arise from the assumptions that the use of opioids and sedatives hastens dying, but this is contradicted by available evidence. 2008 Elsevier Ltd. All rights reserved.

Source: EMBASE
110. Out-of-hours palliative care offers choice of a home death.

Citation: Nursing Standard, 23 April 2008, vol./is. 22/33(11-11), 00296570
Publication Date: 23 April 2008
Abstract: Teams of out-of-hours palliative care nurses have helped more terminally ill patients to die at home rather than in hospital -- at no extra cost to the NHS.
Source: CINAHL

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Available in print at Pilgrim Hospital Staff Library

111. Do palliative consultations improve patient outcomes?

Author(s): Casarett D, Pickard A, Bailey FA, Ritchie C, Furman C, Rosenfeld K, Shreve S, Chen Z, Shea JA
Citation: Journal of the American Geriatrics Society, 01 April 2008, vol./is. 56/4(593-599), 00028614
Publication Date: 01 April 2008
Abstract: OBJECTIVES: To determine whether inpatient palliative consultation services improve outcomes of care. DESIGN: Retrospective telephone surveys conducted with family members of veterans who received inpatient or outpatient care from a Department of Veterans Affairs (VA) medical facility in the last month of life. SETTING: Five VA Medical Centers or their affiliated nursing homes and outpatient clinics. PARTICIPANTS: Veterans had received inpatient or outpatient care from a participating VA in the last month of life. One family member completed each survey. MEASUREMENTS: The telephone survey assessed nine aspects of the care the patient received in his or her last month of life: the patient's well-being and dignity (4 items), adequacy of communication (5 items), respect for treatment preferences (2 items), emotional and spiritual support (3 items), management of symptoms (4 items), access to the inpatient facility of choice (1 item), care around the time of death (6 items), access to home care services (4 items), and access to benefits and services after the patient's death (3 items). RESULTS: Interviews were completed with 524 respondents. In a multivariable linear regression model, after adjusting for the likelihood of receiving a palliative consultation (propensity score), palliative care patients had higher overall scores: 65 (95% confidence interval (CI)=62-66) versus 54 (95% CI=51-56; P<.001) and higher scores for almost all domains. Earlier consultations were independently associated with better overall scores (beta=0.003; P=.006), a difference that was attributable primarily to improvements in communication and emotional support. CONCLUSION: Palliative consultations improve outcomes of care, and earlier consultations may confer additional benefit.
Source: CINAHL

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Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.
112. Truth-telling at the end of life: a pilot study on the perspective of patients and professional caregivers.

Author(s): Deschepper R, Bernheim JL, Vander Stichele R, Van den Block L, Michiels E, Van Der Kelen G, Mortier F, Deliens L

Citation: Patient Education & Counseling, 01 April 2008, vol./is. 71/1(52-56), 07383991

Publication Date: 01 April 2008

Abstract: OBJECTIVE: To describe the attitudes towards truth-telling of both terminal patients and professional caregivers, and to determine their perceived barriers to full information exchange. METHODS: In-depth interviews with 17 terminal patients selected through GPs and staff members of Flemish palliative care centres, and 3 focus groups with different professional caregivers. Analysis was based on grounded theory. RESULTS: There was considerable variability in the preferences of patients regarding when and how they wanted to be informed of their diagnosis, prognosis, expected disease course and end-of-life decisions. Major ambivalence was observed regarding the degree to which patients wanted to hear 'the whole truth'. Patients and caregivers agreed that truth-telling should be a 'dosed and gradual' process. Several barriers to more complete and timely truth-telling were identified. CONCLUSION: The preferences of both patients and caregivers for step-by-step—and hence slow and limited—information prevents terminal patients from reaching the level of information needed for informed end-of-life decision-making. PRACTICE IMPLICATIONS: The preference of patients and caregivers to 'dose' the truth may entail some risks, such as a 'Catch 22' situation in which both patients and caregivers wait for a signal from each other before starting a dialogue about impending death.

Source: CINAHL

113. Choosing between life and death: patient and family perceptions of the decision not to resuscitate the terminally ill cancer patient

Author(s): Eliott J., Olver I.

Citation: Bioethics, March 2008, vol./is. 22/3(179-189), 0269-9702 (Mar 2008)

Publication Date: March 2008

Abstract: In keeping with the pre-eminent status accorded autonomy within Australia, Europe, and the United States, medical practice requires that patients authorize do-not-resuscitate (DNR) orders, intended to countermand the default practice in hospitals of instituting cardiopulmonary-resuscitation (CPR) on all patients experiencing cardiopulmonary arrest. As patients typically do not make these decisions proactively, however, family members are often asked to act as surrogate decision-makers and decide on the patient's behalf. Although the appropriateness of patients or their families having to decide about the provision of CPR has been challenged, there has been little examination of how patients and their families talk about and negotiate such decisions, particularly in the context of the patient's imminent death. In this article, part of a larger study analysing interviews with 28 patients (13 female) with cancer within weeks of their death, and 20 others (predominantly family) attending, we argue that a common assumption underpinning participants' talk about the DNR decision (i.e. forgoing CPR) is that it requires a choice between life and death. Using illustrative examples, we demonstrate that in making decisions about CPR, patients and their families are implicitly required to make moral judgements about the value of the patient's life, including their relationships with significant others. We identify some implications of these empirical observations for the development of ethically appropriate policies and practices regarding patient autonomy and surrogacy at the end of life.

Source: EMBASE

Full Text: Available in fulltext at EBSCOhost

Available in fulltext at EBSCOhost
114. End of life care preferences

Author(s): Borreani C., Miccinesi G.

Citation: Current opinion in supportive and palliative care, March 2008, vol./is. 2/1(54-59), 1751-4266 (Mar 2008)

Publication Date: March 2008

Abstract: PURPOSE OF REVIEW: This review considers how end of life care preferences have been dealt with recently in the scientific literature. RECENT FINDINGS: The ability to make decisions about one's own dying and death is commonly considered a necessary component of a 'good death'. It is important to allow people to express, if they wish, their end of life preferences. Most of the studies were conducted in patients at advanced stages of terminal illness and involved asking them about what their wishes would be in certain scenarios. Half of the papers specifically addressed the issues of life-shortening medical decisions. On considering the findings of the various studies reported in detail here, it becomes clear that end of life preferences would best be studied using a longitudinal design, because of the fluctuation of these preferences over time and their association with dynamic components of quality of life, such as functional status, and psychosocial and spiritual dimensions. SUMMARY: Both patients and health care workers can be assisted in addressing the issue of what is the right time for a patient to record their preferences, in recognizing psychological defences and their evolution during the end of life process, and in managing conflicts and suffering in the patient-family unit. Guidelines and practical tools have begun to be designed and tested.

Source: EMBASE

115. Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers.

Author(s): Stajduhar KI, Allan DE, Cohen SR, Heyland DK

Citation: Palliative Medicine, 01 January 2008, vol./is. 22/1(85-88), 02692163

Publication Date: 01 January 2008

Abstract: Previous studies involving palliative patients suggest a preference for dying at home. The purpose of this paper is to examine, prospectively, patient and family caregiver preferences for, and congruence with, location of death for hospitalized patients with cancer and end-stage medical conditions. Questionnaires were administered to 440 eligible in-patients and 160 family caregivers in five hospitals across Canada. This paper reports results of 138 patient/family caregiver dyads who answered a question about preference for location of death. The results suggest that only half of all patients and family caregivers report a preference for a home death. Furthermore, half of the patient/family caregiver dyads disagree on preferred location of death. If one of the primary goals of end of life care is to enhance the quality of life of dying patients and their family caregivers, policies directed towards ensuring that patients die in their location of choice ought to be a priority and resources should be allocated to promote the development of excellent care, not only in the home, but also within our institutional settings.

Source: CINAHL

Full Text: Available in fulltext at EBSCOhost

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Results from AMED, BNI, MEDLINE and PsychINFO

(Results may duplicate those in the CINAHL/EMBASE set)

1. End-of-life care pathways as tools to promote and support a good death: a critical commentary.
Author(s): Watts T

Citation: European Journal of Cancer Care, January 2012, vol./is. 21/1(20-30), 0961-5423;1365-2354 (2012 Jan)

Publication Date: January 2012

Abstract: This paper calls into question whether and how end-of-life care pathways facilitate the accomplishment of a 'good death'. Achieving a 'good death' is a prominent social and political priority and an ideal which underpins the philosophy of hospice and palliative care. End-of-life care pathways have been devised to enhance the care of imminently dying patients and their families across care settings and thereby facilitate the accomplishment of a 'good death'. These pathways have been enthusiastically adopted and are now recommended by governments in the UK as 'best practice' templates for end-of-life care. However, the literature reveals that the 'good death' is a nebulous, fluid concept. Moreover, concerns have been articulated regarding the efficacy of care pathways in terms of their impact on patient care and close analysis of two prominent end-of-life pathways reveals how biomedical aspects of care are privileged. Nonetheless drawing on a diverse range of evidence the literature indicates that end-of-life care pathways may facilitate a certain type of 'good death' and one which is associated with the dying process and framed within biomedicine. Copyright 2011 Blackwell Publishing Ltd.

Source: MEDLINE

2. The use of palliative care services associated with better dying circumstances. Results from an epidemiological population-based study in the brussels metropolitan region.

Author(s): Cohen J, Houttekier D, Chambaere K, Bilsen J, Deliens L

Citation: Journal of Pain & Symptom Management, December 2011, vol./is. 42/6(839-51), 0885-3924;1873-6513 (2011 Dec)

Publication Date: December 2011

Abstract: CONTEXT: There is some consensus that a "good death" is one which occurs at home, in the presence of loved ones, and is free of distress. Involvement of palliative care services is assumed to improve these circumstances.OBJECTIVES: This population-based study describes characteristics of the end of life of patients dying in Brussels and examines their associations with the involvement of palliative care services.METHODS: In 2007, an anonymous large-scale mortality follow-back survey was conducted in Brussels by mailing questionnaires regarding end-of-life care and characteristics to the attending physicians of a representative sample of 1961 deaths.RESULTS: Response rate was 41% (n=701). Of all deaths, 59% were nonsudden. Of these, 12% took place at home. For 27%, the attending physician was informed about the patient's preferred place of death. When the preference to die at home was known, 66% died at home. At the moment of death, in 47% of nonsudden deaths, loved ones were present. In a quarter of deaths, palliative care services were involved. Involvement with palliative care services was more likely for cancer patients than noncancer patients and was associated with the attending physicians more often being informed about the preferred place of death, with patients more often dying at home, with loved ones more often being present, and with a better feeling of well-being on the last day.CONCLUSION: Overall, circumstances at the very end of life are suboptimal in Brussels. This study provides a case for stronger involvement of palliative care as a focal point for policies to improve end-of-life circumstances in a metropolitan area such as Brussels. Copyright Copyright 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Source: MEDLINE


Author(s): Neergaard MA, Jensen AB, Sondergaard J, Sokolowski J, Olesen F, Vedsted P

Citation: Scandinavian Journal of Caring Sciences, December 2011, vol./is. 25/4(627-36), 0283-9318;1471-6712 (2011 Dec)

Publication Date: December 2011
Abstract: Achieving home death is often seen as an important endpoint in palliative care, but no studies of the preferred place-of-death have yet been conducted in Scandinavia. Furthermore, we do not know if professionals' report on deceased patients' preference of place-of-death is a valid information. The aim of this study was to describe where terminally ill Danish cancer patients prefer to die and to determine if their preference changed during the palliative period, as reported retrospectively by bereaved relatives, general practitioners (GPs) and community nurses (CNs) and to assess the agreement of their accounts. The study was a population-based, cross-sectional combined register and questionnaire study in Aarhus County, Denmark. The population comprised 599 deceased adult cancer patients who had died from 1 March to 30 November 2006 and were identified through merging of health registers. Relatives returned 198 questionnaires about patients' preferred place-of-death, GPs 333 and CNs 201. The study showed that most terminally ill cancer patients preferred home death (up to 80.7%). The reported preference for home death weakened as death approached (down to 64.4%). A better congruence was seen between relatives' and GPs' accounts of preference for place of death at the end of the palliative period (kappa 0.71) than between relatives' and CNs' accounts (kappa 0.37). In conclusion, bereaved relatives (and GPs and CNs) report retrospectively that most terminally ill cancer patients wish to die at home. The preference weakened significantly as death approached. The agreement between relatives' and GPs' accounts of preference at the end of the palliative period was 'substantial', whereas the agreement between relatives' and CNs' accounts at the same time was significantly less outspoken. This indicates that CNs may be facing a problem in assessing their patients' wishes retrospectively. Copyright 2011 The Authors. Scandinavian Journal of Caring Sciences Copyright 2011 Nordic College of Caring Science.


Author(s): Zieske M, Abbott J

Citation: Academic Emergency Medicine, November 2011, vol./is. 18/11(1201-7), 1069-6563;1553-2712 (2011 Nov)

Publication Date: November 2011

Abstract: Emergency physicians (EPs) are asked to evaluate and treat a growing population of hospice patients who present to the emergency department (ED) for a number of important reasons. Hospice patients pose unique ethical challenges, and "best practices" for these patients can differ from the life-preserving interventions of usual ED care. Having a solid understanding of professional responsibilities and ethical principles is useful for guiding EP management of these patients. In end-of-life care, EPs need to recognize that there are barriers and complexities to the best management of hospice patients, but they need to commit to strategies that optimize their care. This article describes the case of a hospice patient who presented with sepsis and end-stage cancer to the ED. Patient, system, and physician factors made management decisions in the ED difficult. The goal in the ED should be to determine the best way to address terminally ill patient needs while respecting wishes to limit interventions that will only increase suffering near the end of life. Copyright 2011 by the Society for Academic Emergency Medicine.

Source: MEDLINE

5. Influence of location on a good death.

Author(s): Paddy M

Citation: Nursing Standard, September 2011, vol./is. 26/1(33-6), 0029-6570;0029-6570 (2011 Sep 7-13)

Publication Date: September 2011

Abstract: With the recent emphasis of the Department of Health on reducing unnecessary hospitalisation at the end of life and improving community care for people dying at home, it could be assumed that dying at home is the gold standard. However, healthcare professionals should be able to give a patient choice over where they die, whether that is at home, in hospital or in a hospice. This article asks the reader to consider whether
location of death has an influence on the quality of death.

**Source:** MEDLINE

**Full Text:**

Available in fulltext at EBSCOhost

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

Available in print at Louth County Hospital Medical Library

Available in print at Pilgrim Hospital Staff Library

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6. **Perceptions of terminally ill patients and family members regarding home and hospice as places of care at the end of life.**

**Author(s):** Luijkx KG, Schols JM

**Citation:** European Journal of Cancer Care, September 2011, vol./is. 20/5(577-84), 0961-5423;1365-2354 (2011 Sep)

**Publication Date:** September 2011

**Abstract:** To enable demand-based palliative care, it is important to know the perceptions of terminally ill patients and their family members regarding home and hospice as places of care at the end of life. Eight women and five men suffering from cancer and with a life expectancy of 3 months or less were interviewed. In each case one of the family members was also interviewed. Four patients spent their last phase of life at home, nine in a hospice. This paper provides further insight in the patient perspective in palliative care. The results reveal that a cohabiting partner seems an important prerequisite for terminally ill patients to stay at home. For spouses it is an obvious choice to facilitate the patients' stay at home, even when it becomes too demanding, something not discussed between spouse and patient. When sufficient care at home seems impossible and the negotiation between patients and family members results in the opinion that living at home is no longer an option, it is decided that the patient moves to a hospice. The choice for the specific setting of the patients' new residence seems to be random; one possibility is pointed out to them and seems appropriate. Copyright 2010 Blackwell Publishing Ltd.

**Source:** MEDLINE

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7. **'I am part of the community but...': The changing context of rural living for persons with advanced cancer and their families.**

**Author(s):** Duggleby WD, Penz K, Leipert BD, Wilson DM, Goodridge D, Williams A

**Citation:** Rural & Remote Health, July 2011, vol./is. 11/3(1733), 1445-6354;1445-6354 (2011 Jul-Sep)

**Publication Date:** July 2011

**Abstract:** INTRODUCTION: Older rural persons who are receiving palliative care experience multiple co-existing transitions that can be distressing. These transitions do not occur in a vacuum, but occur in a context that reflects the uniqueness of rural living and the complexities of end of life in rural settings. The context or situation (geographical, physical, and social) in which an experience occurs influences the way people view and interpret the world around them; this contextual perspective contributes greatly to perceptions held by rural residents. Purpose: The purpose of this study was to explore the context in which older rural patients receiving palliative care and their families experience transitions. Following a study of the transition experiences of older rural palliative patients, an in-depth interpretive description analysis was conducted specific to the context in which the participants’ transitions occurred.METHODS: Twenty-seven open-ended, individual, audio-taped, qualitative interviews were conducted and 4 focus group discussions were held to gather data. Individual audio-taped interviews were conducted with six older rural persons with advanced cancer and 10 bereaved (post-death) family caregivers. Four focus groups were conducted with 12 palliative care healthcare professionals. Participants were recruited from 3 rural health regions in a western Canadian province classified as one of the most 'rural' Canadian provinces. All interviews were transcribed verbatim, coded, and analyzed using Thorne's interpretive description qualitative approach.RESULTS: From the
data analysis four themes emerged: (1) community connectedness/isolation; (2) lack of accessibility to care; (3) communication and information issues; and (4) independence/dependence. Participants described feelings of being connected to the community at the same time as they also reported feeling isolated. They described their value of independence at the same time as finding themselves becoming increasingly dependent on others. At times this value of independence interfered with their seeking and accessing needed health or supportive care. They perceived their lack of access to health care resulted in little or no choice in where they die. CONCLUSIONS: These findings reveal that the rural context has a major impact on the types of community support and healthcare services needed by older persons with advanced disease and their families. With advanced disease, the participants’ sense of solitude became one of isolation, and with increasing dependence on others, they needed more connection and support from others. The findings reflected a more complex view of rural aging and dying than has been cited in the literature to date. This study suggests there is a need to renegotiate community supports and the independence available to persons with advanced disease as they undergo multiple transitions near the end of life.

Source: MEDLINE

Full Text:
Available in fulltext at EBSCOhost

8. What are patients’ priorities when facing the end of life? A critical review.

Author(s): Black J

Citation: International Journal of Palliative Nursing, June 2011, vol./is. 17/6(294-300), 1357-6321;1357-6321 (2011 Jun)

Publication Date: June 2011

Abstract: This critical review aimed to investigate what patients’ priorities are when facing the end of life, in order to gain further understanding of this issue. Academic databases were searched using key terms, and through a method of elimination and deduction using specific inclusion/exclusion criteria, suitable research studies were found. These articles were then assessed for their quality, and specific data was extracted from the final selection using appropriate information-gathering tools. In these final four articles the methodological processes used to explore terminally ill patients’ needs were generally appropriate, although there was a lack of reflexivity (researcher reflection on the experience). Useful narrative themes were produced from all four papers for further discussion. The patients had similar priorities across all four articles, which were related to understanding and accepting their changing health status, the need to hold on to some normality in life, the need to feel supported by friends and family and to know they will be taken care of after the death, and the need to have good and trusting relationships with health professionals.

Source: MEDLINE

Full Text:
Available in fulltext at EBSCOhost


Author(s): Wittenberg-Lyles E, Goldsmith J, Ragan S

Citation: Clinical Journal of Oncology Nursing, June 2011, vol./is. 15/3(304-10), 1092-1095;1538-067X (2011 Jun 1)

Publication Date: June 2011

Abstract: For the current study, clinical observations of communication between patients, families, and clinicians during chronic, serious, or terminal illness in a cancer care trajectory were examined for patterns and trends. Five communication characteristics were concluded, which informed a typology of illness journeys experienced by patients with cancer and their families. The isolated journey characterizes an illness path in which communication about terminal prognosis and end-of-life care options are not present;
communication is restricted by a curative-only approach to diagnosis as well as the structure of medical care. The rescued journey signifies a transition between curative care (hospital narrative) to noncurative care (hospice narrative), challenging patients and their families with an awareness of dying. The rescued journey allows communication about prognosis and care options, establishes productive experiences through open awareness, and affords patients and families opportunities to experience end-of-life care preferences. Finally, palliative care prior to hospice provides patients and families with an illness journey more readily characterized by open awareness and community, which facilitates a comforted journey. Nurses play a pivotal role in communicating about disease progression and plans of care. The typology presented can inform a structured communication curriculum for nurses and assist in the implementation of early palliative care.

Source: MEDLINE

10. What are patients' priorities when facing the end of life? A critical review.

Author(s): Black, J

Citation: Int J Palliative Nursing, June 2011, vol./is. 17/6(294-300), 1357-6321 (2011 Jun)

Publication Date: June 2011

Abstract: Critical review of the desires and priorities of dying patients. Terminally ill patients' need to hold on to normality, their concern for friends and family, and their acceptance of health care support from professionals, are described. 37 refs.

Source: BNI

Full Text: Available in fulltext at EBSCOhost

11. [Advanced knowledge of patient preferences for end-of-life care in national health service hospitals of the Murcia Region]. [Spanish] Conocimiento de las preferencias de los pacientes terminales en los hospitales publicos de la Region de Murcia.

Author(s): Franco Tovar B, da Silva Gama ZA, Saturno Hernandez PJ

Citation: Revista de Calidad Asistencial, May 2011, vol./is. 26/3(152-60), 1134-282X;1887-1364 (2011 May-Jun)

Publication Date: May 2011

Abstract: BACKGROUND AND OBJECTIVE: Provision of unwanted end-of-life care is an adverse event that can be avoided and is regulated by law. One of the Safe Practices recommended by the National Quality Forum (NQF) is "Ensure that patient preferences regarding end-of-life care are known". Our objective is to assess compliance with this recommendation, and the associated socio-professional factors, in the National Health Service hospitals in the Murcia Region (Spain).METHODS: Cross-sectional study in 8 hospitals. We measured structure (existence and characteristics of guidelines about advance directives) and process (frequency with which healthcare provider enquire about the preferences of terminally ill patients) indicators, constructed according to the NQF recommendation. The process indicator was measured using a questionnaire distributed to a sample of clinical personnel (n=3141). A descriptive analysis of the results was performed. The association of socio-professional variables with asking patient's preferences (dependent variable) was analysed using multivariate logistic regression.RESULTS: One of the eight assessed hospitals has valid guidelines. Only 12% of professionals (n=607), (95% confidence interval [CI], 9.4-14.6), responded that they always enquire about the preferences of terminally ill patients in their departments. The existence of guidelines is significantly associated with this response (odds ratio [OR]=18.1; 95% CI, 2.28-143.83) and working in surgical departments with a negative response (OR=0.15; 95% CI, 0.04-0.65).CONCLUSIONS: There is a very low compliance with the NQF recommendation, evidenced by the lack of guidelines and the low frequency in which terminally ill patients are asked about their preferences for life-sustaining treatment. Implementation of guidelines may help to improve this situation, which is significantly worse in surgical services. Copyright Copyright 2010 SECA. Published by Elsevier Espana. All rights reserved.
12. Preferences for end of life: views of hospice patients, family carers, and community nurse specialists.

Author(s): Holdsworth L, King A

Citation: International Journal of Palliative Nursing, May 2011, vol./is. 17/5(251-5), 1357-6321;1357-6321 (2011 May)

Publication Date: May 2011

Abstract: An exploratory qualitative study was undertaken with the aim of identifying issues around discussing and recording preferences on place of death from the perspective of hospice patients, carers, and hospice community nurses. A purposive sample was selected from three hospices in the south east of England of six community nurse specialists (CNSs), five patients, five carers, and five bereaved carers. The patients and carers said it was important to them to discuss their preferences, but they acknowledged that discussing dying was difficult. The CNSs stated that there were several barriers that inhibited end-of-life discussions and that discussing preferences was not always a primary goal of care planning. It was felt among the service users, particularly the bereaved carers, that having more knowledge about what to expect of the dying process, knowing their relative’s wishes, and understanding the role of hospice and palliative care could improve the experience of events leading up to death.

Source: MEDLINE

Full Text: Available in fulltext at EBSCOhost

13. Doing the right thing at the right time.

Author(s): Dee, J, Endacott, R

Citation: J Nursing Management, March 2011, vol./is. 19/2(186-92), 0966-0429 (2011 Mar)

Publication Date: March 2011

Abstract: Qualitative research investigating factors influencing the timing of nurses and doctors diagnosing when patients are entering the last few days of life and implementing the Liverpool Care Pathway (LCP) for the Dying. Extracts from interviews are used to illustrate barriers and facilitators to the identification process and the importance of implementing the LCP at the right time. 24 refs.

Source: BNI

Full Text: Available in fulltext at the ULHT Library and Knowledge Services’ eJournal collection

14. Family perceptions of wishes of dementia patients regarding end-of-life care.

Author(s): van der Steen, Jenny T, van soest-Poortvliet, Mirjam C, Achterberg, Wilco P, Ribbe, Miel W, de Vet, Henrica C. W

Citation: International Journal of Geriatric Psychiatry, February 2011, vol./is. 26/2(217-220), 0885-6230,1099-1166 (Feb 2011)

Publication Date: February 2011

Abstract: The aim of this study is to assess preferences relevant to dementia patients, pilot-testing the ‘Preferences About Death and Dying’ (PADD) instrument for palliative care. The PADD assesses preferences pre-death. Agreement between family-reported and self-reported preferences was also moderate for more subjective items. The PADD is based on the quality of dying and death (QODD) instrument, which has been used extensively after a patient's death by family and professional caregivers, and is the most suitable validated instrument for non-sudden deaths in several settings. Only two out of 30 patients (7%) were male; 60% had severe dementia. The mean age was 89 years (SD 6) and 90% were religious according to the respondents. Most of them were protestant (50%) or catholic
(33%). The respondents included children (87%) or other family (13%), but no spouses. Pain under control, comfortable breathing and dignity were most important (means 8.3), with the lowest SDs (<2.0), and nobody rating these as unimportant. Two items in the areas of 'Preparation for end of life' (costs, and spiritual service) and 'Family' (spend time alone, and with pets) were least important (means <4.0). The SD was large (around 3.5) with substantial numbers of respondents rating these important or unimportant for several items regarding Preparation and 'Treatment preferences', but smaller for 'Symptoms and personal care' (SD 1.5-3.1). (PsycINFO Database Record (c) 2011 APA, all rights reserved)

**Source:** PsycINFO

15. **Hospital at home: home-based end of life care.**

**Author(s):** Shepperd S, Wee B, Straus SE

**Citation:** Cochrane Database of Systematic Reviews, 2011, vol./is. /7(CD009231), 1361-6137;1469-493X (2011)

**Publication Date:** 2011

**Abstract:** BACKGROUND: The policy in a number of countries is to provide people with a terminal illness the choice of dying at home. This policy is supported by surveys indicating that the general public and patients with a terminal illness would prefer to receive end of life care at home.OBJECTIVES: To determine if providing home-based end of life care reduces the likelihood of dying in hospital and what effect this has on patients' symptoms, quality of life, health service costs and care givers compared with inpatient hospital or hospice care.SEARCH STRATEGY: We searched the Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library) to October 2009, Ovid MEDLINE(R) 1950 to March 2011, EMBASE 1980 to October 2009, CINAHL 1982 to October 2009 and EconLit to October 2009. We checked the reference lists of articles identified for potentially relevant articles.SELECTION CRITERIA: Randomised controlled trials, interrupted time series or controlled before and after studies evaluating the effectiveness of home-based end of life care with inpatient hospital or hospice care for people aged 18 years and older.DATA COLLECTION AND ANALYSIS: Two authors independently extracted data and assessed study quality. We combined the published data for dichotomous outcomes using fixed-effect Mantel-Haenszel meta-analysis. When combining outcome data was not possible we presented the data in narrative summary tables.MAIN RESULTS: We included four trials in this review. Those receiving home-based end of life care were statistically more likely to die at home compared with those receiving usual care (RR 1.33, 95% CI 1.14 to 1.55, P = 0.0002; Chi (2) = 1.72, df = 2, P = 0.42, I(2) = 0% (three trials; N=652)). We detected no statistically significant differences for functional status (measured by the Barthel Index), psychological well-being or cognitive status, between patients receiving home-based end of life care compared with those receiving standard care (which included inpatient care). Admission to hospital while receiving home-based end of life care varied between trials and this was reflected by high levels of statistically significant heterogeneity in this analysis. There was some evidence of increased patient satisfaction with home-based end of life care, and little evidence of the impact this form of care has on care givers.AUTHORS' CONCLUSIONS: The evidence included in this review supports the use of end of life home-care programmes for increasing the number of patients who will die at home, although the numbers of patients being admitted to hospital while receiving end of life care should be monitored. Future research should also systematically assess the impact of end of life home care on care givers.

**Source:** MEDLINE

**Full Text:**

Available in fulltext at Wiley

16. **Nurse and physician preferences for end-of-life care for trauma patients.**

**Author(s):** Jacobs LM, Burns KJ, Jacobs BB

**Citation:** Journal of Trauma-Injury Infection & Critical Care, December 2010, vol./is. 69/6(1567-73), 0022-5282;1529-8809 (2010 Dec)
**Abstract:** BACK GROUND: End-of-life care for trauma patients requires unique practice guidelines because it is fraught with difficulties not encountered in end-of-life care for terminally ill patients. The purpose of this project was to analyze survey information from nurses and physicians regarding preferences for end-of-life care in trauma that would inform best-practice guidelines. METHODS: A survey was sent via the US Postal Service to a convenience sample of trauma professionals, including physicians, nurses, and emergency medical technicians. Questions were designed to provide information on difficult issues related to death and dying from trauma. The general public was also surveyed, and all results were used to develop a best-practice model for end-of-life care. RESULTS: Seven hundred seventy-four trauma professionals returned the survey for a response rate of 51%. This included 460 nurses and 181 physicians. Some salient findings include: (1) If a loved one required resuscitation in the emergency department, more nurses (78.4%) than physicians (38.7%) prefer to be in the treatment room rather than in the waiting room; (2) similar percentages of nurses (97.7%) and physicians (99.4%) agree that life-sustaining treatment should be withdrawn in cases in whom there is no hope of recovery; and (3) a larger percentage of nurses (58.8%) than physicians (20.6%) believe that patients have the right to demand care that physicians think is medically futile. CONCLUSIONS: Nurses and physicians agree on some issues about end-of-life care in trauma but disagree on others. Education and discourse among trauma professionals are needed to bring understanding to the issues.

**Source:** MEDLINE

**Full Text:** Available in fulltext at the ULHT Library and Knowledge Services’ eJournal collection

17. A review of an out-of-hours telephone support service for palliative care patients and their families.

**Author(s):** Carlebach S, Shucksmith J

**Citation:** International Journal of Palliative Nursing, September 2010, vol./is. 16/9(445-50), 1357-6321;1357-6321 (2010 Sep)

**Publication Date:** September 2010

**Abstract:** Offering people at the end stages of life the chance to die in their own homes is acknowledged good practice and can bring comfort to terminally ill people, but it can also be a hard choice to sustain. Carers may find it extremely difficult to cope with the emotional ordeal of losing a loved one and dealing with the medical problems that are involved but their voices are infrequently heard. This study reports an evaluation of an out-of-hours service operating in one primary care trust in north east England, and focuses on the use of a telephone support service, which backed up domiciliary visits by specialist palliative care nurses. Interviews, focus groups and an open-ended questionnaire were carried out with 27 participants. Results revealed that staff, patients and carers appreciated being able to telephone the service (reactive). In addition carers felt particularly well supported by the service staff who proactively telephoned them on an agreed basis as part of the highly individualized telephone monitoring scheme. Such services support the call for the creation of a whole system approach for both palliative care patients and their carers.

**Source:** MEDLINE

**Full Text:** Available in fulltext at EBSCOhost

18. Dying at home: Community nurses’ views on the impact of informal carers on cancer patients’ place of death.

**Author(s):** Jack, B, O’Brien, M

**Citation:** European Journal of Cancer Care, September 2010, vol./is. 19/5(636-642), 0961-5423;1365-2354 (Sep 2010)

**Publication Date:** September 2010

**Abstract:** Giving patients with cancer a choice in where they want to die including the
choice to die at home if they so wish, underpin the recent UK government policies and is embedded in the End of Life Care Programme. However, this presents increasing challenges for the informal carers particularly with an increasingly aging population. Despite the policy initiatives, there remain a persistent number of patients with cancer who had chosen to die at home being admitted to hospital in the last days and hours of life. A qualitative study using two focus group interviews with community nurses (district nurses and community specialist palliative care nurses) was undertaken across two primary care trusts in the north-west of England. Data were analysed using a thematic analysis approach. The results indicated that informal carer burden was a key reason for prompting hospital admission. Recommendations for the development of a carer assessment tool with appropriate supportive interventions are made. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

Source: PsycINFO
Full Text:
Available in fulltext at EBSCOhost
Available in fulltext at EBSCOhost

19. Shared care in basic level palliative home care: Organizational and interpersonal challenges

Author(s): Neergaard MA, Olesen F, Jensen AB, Sondergaard J

Citation: Journal of Palliative Medicine, September 2010, vol./is. 13/9(1071-7), 1096-6218 (2010 Sep)
Publication Date: September 2010

Abstract: Background: Little is known about the existing barriers to cooperation among health professionals in basic level palliative care for terminally ill patients with cancer in primary health care. Objective: The aim of this study was to analyze health professionals' views on interprofessional cooperation in basic level palliative home care for terminally ill cancer patients. Method: This study was a qualitative, descriptive study based on 7 semistructured group interviews conducted in the former Aarhus County, Denmark. Forty-three health professionals (23 family physicians, 5 chief physicians, and 15 home care nurses) were interviewed. Results: Two main categories of problems were identified: (1) the organization of palliative home care (need for proactive planning from the start of the palliative trajectory, clear distribution of tasks, advancement of more efficient communication pathways, and improved accessibility to all health professionals) and (2) interaction between health professionals (increased knowledge of and respect for the competencies of other health occupations and individuals). Conclusion: The study indicates problems with respect to both the organization of the basic level palliative home care and the working culture among health professionals. The main issues: distribution of tasks, information exchange, availability, respect, and personal acquaintance are pivotal to improve the delivery of palliative home care, to training in palliative care and warrant future research.

Source: AMED
Full Text:
Available in fulltext at EBSCOhost

20. A review of an out-of-hours telephone support service for palliative care, patients and their families

Author(s): Carlebach S, Shucksmith J

Citation: International Journal of Palliative Nursing, September 2010, vol./is. 16/9(445-50), 1357-6321 (2010 Sep)
Publication Date: September 2010

Abstract: Offering people at the end stages of life the chance to die in their own homes is acknowledged good practice and can bring comfort to terminally ill people, but it can also be a hard choice to sustain. Carers may find it extremely difficult to cope with the emotional ordeal of losing a loved one and dealing with the medical problems that are involved but
their voices are infrequently heard. This study reports an evaluation of an out-of-hours service operating in one primary care trust in north east England, and focuses on the use of a telephone support service, which backed up domiciliary visits by specialist palliative care nurses. Interviews, focus groups and an open-ended questionnaire were carried out with 27 participants. Results revealed that staff, patients and carers appreciated being able to telephone the service (reactive). In addition carers felt particularly well supported by the service staff who proactively telephoned them on an agreed basis as part of the highly individualized telephone monitoring scheme. Such services support the call for the creation of a whole system approach for both palliative care patients and their carers.

Source: AMED
Full Text:
Available in fulltext at EBSCOhost [open new window]

21. Improving integrated team working to support people to die in the place of their choice.

Author(s): Bowers B, Roderick S, Arnold S
Citation: Nursing Times, August 2010, vol./is. 106/32(14-6), 0954-7762;0954-7762 (2010 Aug 17-23)
Publication Date: August 2010
Abstract: Dying in a place of one's choice is considered to be a quantifiable measure of the effectiveness of end of life services in primary care. Although most people say they would prefer to die in their own home, very few actually do so. This article looks at how a team of community nurses and GPs changed their practice by using recognised end of life care tools. These helped practitioners in supporting adults with terminal illnesses to die in a place of their choice. A subsequent audit of patients' actual place of death against their preferred place demonstrates how working in more integrated ways has helped.
Source: MEDLINE
Full Text:
Available in fulltext at the ULHT Library and Knowledge Services' eJournal collection [open new window]
Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.
Available in print at Pilgrim Hospital Staff Library

22. Barriers to dying at home: the impact of poor co-ordination of community service provision for patients with cancer.

Author(s): O'Brien M, Jack B
Citation: Health & Social Care in the Community, July 2010, vol./is. 18/4(337-45), 0966-0410;1365-2524 (2010 Jul)
Publication Date: July 2010
Abstract: For patients dying of cancer, there is an emphasis on giving choice regarding preferred location for care, with the option of dying at home, which is integral to UK government health initiatives such as the End of Life Care Programme. However, patients continue to be admitted to hospital in the terminal phase of their illness when they have expressed a desire to die at home. A qualitative study, using two audio tape-recorded focus group interviews, with a purposive sample of district nurses and community specialist palliative care nurses (19) was undertaken across two primary care trusts in the north west of England. Data were analysed using a thematic analysis approach. From a service provision perspective, the results reveal that poor discharge planning and co-ordination, difficulty in establishing additional equipment and services together with inadequate out of hours medical provision were all factors contributing to hospital admissions for patients with cancer in the last hours and days of life, and thus were barriers to dying at home.
Source: MEDLINE
Full Text:
23. Factors influencing death at home in terminally ill cancer patients.

**Author(s):** Nakamura S, Kuzuya M, Funaki Y, Matsu W, Ishiguro N

**Citation:** Geriatrics & gerontology international, April 2010, vol./is. 10/2(154-60), 1447-0594;1447-0594 (2010 Apr)

**Publication Date:** April 2010

**Abstract:** AIM: The purpose of this study is to investigate factors affecting terminally ill cancer patients dying at home.

**MATERIAL:** Ninety-two terminally ill cancer patients who were receiving home medical care services and died between April 2005 and December 2006 were included in the study. The data included patients' and caregivers' demographic characteristics, disease-related information, place of death, and status of home care support. To identify the factors predicting the place of death, multivariate logistic regression analyses were performed.

**RESULTS:** Patients of families who had no preference regarding the place of death or a preference for death at home were more likely to die at home (vs preference for hospital death, odds ratio = 5.87, 95% confidence interval = 1.02-36.53; odds ratio = 90.35, 95% confidence interval = 8.15-1001.51, respectively) after adjusting for potential confounders. Meanwhile, if the patient's family preferred that the patient not die at home, the patient's place of death was not at his/her home irrespective of his/her preference.

**CONCLUSION:** The results suggested the stronger involvement of families' preferences regarding the patients' place of death over patients' own preferences. Therefore, factors affecting families' preferences need to be clarified for the dissemination of death at home for terminally ill cancer patients.

**Source:** MEDLINE

24. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences.

**Author(s):** Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG

**Citation:** Journal of Clinical Oncology, March 2010, vol./is. 28/7(1203-8), 0732-183X;1527-7755 (2010 Mar 1)

**Publication Date:** March 2010

**Abstract:** PURPOSE: Physicians have an ethical obligation to honor patients' values for care, including at the end of life (EOL). We sought to evaluate factors that help patients to receive care consistent with their preferences.

**METHODS:** This was a longitudinal multi-institutional cohort study. We measured baseline preferences for life-extending versus symptom-directed care and actual EOL care received in 325 patients with advanced cancer. We also measured associated sociodemographic, health, and communication characteristics, including EOL discussions between patients and physicians.

**RESULTS:** Preferences were assessed a median of 125 days before death. Overall, 68% of patients (220 of 325 patients) received EOL care consistent with baseline preferences. The proportion was slightly higher among patients who recognized they were terminally ill (74%, 90 of 121 patients; P = .05). Patients who recognized their terminal illness were more likely to prefer symptom-directed care (83%, 100 of 121 patients; v 66%, 127 of 191 patients; P = .003). However, some patients who were aware they were terminally ill wished to receive life-extending care (17%, 21 of 121 patients). Patients who reported having discussed their wishes for EOL care with a physician (39%, 125 of 322 patients) were more likely to receive care that was consistent with their preferences, both in the full sample (odds ratio [OR] = 2.26; P < .0001) and among patients who were aware they were terminally ill (OR = 3.94; P = .0005). Among patients who received no life-extending measures, physical distress was lower (mean score, 3.1 v 4.1; P = .03) among patients for whom such care was consistent with preferences.

**CONCLUSION:** Patients with cancer are more likely to receive EOL care that is consistent with their preferences when they have had the opportunity to discuss their wishes for EOL care with a physician.
25. End-of-life issues in acute stroke care: a qualitative study of the experiences and preferences of patients and families

**Author(s):** Payne S, Burton C, Addington-Hall J, Jones A

**Citation:** Palliative Medicine, March 2010, vol./is. 24/2(146-53), 0269-2163 (2010 Mar)

**Publication Date:** March 2010

**Abstract:** The aims of this qualitative study were to identify patients' and family members' experiences of acute stroke and their preferences for end-of-life care. Twenty-eight purposely sampled patients with an acute stroke who had high (n = 13) and low (n = 15) disability were selected from 191 sequential cases admitted to two general hospitals in north-east England. In addition, 25 family members of other stroke patients were recruited. Views about current stroke services and preferences for end-of-life care were elicited in semi-structured interviews. Communication between patients and family members and healthcare professionals was consistently highlighted as central to a positive experience of stroke care. Honesty and clarity of information was required, even where prognoses were bleak or uncertain. Patients and family members appeared to attach as much importance to the style of communication as to the substance of the transfer of information. Where decisions had been made to shift the focus of care from active to more passive support, families, and where possible patients, still wished to be included in ongoing dialogue with professionals. Where patients were thought to be dying, family members were keen to ensure that the death was peaceful and dignified. Families reported few opportunities for engagement in any form of choice over place or style of end-of-life care. No family member reported being offered the possibility of the patient dying at home. Uncertainty about prognosis is inevitable in clinical practice, and this can be difficult for patients and families. Our findings demonstrate the importance of improving communication between patient, family and health professionals for seriously ill patients with stroke in UK hospitals.

**Source:** AMED

**Full Text:**
Available in fulltext at EBSCOhost

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.


**Author(s):** Jennings, Bruce, Ryndes, True, D'Onofrio, Carol, Baily, Mary Ann

**Citation:** Palliative care: Transforming the care of serious illness., 2010(159-164) (2010)

**Publication Date:** 2010

**Abstract:** This chapter originally appeared as a special supplement to the Hastings Center Report in (The Hastings Center, 2003, March-April, Suppl:S3-7, S9-13, S15-21). This chapter is a report drawn from a three-year study of hospice access and values issues conducted by the Hastings Center and the National Hospice Work Group, a voluntary association of progressive hospices, was published as a special supplement accompanying the March/April 2003 issue of the bioethics journal The Hastings Center Report. The purpose of the study was to contribute to the broad goal of improving end-of-life care by addressing specific problems in access to and delivery of hospice care. Its distinctive contribution is to pay explicit attention to the human values involved in hospice care policy and practice. The report examines the problem of hospice access from the perspective of social justice, equity or fairness and makes an ethical case for equitable access on the basis of the vulnerability of the population served, the moral importance of meeting their needs and the values upon which comprehensive, high-quality hospice care is constructed. The report also offers a new vision of hospice, one that holds firm to many of the traditions and values of the past but finds new and more flexible ways to deliver care. The model of traditional hospice care as an independent and specialized service will...
gradually be transformed into a more comprehensive model in which hospice becomes the
coordinating center for a range of services and types of expertise that can be accessed by
patients. In the authors' new vision, America's hospices will play an expanded role in
addressing more of the supportive and symptom-relief needs of patients confronting life-
limiting illnesses and their families for longer periods and in a wider variety of settings and
contexts. To achieve this ambitious goal, policies must change, and powerful cultural
tabois surrounding death and dying must be overcome. What's needed are a national
program of professional education about hospice and palliative care and a massive social
marketing campaign regarding hospice programs' abilities to address and resolve many of
the most widely held fears about the end of life. (PsycINFO Database Record (c) 2010
APA, all rights reserved)

Source: PsycINFO

27. Determinants of place of death for recipients of home-based palliative care.

Author(s): Masucci L, Guerriere DN, Cheng R, Coyte PC

Citation: Journal of Palliative Care, 2010, vol./is. 26/4(279-86), 0825-8597;0825-8597
(2010)

Publication Date: 2010

Abstract: INTRODUCTION: Health system restructuring combined with the preferences of
many terminally ill care recipients and their caregivers has led to an increase in home-
based palliative care, yet many care recipients die within institutional settings such as
hospitals. This study sought to determine the place of death and its predictors among
palliative care patients with cancer.METHODS: Study participants were recruited from the
Temmy Latner Centre for Palliative Care, a regional palliative care program based in
Toronto, Canada. A total of 137 patients and their family caregivers participated in the
study; application of various exclusion criteria restricted analysis to a sub-sample of 110.
Bivariate (chi-square) and multivariate (logistic regression) analyses were
conducted.RESULTS: 66 percent of participants died at home. Chi-square analysis
indicated that women were more likely to die at home than men; multivariate analysis
indicated that women and those living with others were significantly more likely to die at
home than men or those who lived alone.CONCLUSION: Place of death is influenced by
the socio-demographic characteristics of patients, the characteristics of their caregivers,
and health service factors. Palliative care programs need to tailor services to men and
those living alone in order to reduce institutional deaths.

Source: MEDLINE

28. Responding to suffering: providing options and respecting choice.

Author(s): Berry ZS

Citation: Journal of Pain & Symptom Management, November 2009, vol./is. 38/5(797-
800), 0885-3924;1873-6513 (2009 Nov)

Publication Date: November 2009

Abstract: Voluntary stopping of eating and drinking (VSED) as a legal means to hasten
death has been discussed by some as an option for persons who wish to end their lives. A
case is presented of a woman who elected to forgo eating and drinking to end intractable
suffering. The potential for benefit and harm in physicians discussing VSED is discussed.
Physicians working with terminally ill patients need to consider the discussion of VSED as
a therapeutic tool in their support and care of patients with intractable suffering.

Source: MEDLINE

Full Text:
Available in print at Lincoln County Hospital Professional Library ; Note: Click the library
link to request this article. NHS Copyright applies.

29. Policy issues in end-of-life care

Author(s): Tilden VP, Thompson S

Citation: Journal of Professional Nursing, November 2009, vol./is. 25/6(363-8), 8755-7223
**Publication Date:** November 2009

**Abstract:** The purpose of this policy brief is to bring attention to the urgent systems-level matters that impede progress in improving end-of-life care in the United States. Despite advances in care of the dying over the last 20 years, many recalcitrant system-level barriers prevent high-quality end-of-life care that is consistent with clinical and ethical standards and reasonably adheres to patient and family wishes for care and compassion. A major barrier is the orientation of health care toward rescue medicine despite the fact that most deaths today result from long-standing chronic disease. Recommendations for policy changes are suggested, and nursing's role in advocating for policy change is explored.

**Source:** AMED

- **30. The campaign to deny terminally ill patients information and choices at the end of life.**
  - **Author(s):** Tucker KL
  - **Citation:** Journal of Legal Medicine, October 2009, vol./is. 30/4(495-514), 0194-7648;1521-057X (2009 Oct-Dec)
  - **Publication Date:** October 2009
  - **Source:** MEDLINE
  - **Full Text:** Available in fulltext at EBSCOhost

- **31. Construction of health preferences: a comparison of direct value assessment and personal narratives.**
  - **Author(s):** Kerstholt JH, van der Zwaard F, Bart H, Cremers A
  - **Citation:** Medical Decision Making, July 2009, vol./is. 29/4(513-20), 0272-989X;0272-989X (2009 Jul-Aug)
  - **Publication Date:** July 2009
  - **Abstract:** BACKGROUND: Most terminally ill patients prefer to die at home rather than at an institution. However, patients are often insufficiently aware of the downsides of staying at home, which signals a need for effective decision aids.OBJECTIVES: The main purpose of the present study was to compare indirect methods of value elicitation (personal narratives["stories"] in text or video) with a direct method (assessment of the subjective importance of each attribute).METHODS: The authors asked 183 participants to evaluate 3 possible places to die: home, hospice, and nursing home. The participants received 1 of 3 value elicitation methods. The main dependent variable was participants' evaluations of the choice options before and after value elicitation, measured on a 100-point scale.RESULTS: A shift occurred between pre- and posttest, $F(4, 342) = 4.11$, $P = 0.003$, only with the indirect methods. When text and videos were used, participants became more positive about a hospice (text: 41.9 to 49.1; video: 52.9 to 60.3). In the video condition, participants also became more positive about a nursing home (from 20.9 to 24.9).CONCLUSION: Stories have more impact in shaping people's preferences than merely asking for an assessment of attribute importance. The most straightforward explanation for this effect is that stories, particularly when presented in video, provide a better image of potential consequences.
  - **Source:** MEDLINE

- **32. Oncology nurses' perceptions of obstacles and supportive behaviors at the end of life.**
  - **Author(s):** Beckstrand RL, Moore J, Callister L, Bond AE
  - **Citation:** Oncology Nursing Forum, July 2009, vol./is. 36/4(446-53), 0190-535X;1538-0688
Publication Date: July 2009

Abstract: PURPOSE/OBJECTIVES: To determine the magnitude of selected obstacles and supportive behaviors in providing end-of-life (EOL) care to patients with cancer as perceived by oncology nurses. DESIGN: Cross-sectional survey. SETTING: National survey sample. SAMPLE: A geographically dispersed national random sample of 1,000 Oncology Nursing Society members who had cared for inpatient patients with cancer, could read English, and had experience in EOL care. METHODS: Eligible respondents received a 68-item questionnaire in the mail adapted from previous studies and were asked to rate the size of obstacles and supportive behavior items in caring for patients with cancer at the EOL. MAIN RESEARCH VARIABLES: EOL, oncology, barriers, supportive behaviors, oncology nurses, and survey research. FINDINGS: Returns after three mailings yielded 375 usable questionnaires from 907 eligible respondents for a return rate of 41%. The items with the highest perceived obstacle magnitude were (a) dealing with angry family members, (b) families not accepting what they are told about patients' poor prognosis, and (c) nurses being called away from dying patients to care for other patients. The three-highest scoring supportive behaviors were (a) allowing family members adequate time alone with patients after they died, (b) having social work or palliative care staff as part of the patient care team, and (c) having family members accept that patients are dying. CONCLUSIONS: EOL care can be improved by working to decrease the highest-rated barriers and by continuing to support the highest-rated supportive behaviors. IMPLICATIONS FOR NURSING: Oncology nurses are dedicated, experienced, and comfortable handling most issues in EOL care. Recommendations to support oncology nurses include strategies to interact effectively with angry, anxious, or overly optimistic family members as well as involving social work and palliative care staff on the oncology interdisciplinary team. In addition, the information regarding identified obstacles and supportive behaviors in oncology EOL care can be used to facilitate discussion and change within oncology interdisciplinary teams and improve EOL care for patients with cancer and their families.

Source: MEDLINE

Full Text:
Available in fulltext at EBSCOhost


Author(s): Munday, M, Petrova, M, Dale, J

Citation: BMJ, July 2009, vol./is. 339/7714(214-8), 0959-8138 (2009 25 Jul)

Publication Date: July 2009

Abstract: Qualitative research in England into the experiences of GPs and community nurses of discussing preferences for place of death with terminally ill patients. Staff from practices enrolled in the Gold Standards Framework for palliative care were interviewed concerning how place of death was raised, how changes in condition could alter preferences and their feelings about discussing it with patients. 8 refs.

Source: BNI

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Available in print at Pilgrim Hospital Staff Library

34. Hospital staff attributions of the causes of physician variation in end-of-life
treatment intensity.

Author(s): Larochelle, M. R, Rodriguez, K. L, Arnold, R. M, Barnato, A. E

Citation: Palliative Medicine, July 2009, vol./is. 23/5(460-470), 0269-2163;1477-030X (Jul 2009)

Publication Date: July 2009

Abstract: Discrepancies between patient wishes and end-of-life treatment decisions have been documented, and the determinants of end-of-life treatment decisions are not well understood. Our objective was to understand hospital staff perceptions of the role of acute care hospital medical doctors in end-of-life treatment intensity. In 11 purposively sampled Pennsylvania hospitals, we completed 108 audiotaped semistructured interviews with key informants involved in decision making or discharge planning. Using grounded theory, we qualitatively analyzed transcripts using constant comparison to identify factors affecting end-of-life treatment decisions. A predominant theme identified was that end-of-life treatment intensity depends on the doctor. Communication with patients and families and collaboration with other care team members also were reported to vary, contributing to treatment variation. Informants attributed physician variation to individual beliefs and attitudes regarding the end-of-life (religion and culture, determination of when a patient is dying, quality-of-life determination and fear of failing) and to socialization by and interaction with the healthcare system (training, role perception, experience and response to incentives). When end-of-life treatment depends on the doctor, patient and family preferences may be neglected. Targeted interventions may reduce variability and align end-of-life treatment with patient wishes. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

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35. Oncology nurses' perceptions of obstacles and supportive behaviors at the end of life.

Author(s): Beckstrand, Renea L, Moore, Josie, Callister, Lynn, Bond, A. Elaine

Citation: Oncology Nursing Forum, July 2009, vol./is. 36/4(446-453), 0190-535X;1538-0688 (Jul 2009)

Publication Date: July 2009

Abstract: Purpose/Objectives: To determine the magnitude of selected obstacles and supportive behaviors in providing end-of-life (EOL) care to patients with cancer as perceived by oncology nurses. Design: Cross-sectional survey. Setting: National survey sample. Sample: A geographically dispersed national random sample of 1,000 Oncology Nursing Society members who had cared for inpatient patients with cancer, could read English, and had experience in EOL care. Methods: Eligible respondents received a 68-item questionnaire in the mail adapted from previous studies and were asked to rate the size of obstacles and supportive behavior items in caring for patients with cancer at the EOL. Main Research Variables: EOL, oncology, barriers, supportive behaviors, oncology nurses, and survey research. Findings: Returns after three mailings yielded 375 usable questionnaires from 907 eligible respondents for a return rate of 41%. The items with the highest perceived obstacle magnitude were (a) dealing with angry family members, (b) families not accepting what they are told about patients' poor prognosis, and (c) nurses being called away from dying patients to care for other patients. The three-highest scoring supportive behaviors were (a) allowing family members adequate time alone with patients after they died, (b) having social work or palliative care staff as part of the patient care team, and (c) having family members accept that patients are dying. Conclusions: EOL care can be improved by working to decrease the highest-rated barriers and by continuing to support the highest-rated supportive behaviors. Implications for Nursing: Oncology nurses are dedicated, experienced, and comfortable handling most issues in EOL care. Recommendations to support oncology nurses include strategies to interact effectively with angry, anxious, or overly optimistic family members as well as involving social work and
palliative care staff on the oncology interdisciplinary team. In addition, the information regarding identified obstacles and supportive behaviors in oncology EOL care can be used to facilitate discussion and change within oncology interdisciplinary teams and improve EOL care for patients with cancer and their families. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

Source: PsycINFO

Full Text: Available in fulltext at EBSCOhost

36. Do older adults know their spouses' end-of-life treatment preferences?

Author(s): Moorman, Sara M, Hauser, Robert M, Carr, Deborah

Citation: Research on Aging, July 2009, vol./is. 31/4(463-491), 0164-0275 (Jul 2009)

Publication Date: July 2009

Abstract: When terminally ill patients become mentally incapacitated, their surrogates often make treatment decisions in collaboration with health care providers. The authors examined how surrogates' errors in reporting their spouses' preferences are affected by their gender, status as durable power of attorney for health care (DPAHC), whether they and their spouses discussed end-of-life preferences, and their spouses' health status. Structural equation models were applied to data from married couples in their mid-60s from the 2004 wave of the Wisconsin Longitudinal Study. Surrogates reported their spouses' preferences incorrectly 13% and 26% of the time in end-of-life scenarios involving cognitive impairment and physical pain, respectively. Surrogates projected their own preferences onto their spouses'. Similar patterns emerged regardless of surrogate gender and status as DPAHC, marital discussions about end-of-life preferences, or spousal health status. Implications for the process of surrogate decision making and for future research are discussed. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

Source: PsycINFO

37. Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care.

Author(s): Black, Betty S, Fogarty, Linda A, Phillips, Hilary, Finucane, Thomas, Loreck, David J, Baker, Alva, Blass, David M, Rabins, Peter V

Citation: Journal of Aging and Health, June 2009, vol./is. 21/4(627-650), 0898-2643 (Jun 2009)

Publication Date: June 2009

Abstract: Objectives: This study examines how surrogate decision makers for dementia patients developed an understanding of patient preferences about end-of-life (EOL) care and patient wishes. Methods: Semistructured interviews were conducted with 34 surrogate decision makers for hospice-eligible nursing home patients with dementia. The data were content analyzed. Results: Most surrogates reported that patients had previously completed an advance directive (59%), discussed preferences for EOL care (56%), or done both (38%). Catalysts for and barriers to completing an advance directive or having EOL care discussions included factors that were both intrinsic and extrinsic to the patient. The most commonly reported wish for EOL care was to not be kept alive by "machines" or "extraordinary measures." Discussion: Health care providers may be able to assist patients and families by normalizing discussions of dying, encouraging advance care planning, helping them identify goals for EOL care, and providing information to support treatment decisions consistent with patients' wishes. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

Source: PsycINFO

38. Patients need to be provided with real choice in end-of-life care.

Author(s): Pooler, J
39. Determinants of the place of death in the Brussels metropolitan region

Author(s): Houttekier D, Cohen J, Bilsen J, Deboosere P, Verduyckt P, Deliens L

Citation: Journal of Pain and Symptom Management, June 2009, vol./is. 37/6(996-1005), 0885-3924 (2009 Jun)

Abstract: The place where people die is not only considered an indicator of quality of death, but also has implications for health care costs and the organization of end-of-life care. Advancing urbanization, combined with social fragmentation, poor social conditions, and concentration of inpatient care in large cities make it relevant to study the place of death in a metropolitan context. The objective of this article is to examine determinants of place of death (home, care home, hospital) in a Belgian metropolitan region (Brussels) for patients suffering from chronic diseases eligible for palliative care. Using death certificate data, we describe place of death and associated factors for all deaths after chronic diseases in 2003 in Brussels (n=3672). Of all chronically ill patients, 15.1% died at home, 63.0% in hospital, and 21.6% in a care home. Of those residing in care homes, 23.8% died in hospital. Noncancer patients and residents of districts with higher socioeconomic status had a higher chance of dying at home or in a care home if they resided in one. Home death was also more likely for patients not living alone. Care home death was more likely with increasing age. Compared with other parts of Belgium and other big cities worldwide, few patients eligible for palliative care in Brussels died at home. Both the overall low proportion of people dying in familiar surroundings and the inequality between different districts in Brussels imply that a health policy aiming at facilitating dying in the place of choice might also need to develop specific approaches for metropolitan cities.

Source: AMED

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Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

40. When hospice is the best option: an opportunity to redefine goals.

Author(s): Prince-Paul M

Citation: Oncology (Williston Park), April 2009, vol./is. 23/4 Suppl Nurse Ed(13-7), 0890-9091:0890-9091 (2009 Apr)

Abstract: More than 50% of patients diagnosed with cancer in 2008 died in the same year, according to estimates from the American Cancer Society. Clearly, while survival rates for many cancers continue to improve, a significant number of patients with cancer will not survive their disease. Hospice care provides terminally ill patients with a unique set of benefits, services, and support. Its goal is neither to prolong life nor hasten death, but rather to provide total care that maximizes quality of life. Less than one-third of patients receive hospice care near the end of life, however, and many referred patients die within days. Many barriers and misconceptions related to hospice care can prevent timely
referrals and impede discussions. Also, conversations about goals of care, treatment preferences, and advanced care planning can be challenging and overwhelming. This article reviews the hospice care model and highlights ways in which oncology nurses can make a difference in how patients live their final days.

Source: MEDLINE

Full Text:
Available in fulltext at EBSCOhost

41. A profile of the belief system and attitudes to end-of-life decisions of senior clinicians working in a National Health Service hospital in the United Kingdom.

Author(s): Pugh, E, Song, R, Whittaker, V

Citation: Palliative Medicine, March 2009, vol./is. 23/2(158-63), 0269-2163 (2009 Mar)

Publication Date: March 2009

Abstract: Research into the spirituality and beliefs of consultants, nurses and specialist registrars and how those beliefs influence decisions made during care of the dying patient. End of life decision making, and conflicts between patient choice and personal belief are discussed. 18 refs.

Source: BNI

Full Text:
Available in fulltext at EBSCOhost

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

42. Exploring the quality of dying of patients with chronic obstructive pulmonary disease in the intensive care unit: a mixed methods study.

Author(s): Goodridge, D, Duggleby, W, Gjevre, J

Citation: Nursing in Critical Care, March 2009, vol./is. 14/2(51-60), 1362-1017 (2009 Mar/Apr)

Publication Date: March 2009

Abstract: Qualitative and quantitative research in Canada into nurses' perspectives of end of life care for COPD patients in the ICU. Interviews, focus groups and a survey were conducted to explore nurses' ratings of the quality of the patient's experience of dying, the appropriateness of ICU admission and conflicting priorities. Differences between COPD patients and those with other disorders were compared. 53 refs.

Source: BNI

Full Text:
Available in fulltext at EBSCOhost

43. Shared priorities for the end-of-life period.

Author(s): Downey, L, Engelberg, R, Curtis, J

Citation: J Pain & Symptom Management, February 2009, vol./is. 37/2(175-88), 0885-3924 (2009 Feb)

Publication Date: February 2009

Abstract: Quantitative research in the USA investigating end-of-life priorities for terminally ill patients and their significant others. The importance attached to items in a scale relating to preferences about death and dying and differences between racial, socio-demographic and clinical sub-groups were reported. The key emergent themes of pain control and spending time with others are described. 24 refs.

Source: BNI
44. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: Prospective longitudinal qualitative study.

Author(s): Worth, Allison, Irshad, Tasneem, Bhopal, Raj, Brown, Duncan, Lawton, Julia, Grant, Elizabeth, Murray, Scott, Kendall, Marilyn, Adam, James, Gardee, Rafik, Sheikh, Aziz

Citation: BMJ: British Medical Journal, February 2009, vol./is. 338/7693(1-19), 0959-8138 (Feb 2009)

Publication Date: February 2009

Abstract: Objectives: To examine the care experiences of South Asian Sikh and Muslim patients in Scotland with life limiting illness and their families and to understand the reasons for any difficulties with access to services and how these might be overcome. Design: Prospective, longitudinal, qualitative design using in-depth interviews. Setting: Central Scotland. Participants: 25 purposively selected South Asian Sikh and Muslim patients, 18 family carers, and 20 key health professionals. Results: 92 interviews took place. Most services struggled to deliver responsive, culturally appropriate care. Barriers to accessing effective end of life care included resource constrained services; institutional and, occasionally, personal racial and religious discrimination; limited awareness and understanding among South Asian people of the role of hospices; and difficulty discussing death. The most vulnerable patients, including recent migrants and those with poor English language skills, with no family advocate, and dying of non-malignant diseases were at particularly high risk of inadequate care. Conclusions: Despite a robust Scottish diversity policy, services for South Asian Sikh and Muslim patients with life limiting illness were wanting in many key areas. Active case management of the most vulnerable patients and carers, and "real time" support, from where professionals can obtain advice specific to an individual patient and family, are the approaches most likely to instigate noticeable improvements in access to high quality end of life care. Improving access to palliative care for all, particularly those with non-malignant illnesses, as well as focusing on the specific needs of ethnic minority groups, is required. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

Source: PsycINFO

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Available in print at Louth County Hospital Medical Library

Available in print at Pilgrim Hospital Staff Library

45. Shared priorities for the end-of-life period.

Author(s): Downey L, Engelberg RA, Curtis JR, Lafferty WE, Patrick DL

Citation: Journal of Pain & Symptom Management, February 2009, vol./is. 37/2(175-88), 0885-3924;1873-6513 (2009 Feb)

Publication Date: February 2009

Abstract: This study investigated end-of-life priorities of terminally ill patients and their intimate associates. A primary goal was to reduce the number of items in an existing instrument measuring survivors' evaluations of the quality of dying and death. Three Seattle-area patient samples (chronic obstructive pulmonary disease patients, hospice patients, and participants in an efficacy trial of complementary comfort care) and their significant others provided priority rankings of 26 experiences at end of life. Two items represented top priorities for all subgroups: time with family/friends and pain control.
Clustered multivariate probit regression models suggested only a few significant differences between participant groups in priority rankings: higher education increased the priority placed on having available means to hasten death, cancer patients and persons in the hospice sample (likely those experiencing disproportionate pain) assigned pain control higher priority than other groups, persons in the clinical trial (which included massage as an intervention) assigned higher priority to human touch, and racial/ethnic minorities emphasized the importance of having funeral arrangements made. In the clinical trial sample (the most recently interviewed), the importance attributed to taking care of health care costs increased over time. If researchers were to use a reduced set of the 17 items mentioned among the top five priorities by at least 10% of the sample, none of the items that varied significantly between subgroups or over time would be eliminated. This change would reduce respondent burden in future investigations, simplify analyses aimed at identifying domains underlying the dying-and-death experience, and exclude the top-priority item of fewer than 4% of respondents.

Source: MEDLINE

Full Text:

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.


Author(s): Murray MA, Fiset V, Young S, Kryworuchko J

Citation: Oncology Nursing Forum, January 2009, vol./is. 36/1(69-77), 0190-535X;1538-0688 (2009 Jan)

Publication Date: January 2009

Abstract: PURPOSE/OBJECTIVES: To describe the determinants of place of end-of-life (EOL) care for patients with cancer.DATASOURCES: A systematic literature review of primary research studies (1997-2007) was conducted. Studies that investigated place of EOL care or identified place of EOL care in relation to outcomes were examined, their critical quality was appraised, and references were mapped.DATASYNTHESIS: Of the 735 articles identified, 39 (representing 33 studies) met inclusion criteria. Two main research designs emerged: large-scale epidemiologic reports and smaller descriptive studies. Findings suggest that factors related to the disease, the individual, and the care and social environment influence place of EOL care for patients with cancer. Social support, healthcare inputs (from services and programs and healthcare provider contact), and patient preferences were the most important factors.CONCLUSIONS: Most patients with terminal cancer prefer home palliation; however, most die in an institution. The reasons are complex, with various determinants influencing decisions regarding place of EOL care.IMPLICATIONS FOR NURSING: Findings may highlight evidence-based interventions to assist patients and families facing decisions regarding place of EOL care. A clearer understanding of factors that influence place of EOL care for patients with cancer could enhance healthcare policy and guide needs-based modifications of the healthcare system.

Source: MEDLINE

Full Text:

Available in fulltext at EBSCOhost

47. Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England.

Author(s): Munday D, Petrova M, Dale J

Citation: BMJ, 2009, vol./is. 339/(b2391), 0959-535X;1468-5833 (2009)

Publication Date: 2009

Abstract: OBJECTIVE: To explore the experiences and perceptions of general practitioners and community nurses in discussing preferences for place of death with
Design: Qualitative study using semistructured interviews and thematic analysis. Participants: 17 general practitioners and 19 nurses (16 district nurses, three clinical nurse specialists). Setting: 15 general practices participating in the Gold Standards Framework for palliative care from three areas in central England with differing socio-geography. Practices were selected on the basis of size and level of adoption of the standards framework. Results: All interviewees bar one had experience of discussing preferred place of death with terminally ill patients. They reported that preferences for place of death frequently changed over time and were often ill defined or poorly formed in patients' minds. Preferences were often described as being co-created in discussion with the patient or, conversely, inferred by the health professional without direct questioning or receiving a definitive answer from the patient. This inherent uncertainty challenged the practicability, usefulness, and value of recording a definitive preference. The extent to which the assessment of enabling such preferences can be used as a proxy for the effectiveness of palliative care delivery is also limited by this uncertainty. Generally, interviewees did not find discussing preferred place of death an easy area of practice, unless the patient broached the subject or led the discussions.

Conclusions: Further research is needed to enable development of appropriate training and support for primary care professionals. Better understanding of the importance of place of death to patients and their carers is also needed.

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Available in print at Louth County Hospital Medical Library
Available in print at Pilgrim Hospital Staff Library

48. Patient awareness of prognosis, patient-family caregiver congruence on the preferred place of death, and caregiving burden of families contribute to the quality of life for terminally ill cancer patients in Taiwan.

Author(s): Tang, S, Liu, T, Tsai, C

Citation: Psycho-Oncology, December 2008, vol./is. 17/12(1202-9), 1057-9249 (2008 Dec)

Publication Date: December 2008

Abstract: Research into end-of-life care and quality of life for terminally ill cancer patients and their carers in Taiwan. The study highlighted the increased dependence upon carers when the patient is at the end of their life, and whether the caregiving burden has impact on preferences concerning preferred place of death. 50 refs.

Source: BNI

Full Text:
Available in fulltext at EBSCOhost

49. User involvement in EoLC: how involved can patients/carers be?

Author(s): Black, J

Citation: End of Life Care, November 2008, vol./is. 2/4(64-9), 1754-1069 (2008 Nov)

Publication Date: November 2008

Abstract: Concept of patient and carers' participation in care and its application to end of life care. The legal requirements and policy documents governing user involvement are reviewed and the specific issues affecting terminally ill people are discussed, including barriers to involvement and some practical examples. 7 refs.

Source: BNI
50. Preference for place of care and place of death in palliative care: are these different questions?

Author(s): Agar, M, Currow, D, Shelby-James, T

Citation: Palliative Medicine, October 2008, vol./is. 22/7(787-95), 0269-2163 (2008 Oct)

Publication Date: October 2008

Abstract: Secondary research in Australia analysing longitudinal data concerning preferences of terminally-ill patients and their carers for place of care and place of death. Changes in preferences over time and the relationship between preferred and actual place of death are described and the need to consider how questions are worded and to empower both to state their preferences earlier is highlighted. 23 refs.

Source: BNI

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51. Eliciting individual preferences about death: development of the End-of-Life Preferences Interview.

Author(s): Borreani C, Brunelli C, Miccinesi G, Morino P, Piazza M, Piva L, Tamburini M

Citation: Journal of Pain & Symptom Management, October 2008, vol./is. 36/4(335-50), 0885-3924;1873-6513 (2008 Oct)

Publication Date: October 2008

Abstract: The capability to make decisions about one's own dying and death is commonly considered a necessary component of a good death, but difficulties in communicating about imminent death have been documented. This paper attempts to describe the process of constructing an instrument to elicit individual preferences concerning dying, while respecting the patient's awareness, and to verify its applicability in a palliative care setting. The development of the End-of-Life Preferences Interview (ELPI) was performed through (a) a literature search aimed at identifying relevant issues; (b) examination by a panel of experts in the field of palliative care of the items generated; and (c) pretesting of feasibility on all eligible consecutive patients referred to three centers of palliative care during a two-month period. The final version of the ELPI consisted of two parts: The first level explores preferences about issues regarding the caregiving process, and the second level focuses on preparation for death. Each of the two parts is introduced by key questions aimed at allowing the patient to decide whether and when to stop exploring such sensitive matters. Among the 49 eligible patients (41%), the interview was proposed to only 13 of them (27%), and only one of them refused. The reasons for such a low compliance of physicians in proposing the ELPI were evaluated by a semi-structured interview and are herein discussed. The use of the ELPI in clinical practice can favor the passage to a greater consideration of the self-determination of the patient at the end of life, with due consideration of his or her cultural and emotional needs.

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52. Physicians’ preferences and attitudes about end-of-life care in patients with an implantable cardioverter-defibrillator.

Author(s): Sherazi S, Daubert JP, Block RC, Jeevanantham V, Abdel-Gadir K, DiSalle MR, Haley JM, Shah AH

Citation: Mayo Clinic Proceedings, October 2008, vol./is. 83/10(1139-41), 0025-6196;1942-5546 (2008 Oct)
Abstract: Clinical guidance is deficient regarding deactivation of implantable cardioverter-defibrillators (ICDs) in patients with terminal illnesses. We hypothesized that many physicians are apprehensive about discussing ICD deactivation with their dying patients. Thus, we conducted an anonymous survey of all the physicians in the Department of Medicine at Unity Health System in Rochester, NY. The survey collected information about the knowledge and preferences of these physicians regarding the medical, ethical, and legal issues involved in caring for patients with an ICD and terminal illness. Of the 204 surveys distributed, 87 (43%) were returned. Among the physicians who responded, 64 (74%) reported experience caring for a patient with an ICD and terminal illness. Forty physicians (46%) either thought it was illegal or were not sure if it was legal to deactivate an ICD in these circumstances. However, if reassured about the legality of discontinuing ICD therapy, 79 (91%) of these same respondents said that they would be willing to discuss voluntary ICD deactivation with their dying patients. With increased knowledge about managing the withdrawal of this potentially life-prolonging therapy, physicians are likely to become more skilled at caring for dying patients with an ICD.

Source: MEDLINE

Full Text: Available in fulltext at EBSCOhost

53. Palliative care intervention for choice and use of opioids in the last hours of life.

Author(s): Bailey FA, Ferguson L, Williams BR, Woodby LL, Redden DT, Durham RM, Goode PS, Burgio KL

Citation: Journals of Gerontology Series A-Biological Sciences & Medical Sciences, September 2008, vol./is. 63/9(974-8), 1079-5006;1079-5006 (2008 Sep)

Publication Date: September 2008

Abstract: BACKGROUND: The purpose of this study was to evaluate the effects of a multicomponent palliative care intervention on choice and use of opioid pain medications for symptom control for patients dying in an acute care inpatient setting.METHODS: A preintervention/postintervention trial was conducted between 2001 and 2003. Participants were physician, nursing, and ancillary staff of inpatient services of an urban, tertiary care Veterans Affairs (VA) Medical Center. The intervention included staff education to better identify actively dying patients and a Comfort Care Order Set to guide care in the last hours of life. Data abstracted from computerized medical records of 191 veterans who died during a 6-month period before (N=98) and after (N=93) the intervention were used to examine changes in choice and amount of medication administered in the last 3 days of life.RESULTS: Findings show a significant increase in orders specifically for morphine from 47.4% to 81.7% (p<.001). Orders for hydromorphone or oxycodone did not increase significantly, and no patients had orders for meperidine or codeine. There was an increase in the administration of opioids from 16.7% to 73.0% of patients (p<.001). The amount of opioid administered (in oral morphine equivalents) increased from 31.9 mg/72 hours preintervention to 52.9 mg/72 hours postintervention (p=.12).CONCLUSIONS: The results indicate that the availability of morphine as a preferred opioid and the number of patients who received opioid medication during the last 3 days of life increased after introduction of the inpatient palliative care program.

Source: MEDLINE

54. Determinants of home death in palliative home care: using the interRAI palliative care to assess end-of-life care.

Author(s): Brink P, Frise Smith T

Citation: American Journal of Hospice & Palliative Medicine, August 2008, vol./is. 25/4(263-70), 1049-9091;1049-9091 (2008 Aug-Sep)

Publication Date: August 2008

Abstract: Many terminally ill patients are given the choice to die at home. This study identified determinants of home death among patients receiving palliative home care.
Health information was collected using the interRAI palliative care assessment tool. The sample included health information from 536 patients receiving home health care from one community care access centre in Ontario, Canada. Patients who died at home were more likely to be functionally impaired and less likely to live alone. The patients' wish to die at home and the family's ability to cope were strong determinants of home death. This study suggests that the presence of a supportive family that is able to work with the health care team to implement a plan of care is important to the patients' ability to die at home. This study highlights the need to treat the patient and the caregiver(s) as a unit of care.

Source: MEDLINE

Author(s): Wasserman, Linda S
Citation: Clinical Journal of Oncology Nursing, August 2008, vol./is. 12/4(621-626), 1092-1095;1538-067X (Aug 2008)
Publication Date: August 2008
Abstract: The Respectful Death Model (RDM) is a research-based, holistic, and practical model developed to improve end-of-life care. A respectful death is one which supports dying patients, their families, and professionals in the completion of life cycles and can be used by all members of the healthcare team. The model is a process method commencing with the establishment of a therapeutic relationship with the dying patient and his or her family and, as a result, their stories are heard and incorporated into the care plan. This article demonstrates that hospice and palliative care nurses have been practicing this model since the origination of care of the dying. Other topics addressed are the current culture toward death in the United States, the roles of nurses in the RDM, and the barriers and benefits of the RDM. Recommendations for future research in end-of-life care also are addressed. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)
Source: PsycINFO
Full Text:
Available in fulltext at EBSCOhost

56. A good death.
Author(s): Hartley, J
Citation: Nursing Times, July 2008, vol./is. 104/30(18-20), 0954-7762 (2008 29 Jul)
Publication Date: July 2008
Abstract: Poor quality of terminal care received by many dying patients and the publication of a new Department of Health strategy 'End of Life Care Strategy' (2008). Barriers to good end of life care facing nurses and other health professionals are explained and suggestions for improvement are made. Comments from nurses and an account by a terminally ill patient are included.
Source: BNI
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Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.
Available in print at Pilgrim Hospital Staff Library

57. Managing a good death in critical care: can health policy help?.
Author(s): Coombs M, Long T
Citation: Nursing in Critical Care, July 2008, vol./is. 13/4(208-14), 1362-1017;1478-5153 (2008 Jul-Aug)
Publication Date: July 2008

Abstract: AIM: This paper discusses end-of-life care (EoLC) in critical care through exploration of what is known from the international literature and what is currently presented within UK policy. BACKGROUND AND CONTEXT: EoLC is an important international critical care issue, and currently provides a key focus for health care policy in the UK. While society holds that critical care is delivered in a highly technical area with a strong focus on cure and recovery, mortality rates in this specialty remain at approximately 20%. When patient recovery is not an outcome, discussions with patient, family and extended care teams turn towards futility of treatment and end-of-life management. However, there are specific barriers to overcome in EoLC for the critically ill.

CONCLUSION: A key issue for EoLC in critical care is a lack of robust systems to prospectively identify individuals who are most at risk of dying. A further challenge is divergent perspectives within and across clinical teams on treatment withdrawal and limitation practices. To streamline patient management and underpin a hospice approach to care, EoLC policies are currently being used within the UK. While this provides a national framework to address some key critical care clinical issues in the UK, there is a need for further refinement of the tool to reflect the reality of EoLC for the critically ill. It is important that international best practice exemplars are examined and clinicians actively engage and contribute to ensure that any local EoLC frameworks are fit for purpose.

Source: MEDLINE

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Available in print at Grantham Hospital Staff Library

58. General practitioners' experiences of the psychological aspects in the care of a dying patient.


Citation: Palliative & Supportive Care, June 2008, vol./is. 6/2(125-31), 1478-9515;1478-9515 (2008 Jun)

Publication Date: June 2008

Abstract: OBJECTIVE: General practitioners (GPs) play an integral role in addressing the psychological needs of palliative care patients and their families. This qualitative study investigated psychosocial issues faced by GPs in the management of patients receiving palliative care and investigated the themes relevant to the psychosocial care of dying patients.

METHOD: Fifteen general practitioners whose patient had been recently referred to the Mt. Olivet Palliative Home Care Services in Brisbane participated in an individual case review discussions guided by key questions within a semistructured format. These interviews focused on the psychosocial aspects of care and management of the referred patient, including aspects of the doctor/patient relationship, experience of delivering diagnosis and prognosis, addressing the psychological concerns of the patients' family, and the doctors' personal experiences, reactions, and responses. Qualitative analysis was conducted on the transcripts of these interviews.

RESULTS: The significant themes that emerged related to perceived barriers to exploration of emotional concerns, including spiritual issues, and the discussion of prognosis and dying, the perception of patients’ responses/coping styles, and the GP's personal experience of the care (usually expressed in terms of identification with patient).

SIGNIFICANCE OF RESULTS: The findings indicate the significant challenges facing clinicians in discussions with patients and families about death, to exploring the patient's emotional responses to terminal illness and spiritual concerns for the patient and family. These qualitative data indicate important tasks in the training and clinical support for doctors providing palliative care.

Source: MEDLINE

59. End of life issues.

Author(s): Sykes N

Citation: European Journal of Cancer, May 2008, vol./is. 44/8(1157-62), 0959-8049;0959-
Publication Date: May 2008

Abstract: Despite advances in cancer survival rates, end of life care remains a vital aspect of cancer management. The use of integrated care pathways can facilitate effective care of dying patients in a generalist setting. However, it remains important that staff are able to recognise the onset of the dying process, not only in order to make symptom control provision, but also that appropriate communication can occur with patients and those close to them. This allows the exercise of choice over place and style of care. The key symptoms at the end of life are restlessness, agitation, breathlessness, pain and noisy respiration from retained airway secretions. Ethical tensions arise from the assumptions that the use of opioids and sedatives hastens dying, but this is contradicted by available evidence.

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60. The potential impact of decision role and patient age on end-of-life treatment decision making.

Author(s): Zikmund-Fisher BJ, Lacey HP, Fagerlin A

Citation: Journal of Medical Ethics, May 2008, vol./is. 34/5(327-31), 0306-6800;1473-4257 (2008 May)

Publication Date: May 2008

Abstract: BACKGROUND: Recent research demonstrates that people sometimes make different medical decisions for others than they would make for themselves. This finding is particularly relevant to end-of-life decisions, which are often made by surrogates and require a trade-off between prolonging life and maintaining quality of life. We examine the impact of decision role, patient age, decision maker age and multiple individual differences on these treatment decisions.METHODS: Participants read a scenario about a terminally ill cancer patient faced with a choice between an aggressive chemotherapy regimen that will extend life by two years and palliative treatments to control discomfort for one remaining month. Participants were randomly assigned to one of three decision roles (patient, physician, or an abstract other) and the scenario randomly varied whether the patient was described as 25 or 65-years old.RESULTS: When deciding for a 65-year old patient, approximately 60% of participants selected aggressive chemotherapy regardless of decision role. When deciding for a 25-year old patient, however, participants were more likely to select chemotherapy for a patient (physician role) or another person (abstract other) than for themselves (70%, 67%, and 59%, respectively). In addition, confidence that powerful others (eg, physicians) control one's health, as well as respondents' age and race, consistently predicted treatment choices.CONCLUSIONS: Patient age appears to influence medical decisions made for others but not those that we make for ourselves. These findings may help to explain the discord that often occurs when younger cancer patients refuse life-extending treatments.

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61. Patients dying with dementia: experience at the end of life and impact of hospice care.

Author(s): Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA

Citation: Journal of Pain & Symptom Management, May 2008, vol./is. 35/5(499-507), 0885-3924;0885-3924 (2008 May)
Publication Date: May 2008

Abstract: To evaluate the impact hospice enrollment has on the terminal care of patients with dementia and describe the symptom burden these patients experience, caregivers of dementia decedents were assessed in a mortality follow-back survey. Patients had been managed through academic outpatient geriatric clinics in Chicago, IL. A total of 135 family members or other knowledgeable informants of persons who had died with dementia were queried about the patient's preferred location of death, location of death, satisfaction with patient care, and assessment of patient's pain and most bothersome symptom. Patients who were enrolled in hospice were significantly more likely to die in their location of choice (odds ratio [OR] 9.67; 95% confidence interval [CI] 2.57-37.0), and less likely to die in the hospital, (OR 0.04; 95% CI 0.01-0.18), compared to nonenrollees. Caregivers of hospice enrollees were more likely to rate patient care as excellent or very good (OR 5.65; 95% CI 2.61-10.34), compared to nonenrollees. Over 50% of caregivers of hospice enrollees and nonenrollees reported patient pain at a moderate intensity or higher on average in the last two weeks of life. No effect was observed between a caregiver reporting pain at a moderate level or higher and whether the patient was enrolled in hospice (OR 0.58; 95% CI 0.22-1.54). Hospice enrollees did not experience improvement in their most bothersome symptom’s frequency, severity, or amount of distress caused (P=0.21, 0.39, 0.95, respectively), compared to nonenrollees. These results suggest that dying patients with dementia who are enrolled in hospice programs are more likely to die in their locations of choice and their caregivers are more likely to perceive that care is excellent or good than those who do not obtain hospice services. No effect on pain or other symptoms could be demonstrated in this analysis.

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62. A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia.

Author(s): Birch D, Draper J

Citation: Journal of Clinical Nursing, May 2008, vol./is. 17/9(1144-63), 0962-1067;1365-2702 (2008 May)

Publication Date: May 2008

Abstract: AIM: This paper considers the challenges of delivering effective palliative care to older people with dementia and the possible strategies to overcome barriers to end-of-life care in these patients.BACKGROUND: In UK alone, approximately 100,000 people with dementia die each year and as the number of older people increases, dementia is set to become even more prevalent. Dementia is a progressive terminal illness for which there is currently no cure. Patients dying with dementia have significant health-care needs and in recent years it has been recognised that palliative care should be made available to everyone regardless of diagnosis, as this improves comfort and quality of life. Despite this, patients dying with dementia are often still not given access to palliative care services.METHOD: A review of English language literature published after 1996 to the present day relating to older people with dementia during the terminal phase of their illness.RESULTS: Twenty-nine articles met inclusion criteria for the review. Most originated from North America and UK and were mostly quantitative in nature. Four key themes were identified: difficulties associated with diagnosing the terminal phase of the illness (prognostication); issues relating to communication; medical interventions; and the appropriateness of palliative care intervention.CONCLUSIONS: This review reinforces the importance of providing appropriate palliative care to individuals suffering from end-stage dementia and identifies some of the barriers to extending such specialist palliative care provision.RELEVANCE TO PRACTICE: There is an urgent need to improve palliative care provision for older people with end-stage dementia and, in addition, more research is required on the needs of patients entering the terminal phase of dementia to assist the allocation of appropriate resources and training to ensure quality and equality in the provision of end-of-life care.

Source: MEDLINE
63. A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia.

Author(s): Birch, Deborah, Draper, Jan

Citation: Journal of Clinical Nursing, May 2008, vol./is. 17/9(1144-1163), 0962-1067;1365-2702 (May 2008)

Publication Date: May 2008

Abstract: Aim: This paper considers the challenges of delivering effective palliative care to older people with dementia and the possible strategies to overcome barriers to end-of-life care in these patients. Background: In UK alone, approximately 100 000 people with dementia die each year and as the number of older people increases, dementia is set to become even more prevalent. Dementia is a progressive terminal illness for which there is currently no cure. Patients dying with dementia have significant health-care needs and in recent years it has been recognised that palliative care should be made available to everyone regardless of diagnosis, as this improves comfort and quality of life. Despite this, patients dying with dementia are often still not given access to palliative care services.

Method: A review of English language literature published after 1996 to the present day relating to older people with dementia during the terminal phase of their illness. Results: Twenty-nine articles met inclusion criteria for the review. Most originated from North America and UK and were mostly quantitative in nature. Four key themes were identified: difficulties associated with diagnosing the terminal phase of the illness (prognostication); issues relating to communication; medical interventions; and the appropriateness of palliative care intervention. Conclusions: This review reinforces the importance of providing appropriate palliative care to individuals suffering from end-stage dementia and identifies some of the barriers to extending such specialist palliative care provision. Relevance to practice: There is an urgent need to improve palliative care provision for older people with end-stage dementia and, in addition, more research is required on the needs of patients entering the terminal phase of dementia to assist the allocation of appropriate resources and training to ensure quality and equality in the provision of end-of-life care. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

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Available in print at Pilgrim Hospital Staff Library

64. Gap analysis of cultural and religious needs of hospitalized patients.

Author(s): Davidson JE, Boyer ML, Casey D, Matzel SC, Walden CD

Citation: Critical Care Nursing Quarterly, April 2008, vol./is. 31/2(119-26), 0887-9303;0887-9303 (2008 Apr-Jun)

Publication Date: April 2008

Abstract: PURPOSE: Identify patient and family needs specifically related to an in-hospital birth or death. This study aimed to perform a gap analysis between identified needs and current hospital practice, services, and resources.METHODS: With the IRB approval, and purposive sampling using the demographics of a community hospital plus subgroups from problematic cases. Twenty-two semistructured interviews were audiotaped, and 6 lectures and 2 panel discussions were videotaped. Transcriptions were distributed to the research team and manually coded for gaps between current practices versus stated needs. Group process was used to form consensus regarding findings.PARTICIPANTS: The following subgroups were targeted: Muslim, Baha’i, Catholic, Protestant, Jewish, Buddhist, Mormon,
Jehovah's Witness, Latino, Filipino, Chinese, African American. RESULTS: Gaps in available resources, such as prayer books, rugs, and compasses, were identified. Knowledge gaps included many issues such as the Muslim preference for decreasing sedatives at end of life to be able to recite the sacred prayer while dying. Practice issues such as respecting plain-clothed clergy, the impact of "rule-orientation" on family needs, and the universal need to call clergy early were identified.

Source: MEDLINE

65. End of life care preferences.

Author(s): Borreani C, Miccinesi G

Citation: Current Opinion in Supportive & Palliative Care, March 2008, vol./is. 2/1(54-9), 1751-4258;1751-4266 (2008 Mar)

Publication Date: March 2008

Abstract: PURPOSE OF REVIEW: This review considers how end of life care preferences have been dealt with recently in the scientific literature. RECENT FINDINGS: The ability to make decisions about one's own dying and death is commonly considered a necessary component of a 'good death'. It is important to allow people to express, if they wish, their end of life preferences. Most of the studies were conducted in patients at advanced stages of terminal illness and involved asking them about what their wishes would be in certain scenarios. Half of the papers specifically addressed the issues of life-shortening medical decisions. On considering the findings of the various studies reported in detail here, it becomes clear that end of life preferences would best be studied using a longitudinal design, because of the fluctuation of these preferences over time and their association with dynamic components of quality of life, such as functional status, and psychosocial and spiritual dimensions. SUMMARY: Both patients and health care workers can be assisted in addressing the issue of what is the right time for a patient to record their preferences, in recognizing psychological defences and their evolution during the end of life process, and in managing conflicts and suffering in the patient-family unit. Guidelines and practical tools have begun to be designed and tested.

Source: MEDLINE

66. Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers.

Author(s): O'Leary, N, Tiernan, E

Citation: Palliative Medicine, January 2008, vol./is. 22/1(77-83), 0269-2163 (2008 Jan)

Publication Date: January 2008

Abstract: Research in Ireland into specialist palliative care services (SPC) for noncancer patients, by surveying SPC service managers. Availability of the service to noncancer patients, numbers taken on, admission policies and perceived barriers to the extension of care to these patients are described and the unmet needs of those who are terminally ill who do not have cancer are highlighted. 38 refs.

Source: BNI

Full Text: Available in fulltext at EBSCOhost

Available in print at Lincoln County Hospital Professional Library; Note: Click the library link to request this article. NHS Copyright applies.

67. Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers.

Author(s): Stajduhar KI, Allan DE, Cohen SR, Heyland DK

Citation: Palliative Medicine, January 2008, vol./is. 22/1(85-8), 0269-2163;0269-2163 (2008 Jan)

Publication Date: January 2008
Abstract: Previous studies involving palliative patients suggest a preference for dying at home. The purpose of this paper is to examine, prospectively, patient and family caregiver preferences for, and congruence with, location of death for hospitalized patients with cancer and end-stage medical conditions. Questionnaires were administered to 440 eligible in-patients and 160 family caregivers in five hospitals across Canada. This paper reports results of 138 patient/family caregiver dyads who answered a question about preference for location of death. The results suggest that only half of all patients and family caregivers report a preference for a home death. Furthermore, half of the patient/family caregiver dyads disagree on preferred location of death. If one of the primary goals of end of life care is to enhance the quality of life of dying patients and their family caregivers, policies directed towards ensuring that patients die in their location of choice ought to be a priority and resources should be allocated to promote the development of excellent care, not only in the home, but also within our institutional settings.

Source: MEDLINE

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68. A 'pain-free' death.

Author(s): Hicks F, Rees E

Citation: British Medical Bulletin, 2008, vol./is. 88/1(23-41), 0007-1420;1471-8391 (2008)

Publication Date: 2008

Abstract: BACKGROUND: The time around a patient's death is often filled with sadness, but good medical and nursing care can provide comfort to patients and their carers at this critical time. For many, a 'pain-free' death is a priority although there are other aspects to providing good care at the end of life. Honest, open discussion with patients and carers about their wishes is an essential prerequisite to individualized care.SOURCES OF DATA: Relevant literature was reviewed with regards to policy, education and delivery of end of life care.AREAS OF AGREEMENT: Pain management must be tailored to the individual with due regard to the route of analgesic administration in those unable to swallow, and consideration to the other circumstances surrounding a person's care. All staff caring for dying patients should address pain as a priority in managing end of life care, to promote the best possible death for patients and prevent undue distress for carers and staff.AREAS OF CONTROVERSY: This review has approached patient care at the end of life within current UK legislation, outlining what can be done to promote a 'pain-free' death. Debate continues about the role of euthanasia within end of life care and the use of analgesics and sedatives in pain management in terminal care.GROWING POINTS: There is a range of tools available to help staff to care for dying patients, such as the Liverpool Care Pathway (LCP) for the Dying. It is most effective when introduced as part of a wider system of staff education in relation to terminal care. AREAS TIMELY FOR DEVELOPING RESEARCH: Research into care of the dying will continue to be challenging. Priorities include; whether the use of tools such as the LCP improve the care patients receive, and the development of routine outcome measures including validated reports from patients and proxies.

Source: MEDLINE

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Influence of patients' preferences and treatment site on cancer patients' end-of-life care Lancashire Teaching Hospitals
AA Wright, JW Mack, PA Kritek, TA Balboni… - Cancer, 2010 - Wiley Online Library
BACKGROUND: Research suggests that patients' end-of-life (EOL) care is determined primarily by the medical resources available, and not by patient preferences. The authors
examined whether patients' desire for life-extending therapy was associated with their ... Cited by 2 - Related articles - The Christie Online Journals - All 4 versions

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AA Wright, JW Mack, ED Trice… - J Clin Oncol (…, 2009 - meeting.ascopubs.org
Background: Medical treatment at the end-of-life (EOL) should be responsive to patient values, but research shows it may instead reflect the regional supply of health services and/or physician practice patterns. We sought to determine whether patients' preferences ...

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B Gomes, P McCrone, S Hall, J Koffman… - BMC cancer, 2010 - biomedcentral.com
Background: Emerging trends and new policies suggest that more cancer patients might die at home in the future. However, not all have equal chances of achieving this. Furthermore, there is lack of evidence to support that those who die at home experience better care and ...

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SN Davison - Clinical Journal of the American Society of …, 2010 - Am Soc Nephrol
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KL Hannon, HE Lester…. - Palliative Medicine, 2011 - pmj.sagepub.com
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JA Billings... - Archives of internal medicine, 2011 - Am Med Assoc
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